

**Decision Making by Youth With and Without Intellectual Disabilities:**

**A Comparison of Perceptions**

**by**

**Barbara J. Melnychuk**

**A Thesis submitted to the Faculty of Graduate Studies of**

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**in partial fulfillment of the requirements for the degree of**

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## **Abstract**

This qualitative study includes a comparison of the perceptions of students with and without intellectual disabilities regarding the opportunities they have to make decisions during the school day and school year. The data from the student groups were shared with adults in the school who then explored their perspectives regarding reasons for any similarities or differences in the perceptions of the student groups. Within-case and cross-case analysis of the data obtained from the three student focus groups, one teacher focus group, one educational assistant focus group and an interview with an administrator resulted in the identification of three major themes: structure of the system, role of adults and safety. Various ways that each of these can facilitate or limit opportunities for students with and without intellectual disabilities to make decisions during the school day and school year are discussed.

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## Chapter I

I designed this study to explore and compare the perception of opportunities that transition aged youth with and without intellectual disabilities have to make decisions within the context of their high school setting. I collected data from students with and without intellectual disabilities, teachers, educational assistants (EAs) and an administrator through focus groups and an interview in one Manitoba high school setting. In the first chapter of the thesis, I present the context of the study, the questions I tried to address, an overview of the research methods that were used and definitions of some special terms used in my thesis. The chapter concludes with a discussion of the significance of my study as it relates to the professional literature reviewed in chapter II.

### **Background of the Study**

During a self-advocacy summit meeting in Phoenix, Arizona, a young man who has Down syndrome stood up at the microphone and said, “Dad, I have something to tell you. I want to make my own decisions.”

This resulted in thunderous applause from the many self-advocates in the room (Van-Belle, Marks, Martin and Chun, 2006, p. 46).

This anecdote highlights the focus of my thesis, which is the importance of decision making in the lives of youth and adults with intellectual disabilities.

Throughout much of my life, I have played a variety of employment-related and volunteer roles working with and on behalf of students with and without intellectual disabilities in the public school system in Manitoba. Something that strikes me repeatedly

is that educators and parents tend to be zealous in ensuring that students with intellectual disabilities are safe and cared for. However, in our zeal and with good intentions, we often remove opportunities for individuals to make decisions, and, even more frequently, to live with and learn from the consequences of their decisions. For example, I once worked with a high school student who had a significant intellectual disability, and who also demonstrated some significant behavioural challenges. I will refer to him as Mark. Mark's special needs were perceived to be so severe that the school arranged for the equivalent of a full time educational assistant (EA) to work with and monitor him throughout the entire school day. It was extremely rare that Mark was not being directly supervised and therefore he had rare opportunities to act independently. One day, Mark 'escaped' from the EA during the lunch hour and made his way into the school gymnasium where a rehearsal for the Grad Student Fashion Show was underway. It was very near the date of the show and tensions were high. Mark very quickly made his way onto the stage, where he took the microphone and began to put on his own version of a show. He loved the stage! In spite of efforts by the students and staff involved in the show, Mark refused to give up the microphone making it impossible for the rehearsal to continue. Within a few minutes, the EA assigned to Mark, came into the gym to find him. The EA was successful in coaxing him off the stage and escorted him back to the student services area. Later that day, the EA was paged to the office where a school administrator got after him for allowing his charge to 'escape' and interrupt the rehearsal. The administrator did not call Mark into the office.

This incident placed Mark at a disadvantage in two ways. First, he rarely had an opportunity to make decisions as he was only provided with limited choices by the adults

around him as we ‘took care of him’. This realization made me wonder how Mark could be expected to make good decisions about using his free time without opportunities to practice. The administrator’s actions were also borne out of a protective stance, assuming that Mark did not know any better. However, by being protective, the administrator also removed an opportunity for Mark to take responsibility for his own actions. How could we expect Mark to learn from his mistakes if he did not get to experience the consequences of his poor decisions? Mark was 16 years old at the time, and the plan was for him to stay in school until the age of 21. Even though Mark’s receptive language skills were limited, he would have understood that the administrator was not happy with his behaviour. Mark needed to be called into the office and reprimanded in order to increase his chances of making a different decision next time he was presented with such an opportunity. This was only one incident involving one particular student. It made me wonder how many decisions students with intellectual disabilities actually get to make when they are in high school and how often they get to experience the consequences of their decisions. It caused me to observe my own behaviour and examine my own practice with regard to the students with whom I was working at the time. It also led me to explore this topic for my thesis.

Many other researchers have focused on this issue. Cavet and Sloper (2004), for example, after completing a literature review on the participation of children with disabilities in decision making, concluded that “there is support for the concept of disabled children’s involvement in decision making from law, policy and respected professional opinion” (p. 280). They further stated that “one criterion of quality in services from a disabled child’s point of view is having the opportunity to make real

choices....children want respect for their views” (p. 282). Similarly, Miller and Byrnes (2001) suggested that decision making takes on increasing importance with age because an increase in independence [which generally also comes with age] necessitates that people make more decisions for themselves.

### **Laws and policies related to children and youth with and without disabilities.**

The concept of involvement in decision making by all children and youth is supported by human rights guidelines in many parts of the world. Internationally, all children’s right to expression, and to receive information, are underpinned by Articles 12 and 13 of the United Nations (UN) *Convention on the Rights of the Child*. Article 12 stresses the child’s right to express his/her views and to have them given due weight in all matters affecting the child. Article 13 is particularly relevant to children with communication-related disabilities as it declares that a child shall be free to seek, receive and impart information and ideas in any media of the child’s choice. Unfortunately, such conventions afford only a moral obligation to allow children and youth to participate in decision making. A legal obligation would require civil rights legislation. Children and youth under the age of majority have few legal rights, and I would argue that children and youth with intellectual disabilities have even fewer legal rights and/or opportunities to exercise them. Finally, specific policies may actually be in conflict with the law.

Evidence of this can be found in the field of medicine related to capacity and rights of individuals with and without disabilities to make decisions about medical treatment. According to a report by the Bioethics Committee of the Canadian Pediatric Society (2004), there is considerable variation in Canadian provincial and territorial law about the legal rights of children and adolescents to provide their own consent for

medical treatment. In some provinces and territories, the age of legal majority is presumed to also be the age of consent for medical treatment. In these cases, children or youth under the age of majority may be asked for assent, as opposed to consent. Some provinces stipulate an age of consent for medical treatment; while others follow a process whereby one's right to consent depends on decision making capacity, rather than age. To assist medical practitioners in Canada, The Canadian Pediatric Society has published a set of principles to guide treatment decisions regarding infants, children and adolescents. In the introduction to that document, the following statement is made: "Children and adolescents should be involved in decision making to an increasing degree as they develop, until they are capable of making their own decisions about treatment." (Bioethics Committee, Canadian Pediatric Society, 2004). In this same document, decision making capacity is described as "the ability to receive, understand and communicate information, and the appreciation of the personal effects of interventions, alternatives and nontreatment." Further discussion of capacity is contained in the document, acknowledging that an assessment of capacity is difficult and finally stating that "the majority of children will not have decision making capacity and will require a proxy to make decisions for them". It is further stated that adult patients are considered incapable of making decisions and therefore require a proxy or substitute decision maker for health care decisions if they are "unconscious, mentally ill or handicapped, delirious or intoxicated" and that the same holds true of many, but not all, children and adolescents.

In these principles, being unconscious or intoxicated is viewed as similar to being mentally ill or handicapped when it comes to judging decision making capacity. Based on

this statement, it appears that in Canada medical professionals would find few children or youth as having the capacity to make decisions about their own medical treatment, and that if adults who are ‘mentally ill or handicapped’ are believed to require a proxy or substitute decision maker, then children or youth with a cognitive disability would almost certainly not be permitted to make a decision about their own medical treatment.

Similarly, the United Kingdom Department of Health, Social Services and Public Safety published a document entitled *Seeking Consent: Working with Children* (2003). This document guides health care providers through the process of seeking consent for medical treatment from children with and without disabilities. In this document, it is stated that when children reach the age of sixteen, they are treated as adults with respect to providing consent for all medical, dental and social care. In addition, children under the age of sixteen will be considered competent to provide valid consent for medical treatment if they have what is referred to as “Gillick competence”<sup>1</sup>, defined as having “sufficient understanding and intelligence to enable [one] to understand fully what is proposed” (p.7). Where children are unable to give consent for themselves, it is recommended that they be as involved as possible in healthcare decisions. In order for consent for medical treatment to be considered valid, it must meet the following three conditions: the individual is competent (“Gillick competence”); the individual is acting voluntarily (not under pressure or duress from anyone); the individual is provided with enough information to enable him/her to make the decision. It is the responsibility of the health and social service professional to ensure that information is provided in a form that

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1. In this landmark judgment the House of Lords resolved that a child, rather than his parent, has, in the words of Lord Scarman, a right ‘to make his own decision when he reaches a sufficient understanding and intelligence to be capable of making up his own mind on the matter requiring decision’. (*Gillick v West Norfolk and Wisbech A.H.A.* [1986] AC 112, 186) as cited in Archard, D. and Skivenes, M. (2009).

is understandable to the child, using language that is appropriate to the age and ability of the child including the use of pictures, toys and play. The information is also to be provided at the child's own pace, allowing time to ask and answer questions. The document acknowledges that this process may involve an interpreter and that special care should be taken when communicating with an individual with a disability. This is different than the guidelines from Canada as it appears that children and youth with intellectual disabilities in the United Kingdom are not automatically disqualified from making decisions about their medical treatment because of their disability.

A document with similar guidelines was published by the New Zealand Ministry of Health in 1998, entitled *Consent in Child and Youth Health: Information for Practitioners*. In this document, issues around consent for medical treatment are viewed differently for children than for "young people". Young people are defined as those between the ages of 12 and 18. For example, "Where there is a difference of opinion about consent to treatment it will be between the young person themselves and the health care provider rather than their parents and the provider (although the parents may be involved with the young person's consent)" (p. 4). It is also stated that those over 16 have the same right to provide consent for medical treatment as an adult.

From the field of education, several pieces of legislation from the United States (US) address the issue of decision making related to children or youth. The *Individuals with Disabilities Education Act (IDEA)*, 2004, includes the requirement for active involvement by students with exceptional needs even prior to reaching the age of majority by mandating that transition services provided to each student be "based on the individual child's needs, taking into account the child's strengths, preferences, and

interests” (U.S. Department of Education, 2004). Wehmeyer et al. (1998) suggest that the intent of the *Individuals with Disabilities Education Act* is that students become equal partners in transition planning and decision making to the greatest degree possible, and in order to do this, they need to learn to solve problems and make decisions (p. 57).

A limited amount of research has been conducted about parent and teacher perceptions of the opportunities that children with intellectual disabilities have to practice self-determination skills at school. Reporting on a study of 482 parents, caregivers and teachers in a North American mid-Atlantic state, Grigal, Neubert, Moon and Graham (2003) suggest that opportunities for students with special needs to engage in self-determined behaviours may be quite limited in typical secondary schools. Few known studies have asked children or youth about their perceptions of opportunities to practice self-determination at school and no known study has asked young people with intellectual disabilities about their perceptions of opportunities to practice decision making. In this study, I have asked youth with and without intellectual disabilities to share their perceptions about opportunities to make decisions at school.

### **Laws and policies related to adults with intellectual disabilities.**

The concept of involvement in decision making by Manitoba adults [over the age of 18 years] living with intellectual disabilities is supported by *The Vulnerable Persons Living with a Mental Disability Act* (referred to as Chapter V90 of the *Continuing Consolidation of the Statutes of Manitoba*) which received assent in 1993. The content of this Act is important to my thesis for two reasons. First, it is important for educators and supportive others to know what is contained in this Act so that we can work together to

help prepare our students for their adult responsibilities. Second, individuals with special needs often continue to attend high school until June of the calendar year in which they turn 21 years old because funding for supports from the adults services sector is generally not available until that time. This means that the relationship among the student with special needs, his/her parents or caregivers, and the school system should change once the student reaches the age of 18, just as the relationship among these parties changes for teens without intellectual disabilities.

Under this Act, a vulnerable person is defined as “an adult living with a mental disability who is in need of assistance to meet his or her basic needs with regard to personal care or management of his or her property” (Dozar and Flaig, 2005, p. 10). The five guiding principles of *The Vulnerable Persons Living with a Mental Disability Act* (VPA) indicate that within the province of Manitoba, once vulnerable people reach the age of majority, they should expect to have the same rights and privileges as adults without disabilities. According to the VPA, vulnerable persons are presumed to have the capacity to make decisions that affect themselves and should be encouraged to make their own decisions independently, or with the assistance of their support network. The fifth guiding principle states “it is recognized that substitute decision making should be invoked only as a last resort when a vulnerable person needs decisions to be made and is unable to make these decisions by himself or herself even with the involvement of members of his or her support network” (VPA, 1993, p.1).

In spite of this type of legislation, adults with intellectual disabilities are frequently prohibited from making decisions due to the assumption of incompetence. Lutfiyya, Updike, Schwartz and Mactavish (2007) conducted a study where they

collected data from vulnerable persons and other stakeholders throughout Manitoba related to the implementation and impact of the VPA. Their findings suggest it is possible that the VPA is not being implemented as it was intended since the criteria outlined in the fifth guiding principle appears to “have various meanings and related practices, some of which may be inconsistent with the VPA” (p. 69). For example, they found that applications for substitute decision makers are sometimes being submitted proactively, in case a decision needs to be made in the future. Other times vulnerable persons “bump into other systems where they are presumed to be incompetent. Even though the community services worker believes the person is able to make the decision, they need to apply for a substitute decision maker. These situations involve income tax, banking and the medical community” (p. 115). This finding is congruent with the contents of the guidelines developed by the Bioethics Committee of the Canadian Pediatric Society previously reported.

Further findings indicated confusion around whether it is necessary to apply for a substitute decision maker if a vulnerable person has a support network. In some cases, “the support network becomes the de facto substitute decision maker” and results in members of the support network believing that they should be involved in all decisions (p. 71). Furthermore, according to the VPA, when a substitute decision maker is appointed, he or she has a responsibility to consult the vulnerable person about the decision to be made, and to be guided by the vulnerable person’s wishes. Based on discussions with various stakeholders, it was reported that “once an appointment of a substitute decision maker is granted, vulnerable people are often left out of the

consultation process...Vulnerable people noted that decisions were made without their consultation and contrary to their wishes” (p. 82-83).

Wehmeyer and Metzler (1995) conducted a study in the United States, in which they concluded that the majority of both adults and youth with intellectual disabilities were excluded from major decisions that impacted their lives, including where they lived or worked and what kind of medical treatment they received. Several years later, Millar (2007) reported on two studies that involved a review of 220 guardianship court files in the state of Michigan. It was found that the main reason why guardians were appointed is that young adults with intellectual disabilities were perceived as having little or no ability to make decisions.

Shogren et al. (2007) wrote that in spite of 15 years of attention focused on self-determination in the education of students with disabilities in the United States, there remains very little knowledge about the impact of personal characteristics (e.g., level of disability, gender) and environmental factors (e.g., opportunities to practice, inclusion, presence of support staff) on level of self-determination. Research with adults with intellectual and developmental disabilities has suggested that environmental factors have a significant influence on self-determination. If adults with intellectual disabilities are to be recognized as having the ability to make decisions according to the intent of the VPA and other legislation, then children and youth with intellectual disabilities need to learn how to make decisions and need to master ways to express their preferences and interests. They need opportunities to practice these skills at school, at home and in the community during the years prior to reaching the age of majority.

In this study, I endeavoured to contribute to the literature base by asking youth with and without intellectual disabilities to provide information about their opportunities to make decisions within the high school setting, by examining the similarities and differences in their perceptions, and exploring the environmental factors and personal characteristics affecting those opportunities with both students and educators.

### **The Purpose of the Study**

This study had two purposes. The first was to compare the perceptions of two groups of high school students regarding their opportunities to make decisions in the high school setting. The first group included grade 10 and 11 high school students without intellectual disabilities. The second group included high school students with intellectual disabilities perceived to be significant enough to have been provided with the support and/or supervision of an educational assistant during 50 per cent or more of the school day. The second purpose was to find out what teachers, educational assistants (EAs) and an administrator thought about perceptions, themes and issues identified by these two groups of students.

### **Research Questions**

Specifically, I have examined the following questions.

1. (a) What is the range of opportunities for decision making during a typical school day or school year, as perceived by grade 10 and 11 students without intellectual disabilities from one Manitoba high school?

- (b) What is the range of opportunities for decision making during a typical school day or school year in one Manitoba high school, as perceived by students with intellectual disabilities perceived as severe enough to be provided with the support and/or supervision of an EA during 50% or more of the school day?
2. How do the students' perceptions of the range of opportunities for decision making between these two groups compare?
  3. When professional staff and EAs from the school see the comparative results, how do they explain any similarities or differences? What personal characteristics and/or environmental factors are perceived as having an influence on the similarities and differences?

I asked about the opportunities for decision making across many aspects of school life, including:

1. Less structured times of the school day (i.e., upon arrival, which included prior to start of classes, breaks between classes, lunch hour, spare periods, and after last class, prior to leaving the school).
2. Class time (i.e., activities that occur during class time, tasks/assignments students are expected to complete).
3. Participation in co-curricular or extra-curricular activities (i.e., student government, sports teams, intra-murals, music program activities, yearbook, other clubs or committees).

4. Participation in special events (i.e., assemblies, school dances, spirit week, pep rallies, drama or music productions, charity drives, other special events).
5. Participation in course selection or decisions around program of studies, IEP goals, work experience placements.

### **Overview of Methods**

This section provides a brief overview of the research methods used in this study including the research perspective, context, participants, data collection and analysis procedures. A more detailed explanation is found in Chapter III.

This is an exploratory qualitative study that was conducted in three phases. The first two phases were focused on gathering data related to the first two research questions, exploring the opportunities for decision making during a typical school day and school year as perceived by high school students with and without intellectual disabilities. The third phase was focused on the third research question, exploring the reasons for similarities and differences as articulated by involved school personnel.

Focus groups and an interview were used as the methods of data collection. I facilitated and audio-recorded all focus groups and conducted the interview. Data from the three student focus groups were also recorded graphically by a graphic facilitator whose services were contracted by the researcher. In the first phase of the study, data were collected from a mixed focus group which included students with and without intellectual disabilities in order to test the effectiveness of the focus questions and to draft a list of codes for analysis. In the second phase of the study, two different focus groups provided perspectives of their opportunities to make decisions during the hours they were

at school. One group included high school students with intellectual disabilities and the other included grade 10 and 11 students without intellectual disabilities. In the third phase of the study, the graphic record and relevant analyzed data from the first and second phase were shared with members of the two adult focus groups (teachers and EAs) and the interview participant (school administrator). Participants were asked to comment on the similarities and differences in opportunities for decision making reported by students with and without intellectual disabilities, and to explore possible reasons for the similarities and differences.

Recorded data were transcribed and coded. I then conducted within-case and cross-case analyses, as I looked for patterns, similarities and differences in responses to questions from the perspectives of the different focus groups and interview. The sorting function of an Excel spreadsheet was used as a tool to support analysis of the data.

A more detailed explanation of the methods is provided in Chapter III.

## **Definitions**

In this section, I have defined and provided clarification of terms that are used with specific intent in my thesis. As the focus of my study was to examine differences between two populations of students attending the same high school, it was necessary to identify or define the two groups. I am sensitive to the difficulty around labeling individuals, since such labels are generally based on societal constructs and do not represent the range of strengths and needs of the individuals to whom the labels are applied. In order to meet my need to define the populations for purposes of my study, I

have attempted to use language that is respectful and that provides enough information to define the populations in a way that would be recognizable to the reader.

**Administrator.** In my study, this term is used to refer to a school leader who may also be referred to as *vice principal, assistant principal, principal*.

**Classroom teacher.** In my study, this term refers to classroom teachers who teach in regular or general education classroom settings. In the school where I did my research, regular classroom teachers taught in classrooms where students with and without intellectual disabilities and those with other special educational needs are all included for some or all of each class period.

**Decision making.** In this study, decision making is defined as opportunities for students to act as the primary causal agent within the context of the school environment by setting a goal, determining options and selecting a course of action to achieve that goal free from external influence or interference by an adult. It is acknowledged that students may or may not consciously go through decision making steps. It is also acknowledged that their goals, options and courses of action may not coincide with the goals, options and courses of action that adults would have for them. For purposes of this study, decision making is considered different from choice making. When making choices, options would be offered to a student, whereas when decision making, the student would determine options on his/her own or with the guidance of others (Wehmeyer, Agran and Hughes, 1998). It is recognized that data regarding choice making may enter this study as the two are closely related.

**Educational Assistant (EA).** In this study, the term educational assistant will be used to include individuals who work in the school system in the role of supporting

students with exceptional learning needs. In different school divisions/districts, these individuals may have other titles such as *instructional assistant*, *student assistant*, *paraprofessional*, *para-educator*, *teacher aide*.

**Opportunity.** This term refers to the chance or opening a student may have to make a decision during the school day. These decisions may or may not have long-term consequences. Some examples of decisions include how to behave, where to go or with whom, the degree of participation in a particular class, course, activity or event, work experience placements, course selection and long-term goals.

**Peers.** Peers are defined as other students of similar chronological age attending the same high school.

**Self-Determination.** In my study, I have employed Wehmeyer's definition of self-determination which is: Acting as the primary causal agent in one's life and making choices and decisions regarding one's quality of life free from undue external influence or interference. Wehmeyer also outlined nine essential elements of self-determination including: (a) choice making, (b) decision making, (c) problem solving, (d) goal setting and attainment, (e) self-observation, (f) evaluation and reinforcement, (g) internal locus of control, (h) positive attributions of efficacy and outcome expectancy, (i) self-awareness, and (j) self-knowledge. (Wehmeyer, 1996, 1998; Wehmeyer, Kelchner and Richards, 1996; Wehmeyer, Agran and Hughes, 1998, pp. 6-24). Throughout my thesis, I have cited self-determination research that I considered to be supportive of decision making, given that decision making is one of the elements of self-determination.

**Student services staff.** I used this term to refer to teachers who work in the school system in the role of supporting students with exceptional learning needs and also

supporting classroom teachers in their efforts to meet the needs of this population. In different school divisions/districts, these individuals may have other titles such as *resource teacher, special education teacher, inclusion teacher, special needs teacher, special needs integration teacher.*

**Students with Intellectual Disabilities.** In my study, this phrase refers to students whose cognitive/academic and social and/or behavioural needs are perceived to be significant enough so that they are provided with the support and/or supervision of an EA during 50 per cent or more of the school day, in addition to ongoing support from professional student services staff in the school setting. Typically, this would include students with moderate to severe intellectual disabilities. In this thesis, the following terms are used interchangeably when referring to individuals with intellectual disabilities: *students with special needs, exceptional needs, cognitive disabilities, mental handicaps, mental retardation, and developmental disabilities.* When the phrase *students with disabilities* is utilized, the referents include individuals with intellectual disabilities as well as those with other disabling conditions such as physical disabilities, sensory disabilities, or autism spectrum disorders.

**Students without Intellectual Disabilities.** Students whose cognitive/academic, social and behavioural needs are such that they do not require ongoing support from professional student services staff or EAs in the school setting.

### **Professional Significance of the Study**

I hope this study will serve as a contribution to the bodies of research related to decision making, self-determination and the role of administrators, teachers and EAs in

schools. While the topic of decision making has been studied extensively from various perspectives as established in chapter II of this thesis, far less is known about decision making opportunities for students with intellectual disabilities as compared to students without intellectual disabilities. This study has the potential to encourage educators and parents to examine the opportunities afforded students with and without intellectual disabilities to practice decision making in the school setting, and to explore ways to expand those opportunities.

While some research has been conducted on the opportunities of adolescents with intellectual disabilities to practice self-determination in high schools, this research has generally been based on the perceptions of parents, teachers and care givers (Carter et al., 2006; Doss and Hatcher, 1996; Grigal et al., 2003; Moloney et al., 2000). In this study, I contribute the perception of students with and without intellectual disabilities to this topic. Further, little research has been carried out that explores the impact of environmental factors and personal characteristics on student opportunities to practice self-determination at school. Part of this study explores the reasons perceived by involved staff members for the similarities and differences in opportunities reported by these two groups of students, and the degree to which these are explained in terms of personal characteristics and environmental factors. Much research has been conducted regarding the role of the EA and the impact of that role on the level of independence of students with various disabilities (Giangreco, Broer and Edelman, 1999; Giangreco and Doyle, 2007; Giangreco, Smith and Pinckney, 2006; Giangreco, Yuan, McKenzie, Cameron and Fialka, 2005). The perspective of young people with intellectual disabilities was included in at least one such study (Broer et al., 2005). My study will add to that discussion.

Limited research exists where young people with intellectual disabilities are offered the opportunity to provide their perspectives. This study is somewhat unique in that it seeks the perspective of students with and without intellectual disabilities related to the research questions through the use of focus groups. This will yield some methodological information that may be valuable in the field of qualitative research.

In chapter II, you will find a review of the relevant literature.

## Chapter II: Literature Review

In this chapter, I will briefly describe the process I used to search the literature related to my thesis questions, and explain how the literature review is organized. The remainder of the chapter provides a review of the literature and concludes by demonstrating how the themes in the literature review are connected to my research.

I began my search through the University of Manitoba (U of M) libraries website which allows access to the library catalog, article collections, databases and collections of e-journals. My search included databases from the fields of education, medicine, psychology and social work. Some of the collections utilized were: SAGE Full-text Collection, ERIC (CSA Illumina), PsycINFO, PsycBOOKS, PsycARTICLES, OVID, and EBSCOhost. In addition, the reference librarian assisted me in locating resources from other libraries and universities in Canada.

I used various search terms synonymous with “intellectual disabilities” combined with various terms synonymous with "decision making", and began by limiting the search to the past 5 years. This produced so few results I ended up having to broaden the parameters of my search significantly in terms of topics, population and number of years. Once I was successful in locating a small number of articles and books, my most fruitful sources became the references listed in those and subsequent resources. In order to focus on the topic of decision making as opposed to choice making, I chose to exclude the literature on choice making.

As a result, this literature review has been organized into six bodies of research connected to decision making as it applies to individuals with and without intellectual

disabilities. These include (a) quality of life, (b) self-determination, (c) decision making theory and practice, (d) risks related to decision making, (e) decision making and perception of competence, (f) opportunities to practice decision making, and (g) the impact of EAs on decision making. This organizational structure assisted me in making sense of the literature and connecting it to the purpose of my study. It begins with the broad philosophical construct “quality of life”, and connects that with the importance of decision making in the lives of all people, including those with intellectual disabilities. The literature on self-determination and decision making theory and practice begins to narrow the focus. The theory and practice literature focuses specifically on how decisions are made, and establishes that all people learn and improve upon their decision-making skills with practice and support. This information also establishes roles for school staff and parents in the development of decision making skills. The self-determination literature contributes to context as decision-making is identified as one of the critical elements of self-determination. This research is also specific to individuals with intellectual disabilities. The remaining four topics are even narrower in focus. The research on risk and opportunities addresses factors that limit or expand decision-making opportunities for individuals with intellectual disabilities. These bodies of research counter and support each other, and are therefore juxtaposed. Perceived competence or incompetence is addressed separately as it is shown to have a powerful impact on decision making opportunities for individuals with intellectual disabilities. The final topic, the impact of EAs on decision making, contributes to the focus on the roles that adults can play in limiting or expanding decision-making opportunities for the students with whom they work. Of course, these seven topic areas are not completely distinct in

the literature as they are all related to my topic of interest; therefore the reader will observe some overlap between sections in this chapter.

I found little connection in the literature in these topic areas between individuals with and without intellectual disabilities, or between children/adolescents and adults. The quality of life literature includes information related to individuals with and without intellectual disabilities, highlighting concepts such as empowerment and meaningful participation. The self-determination literature reported is exclusively related to individuals with intellectual disabilities. I did find a body of literature related to self-determination and individuals living in locations or under conditions where they experience oppression in terms of political or socioeconomic circumstances. While it could be argued that this literature base is relevant, I chose to disregard it for purposes of my thesis. Research in the area of decision making theory and practice is almost exclusively related to individuals without intellectual disabilities, and primarily focuses on adults. Conversely, the research related to risks, perceived competence and the importance of finding opportunities for decision making primarily focuses on individuals with intellectual disabilities, except in situations where comparisons are being made to individuals without disabilities. Once again, much of this literature is focused on adults. Finally, as expected, research related to the impact of EAs on decision making opportunities is focused exclusively on school aged children and adolescents who have various disabilities. A search for literature connecting the role of teachers to student opportunities for decision making resulted only in articles focused on the decision making processes of teachers and student teachers, and included information about the

influence of administrators, parents and the physical structure of the classroom or school on decisions made by teachers. I chose to disregard this literature.

The issue of labeling of individuals arose once again, when reading and reporting on the research contained in this literature review. The terminology used to refer to individuals with intellectual disabilities in some of the quoted portions of this chapter would be considered offensive given the context of Manitoba in the year 2010. I trust that the readers of this thesis will understand and make allowances for the context of the studies that resulted in the use of these quotes. When paraphrasing research results, I attempted to use language that is respectful in our current context, and that provides enough information to define the populations in a way that would be recognizable to the reader. A number of terms are used interchangeably with “intellectual disabilities” as listed in the definitions found in Chapter 1.

### **Decision Making and Quality of Life**

In philosophical and educational literature, connections arose between quality of life and empowerment as it related to decision making. UNESCO introduced *Education for All (EFA)* in 2001, which is a global initiative that identifies education as a fundamental human right and recognizes that education provides people with the power to reflect, make choices and enjoy a better life. Philosopher Hannah Arendt (1958) utilized the term “worthwhile life” as a purpose of education and contended that central to a worthwhile life is building webs of relationships with other human beings that allow us to define who we are and what kind of lives we want to lead. In 2001, Manitoba Education Citizenship and Youth released a Philosophy of Inclusion which states that “an

inclusive community provides meaningful involvement and equal access to the benefits of citizenship”, with the promise of “a richer future for all of us” (Manitoba Education Citizenship and Youth, 2001, p. 1).

The editor (1997) of the *International Journal of Disability, Development and Education*, wrote about the various doctrines that have been advocated for individuals with disabilities over time: “the passive life”, “the developmental life” and “the functional life”; leading up to the newest doctrine, that of “the empowered life”. “This doctrine stresses the value of ensuring that individuals with disabilities determine the direction of their own lives.” (Editorial, p. 284). I recognize that this article, referring to “the newest doctrine” of “the empowered life”, is thirteen years old. However, my research and that of others would suggest that many individuals with intellectual disabilities have not yet achieved “empowered lives”, therefore the quote is still relevant (Lutfiyya, Updike, Schwartz and Mactavish, 2007).

Roy Brown (1991) was a Canadian researcher who studies quality of life issues related to adults with developmental disabilities. Through a review of the literature, he discovered that several authors define quality of life according to “the extent to which an individual increasingly controls aspects of life regardless of original baseline” (Brown, 1991, p. 101). Brown included individuals with mild, moderate, and severe-profound developmental disabilities, as he wrote about the importance of opportunities to exercise a sense of control to improve quality of life.

Based on a review of the literature on empowerment as an outcome of disability service provision, Dempsey and Foreman (1997) determined seven essential components of empowerment. The three that are relevant to this thesis are (a) self-efficacy (i.e., the

belief in the ability to produce intended results), (b) participation and collaboration (i.e., “the development of a collaborative relationship between help-seeker and help-giver in which the former is encouraged to assume as much responsibility as possible in decision making”), and (c) sense of control over one’s life.

It appears that when examined from many different perspectives, quality of life for all human beings is enhanced by having the opportunity for meaningful participation in making choices and decisions, either independently or within the context of a collaborative relationship. It is apparent that education has an important role to play in providing human beings with experiences and relationships that will assist them in their pursuit of a worthwhile life.

### **Self-Determination and Decision Making**

The literature related to self-determination encompasses decision making as well as several other elements, and makes a connection with quality of life for all individuals and particularly for those living with intellectual disabilities.

Self-determination is not a new concept in relation to individuals with intellectual disabilities. Nirje introduced the concept of self-determination into disability literature in 1972 in a chapter entitled “The Right to Self-Determination” in the classic text *Normalization* (Wolfensberger, 1972). Nirje stated: “the choices, wishes, desires, and aspirations of a handicapped person have to be taken into consideration as much as possible in actions affecting him” (p.176). Nirje was writing in reference to individuals who experienced a significant intellectual disability, and who were living in institutions at the time.

Michael Wehmeyer and others have written extensively regarding the definition and impact of self-determination (Wehmeyer, 1996, 1998, Wehmeyer, Kelchner and Richards, 1996, Wehmeyer, Agran and Hughes, 1998, pp. 6-69). Wehmeyer defined self-determination as “acting as the primary causal agent in one’s life and making choices and decisions regarding one’s quality of life free from undue external influence or interference”. He went on to outline the four essential characteristics of self-determined behaviour as (a) the individual acted autonomously, (b) the behaviours were self-regulated, (c) the person initiated and responded to events in a psychologically empowered manner, and (d) the person acted in a self-realizing manner (i.e., to the best of his/her potential).

The validity of this definitional framework was evaluated through a study where over 400 adults with cognitive disabilities were surveyed using instruments that measured self-determined behaviour as well as these four essential characteristics (Wehmeyer, Kelchner and Richards, 1996). Wehmeyer (1996) also outlined nine component elements that are considered essential to the emergence of the four essential characteristics. This is not intended to be an exhaustive list, but are elements seen as particularly important to the emergence of self-determined behaviour. The nine essential elements are: (a) choice making, (b) decision making, (c) problem solving, (d) goal setting and attainment, (e) self-observation, (f) evaluation and reinforcement, (g) internal locus of control, (h) positive attributions of efficacy and outcome expectancy, (i) self-awareness, and (j) self-knowledge. These elements are clearly in congruence with Byrnes’ research related to decision making theory and practice as outlined in the next section. Wehmeyer and colleagues indicated that there is considerable overlap in theory and practice among

choice making, decision making and problem solving and stated that “all three are important to becoming autonomous and self-regulating” (p. 14, Weymeyer et al. (1996).

Regarding quality of life and self-determination, Wehmeyer, Agran and Hughes (1998) wrote the following.

An individual’s quality of life is determined across settings, environments, and opportunities; and virtually all choices and decisions, at some level, contribute to an individual’s quality of life. Conceptualizing self-determination as contributing to an enhanced quality of life reflects the importance of both major decisions that occur infrequently (e.g., buying a house, medical decisions) and daily choices that are less consequential but more frequent, such as what to wear or eat and how to spend one’s free time (p. 47).

The ability to make effective choices and decisions is one of the most important competencies students need in order to be successful after high school. Promoting self-determination is an excellent framework within which to teach students how to make effective choices and decisions. If we support the development of self-determination skills, we are also enabling students to learn how to make choices and decisions based on their own values and beliefs (ERIC Development Team, 2003). This contributes significantly to their ability to live more self-sufficient and fulfilling lives.

There is an emerging evidence-base that students with intellectual and developmental disabilities who leave school as more self-determined young people do, indeed, achieve more positive adult outcomes, including employment and independent living than those who are less self-determined when they leave school (Wehmeyer, 2006;

Wehmeyer and Palmer, 2003; Wehmeyer and Schwartz, 1998). There are several studies that connect decision making, choice making, autonomy and self-determination with improved quality of life for all individuals, and more specifically for individuals with intellectual and developmental disabilities (Wehmeyer, 2006). Two such studies involved 94 students with intellectual disabilities or learning disabilities and compared adult outcomes one year and three years after the students left high school with their level of self-determination upon graduation. Students were divided into two matched groups for purposes of this study - the high self-determination group (those scoring 1 or more standard deviations above the mean of the group on a measure of self-determination) and the low self-determination group (those scoring 1 or more standard deviations below the mean of the group). Researchers also identified members of the high and low groups for both disability categories (based on mean self-determination scores for students in that disability category) in order to ensure that the two groups did not contain disproportionate numbers of students in a particular disability category. Results indicated that students in the high self-determination group were disproportionately more likely than those in the low self-determination group to (a) have moved from where they were living during high school, (b) be living independently, (c) be demonstrating a trend toward greater financial independence, (d) be holding a job or receiving job training, and (e) to have made significant advances in obtaining employee benefits, including vacation, sick leave and health insurance (Wehmeyer and Palmer, 2003; Wehmeyer and Schwartz, 1998). These are impressive results in support of the development of self-determination skills, including choice and decision making.

In another study, Wehmeyer, Kelchner and Richards (1996) examined the essential characteristics of self-determined behaviour of individuals with intellectual disabilities. One of the correlations they examined was between disability level and level of self-determination. They found there was a relationship between the severity of the disability level and the self-determination score (i.e., students with more severe disabilities tended to show lower self-determination scores). However, they did not believe this was a causal relationship and that level of disability was only one factor among several to consider.

Shogren et al. (2007) found some conflicting research results in studies related to self-determination. Some studies found no significant difference in the level of self-determination between men and women with intellectual disabilities, and yet one study found that women with intellectual disabilities tended to be more self-determined than men. Further, teacher ratings of opportunities for self-determination correlated with student self-ratings on only one of the two self-rating measures used by Shogren and colleagues. Similarly, student capacity correlated positively with student self-ratings of self-determination on only one of the two self-rating measures used in the study, and negatively with the other measure, resulting in a recommendation for further study. Over 90% of the students included in the study attended their last IEP meeting; this appeared to have no significant impact on self-determination scores. Finally, results of the Transition Empowerment Scale (Powers, Turner et al., 2001 as cited in Shogren et al.), a measure of youth empowerment within the context of the transition planning process, “was a significant and equivalent predictor of self-determination as measured by both self-rating measures used in this study.” This suggested strongly that “it is the active involvement

and empowerment in the transition process that has the potential to impact self-determination” (p. 505), not simply attending IEP meetings. This is supported by Halpern (1994) in a position statement on transition for the Division for Career Development and Transition (DCDT) of the Council for Exceptional Children which states, “If the transition process is to be successful, it must begin with helping students to gain a sense of empowerment with respect to their own transition planning (cited in Wehmeyer et al., 1998, p. 61). A sense of empowerment can only be gained through meaningful involvement in the processes of decision making and problem solving, as an active member of the transition planning team. In order for students to be adequately prepared to take an active role in planning at this stage of their educational careers, they need to have had many opportunities to practice making decisions and solving problems throughout their lives, both at home and at school.

Wehmeyer and his colleagues caution against several identified misinterpretations of the concept that could stand in the way of people with more significant disabilities achieving self-determination. The first is seeing self-determination as “independent performance”, “absolute control”, or “self-reliance”. All individuals have any number of specific tasks or activities that they are unable to perform independently, and any number of decisions that would not be made without advice or assistance. However, as long as the task or activity is directed by an individual or that individual has final say or at least some say in the decision, he or she is operating in a self-determined manner (Ward, 1996). An individual is also considered to be making his/her own decision if he/she chooses to grant control or decision making authority to someone who has greater expertise or experience regarding that particular aspect of life. For example, when a

patient consents to have surgery, the surgeon decides how best to repair the patient's tendon damage; some people hire an accountant to complete their income tax returns or a financial advisor to invest their money; many people rely on the advice of a mechanic regarding whether to repair or replace a part on their car (Wehmeyer, 1996; Wehmeyer, Kelchner and Richards, 1996; Shoultz, 1995).

### **Decision Making Theory and Practice**

I was able to find very little recent research on the topic of decision making theory and practice, therefore most of the research base is from the years prior to 1999. Byrnes appears to be the most frequently cited researcher on this topic. Many references in this section came from the extensive literature review he completed. After this comprehensive review, Byrnes indicated that little research has been done on the topic of decision making in children and adolescents. I was able to find no studies related to decision making theory and practice that involved individuals with intellectual disabilities.

#### **Decision making processes.**

Byrnes (1998) provided a comprehensive review of the literature on decision making and proposed a theoretical model which he calls the Self-Regulation Model (SRM). To develop this model of decision making, Byrnes evaluated a representative sample of other decision making theories, and then integrated aspects of the models that fared well according to his evaluation (p. ix). He then used a rational task analysis approach, as used by lead scholars in the area of artificial intelligence, to determine that

there are at least four things that one needs to be able to do in order to make decisions: create options, evaluate them, implement them and learn.

During the first process, which is also referred to as the generation phase, the individual creates a set of options. If the individual is presented with options, this phase is bypassed. If options must be generated, this is initiated in response to a cue (either internal or environmental) that sets in motion a process of goal setting. Once goals are set, the individual creates a set of possible actions (strategies) which may allow him/her to reach that goal. These strategies may be generated in a variety of ways including retrieval from memory, analogy, causal reasoning or advice-seeking.

Once an individual has generated one or more options, the evaluation phase begins. In this phase, the individual examines pros and cons of each option and then gives each a rating, allowing the best option to be selected. If none of the options are deemed acceptable, the individual returns to phase one to generate new options and then back to the evaluation phase. If a person did not have the ability to do this, he/she would be forced to choose options at random.

Once an option has been selected, the individual enters the implementation and learning phase. This is the process that allows us to accomplish things or, at least, to test out our decisions and pay attention to the results. The individual observes whether or not the implementation of that option has helped to reach the goal, and then makes note of the result in memory to be used when faced with the next decision. This is the learning process that allows humans to alter knowledge such that more of the options we create or choose in the future will result in success. These processes appear to be well-established in literature and practice, as outlined in Table 1.

**Table 1**  
**Decision making models or processes**

<b>Byrnes (1998)</b>	<b>ERIC Resource Center (2003)</b>	<b>Beyth-Marom, Fischhoff, Jacobs, Quandrel and Furby (1991)</b>	<b>Platt and Hermalin (1989)</b>
Internal or environment cue that sets in motion process of goal setting		Identify the problem to be solved	Recognition of the problem
Generation phase where options are generated	Identify options	List relevant action alternatives	Optional thinking or generation of alternatives
Evaluation phase where individual examines pros and cons and rates options	Anticipate potential consequences and accessing resources and information	Identify possible consequences of those actions; assess the probability of each consequence occurring and the relative importance of each consequence	Causal thinking; means-end thinking or step-by-step planning; consequential thinking; role taking or meta-representation
Implementation and learning phase where selected option is implemented and individual observes whether or not implementation helped to reach the goal, and makes note of this in memory	Practice skills and reflect on and learn from experiences	Integrate these values and probabilities to identify the most attractive course of action	

In an article about teaching decision making to students with learning disabilities (ERIC Resource Center, 2003), it was suggested that in order to make effective decisions and choices, students need opportunities to (a) acquire skills such as identifying options, anticipating potential consequences, and accessing resources and information, (b) practice the skills, and (c) reflect on and learn from their experiences (p. 5).

Wehmeyer, Agran and Hughes (1998) suggested that there is considerable overlap in theory and practice amongst choice making, decision making and problem solving, three of the nine components of self-determination. They described choice making as a process of selecting between alternatives, usually presented to the choice maker. Decision making generally refers to a broader set of skills that include choice making as one component. They referred to work by Beyth-Marom, Fischhoff, Jacobs, Quadrel and Furby (1991) outlining the following five steps: (a) listing relevant action alternatives, (b) identifying possible consequences of those actions, (c) assessing the probability of each consequence occurring (if the action were undertaken); (d) establishing relative importance (value or utility) of each consequence, and (e) integrating these values and probabilities to identify the most attractive course of action (pp. 14, 121, 125). Problem solving is presented as a step before the first step in decision making. One must identify the problem to be solved prior to coming up with action alternatives.

Similarly, Platt and Hermalin (1989) proposed the following set of six “adaptive social problem solving skills” that they deemed necessary to deal with real-life problems (a) recognition of the problem, (b) optional thinking or generation of alternatives, (c) causal thinking, (d) means-end thinking or step by step planning, (e) consequential thinking, and (f) role taking or metarepresentation. We can see that the steps or skills

suggested by other researchers appear to be similar to or within the three processes of Byrnes' model of decision making. To put it another way, "the core steps remain constant no matter what decisions are made" (Wehmeyer et al., 1998, p. 125), as established in Table 1.

### **Decision making styles.**

In further review of the literature, Byrnes (1998) discovered that other constructs or factors were shown to have an impact on the ability of individuals to make good decisions, and that any of the three processes can be affected by these moderating factors (pp. 27-29). These factors were incorporated into this decision making model through the hybrid concept of self-regulation which comes from a variety of social science research domains including research in the area of self-determination. Self-regulation as a construct is based upon three assumptions. The first assumption is that there is a goal-directed quality to human behaviour and that goals are adaptive in nature. The second assumption is that successful people are adaptive and engage in behaviours that maximize attainment of adaptive goals. The third is that it is difficult to be successful because humans all have natural limitations (e.g., working memory capacity), biases (e.g., beliefs) and tendencies (e.g., emotionality) that can interfere with the attainment of adaptive goals. These factors affect how well the decision maker operates during each of the phases. Self-regulated decision makers engage in behaviours that help them overcome their natural limitations, biases and tendencies, therefore increasing their chances of achieving their goals (pp. 30-33).

Heppner and Petersen (1982) suggested similar dimensions that are required for success in social problem solving including confidence in one's ability to solve the

problem, the approach-avoidance style of the problem solver, and perceptions of personal control (as cited in Wehmeyer et al., 1998, p. 123). Based on these assumptions, Byrnes argued that self-regulated decision making involves making choices that increase the chances of adaptive goals being attained. He further argued that self-regulated decision makers are more successful than dysregulated decision makers, and that decision makers can be arrayed along a continuum ranging from poor to very good, with higher self-regulation being nearer to the 'very good' end of the continuum (pp. 30-31).

In a later paper, Byrnes, Miller and Reynolds (1999) extended this thinking and stated that a decision maker's values and beliefs about options determine which options are entertained in a particular instance, as well as the rankings assigned to options. Beliefs about decision making strategies determine the approaches that are used to compile and evaluate options. Consistent success is very much dependent upon the accuracy of these beliefs about options and strategies. It is important, then, that people's beliefs become more accurate if that is at all possible.

### **Development of decision making skills in children and adolescents.**

The extensive literature review conducted by Byrnes is reported to include all studies on the topic of the development of decision making skills in children and adolescents available at the time of his writing. Byrnes concluded that relatively little research had been done in this area; therefore many unanswered questions remain. He also identified many potential topics for future studies. However, he did draw some conclusions based on the research that was available at the time. Following his lead, I have organized this information according to the three phases of the SRM.

During the generation phase of the SRM, internal or environmental cues are received by the decision maker who then sets a goal and generates strategies that may assist in the attainment of that goal. The interpretation of the cues that are received determines what the goal and subsequent strategies might be. Byrnes postulated that some cues are easier to interpret than others. It is logical that easier cues (e.g., hunger pangs) would be equally interpretable by young children and adults. However, cues that are less obvious or more ambiguous (e.g., facial expressions) leave more room for error of interpretation. Byrnes suggested that “experience and feedback from others promote the acquisition of knowledge about cues” (p. 47). In other words, when individuals misinterpret a cue and then proceed with decision making based on that interpretation, the result is generally negative. The individual learns from this experience on his or her own or turns to others with more experience or competence for an explanation of the failure and learns from that information. Testing out their naive theories helps children “gain progressive insight into the causal structure of themselves, others, and the world” (Byrnes, 1998, p. 47).

Byrnes reported conflicting research on the goal setting aspect of the generation phase in that some researchers suggested that there is a developmental increase in working memory capacity between preschool and early adolescence. Others suggested that memory capacity does not increase, but knowledge and strategies do increase, therefore allowing the decision maker to encode more information from the environment (cues) with the same memory capacity. In either case, it appears that older decision makers, who have more experience, will have increased ability to envision outcomes or goals based on the cues that are received, theoretically making them more successful in

their decisions. When it comes to generating strategies to meet goals, the literature suggested that “older children have a larger repertoire of strategies to draw upon than younger children”. When depending upon analogical reasoning, causal reasoning and advice seeking to generate possible strategies, the available research demonstrated variability among decision makers, but not necessarily based upon age or decision making experience.

During the evaluation phase, issues such as (a) causal power (i.e., effectiveness of potential strategies), (b) self-efficacy, (c) the resources required to implement the strategy, and (d) social and moral appropriateness of choices are all taken into consideration. The literature showed that even pre-school children seemed to demonstrate a good sense of causal power and were able to tell which strategies may actually work; this did not appear to change much as children got older or more experienced.

Researchers who have studied age differences in self-efficacy have found that, as children gained skills with age, they tended to feel more self-efficacious about their abilities in those areas, particularly when they experienced a greater proportion of successes relative to failures. They also learned that they lack skills or abilities in certain areas. The most important learning seemed to be that self-regulated decision makers, generally those with more successful experience, “utilize feedback from the environment to develop perceptions of ability that are realistic” (Byrnes, 1998, p. 71).

Related to resources, it appears that children without intellectual disabilities at a variety of ages demonstrate a preference for the most efficient strategy possible. However, research also suggested that, with age, children get better at reducing the amount of time and energy spent processing information that does not lead to their goals.

Very young children seem to demonstrate some basic awareness of social and moral appropriateness of choices. This awareness is believed to continue to grow in all individuals based on experience in different contexts. From a self-regulated decision making perspective, the important thing is the ability to adapt to contexts and make successful decisions based on knowledge of the rules in that context. In other words, it is important to be able to read a situation and adapt accordingly. In general, “the data suggest a steady, monotonic increase in evaluative skills” (Byrnes, 1998, p. 75) as decision makers gain in age and experience, particularly if they receive feedback and instruction from those with more experience and greater competence (Byrnes, 1998, pp.70-75).

#### **Learning phase: improving decision making skills.**

The literature regarding the learning phase of decision making is likely the most relevant to my thesis because it provides information related to what educators and parents can do to support the development of decision making skills in students with and without intellectual disabilities.

Byrnes (1998) stated that the “primary assumption of the SRM is that self-regulated decision makers are more successful than dysregulated decision makers, in part, because the former are more likely to learn from their decision making experiences than the latter” (p. 109). This assumption was derived from four other assumptions: (a) decision makers must have accurate knowledge of contexts, strategies and themselves in order to be consistently successful, (b) individuals have to acquire this knowledge and therefore, vary with respect to the amount and type of accurate knowledge they have acquired, (c) the primary factor that explains why some people learn effectively from

experience and others do not is their degree of self-regulation, and (d) self-regulation and knowledge tend to increase with age, therefore older decision makers will often be more successful than younger decision makers (p. 110).

***Outcome and verbal feedback.***

Decision makers have the opportunity to gain three types of knowledge based on feedback after implementing a chosen strategy, particularly if the strategy fails to achieve the desired outcome. The first is knowledge about “effective action-outcome linkages” (e.g., the chosen action was or was not causally linked to the desired outcome). The second is knowledge about how to approach a decision (e.g., the decision maker should have approached the decision differently – perhaps gathered more information – before making the choice). The third is self-knowledge (e.g., the outcome was achieved but did not have the desired effect). Knowing the cause of the failure allows one to know what to change or revise. The decision maker then needs access to information that would help with the revision process. This may be available through others who are more knowledgeable or experienced or through independent study or experimentation. Finally, in order to learn, the decision maker needs to overcome obstacles and limitations to their learning (e.g., “doesn’t care” about the failure, “too much trouble” to locate more accurate information, etc) (Byrnes, 1998. p. 110).

Similarly, Field and Hoffman (1994) asserted that self-determination is affected by environmental factors and individuals’ knowledge, skills and beliefs. They went on to explain that the “knowledge, skills and beliefs that lead to self-determination are delineated according to five components: (a) know yourself, (b) value yourself, (c) plan, (d) act and experience outcomes, and (e) learn” (as cited in Field and Hoffman , 2002), p.

116). Price (2002) appeared to concur as it was stated that “an accurate assessment of one’s strengths, weaknesses, needs and preferences as well as confidence in one’s abilities are fundamental to effective choice and decision making (as cited in ERIC, 2003, p. 4).

Byrnes, Miller and Reynolds (1999) went on to theorize that while outcome and verbal feedback are believed to be the primary factors that help decision makers learn, feedback can only be effective if the following three conditions are met. First, the feedback actually must occur. Secondly, the decision maker needs to have an endogenous tendency toward self-regulation as described previously. Thirdly, the feedback needs to be delivered in a form that the decision maker is able to understand and process. Even given these conditions, there is little empirical evidence that verbal feedback actually improves decision making performance.

Byrnes, Millar and Reynolds (1999) did two studies to find out “whether short-term, highly explicit feedback produces age differences in decision making” (p. 1125). In the first study, 96 individuals participated. 40 were grade eight students and 56 were adults. Approximately half of each set were randomly placed into test (i.e., verbal feedback group) and control groups. Participants were asked to individually perform eight decision making trials in a game like format. Participants in the verbal feedback group received an explanation of the best way to approach the task before beginning. They were also shown the game board and told the rules, and given information about why individuals who participated in a prior study only chose the correct path 60% of the time (i.e., ignored one set of game cards and overestimated their abilities to answer difficult questions). They were then provided with the actual questions on the cards and

asked to answer each one. They were told if their answers were correct or incorrect, and at the end were told how many easy and how many hard questions they answered correctly. They were then allowed to start the game. Control group subjects were given an explanation of the rules of the game and an example of one easy question and one difficult question prior to starting the game.

In the second study, 29 adolescents and 26 adults participated. All participants took part in two tasks. In the first, they were to act as a physician and determine which of 3 medicines is most effective for each of 16 patients with the same symptoms. After treating these 16 patients, participants were provided with chart form feedback about the effectiveness of the medications, as well as verbal feedback about how to determine the drug that does best overall. After the feedback was provided, the participants were asked to determine treatment for 16 new patients who all had another medical condition.

The results of these two studies showed that adults were more likely than adolescents (a) to alter their selections based on outcome feedback, (b) to have calibrated beliefs, and (c) to choose options in a consistent manner. They also found that changes were conservative in nature, and outcome feedback was more effective than verbal feedback. These results reinforced the importance of age and experience with decision making opportunities in the development of self-regulation.

### ***Practice.***

Byrnes described a number of studies that demonstrated subjects do improve their decisions when given sufficient trials. For example, Berry and Broadbent (1984) demonstrated that “subjects who were given a single set of 30 trials were far less likely to attain the desired level of production...than subjects given 60 trials to learn the linkages”

(as cited in Byrnes, 1998, p. 120). They also found that the ability to articulate the connection between the action and outcome was totally unrelated to performance. This suggested that metacognition is not necessary for improved decision making. Byrnes also described two other studies by Berry and Broadbent (1988) that demonstrated a similar practice effect. The last of these also demonstrated that “people informed of the nature of the connection between actions and outcomes performed at a higher rate than people not told” (Byrnes, p. 121). Byrnes concluded that “performance is poorest when action-outcome correspondences do not present themselves in relatively simple, salient, and unambiguous patterns that conform to prior experience” (Byrnes, p. 130).

### *Scaffolding.*

In general, Byrnes stated it is likely that young children and those who are not highly self-regulated may also attain adaptive goals with the guidance of others who are more self-regulated. He referred to these individuals as “other-regulated” (Byrnes, 1998, p. 53). Put another way, it is expected that younger children will only make good decisions if they are heavily “other-regulated”. However, older children will be better able to make good decisions on their own if “they have had multiple experiences with negative feedback and have received scaffolded instruction from others” (p. 152). Byrnes further stated that individual differences are also expected at each age because of the following factors: (a) lack of experience with negative feedback (e.g., sheltered, inexperienced children), (b) lack of access to competent decision makers, (c) lack of maturity demands in that parents and teachers rarely require them to be responsible and self-regulated (i.e. they always make decisions for children), and (d) the presence of

stress or temperamental dimensions (e.g., extreme fearfulness or impulsivity) that adversely affect the decision making process.

### **Conclusion.**

In his concluding remarks, Byrnes restated “it is predicted that experience with outcomes and adult scaffolding will serve to modify children’s knowledge of (a) action-outcomes correspondences (i.e., Action X produces Outcome Y), (b) knowledge of decision making strategies (e.g., advice seeking, list making), and (c) knowledge of themselves (i.e., their likes and dislikes). “Removal of either experience or expert scaffolding is expected to slow the acquisition of self-regulatory tendencies” (Byrnes, 1998, p. 191; Byrnes, Miller and Reynolds, 1999).

In a later paper, Byrnes, Miller and Reynolds (1999) described the “endogenous tendency toward self-regulation” which is a self-corrective aspect of the system organized into our long term memories. This trait ensures that changes to the belief system about decisions tend to be conservative and incremental, based upon the decision maker’s history of successes or failures. In practical terms, this means that self-regulated decision makers tend to change their decisions or strategies incrementally as opposed to making radical or abrupt changes based on limited feedback. Young children or dysregulated decision makers tend to make abrupt changes based on only one or two experiences.

Miller and Byrnes (2001) carried out two studies where they administered a number of assessment tools, including the newly developed Decision Making Competency Inventory (DMCI) to two groups of students. In the first study, data were collected from 412 grade nine and eleven students. In the second study, data were

collected from 170 students in grades nine to twelve. Two findings from these studies are relevant to my thesis. Adolescents with a higher level of self-regulated decision making and academic goals tended to engage in more achievement-oriented behaviour than those with a lower level of self-regulated decision making. The two most consistent predictors of adolescents' GPAs were socio-economic status (as defined by having fathers who were more highly educated) and decision making competency. They also reminded the reader that positive outcomes are not always obtained even when self-regulated decision makers engage in appropriate goal-directed behaviour.

### **Decision Making and Risk**

In this section, I summarize research related to decision making and risk as it related to people with intellectual disabilities. Research demonstrates that the risk of negative outcomes is often used to limit decision making opportunities for individuals with intellectual disabilities. Conversely, the importance of experiencing risk and ways to reduce risk are also explored.

In their book, *Keys to the Workplace*, Callahan and Garner (1997) included a section called "The overriding issue of personal choice" in their chapter on "Individualized Planning". They made reference to an analysis of personal choice and autonomy among individuals with disabilities completed by Guess, Benson and Siegel-Causey (1985). Those researchers concluded that many people believe individuals with severe disabilities are incapable of making choices and decisions that would be perceived by caregivers to be in the individuals' best interests. Guess et al. also discussed the fact that there is a certain level of risk inherent in allowing individuals with disabilities to

express preferences and make choices. However, they also expressed that it is a right of all individuals to acquire autonomy, therefore risk is necessary. They stated, “They need to learn, as do persons who are not handicapped, that wrong choices can sometimes have unpleasant consequences” (as cited in Callahan and Garner, p. 30). Callahan and Garner went on to discuss the importance of human service agencies using all available resources to create as great a number of combinations of employment, leisure and recreation options as possible to increase the possibility of meeting the preferences of consumers...to allow consumers to have choices and the opportunity to live their dreams. Callahan and Garner also advocated for encouraging decision making and choice making by individuals with disabilities with regard to employment and leisure, including opportunities to make decisions that may conflict with the direction preferred by family members and professionals, such as resigning from a job. They proposed that supporting decisions and choices is a validation of individuals’ capabilities and an indication that they are accepted and valued for who they are (Callahan and Garner, 1997, p. 32). Wehmeyer, Kelchner and Richards (1996) supported this as they stated, “If interventions to promote self-determination are to succeed, we must also alter the environments within which people with mental retardation live, work, and play to allow greater choice and control and examine the attitudes of service providers, educators, families and others who interact with them” (p. 641).

### **Decision making and duty of care.**

There are those who believe that care-givers should not permit individuals with disabilities to make choices that could be harmful to themselves or others. In their paper, Smyth and Bell (2006) defined “to choose” as the “process by which people come to a

conclusion regarding different options that are perceived to be available”; ‘options’ may be items or courses of action; ‘choice’ refers to the result of the act of choosing (p. 228). They provided background information about improvements in opportunities for individuals with learning disabilities<sup>2</sup> to make decisions, and made reference to research that suggests quality of life is improved with increased opportunities for choice and decision making. However, they then expressed concern over the negative health consequences of decision making related to food and reported a significantly higher percentage of individuals with learning disabilities that are overweight or obese as compared to the normal population in the United Kingdom. Smyth and Bell understood that some would argue that bad choices are an individual’s civil right and should be supported, and made reference to watching television and eating too many doughnuts as examples of ‘simple choices’ that people should be permitted to make. The authors disagreed stating that this position may “neglect to consider the negative and serious consequences of a severely limited diet” (p. 229).

Bannerman, Sheldon, Sherman and Harchik (1990) are quoted as supporting the limiting of choices as they stated that “clients should be encouraged to make as many choices as their abilities allow, as long as these choices are not detrimental to the client or others” (as cited by Smyth and Bell, 2006, pp. 229-230). Smyth and Bell argued that unhealthy choices regarding food and activity could be detrimental to the decision maker.

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<sup>2</sup> Learning disability (in the United Kingdom) was defined in an e-mail communication on August 14, 2008 from Catherine Smyth as follows: “Our definition of ‘learning disability’ is as per the British Psychological Society’s definition... in brief there are three core criteria:

- significant impairment of intellectual functioning
- significant impairment of adaptive/social functioning
- age of onset before adulthood.”

Please note that this is different from the definition of ‘learning disability’ but exactly the same at the definition of ‘intellectual disability’ in North America.

They went on to describe several factors that affect choice-making for people with learning disabilities. Examples relevant to this thesis include (a) cognitive ability (i.e., poor cognitive ability may prevent people from weighing all possible consequences of options prior to choosing), (b) past experience of choice (i.e., choosing what is familiar is not necessarily an informed choice), and (c) lack of knowledge (i.e., insufficient knowledge about choices and lack of awareness of where to get further information). Smyth and Bell discussed the importance of the decision maker understanding the consequences of a choice, as without this understanding, they cannot make a true choice. They further expressed concern over the fact that a person's right to free choice may be taking precedence over duty of care to the point where individuals with disabilities are experiencing harm. They concluded that "creating a more health oriented environment...and effective teaching of choice-making, where the knowledge imparted is fully understood, are...the most important next steps in improving quality of life" for individuals with disabilities (p. 234).

### **Decision making and paternalism.**

Karlsson and Nilholm (2006) wrote about how decision making opportunities are sometimes limited by a perceived need for paternalism when planning for supports and services for individuals with physical and/or cognitive limitations. They did a study involving two habilitation centres in Sweden that make use of the Individualised Service Programmes (ISP) model of service delivery which is a user-centred model based on teamwork. Habilitation centres are described as settings where professionals from the fields of medicine, social work, psychology and education provide support and "help to people with various forms of accredited physical and/or cognitive limitations" (p.195).

These centres operate under legislation that emphasizes the right to self-determination, which is also reported to be one of the goals of the national disability policy in Sweden. The ISP model includes regular team meetings which include the service user, his or her family members and friends, and representatives of the various institutions that provide supports and services to the user. The user is expected to “exercise his/her citizenship by claiming and negotiating his/her social rights”. Self-determination is interpreted as using individualistic influence to gain individual rights (p. 195).

Given these circumstances, Karlsson and Nilholm (2006) studied the dilemma of self-determination versus paternalism with the question, “when and why does the issue of self-determination become problematic and paternalistic actions possibly difficult to avoid?” (p. 196) They defined a paternalistic action as “an action towards the user that is performed with the intention of benefiting him/her but is taken without his/her informed consent” (p. 198). To answer this question, they observed, audio taped and transcribed a number of habilitation centre team meetings which followed the ISP model. They found that, given these definitions, the ideal of self-determination places certain demands on the person or user at the center of these meetings. If the individual cannot meet these demands, then other participants are at risk of behaving in a manner that could be interpreted as paternalistic. These demands on the user are (a) physical presence (in some cases, it was decided by others that users would not attend the ISP meetings because of lack of communicative competence due to severe impairments or low age), (b) interpretable voice (some users participated in meetings but no one at the meeting was able to interpret what he or she was communicating), (c) purposeful voice (one user was asked a question about setting a new goal - neither she nor her mother was able to answer

the question as they did not know what the next level of independence at school should be), (d) sincere voice (one student responded to questions in the affirmative, but without conviction or enthusiasm causing others at the meeting to question his sincerity and wondering whether or not they should proceed with the proposed plan), and (e) realizable voice (e.g., individuals who have aspirations that are difficult if not impossible to fulfill such as regaining ability to walk after suffering paralysis).

It was concluded that individuals with disabilities who attend meetings and are able to express concerns and preferences as well as have ideas about setting goals for themselves will be able to perform within the ideal conceptualization of self-determination at ISP meetings. However, those who are unable to meet any of the demands of self-determination, cause the support team to risk having to act in a paternalistic manner by making decisions on behalf of the individual concerned. The authors believed that even if resources are made available and skills and knowledge are acquired to overcome barriers, there will always be situations where paternalistic actions are unavoidable and therefore should be acknowledged as justifiable.

### **Misinterpretations.**

This conclusion appears to fit with Wehmeyer's concern about self-determination being misinterpreted as "independent performance", "absolute control", or "self-reliance". Wehmeyer and Schwartz (1998) acknowledged that individuals with significant disabilities may begin their journey toward self-determination in a different place along the continuum. However, the focus should remain on providing adequate opportunities for practice, enabling maximum participation in life and community and

ensuring proper accommodations and supports, therefore enabling each individual with significant disabilities to become as self-determined as possible.

Another of the misinterpretations of self-determination outlined by Wehmeyer (1998) is that “self-determined behaviour is always successful behaviour” (p. 11). In agreement with Byrnes and others, Wehmeyer suggested that even people who use the appropriate strategies and steps and have a history of successful decision making do not always end up with an optimal decision. The self-regulation aspect of decision making is that of adjustment so that when an error is made, the decision maker examines, evaluates and adjusts accordingly. Allowing someone with an intellectual disability (or anyone for that matter) to go through life making almost exclusively poor choices and ineffective decisions without assisting him or her to develop self-regulatory skills is an act that could be considered neglectful and disrespectful of the ‘duty of care’, as expressed by Smyth and Bell.

This was supported by Ferleger (1994) as he commented on a situation where a woman with an intellectual disability who lives in a group home is observed to stand for hours looking out the window of the house waiting for a ‘buddy’ who visits once a week. When asked, group home staff indicated that ‘it is her choice to stand there’. In response to this, Ferleger noted that group home staff were ‘invoking choice’ to justify “deprivation or denial of services, or violation of rights, of people with mental retardation” (as cited in Wehmeyer, 1998, p. 13). It was further suggested that situations such as this occur frequently when writers and service providers “elevate ‘choice’ above other elements of normalization”. It seems that Smyth and Bell may support this line of thinking as well.

**The dignity of risk.**

In contrast, several researchers and respected others wrote about the importance and inevitability of risk in all of our lives, including the lives of individuals with intellectual disabilities. In the classic text *Normalization*, (Wolfensberger, 1972), Perske wrote about the importance of people with mental retardation experiencing the ‘dignity of risk’, suggesting that they become even more disabled if they are not permitted to have risk experiences, as follows.

The world in which we live is not always safe, secure and predictable...Every day that we wake up and live in the hours of that day, there is a possibility of being thrown up against a situation where we may have to risk everything, even our lives. This is the way the real world is.

We must work to develop every human resource within us in order to prepare for these days. To deny any person their fair share of risk experiences is to further cripple them for healthy living.

Field and Hoffman’s (2002) research was in agreement with Perske. After going through an extensive systematic process (i.e., literature review, interviews with students and adults with and without intellectual disabilities, interviews with teachers and administrators, review by a national panel of experts and reactions of a group of practitioners), Field and Hoffman (2002) developed a set of nine quality indicators for promoting self-determination in educational settings. Two of these indicators are particularly relevant to my thesis. Quality indicator 3 states: “Students, families, faculty, and staff are provided with opportunities for choice” (p. 117). The rationale for this indicator is that only through the provision of

opportunities for choice can members of the school community practice their self-determination knowledge, beliefs and skills in order for such competencies to be recognized as meaningful and to enable retention and refinement of their competencies after initial acquisition through direct instruction.

The fourth quality indicator is: “Students, families, faculty, and staff are encouraged to take appropriate risks” (p. 117). Field and Hoffman used Nirje’s normalization principle as part of the rationale for this indicator, quoting the term “dignity of risk”. They further explained that members of the school community “need to be encouraged to take calculated risks” and “to celebrate and/or learn from the results of their actions” (p. 118). Instruction is necessary to help individuals minimize potential risks by considering potential consequences of possible actions prior to acting; and ‘safety nets’ are required to provide decision makers with “the opportunity to recover from actions they later deem mistakes”. They ended this section with a quote from Michael Wehmeyer, “Failure is only a learning experience if it is followed by success.” (p. 118).

### ***Levels of risk.***

Concerns about risk taking and threats to personal safety often result in limits on the choices and decisions individuals with disabilities are permitted to make. Schloss, Alper and Jayne (1993), as cited in Wehmeyer et al. (1998), outlined four levels of risk associated with choices or decisions. The first level involves some potential for immediate risk but little possibility for long-term harm to self or others; the second level is mild immediate risk and minimal possibility of long-lasting harm; the third level is moderate possibility for long-lasting harm to self or others; and the fourth level involves

almost certain personal injury. The reality is that the vast majority of choices and decisions in day to day life fall within the first two levels of risk. “Unfortunately, in many cases, these relatively low levels of risk are overemphasized and used to curtail the opportunities students have to make choices and decisions” (Wehmeyer et al., p. 126). In addition, the level of risk may vary by individual, and this should also be taken into consideration. To address these concerns, part of the instruction in most decision making models involves teaching individuals to assess level of risk and weigh the consequences. In addition, students can also be taught safety and health promotion such as skills in job-safety, bus ridership, nutrition, and disease and abuse prevention (Wehmeyer et al., pp. 18-19, 126).

Pumpian (1996) submitted that if professionals honestly examined our reasons for many of the decisions we make on behalf of students, we would realize that the reasons are often associated with convenience or scheduling, costs or the desire to protect them from failure. As a result, they are prevented from having meaningful experiences and having opportunities to practice making choices or decisions. The end result is that people with intellectual disabilities remain child-like and do not develop into adults capable of managing their own lives. In fact, many adults with disabilities experience failure at work due to poor decision making skills and inability to adjust to new situations at work (Hardman, Drew and Winston, 2002 as cited in Hill, 2004).

Powers et al. (1996) suggested that in order to allow children and youth with special needs to experience risk, parents and other caregivers need adequate information about strategies that promote the successful attainment of self-determination skills “yet guard against threats to child safety if such strategies are unsuccessful...parents generally

want to be reasonably sure that serious harm will not result from permitting their children to take certain risks” (pp. 274-275). Doss and Hatcher (1996) wrote from the perspective of parents of a child with a disability. They explained how important it is to start at an early age allowing children with disabilities to take risks and experience some failure as part of the overall learning experience. They believed that the fears of parents should not limit the experiences of the child, and that it is important for parents to perceive their children with disabilities as capable of making decisions and learning from their experiences.

One of the limiting factors identified by Byrnes (1998) in his research on decision making was mental capacity. However, he alleged that limited mental capacity should not necessarily lead to undesirable outcomes if the decision maker recognizes his or her deficiencies and implements strategies to overcome them. It has been shown that these can be learned from a combination of outcome and verbal feedback, which is especially valuable when related to unsuccessful decisions (Miller and Byrnes, 2001). In other words, it is important for young people to have opportunities to practice decision making, as well as other self-determined behaviours, in order to learn from their errors in a supportive context. Wehmeyer (1998) stated, “It is a false dichotomy to conceptualize self-determination as exclusively skills or opportunity, as it clearly depends on equal parts of skills and opportunity mixed liberally with experience and adequate supports” (p. 12). In fact, individuals with intellectual disabilities or other learning difficulties require even more opportunities to practice such skills than their non-disabled peers in order to learn appropriate strategies and increase their decision making success. This is supported by Wehmeyer (2001), as cited by Shogren et al. (2007), as they wrote about the

importance of repeated opportunities to practice self-determination skills, “particularly because students with more significant learning needs require more time to acquire the skills associated with self-determination” (p. 503). Unfortunately, research shows these repeated opportunities do not necessarily occur.

***Importance of support in reducing risk.***

The two facilitative conditions for development of self-determination outlined by Powers et al. (1996) are opportunities for mastery experiences and access to information. Decision making and management of obstacles are two of the mastery experiences that are seen as opportunities to bolster self-determination. Powers et al. stated, “...it is important to permit youth to make choices and decisions...” and added, “few experiences are more empowering than communicating respect and trust for someone’s decision making skills” (p. 263). According to their experience using the TAKE CHARGE self-determination curriculum, it was suggested that when youth are well-informed and respected, they generally make thoughtful and responsible decisions. The authors cautioned that, in some situations, it is prudent to limit the decision making power of an adolescent since some decisions have higher risks or ‘response costs’ than others. In cases where a young person’s decision is most likely to result in negative (and possibly harmful) outcomes, it becomes the responsibility of those with more knowledge and experience (i.e., trusted caregivers or others with expert knowledge or experience) to intervene. It is important that caregivers think carefully about which decisions truly carry this level of response cost and which decisions could really be made by the adolescent. As other researchers suggested, “it is typically through experiencing the consequences of personal decisions that adolescents learn to become wise decision makers” (Powers et al.,

p. 264 as well as Pierangelo and Crane, 1997 as cited in Hill, 2004). When the decisions of adolescents prove to be erroneous or unwise, it becomes the responsibility of their caregivers to assist them in learning from that experience and growing in their self-determination. Without this support, youth can perceive this failure as a permanent situation and may internalize it, making it part of their own identity. Therefore, it is important to ‘coach’ the decision maker to think through what worked and what did not and to attribute the failure accordingly. They then need support to generate new strategies or options to add to their repertoire for the future. This also helps the decision maker to learn how to respond appropriately and productively to a failed decision (p. 266, Powers et al.).

Moloney, Whitney-Thomas and Dreilinger (2000) did a study where they executed a series of open-ended interviews with eleven high school students with and without diagnosed disabilities in Boston. Based on the interviews, they classified students according to two concepts, struggle (defined as degree of reported difficulties in their lives (e.g., family, friends, drugs, health) and self-definition (defined as sense of purpose, knowledge of strengths and weaknesses, ability to communicate this information to others). This information then allowed students to be categorized into one of the following four areas (a) peer dominated, (b) parent dominated, (c) replacements (i.e., replace family support with friends and school), and (d) full array (i.e., multiple sources of support available, comfortable seeking and using it). From their findings, the concept of “supported independence” emerged, which appears to be a concept similar to what Powers et al. (1996) described. Moloney et al. explicate the concept as follows.

In order to gain an adult sense of self-definition, adolescents need opportunities to make decisions and explore their interests independently. However, they also need continued, reliable support from adults and peers. This support enables them to make sense of their experiences, gives them a sense of security, and reduces the severity of stressful situations (p. 3).

One other finding of this study was that the only two students who ended up being categorized into the ‘parent-dominated’ area were both on IEPs, did not participate in inclusive classes and had more significant intellectual disabilities than the other participants in the study. These students were reported as having fewer overt struggles than students in some of the other categories, but were not well-connected with peers or school staff and generally had decisions made for them by their parents.

The second ‘facilitative condition for self-determination’ outlined by Powers et al. (1996) was access to information. This facilitative condition is critical to ‘informed decision making’. It seems obvious that in order to make informed decisions, young people need to know as much information as possible that may impact their decisions. However, “too often, professionals [and caregivers] avoid providing information to adolescents because of its complexity” (p. 267), and then assume they are incapable of making an appropriate decision without that information. A better answer is to find a way to make the necessary information more ‘user friendly’ or universal in its design so that it is accessible to the individuals who need it. In the long term, this approach, if used consistently and infused into school curricula, will also help youth become more

informed consumers about options and resources available to them in the post-school community (Powers et al., 1996).

### **Conclusion.**

Instruction in specific skills in decision making is only the beginning step toward the promotion of self-determination in students with intellectual disabilities. We must provide opportunities for young people with intellectual disabilities to practice making choices and decisions, and to experience the “dignity of risk” in order to build confidence in their ability to exert control in their lives...in order for them to behave in a self-determined way as adults transitioning from school to the adult world (Wehmeyer, 1998, Wehmeyer et al, 1996). “The need to focus on self-determination seems particularly acute for people with mental retardation because they appear to have relatively few opportunities to make choices and decisions and assume control in their lives” (Wehmeyer and Metzler as cited in Wehmeyer et al., 1996).

### **Decision Making and Competence**

In addition to concerns about risk, another factor that limits decision making opportunities for all children and adolescents, and especially for individuals with intellectual disabilities, are judgments made by adults regarding level of competence. In the forward of the book by Wehmeyer, Agran and Hughes (1998), Paul Wehman wrote, “Self-determination – control over one’s life and choices – is the critical difference separating people with disabilities from those without disabilities” (p. xi). This is a disturbingly strong statement that, unfortunately, is supported in research. Based on their

literature review, Cavet and Sloper (2004) reported that even though models of good practice show it is possible to provide opportunities for children to participate in decision making, evidence suggests that this is not common. Evidence also suggests that children with disabilities are even less actively involved in decision making than their non-disabled peers. It appears that many children with disabilities are not afforded their full rights regarding decision making, as granted under the UN Convention on the Rights of the Child. This is of particular concern in the United Kingdom (UK) regarding children with disabilities who are in residential schools and those who require communication aids. Some of the recommendations found by Cavet and Sloper included (a) extension of advocacy services particularly for those most affected, (b) adoption of inclusive approaches, (c) increased staff training and education, and (d) promotion of education and information for disabled children and their parents.

Grigal, Neubert, Moon and Graham (2003), surveyed 248 teachers of high school students (16-21 years of age) who were diagnosed with either high incidence disabilities (e.g., specific learning disability, mild/moderate mental retardation, emotional disability, speech language disability) or low incidence disabilities (e.g., autism, multiple severe disabilities, severe orthopedic disability, significant mental retardation, visual or hearing impairment, traumatic brain injury). They also surveyed 234 parents or primary caregivers who had a child between 16 and 21 years with a high- or low-incidence disability, to determine their beliefs about teaching self-determination as part of the school curriculum and their perceptions of opportunities for students to demonstrate and practice self-determination skills at school. Grigal et al. found that parents and caregivers of students who were in college preparatory or career development programs (i.e. high

incidence) were more likely to believe that students with disabilities should be informed and skilled participants in their own IEP meetings than parents of students receiving community-based/life skills instruction. It was suggested that future research examine what influences parental support of student participation in IEP meetings and transition planning. Another finding was that parents supported the teaching of self-determination skills at school. In fact, 98% of respondents indicated some level of agreement with statements about the responsibility of schools to teach self-determination skills such as decision making. However, only 78% expressed some level of agreement that these skills were actually taught to their own child with a disability. Teacher responses seemed to be in agreement with those of parents as they “slightly agreed” that students with disabilities had the opportunity to acquire, learn and practice self-determination skills at school. They also only “slightly agreed” that they, themselves, were familiar with the concept of self-determination and knew how to teach it. One of the noted limits of this study related to the possible inaccuracy of self-report data.

Life after high school is uncertain and overwhelming for many young people and supports are not as available in the adult world. Powers et al. (1996) argued that, in order to have a chance at success, all youth need to be as prepared as possible to face post-school challenges. Self-determination is not a unique need, right or desire of youth with disabilities; “it is an essential requirement for the future success and personal fulfillment of *all* youth” (p. 259). Further, adolescence appears to be a critical time to focus on self-determination skills because the major psychosocial task of this period of life is to form a personal identity. Adolescence has been described as a period of dramatic physical, intellectual, and socio-emotional development characterized by expansions in self-

awareness, participation in social relationships and personal autonomy (Burchard as cited in Powers et al., 1996). It has been argued that the presence of a disability interferes with this process due to the reliance on caregivers for meeting basic needs, as well as the tendency of caregivers toward over protectiveness and over structuring of environments (Wehmeyer et al., 1998, pp. 59-60). Garrison and McQuiston (as cited in Powers et al.) referred to the following obstacles faced by youth with challenges: (a) limitations due to disability or health issues, (b) restricted access to age-appropriate experiences and social interactions, and (c) attitudinal and architectural barriers. As shown in the literature, caregivers (i.e., parents, guardians, support workers, administrators, teachers, EAs) all have the potential to enhance or impair the development of decision making and other self-determination skills in the children and youth under their care.

#### **Assumption of incompetence.**

Several studies demonstrated that children, adolescents and adults with varying degrees and types of disabilities are often assumed to be incapable of making appropriate decisions. Carter, Lane, Peirson and Glaeser (2006) did a study in the U.S. that examined the capacities and opportunities of adolescents with emotional disturbance (ED) and adolescents with learning disabilities (LD) to engage in self-determined behaviour. Students, parents and special education teachers were asked to evaluate the capacity and opportunities of each of 85 adolescents (39 with ED and 46 with LD, ranging in age from 14 to 19 years) through the use of three different formats of the AIR Self-Determination Scale. They found that educators rated students in both groups as having significantly more opportunities to engage in self-determined behaviour at school than did students or parents. Students rated opportunities to be self-determined at school lower than their

parents. Further, the ratings of capacity for self-determination assigned by teachers were significantly lower than student self-appraisals, especially for students with ED. Similar discrepancies have been found among youth with other diagnoses (Stone and May, 2002 as cited in Carter et al.). The study also reported a strong correlation between rating of student capacity for self-determination and their opportunities to engage in self-determined behaviour.

This finding resulted in the following recommendations. Both skill development and opportunities for practice must be combined in order to increase chances of success. Adolescents need to experience the promotion of self-determination across all settings, as it can be confusing if behaviours are stifled in one context and encouraged in others. Recommendations for further research included the following: the use of direct observation measures to address the discrepancy between the ratings by students and those of parents and teachers; incorporation of other measures of components of the self-determination construct; the need to explore the possibility of a correlation between level of self-determination and acquisition of skills in academic, social, behavioural or vocational domains.

Sands and Kozleski (1994), did a study where they analyzed differences between the quality of life of adults with and without disabilities and concluded that “most importantly, the degree of choice which individuals with disabilities were able to exercise was significantly limited when compared to adults without disabilities” (as cited in Wehmeyer et al., 1998, p. 49). This reported lack of opportunity for decision making extended from relatively low risk activities such as decorating a room to significant decisions such as who shares a bedroom.

People with disabilities are frequently prohibited from making decisions due to the assumption of incompetence. Wehmeyer and Metzler (1995) did a study in which they found that the majority of both adults and youth with intellectual disabilities were excluded from major decisions that impacted their lives such as where they lived or worked, and that less than 50% had provided consent for their most recent medical procedure (as cited in Wehmeyer et al., 1998, pp. 14-15). Minors are also assumed by most adults to be incapable of making informed choices and decisions. Seven different studies cited in the introduction of Wehmeyer et al. supported Byrnes' supposition that limited mental capacity should not necessarily result in poor decision making. These researchers found that youth with learning disabilities, emotional disorders, as well as intellectual disabilities were all able to participate successfully in the decision making process.

Intellectual functioning, adaptive behaviour, social-emotional development, gender, and attitudes of parents about risk have all been linked to self-determination skills and opportunities as shown in several studies cited by Smith, Morgan and Davidson (2005). In their study, Smith, Morgan and Davidson addressed opportunities for choice making available to adults of various ages with varying degrees of intellectual disabilities living in group homes as compared to same age individuals without intellectual disabilities living in family homes. 'Choice' was defined according to Webster's dictionary as "the right, privilege, opportunity or faculty of freely choosing, picking out or deciding" and was seen as involving the concept of self-determination. These researchers focused on 'routine daily living choices' that are deemed to be controlled by most upon reaching adulthood (e.g., food, clothing, hygiene and leisure) as opposed to

‘major life choices’ (e.g., vocational, residential or personal relationship) that often involve input from others for individuals with and without intellectual disabilities. A 16-item choice availability questionnaire was developed for use in this study. It was completed by one or more of the support people who worked with the individuals with intellectual disabilities in group homes and by one or more persons (usually the parent or other senior member of the household) in the case of the comparison group of individuals without intellectual disabilities. For the purpose of analysis, all individuals were divided into two age groupings (17-39 years and 40+ years) and classified into three ability groups (‘no disability’ for those in households and ‘mild-moderate’ and ‘moderate-severe’ disability for those in group homes, based on ratings by support workers).

It was concluded for all three populations that, once adult status is attained, age did not have a significant impact on availability of choice making as there is a plateau in the trajectory toward the end of adolescence. However, level of disability did have an impact. Adults with milder intellectual disabilities had similar choice making opportunities to those of similar age in the comparison group. Individuals with moderate-severe degrees of disability had choice opportunities equivalent to non-disabled children of 11-12 years of age and those with severe intellectual disability had opportunities similar to non-disabled children of 3-4 years of age. Results of this study are reported to support results of previous research. In conclusion, it was suggested that affording a greater sense of control over these regular routine acts where personal control is expected in adulthood may be important in improving quality of life for people with intellectual disabilities.

Millar (2007) shared information from two previous studies which involved the review of 220 guardianship court files (Millar and Renzaglia, 2002; Millar, 2003). It was found that the “main reasons why guardians were appointed included that young adults were perceived as having limited or no ability to make decisions, and youth were reaching the age of majority”. She also found “that guardianship appointment did not necessarily resolve the areas of concern presented in the courts” (p. 120). Millar then did a study to learn more about the understanding and experience related to guardianship from young adults with disabilities, their parents and educators. The study included six focus groups. One included young adults with moderate cognitive disabilities who had court appointed legal guardians. The second group included young adults with moderate cognitive disabilities who did not have court appointed legal guardians. Groups three and four included the parents of the first two groups, group 3 included the court appointed guardians of group one. The last two groups were special educators who work with young adults and their parents. It was shared that during the selection of the first and third group, four sets of parents assumed they had guardianship and were surprised to learn that they did not as they had not gone through the legal process. These parents were not included in the study. Questions posed to the student groups were carefully worded in an effort to prevent biases that have been shown to threaten validity in previous studies. Transcribed information was sorted and analyzed according to group composition and focus questions, and then issues and concerns were sorted into main themes and sub-themes beyond the scope of the questions.

The results showed more common responses and issues across the three groups (students, parents, educators) than differences. “The advice offered by all three groups

was similar: be involved, be informed, stay current, listen, collaborate, and encourage children/students to advocate for themselves” (p. 125). Some statements or findings unique to the groups and relevant to this thesis are as follows. Students stated, “We are adults. They need to accept that.” Parents from both groups reported that “they constantly worried about the decisions their children made or that they would be taken advantage of”. Parents of young adults with exceptional needs who had been appointed guardianship reported that they found it devastating to have to say in court that their child was incompetent. A parent of a young adult with exceptional needs who chose not to petition the court to become a guardian stated, “We all make mistakes, and we all need help sometime – but that doesn’t mean we need guardians”. Millar concluded that it is crucial that parents, educators, the courts and others give serious consideration to the ‘disconnect’ between self-determination and guardian appointments. Millar included the following quote from Wehmeyer, Agran and Hughes (2000): “The fact that someone may not become completely independent in his or her decision making does not mean that he or she cannot become less dependent or more involved in decisions that impact his or her life.” (p. 127).

### **Circular logic.**

Individuals who are assumed to be unable to make decisions independently often remain that way because opportunities to learn and practice are limited due to this assumption. Shogren et al. (2007) did a study to examine the relationship among individual factors, environmental factors, and students’ self-reported level of self-determination. 327 high schools students aged 14 to 21 from 6 states were included, 49% received special education services under the categories “mild or moderate mental

retardation”, 35% under the category “specific learning disability” and 16% “other health impairment”. A number of instruments were completed by students and educators followed by analysis using a technique known as structural equation modeling. The researchers reported several findings. There were pronounced discrepancies across the disability groups related to capacity but teachers did not report greater opportunities to practice self-determination skills for any particular group of students. Beliefs about the self-determination potential of students with intellectual disabilities can influence the number and quality of opportunities, supports and accommodations provided to them to enhance their capacity for self-determination. If people value and believe it is possible for students with more severe disabilities to become more self-determined, they provide more opportunities for these students to practice, “particularly because students with more significant learning needs require more time to acquire the skills associated with self-determination” (Wehmeyer, 2001 as cited by Shogren et al., p. 503).

While there is some logic to the argument that capacity for self-determination can be influenced by level of intelligence or disability, Wehmeyer (2006) suggested that students may lose out on opportunities to become more self-determined due to circular logic. People assume that an individual is not able to learn the skills necessary to become more self-determined due to their level of disability and so do not provide him or her with the opportunities, supports or accommodations needed to develop self-determination skills. This further decreases his or her ability to increase capacity for self-determined behaviours (as cited in Shogren et al., 2007). It can be difficult to know the extent that an individual’s disability is a barrier because the attitudes of others and the type and level of services they receive may limit their opportunities (Kerzner and Gartner, 1996 as cited in

Hill, 2004). Sands, Bassett, Lehmann, and Spencer (1998) noted that students not only need to develop skills for self-determination, but they also require repeated opportunities to apply and generalize skills such as decision making and planning. This notion is further supported by Grigal et al. (2003) in the statement, “students are more likely to develop these skills if they are given opportunities to learn and apply them” (p. 99).

Wehmeyer and Schwartz (1998) asked if individuals with significant disabilities can be self-determined and answered unequivocally ‘yes’, explaining that the available literature clearly shows that individuals with significant disabilities can express preferences, make choices and decisions, become less dependent, and can learn to manage and self-regulate their behaviour. However, instead of a focus on the misinterpretations of self-determination, we must concentrate on providing adequate opportunities for practice, enabling maximum participation in life and community and ensuring proper accommodations and supports. This is what will enable each individual with significant disabilities to become as self-determined as possible.

### **Decision Making and the Impact of EAs**

The final area of research to be explored is the impact of the presence of EAs on decision making opportunities for students with intellectual disabilities.

One of the most commonly selected solutions to supporting students with severe disabilities in general education classes is to assign an individual EA on a full-time or part-time basis (as cited in Giangreco, Broer and Edelman, 1999; Giangreco, Smith and Pinckney, 2006; Broer, Doyle and Giangreco, 2005). EAs are referred to by a variety of titles in various jurisdictions around the world, and are provided to support students with

exceptional needs in several countries including Canada, Finland, Germany, Hong Kong, Iceland, Ireland, Malta, United States and perhaps, other places as well (Giangreco and Doyle, 2007). According to the Vermont Department of Education (as cited in Giangreco, Smith and Pinckney), the percentage of students with diagnosed disabilities included in general education classes has declined from 1990 to 2004, yet the estimated number of EAs has increased from 1186 to 3462.

In Manitoba, most students with moderate to severe intellectual disabilities are supported through provincial low incidence level 2 or level 3 funding (Manitoba Education, 2010, *Special Needs Categorical Funding*). School divisions often translate this funding into the support of an EA for 50% or more of the school day.<sup>3</sup> Sometimes the EA is assigned to the classroom to support all or several students in that class, or may be assigned to work specifically with an individual student or a small group. This range of possible supports appears to be common. In some places, EAs may also be used primarily for clerical duties or supervision, in order to free up the teachers for instruction (Giangreco and Doyle, 2007).

Giangreco and Doyle (2007) reported that, as the number of students with disabilities who are being educated in inclusive settings has been increasing over the past 30 years, the number of EAs has increased dramatically with their roles becoming increasingly instructional in nature. Although they are careful to not place blame on EAs, who tend to be very dedicated and caring of the students in their charge, research has shown that their presence can have unintended detrimental effects. Giangreco and

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<sup>3</sup>Note: I attempted to ascertain an estimate of the total number of EAs employed in Manitoba by speaking to a manager in the Student Services Unit at Manitoba Education and through e-mail contact with an executive member of Educational Assistants of Manitoba. In both cases, I was informed that the information is not known.

colleagues have listed a number of inadvertent detrimental effects of excessive or unnecessary EA proximity including (a) separation from classmates, (b) unnecessary dependence, (c) interference with peer interactions, (d) insular relationships, (e) feeling stigmatized, (f) limited access to competent instruction, (g) interference with teacher engagement, (h) loss of personal control, (i) loss of gender identity, and (j) behaviour problems (Giangreco et al., 2005; Giangreco and Doyle). It could be argued that all of these potentially detrimental consequences would have a significant impact on the development of self-determination skills and many have the potential to directly impact the development of decision making skills. One of the recommended considerations for school teams that may give back some control to the students with exceptional needs is to explore ways to involve them in making decisions about their own supports. Giangreco et al. advised that we should not assume the need for EA support based on appearances or labels, but should first contemplate adapting the school environment and taking into consideration alternatives to EA support such as peer supports and support/instruction by professional educators.

Giangreco and Doyle (2007) believe that,

Decisions about the utilization of teacher assistants appear to be driven more by factors such as politics, local historical practices, and advocacy, than by educational research or theoretical foundations. The literature is devoid of convincing arguments that it is educationally sound to deploy the least qualified personnel to provide the primary instruction to students with the most complex learning characteristics. To the contrary, it has been posited that such scenarios are illogical and reflect devaluing double

standards that likely would be considered unacceptable if they were applied to students without disabilities (p. 432).

They recommended future research on topics such as the effects of EA supports on students with regard to academic/functional achievement, social relationships and self-determination; studies that solicit input from the students with disabilities and their families; study of the effect of school policies, funding and service delivery models on supports for students; and the use of decision making models to determine the most appropriate supports for students in inclusive settings.

In keeping with some of the concerns outlined by Giangreco and other researchers, I have observed that students with moderate to severe cognitive disabilities tend to be specifically supervised from the time they arrive at school until the time they leave, including recess, lunch hour, assemblies and other less-structured periods of the school day, during which other students have more freedom. EAs feel responsible and are made to feel responsible by teachers and administrators who supervise and direct them. In fact, EAs are sometimes even held responsible for the behaviour of the student(s) in their charge. If the student 'gets into trouble', so does the EA. Powers et al. (1996) stated, "Many youth with challenges also have a history of being provided with well-meaning assistance from others that inadvertently deprives them of opportunities to learn problem-solving [and decision making] skills" (p. 270).

Broer, Doyle and Giangreco (2005) studied the perspectives of persons with intellectual disabilities related to the impact of EA support in inclusive settings. They interviewed 16 young adults with intellectual disabilities using a topical interview guide which included four broad categories including (a) rapport building, (b) experience in

school, (c) perspectives about the support they received, and (d) advice they would offer to school personnel. A semi-structured interview format was used to allow for follow-up questions based on individual responses.

The findings revealed the “primacy, and sometime exclusivity, of relationships between these former students and the paraprofessionals assigned to them” (p. 420). This was shown through the four roles that emerged based on the perceptions of the participants: EAs as a mother, a friend, a protector, the primary teacher. Specific comments or concerns included many that are related to limiting opportunities to make choices or decisions. For example, the presence of a EA interfered with opportunities to (a) make friends, (b) to have a girlfriend or boyfriend, (c) to sit at the back of the room with the other kids, (d) have conversations with friends, and (e) be independent in certain classes or during certain times of the day when they did not need support. A common experience reported in this study was that participants would get frustrated with the constancy of EA support. They made comments related to feeling embarrassed or like they had a babysitter or that they were getting tired of having someone with them all of the time. One student stated, “I want to be independent...in the halls, in the cafeteria” (p. 424). Providing protection from bullying was one of the themes identified by Broer et al. (2005). However, participants indicated that they would end up getting bullied anyway, at a time when the EA was not nearby. Therefore, Broer et al. suggested that students with disabilities “need opportunities to learn decision making regarding what to do when confronted in bullying situations” (p. 425).

EAs could play an important role in helping students build skills such as decision making and self-advocacy. However, a better understanding of this potential role is required by the EAs and, more importantly, by those who supervise or direct them.

### **Themes Connecting the Literature Review to My Thesis**

In this section, I will identify the main themes and gaps from the literature review and connect these to my research.

One theme that appears in more than one body of literature is that the ability and opportunity to determine direction and make decisions about our own lives is equated with quality of life for all human beings. A related finding in the self-determination literature is that one of the most critical competencies students need in order to be successful after high school is the ability to make effective choices and decisions. It has been shown that individuals with intellectual disabilities who are highly self-determined when they leave high school demonstrate more positive outcomes as adults, including employment and independent living, than those who are less self-determined. In other words, they enjoy a better quality of life. There is a significant difference in the opportunities to make decisions between individuals with and without intellectual disabilities, with those with intellectual disabilities having fewer opportunities to practice self-determined behaviour, including decision making. Decreased opportunities to participate meaningfully in choices and decisions negatively impacts quality of life, and also reduces the ability of these individuals to advocate for themselves. If you are not recognized as competent to identify your wants and needs and to advocate for them, the likely result is a further reduction in quality of life. The majority of research in these

areas included adults with intellectual disabilities. My research helps address this gap as it focused on comparing the perceptions of high school students with and without intellectual disabilities about their opportunities to make decisions.

A related theme identified in the literature is balancing decision making opportunities with risk. This appears in three ways. The first is the need to find a balance between decision making autonomy and duty of care in situations where an individual's disability affects their judgment and discernment. The second perspective is balancing decision making opportunities with the ability of individuals to participate in a meaningful way (e.g., individuals who are unable to make their needs/wants known). Finally, there is the need to recognize levels of risk and balance this with the importance of taking risks. The research in these topic areas concerns adults and adolescents with exceptional needs, but is generally based on the perspectives of caregivers, parents and educators. The voice of individuals with exceptional needs did not appear in this literature base. In my research, teachers, EAs and an administrator had the opportunity to explore their own perspectives on the topic of risk and decision making as they examined the perceptions of the students.

The research addressing the impact of EAs on self-determination skills, including decision making, demonstrates there is strong potential for a number of inadvertent detrimental effects on students with disabilities. However, it was also suggested that EAs can be valuable in facilitating decision making opportunities, self-determination and self-advocacy skills if they and those who direct them understand and promote this positive role. This body of research does include a small number of studies where individuals with exceptional needs are given a voice, but the majority of studies do not include that voice.

The research in the area of decision making theory and practice firmly established steps or processes involved in making decisions that can be taught to all individuals. The processes involve thinking, evaluating options, implementing the selected option and learning from that experience. It is clear that the only way decision making skills actually improve is through experience. People need to experience both positive and negative outcomes of their decisions in order to improve their decision making competence. It is recommended that children and adolescents have the opportunity to practice making decisions and experiencing the consequences while they have access to encouragement and information from trusted adults, such as parents and educators. This research was used during my discussion with teachers, prompting them to reflect upon their own practice.

It is important to note that in any given population, we will find individuals with a range of decision making capabilities based on each individual's ability to self regulate and compensate for limitations, biases and tendencies. Individuals who recognize their own strengths and weaknesses and use strategies such as doing research or requesting assistance from others tend to enjoy more positive outcomes than those who are not self-aware or who do not seek to improve their decisions. Finally, even highly self-regulated, successful decision makers sometimes make poor decisions, and need to evaluate and adjust accordingly. This research suggests opportunities for competent adults to provide appropriate scaffolding and support to children and youth with and without disabilities in order that they may improve their decision making skills. Research on decision making theory and practice primarily involved adults, with a small number of studies addressing children and adolescents. However, this body of research is also devoid of the studies that

involve individuals with intellectual disabilities. Through my study, I introduce the voice of individuals with intellectual disabilities into the research on decision making.

In Chapter III, I outline the methods I used in my study.

### Chapter III: Methods

In this chapter, I explain the methods used in carrying out my study. The chapter begins with an overview of the three phases of the study, the context in which the data collection occurred and outlines the process followed to acquire approval through the Human Subject Research Ethics Protocol. The latter part of the chapter is used to explain how participants were selected, and how I collected and analyzed my data. The chapter concludes with a brief overview of the research methods. It should be noted that processes evolved as the study progressed since the exploratory nature of qualitative research requires flexibility in design.

I chose a qualitative research design for my study because I wanted to obtain and compare the perspectives of high school students with and without intellectual disabilities regarding their decision making opportunities during the school day and school year. I also wanted to explore with staff members at the school, perceived reasons for similarities or differences in the decision-making opportunities between these two groups of students. Caudle (1994) wrote that the researcher “collecting qualitative data looks for similarities and dis-similarities...[and] asks why there are similarities and why there are differences” (p. 70). This is precisely what I intended in this study.

Focus groups bring together selected knowledgeable persons for discussion of a particular topic or theme under the supervision of a facilitator (Rossi, Freeman and Lipsey, 1999, p. 148). I elected to interview focus groups in recognition of the view that a modest number of focus groups can provide a wealth of descriptive information that can be useful in exploring the complexities of actual experiences of individuals with and

without intellectual disabilities (Rossi et al., 1999; Taylor, Bogdan and Lutfiyya, 1995). In addition, I anticipated that participants would feel more comfortable speaking to me as part of a group rather than individually since I was unfamiliar to them. Generally, only one administrator in a school has primary responsibility for the area of student services, therefore an interview was used to gather data from that perspective.

The study was conducted in three phases as outlined in Table 2.

**Table 2**  
**Three phases of the study**

<b>Phase</b>	<b>Process</b>	<b>Participants</b>
One	Tested the focus questions with a mixed group of students	Mixed group: 3 students with and 3 without intellectual disabilities
Two	Explored perceptions of students with and without disabilities regarding their opportunities to make decisions at school through two focus groups	One focus group: 5 students without intellectual disabilities One focus group: 6 students with intellectual disabilities
Three	Shared results of analysis from first two phases of study with involved staff members and explored perspectives and opinions regarding similarities and differences	One focus group: 3 classroom teachers and 2 professional student services staff One focus group: 5 EAs One interview: 1 School Administrator

As indicated in Table 2, the first phase of the study involved gathering data from a focus group which included students with and without intellectual disabilities. The data from the phase 1 focus group was then used to develop a list of codes representing the types of decisions that students reported to have an opportunity to make in the high school setting during a school day and school year. By including the names of the students in the transcript for this focus group, and knowing which students had a diagnosed intellectual disability, I was able to add the data obtained from this mixed group to the data from the groups in phase 2. The list of codes developed through analysis of the phase 1 focus group data was then used as a starting point for the phase 2 focus groups. The data from phases 1 and 2 were then coded and analyzed, to create a comparison of the perceptions of students with and without intellectual disabilities.

During the third phase of the study, the comparative results were shared with teachers, EAs and an administrator. This phase was used to investigate the third research question, exploring possible reasons for the similarities and differences in the perceptions of the two groups of students with staff members who work in that high school.

### **The Research Context**

One suburban school division in the province of Manitoba was approached to participate in this study. Data were collected at one high school in that suburban school division where a substantial number of students with significant intellectual disabilities are included within the school. For purposes of protecting privacy, the school division, school, and study participants are referred to with fictitious names and/or by titles only. Data were collected during May and June of 2009.

### **Human Subject Research Ethics Protocol**

In the spring of 2008, application was made to the Education/Nursing Research Ethics Board (ENREB) at the University of Manitoba, in accordance with the Human Subject Research Ethics Protocol. Also in spring, 2008, my advisor and I met with the Assistant Superintendent of Student Services of the selected school division to discuss the possibility of conducting my study there. She expressed interest and suggested two high schools that might be approached. In early September, 2008, I received formal approval from the Assistant Superintendent to do the study in that school division. In October, I was given conditional approval by ENREB, which allowed me to make initial contact with the administration of the selected school to work out some details related to my study. I then contacted the school division Coordinator of Student Services who provided support in selecting a high school that had a student population appropriate to the purposes of my study. The Coordinator of Student Services also helped facilitate my initial contact with the administrator and student services department head at the selected high school. Later in October, I made a presentation to the school administrator and the student services department head outlining the purpose and plan for my study, and left them with some print information as they considered my request. Approval was granted via an e-mail message within a few days with an agreement to begin the process of identifying potential participants later in the fall, after ENREB granted full approval. Full approval was received in November, 2008. I notified my school contacts of the approval and asked that they initiate the process of identifying potential participants. Due to a number of unforeseen circumstances, the process of distributing and collecting consent

and assent forms was interrupted several times during the school year, with all forms finally being accounted for in mid-April, 2009. The student focus groups took place in May, 2009 and the adult focus groups and interview with the administrator took place in June.

### **Participant Identification**

Miles and Huberman (1994) described key features of qualitative sampling. They stated that qualitative research generally involves "small samples of people nested within their context" (p. 27). Qualitative samples are further described as purposive rather than random. They go on to advise that qualitative researchers need to set boundaries by defining aspects of our subjects that connect directly with their research questions. One typology of sampling for qualitative research they defined is called criterion sampling, where all cases meet some criterion (p. 28). My research involved small samples of people from one high school in Manitoba. Groups of potential participants were purposefully selected according to various criteria. The sampling in my study also involved a degree of self-selection, in that potential participants had to express interest in order to receive consent and/or assent forms.

Upon my request, a school administrator recommended 11 potential student participants who met the criteria for students without intellectual disabilities, as defined in the introduction of this thesis, and who were considered to be representative of the student body. In addition, the student services department head recommended 10 students with intellectual disabilities who met the criteria for students with intellectual disabilities, also as defined in the introduction of this thesis.

The administrator and department head made initial contact with students and parents to introduce me and the study through a letter I supplied. It included a tear-off signature portion representing an expression of interest to participate in the study (Appendix A). Once these were collected and returned to me, I provided the school with consent and assent forms to be sent home to each student/family who indicated interest in participation (Appendix B). This communication provided a more detailed explanation of the study, what would be expected of the students if they agreed to participate, addressed issues of confidentiality, and offered participants a gift certificate upon completion of the study as an expression of my appreciation. The students with and without intellectual disabilities who returned the signed consent and assent forms were randomly assigned to a group in either phase 1 or 2.

As shown in Table 2, the third phase of the study involved collection of data via two focus groups (teachers and EAs) and one interview (school administrator). I approached the student services department head with a request to meet with a group of teachers who had some involvement with students with intellectual disabilities. I provided her with assent forms to distribute accordingly. The assent forms gave a detailed explanation of the study, what would be expected of the staff members if they agreed to participate, addressed issues of confidentiality, and offered participants a gift certificate upon completion of the study as an expression of my appreciation. Once the date and time was set for the teacher focus group, the department head used e-mail messages to invite teachers who met the criterion and had spares during that class period, to participate in the study. She then provided assent forms to those who expressed interest.

I contacted the school administrator who had primary responsibility for overseeing the Student Services Department at that school, and arranged to do the interview on the same day as the teacher focus group. The administrator and teachers brought the signed assent forms with them to the interview and focus group.

Once the date and time were set for the EA focus group, the student services department head invited EAs to participate in the study. Those who expressed interest were provided with a copy of the assent form and coverage schedules were arranged so that they were freed up to participate. The EAs brought the signed assent forms with them to the focus group.

Groups were interviewed separately in an effort to gather information from diverse perspectives and to help group members feel comfortable sharing information from their particular perspectives.

### **Data Collection**

I facilitated each of the five focus groups and conducted the interview with the administrator. The focus group meetings lasted 60-80 minutes and the interview lasted approximately 40 minutes. Group rules were reiterated at the beginning of each session as follows: no right or wrong answers, what is said in the group stays within the group, and that everyone was encouraged to speak freely.

Two EAs were in the room during the time I met with the phase 1 focus group. They were there provide support to students who required it for communication or other individual needs. As per my request, the EAs allowed the students to respond to questions as independently as possible. One EA was in the room during each of the times I met

with the phase 2 focus groups. While I met with the groups that included students with special needs, the student services department head sat in the room for a portion of each session.

For purposes of transcription, analysis and accuracy in data collection, all focus group discussions and the interview were audio-recorded. In addition, a graphic facilitator assisted me by graphically recording the discussions with all three student groups (O'Brien, Forest, Snow and Hasbury, 1989, p. 52). Immediately after each focus group session, the graphic facilitator and I reviewed the graphic record to confirm accuracy. The graphic record was intended as respectful support to students who found reading challenging or impossible and/or oral communication difficult to follow. In addition, the graphics became very useful references when transcribing the audiotapes. Finally, they were used to start the conversations with the adults who participated in the study.

### **Phase 1: Mixed focus group.**

After brief introductions and establishing ground rules, I asked students to lead me through a typical day from arrival at school to departure, identifying as many decision making opportunities as possible. Students were provided with copies of their timetables to use as a visual prompt. In addition, I prompted students to consider 'less frequent' decision making opportunities (e.g., participation in the Individual Education Planning [IEP] process, course/program selection, work experience placements). Please see interview protocol (Appendix C) for further information.

Following the meeting with the mixed group and before conducting the next two focus groups, the recorded data were transcribed directly into a pre-prepared Microsoft

(MS) Excel spreadsheet and verified with the graphic record (See Figure 1). First, I coded the decision making opportunities identified by the participants according to the parts of the school day (i.e., before school, during class time, lunch hour, etc.). I then noted and coded according to types of decisions (e.g., related to classroom assignments, friends, leisure/free time, etc.) and how decisions were made or on what they were based (e.g., fun, information, long-term goals). This became the draft list of codes for use with the next set of student data. I reviewed the focus questions and data with my advisor. It was determined that the same list of questions would be used with the other student groups because they resulted in useful data from the mixed group. Some minor revisions were made such as adding examples for clarification. One additional question was added.



**Phase 2: Students with and without intellectual disabilities.**

Following an introduction and review of the ground rules, as with the mixed group, the sessions for the groups with and without intellectual disabilities were conducted using the revised list of questions. The question that was added following the mixed focus group was used for the group without intellectual disabilities and then removed for the group with intellectual disabilities because it prompted minimal responses.

Many of the students with intellectual disabilities required more time to express their thoughts and seemed to enjoy sharing information in quite a lot of detail when they had the opportunity. This was especially evident when working with the group comprised exclusively of students with intellectual disabilities. As a result, I ran out of time and was not able to ask the last of the questions that had been asked of the other two groups. Unfortunately, the fact that it was quite late in the school year and that I still had to meet with the adult focus groups, made it impossible to meet with this group for a second time. This outcome was disappointing as it resulted in less data on the topic of course selection. However, I believed it was important to allow the students the time they required to share their perspectives.

All audio-recorded data from the two groups were transcribed directly into a pre-prepared MS Excel spreadsheet that included a column for coding parts of the school day when decision-making opportunities were reported, as well as columns for coding information related to the types of decisions and how decisions were made. A column for limitations on decision making was added after the third focus group. The transcribed data were also verified through comparison with the visual data supplied by the graphic

facilitator (See Figures 2 and 3). Transcription into the spreadsheets resulted in 65 pages of data from the three student focus groups, and took approximately 30 hours to transcribe. I began with the codes developed through the analysis of data from phase 1. During analysis of data from the students without intellectual disabilities, I added additional codes under the phase 1 headings, and added one more group of codes (i.e., who else makes decisions). When the data from the students with intellectual disabilities was added, the code list continued to evolve with the addition of a section related to limits placed on decision making. (See Appendix D for final code list.)

Throughout data collection, coding and analysis, I created memos on the edges of whatever pages I was using at the time. Memos are ‘notes to self’ made by the researcher to record thoughts and ideas as they occur during data collection, coding or analysis. Typically, memos tie together concepts or relationships observed in the data, but may relate to any aspect of the study. In addition, a contact summary sheet (see sample in Appendix E) was completed following transcription of each set of focus group data to facilitate reflection on main concepts, themes, issues and questions noted during each contact (Miles and Huberman, 1994).

Figure 2. Graphic record of data from students without intellectual disabilities





**Phase 3: Teachers, EAs and administrator.**

When each group of adult participants entered the room, they found the graphic records from the student groups on display and were given time to view these prior to the start of the focus group. Following an introduction and review of the ground rules, I reviewed the graphic records and then began asking the focus questions from the protocol. Results of the analysis of the student transcripts were shared as part of the interview protocol. Questions focused on the participants' perceptions of the data and reasons for similarities and differences between data from students with and without intellectual disabilities. (See Appendix F.)

Due to the close proximity in time, all audio-recorded data from the adult focus groups and the interview with the administrator were transcribed after data collection was complete. Once again, audio-recorded data were transcribed into an MS Excel spreadsheet that included a column for coding similarities or differences between data from students with and without intellectual disabilities as per my research question. A column for coding other factors perceived to have had an impact on decision-making opportunities was also included. Transcription into spreadsheets resulted in 73 pages of data from the two adult focus groups and the interview and took approximately 25 hours to transcribe. In addition to coding similarities and differences between perceptions of student groups, I also coded staff observations as to whether statements suggested an opportunity or a limitation on student decision making. Limitations were further coded according to who established that limit (i.e., teacher, EA, parent, student) and what factor(s) came into play (e.g., safety, structures, attitudes, student gender, student age,

presence of an EA). The initial list of codes was based on factors identified in the research outlined in the Chapter II. The codes for the adult data evolved as the analysis progressed so that new codes were added to the initial list. (See Appendix I for final transcription codes.)

Once again, I wrote memos on an ongoing basis throughout data collection, coding and analysis. As with the student focus groups, a contact summary sheet was completed following transcription of data from each adult focus group and the interview.

During the focus group discussions and interview, I used the focus questions to initiate discussion around a particular topic. Once the discussion began, I adjusted my questions and comments throughout my time with each group (and individual during the interview) based on the perspectives and information shared by participants. For example, I may have asked for clarification or followed the lead of a participant by inviting him or her to share further information on a topic of particular interest. This process sometimes resulted in gathering data that was not anticipated when the focus questions were created, resulting in themes that go beyond the focus questions.

### **Data Analysis**

The use of MS Excel spreadsheets allowed me to begin my analysis by selecting and sorting the data based on the codes. As mentioned, the start list of codes from the mixed group of students was used and revised to suit transcribed data collected from subsequent student groups. Once the final codes were established, data from all three groups were re-coded using the revised codes (See Appendix D). Using the sort capabilities of the spreadsheet, I sorted the data using the 'type of decision' codes as they

matched most closely with my thesis questions (i.e., classroom activities [CAC], classroom assignments [CAS], etc.). I then examined the comments made by students with and without intellectual disabilities in each of the three student focus groups separately, looking for themes, similarities and differences in the opportunities and limitations they perceived. (See Appendix G for sample of coded student transcript.) Comments that did not fit any particular pattern were disregarded as outliers. In the next step, I created a new spreadsheet to record summary statements that represented my observations of the coded and sorted data for each student focus group. I also noted the limitations perceived by the students and included other information or comments that appeared significant. This process was termed “pattern coding” (Miles and Huberman, 1994, p. 57) and may also be described as cross-case analysis. (See Appendix H for sample of Pattern Coding-Student Data.) Once again, I used the sorting feature of the second spreadsheet to compare the summary statements amongst the three groups, focusing on the similarities and differences in perceptions between the data from the students with and without intellectual disabilities. Information from memos and contact summary sheets was also reviewed and considered for inclusion at this stage.

Analysis of the transcribed data from the staff focus groups and interview followed a process very similar to that used for analysis of the student data. The start list of codes for analysis of the staff data was based on information from the literature review outlined in Chapter II. This list evolved as it was used to code each set of staff data. Once the final list of codes was established, I re-coded all three sets of staff data using the revised list of codes (See Appendix I). Working with one set of staff data at a time, I began by sorting and counting coded statements where staff members pointed out

similarities or differences between data from students with and without intellectual disabilities. I placed this information in a new spreadsheet created for the summarized data. Next, I sorted data based on the part of the school day/year (i.e., class time [CT], lunch time [LT], etc.) and noted opportunities facilitated and limits placed on student decision making during those times. I also noted other factors perceived to have had an impact on decision making opportunities (i.e., personal characteristics, environmental factors, other). All of this summary data was placed in the summary spreadsheet.

Comments that did not fit any particular pattern were considered to be outliers and were disregarded. Next, I wrote summary statements based on each set of staff data sorted by part of the school day/year and highlighted specific observations or statements from the transcripts. (See Appendix J) Finally, I used the sort feature of the spreadsheet to compare and contrast the summarized data from all three adult sources. As with the student data, I also took into account the information from the memos and contact summary sheets at this stage of analysis.

After analyzing the student and staff data separately, I then completed a key theme analysis as I used the spreadsheet sort function to compare the summarized data from the three student data sources with the summarized data from the three adult data sources. This resulted in the identification of three main themes. Once again, the memos and contact summaries were taken into consideration during this level of analysis.

### **Summary of Methods**

To summarize, I wanted to compare the perspectives of students with and without intellectual disabilities and the perspectives of members of the school teams who support

them. I used qualitative research methods and conducted five focus groups and a single interview to collect data. All of the data were transcribed verbatim directly into pre-prepared MS Excel spreadsheets that contained columns for coding. This resulted in 138 pages of data and took a total of 55 hours to transcribe. Coding the data took place in stages and the codes evolved as analysis progressed. In addition to coding, I wrote memos and completed contact summary sheets, the content of which was considered during analysis. Once data from the students and staff were analyzed separately, a key theme analysis was completed which included data from all six sources.

In the next chapter, I present my findings.

## Chapter IV: Findings

In the first part of this chapter, I summarize the data collected from the students with and without intellectual disabilities. Table 3 is used to provide an overview of the two sets of data, which is organized according to the parts of the school day and events or time periods during the school year, as identified during data collection and analysis. I then expand upon the summarized data obtained from the students with and without intellectual disabilities, providing specific examples from the transcripts and highlighting similarities and differences. Similarly, in the latter portion of this chapter, I summarize the data collected from the teacher focus group, the EA focus group and the interview with the school administrator in Table 4. Once again, the data are organized according to the parts of the school day and events or time periods during the school year, as well as topics or themes that resulted during data collection and analysis. I then expand upon the summarized data by sharing information and examples from the transcripts, while comparing and contrasting the data from the three sources. I end the chapter by sharing the results of a key theme analysis of summarized data from all six sources, culminating in three major factors that appear to impact decision making opportunities for students with and without intellectual disabilities in ways that are sometimes similar and sometimes quite different.

**Student Data**

Data was collected through three student focus groups at one suburban high school in Winnipeg. The first was a mixed group that included three students with and three without intellectual disabilities. The second group was comprised of five students without intellectual disabilities and the third was comprised of six students with intellectual disabilities.

I prompted the students to walk me through their school day, sharing opportunities they perceived they had to make decisions during the hours from the time they left home to come to school until they returned home at the end of the day. The information is organized according to the parts of the school day and events or time periods during the school year. It is summarized in Table 3 and then expanded upon, compared and contrasted in the text following the table.

**Table 3**  
**Overview of data from students with and without intellectual disabilities**

<b>Topics/Themes (Generally part of school day/year)</b>	<b>Students without intellectual disabilities</b>	<b>Students with intellectual disabilities</b>
Classroom Activities	<ul style="list-style-type: none"> <li>• Few decision making opportunities</li> <li>• Some limited choices</li> <li>• Spares offered opportunities to decide what to do, where to be, with whom</li> <li>• Some students chose to not participate; others did not see non-participation as a choice</li> </ul>	<ul style="list-style-type: none"> <li>• Few decision making opportunities</li> <li>• Some limited choices</li> <li>• No students reported having a spare</li> <li>• Students participated in recreational/leisure activities during some class periods</li> </ul>
Classroom Assignments	<ul style="list-style-type: none"> <li>• Occasional choices regarding format of final copy (e.g., scroll, book)</li> <li>• Small number of opportunities when given a framework for a project and then permitted to make most other decisions</li> </ul>	<ul style="list-style-type: none"> <li>• Occasional choices regarding format of final copy (e.g., design, colour)</li> <li>• Frequent opportunities to work on assignments adapted or modified to individual interests/needs</li> <li>• At least one period/day in student services area for support or student specific learning</li> </ul>
Less structured parts of school day	<ul style="list-style-type: none"> <li>• Most decision making opportunities and fewest limits occurred during these parts of day</li> <li>• Students decided when, how to arrive/leave school</li> <li>• Students decided what to do, where to be, with whom before/after school, during breaks and lunch</li> </ul>	<ul style="list-style-type: none"> <li>• Few decision making opportunities during these parts of day</li> <li>• Most traveled to/from school by school bus</li> <li>• Most stayed in or checked in at student service area with EAs before class, during breaks and lunch</li> </ul>

**Table 3 (cont.)**

<b>Topics/Themes (Generally part of school day/year)</b>	<b>Students without intellectual disabilities</b>	<b>Students with intellectual disabilities</b>
Special Events (e.g., pep rallies)	<ul style="list-style-type: none"> <li>• More than half chose to not attend</li> <li>• Those on teams participated</li> </ul>	<ul style="list-style-type: none"> <li>• All attended, no awareness of choice</li> <li>• One student had participated</li> </ul>
Co-curricular Activities	<ul style="list-style-type: none"> <li>• Almost all involved in something</li> <li>• Chose activities they were good at, enjoyed, friends were involved in</li> </ul>	<ul style="list-style-type: none"> <li>• Three students involved-one team/club each</li> </ul>
Course Selection	<ul style="list-style-type: none"> <li>• Strong connection between course selection and post-school choices</li> <li>• If post-secondary plan not established, “keep options open”</li> <li>• Course selection limited and/or influenced by parents and post-secondary plans</li> </ul>	<ul style="list-style-type: none"> <li>• No mention of connection between courses and post-school choices</li> <li>• Decision making opportunities occurred during IEP meetings (students needed prompting to remember)</li> <li>• Few limits placed on them regarding course selection</li> </ul>
Friends	<ul style="list-style-type: none"> <li>• Peer friends play a large role in decisions made throughout school day/year</li> </ul>	<ul style="list-style-type: none"> <li>• Minimal mention of peer friends</li> <li>• Treated EAs and school secretaries as friends</li> </ul>

**Data from students without intellectual disabilities.**

This represents the combined data contributed by the three students without intellectual disabilities in the mixed group as well as the five students in the group comprised only of students without intellectual disabilities as they walked me through a typical school day and through parts of their school year. One topic area addressed in this section, 'friends', does not fit the pattern of the other topics. However, I chose to include it because of how frequently the topic entered into our conversations, in spite of the fact that I did not plan to ask specific questions about friends during the focus group discussion. In addition, analysis of the data suggested that it is a topic worthy of mention because there were significant differences between data from students with and without intellectual disabilities on this topic.

***Classroom activities.***

When talking about classroom activities, students without intellectual disabilities reported that they had few decision making opportunities available to them. Generally, they reported that the teachers orchestrated their classes and made the decisions about what would happen during each class period. During physical education classes, students reported they were sometimes given an opportunity to vote on which activity or game the class would play. This was perceived as a group decision and not one that was made individually. Foods classes also offered some minor decision making opportunities such as what job or role each group member would play during that class period and some limited choices related to ingredients in certain recipes or what condiments to put on the food before eating it. These examples would better be described as limited choices than real decisions.

When a student had a spare period in his/her schedule, he/she had the opportunity to make real decisions around where to be, with whom and what to do. This included being allowed to leave the school premises. The only limit perceived by the students was that they were not permitted to wander the hallways during a spare. If they were in the school, they had to be in the library or cafeteria. One student reported, “You can go to the library and sit with friends or sometimes I do homework...Sometimes I go to the mall or sometimes I go home...”

During scheduled classes, the only decision students perceived was the degree to which they would participate in whatever the teachers had planned. Some students reported making decisions to participate or not on a daily basis, and indicated that they were willing to suffer the consequences of deciding to not participate (e.g., lower marks). More than one student did not appear to make the connection between marks and level of participation. Others indicated that they did not see ‘level of participation’ as a ‘real’ choice because they would ‘fail’ or get low marks if they did not do what was expected by the teacher. One student summed it up by saying, “I don't really see it as choice. I file it as best strategy.” When students were asked how they felt about the fact that they had very few decision making opportunities in classes, most responses were encapsulated in the following statement from one student, “I don't care as long as I'm doing good in the class.”

It is interesting to note that the types of decision making opportunities that offer students without intellectual disabilities the most freedom, the most significant risks and, therefore, the most significant opportunities to improve decision making capacity, occur

in situations outside of class activities when students have the least access to adults who could support and coach them.

*Classroom assignments.*

In some classes, students reported they were given some choices when it came to the presentation of assignments. For example, they might be permitted to choose what format the 'final copy' of a project would take (e.g., a hand-written scroll, a type-written book, etc.). For some projects, students reported being given a framework and some parameters within which they had the opportunity to make a lot of decisions (e.g., write a paper, create a poster, create a video documentary). Students appeared to be more enthusiastic when talking about assignments where they had more freedom. It also appeared that decision making opportunities such as these did not come up very frequently.

There is some risk of failure in allowing students this amount of freedom in an assignment, as students could get off the expected path and would then suffer the consequences of that. This type of freedom also allows students the opportunity to propose an idea and negotiate with a teacher who could coach and support them as they make their decisions. The risk of failure and the opportunity for coaching by an adult both contribute to opportunities for growth in decision making capacity.

*Less structured parts of the day.*

The students without intellectual disabilities shared that most of their decision making opportunities occurred during less structured times of the school day such as before class, during class breaks, at lunch time and after school.

Before classes start, students reported that they had already made a decision about when to arrive at school (i.e., 30+ minutes before class starts, just as class is starting or later than the start time). Many students reported that they also had the opportunity to decide how to get to school (e.g., public transit, getting a ride from parents, walking). The students who chose to arrive early reported that they used that time to ‘hang out’ with one friend or a group of friends. Those who arrived closer to the start of classes had just enough time to get to their lockers and then to their first classes. Some students reported that they arrived late for the start of class or even missed the entire first period at times. These were real decisions that involved the risk of consequences (e.g., detention for being late, displeasing a friend by choosing to spend time with another), which means they provide opportunities to learn to make better decisions in the future.

During the 10-minute break between classes, students indicated that they had several options from which to choose. They could go straight to their next class, go to their lockers, get some food at the cafeteria, hang out with friends, or some combination of these. What they did during that break was determined by the tolerance level of the next teacher for students who were late (possible consequences), whether or not they saw friends in the hallway on their way to class (opportunity), or personal preference. When students had to travel from one building to another for their next class, they needed most of those ten minutes just to get there.

Lunch time appeared to offer many decision making opportunities for students without intellectual disabilities, with few limitations. During that time period, students could choose where to be and with whom, what to do and whether or not to eat lunch. It appeared that most students used that time to be with their friends. Some left the school

grounds over the lunch hour and others stayed inside the school or went outdoors on the grounds. Some were involved in intramurals in the gym while others watched. Sometimes the time was used to complete homework or go shopping at the nearby mall. At times, special events were held over the lunch hour such as spirit week or multi-cultural week. One of the students had been involved in organizing such events during the previous school year and continued to participate in them. Other students took little or no interest in such events and preferred to leave the school or spend time with friends. Very few student participants indicated that they went to the school cafeteria at lunch due to the long line-ups. One student indicated that she avoided the line-up by pre-ordering her food. Others reported that they bought their food during a break or a spare instead and even ate it then so that their lunch hour was free for intramurals or to hang out with friends. A surprising number of students in this group indicated that they often did not eat lunch and just waited until they got home.

This group of students also reported that they had significant freedom to make decisions at the end of the school day. Some of the options included: going straight home, hanging out with friends involved in an activity such as skateboarding or just standing around and talking, participation in co-curricular activities such as school teams, participation in teams at a community club, music lessons, going shopping or to see a movie with friends.

### *Special events.*

Occasionally, special events were held during class time, such as school pep rallies or fund-raising events. More than half of the participants without disabilities indicated that they decided not to attend pep rallies and simply left the school at those

times. The students who were involved in school teams indicated that they were usually in the pep rallies. More students expressed interest in the fund-raising events, indicating that they were fun to watch and that the money was for a good cause. One student indicated that he generally did not have money 'on him' and so could not participate in fund-raisers.

### ***Co-curricular activities.***

Making decisions related to involvement in co-curricular or extra-curricular activities was the first of two types of decisions that require a longer-term commitment that came up in discussions with students without intellectual disabilities. Examples of co-curricular or extra-curricular activities included involvement in sports teams, music lessons, student government, clubs, volunteer work or similar organized activities connected to the school or to a community club/organization outside of school. Students indicated that they got involved in activities they were good at, activities they enjoyed and activities that their friends were involved in. One student indicated that he did not participate in school sports, but went to many of the games to cheer on his friends and classmates.

### ***Course selection.***

The second type of decision requiring a longer-term commitment was course selection. Most students appeared to be very aware of the connection between decisions related to course selection and decisions related to post-school plans and career goals. Students that had career goals, such as going into medicine or law, indicated they were choosing courses that would help them achieve those goals. Students who planned to go

to university or college but had not yet selected a career goal, talked about taking courses that would 'keep their options open' so that their choices would not be limited later on. This was often interpreted as taking higher level math and science courses. One student was focused on getting an athletic scholarship for university and was taking courses and putting a good deal of effort into those courses as well as her athletic interests, in order to achieve her goal.

Most students indicated that their decision making opportunities in the area of course selection were limited, or at least influenced, by their parents. This ranged from parents insisting that a student take certain courses as indicated in this statement, "I knew I was going to have to take Pre-Cal...I have to take all of the sciences next year..." to parents limiting choices as suggested in this statement, "My mom just tells me to take courses that actually involve thinking". Three students indicated that they got to choose their own courses without parent influence. Two of these three had clear career goals that dictated their course selection. When asked if it bothered them that their parents limited their course choices, several students made comments similar to this one, "whatever keeps them happy". Other students expressed understanding of their parents' desire for them to "keep doors open" or to challenge themselves. These responses suggest that some parents may be assisting their teens in the decision making process by helping them weigh pros and cons of selecting certain courses, but still allowing the student the final decision. This would be an ideal opportunity to help students improve decision making skills since adult guidance in decision making steps can be provided and the student has the opportunity to learn from poor choices, with relatively little risk.

***Friends.***

The influence of friends came out very strongly during the focus group discussions with students without intellectual disabilities. Some students indicated a larger circle of friends and others talked about fewer friends or only one close friend. However, friends came up at least once during the focused conversation with every student without an intellectual disability. It appeared that many of their decisions were influenced by what their friends were doing, what activities their friends were involved in or whether or not they saw their friends along the way.

This observation naturally led to a discussion about friendships. Students reported that decisions about with whom to be friends were based on who they liked or got along with and whom they trusted. Some students indicated that knowing someone for a long time did not have anything to do with friendship; if someone changed and they didn't like them any more, the friendship would end. Others indicated that they had the same friend or group of friends for several years.

**Data from students with intellectual disabilities.**

As with the data from the students without intellectual disabilities, this represents the combined data contributed by the three students with intellectual disabilities in the mixed group as well as the six students in the group comprised only of students with intellectual disabilities as they walked me through a typical school day and through parts of their school year. I have also included comments that offer comparisons with the data from the students without intellectual disabilities. As mentioned in Chapter III, many of the students in the focus group comprised exclusively of students with intellectual disabilities required additional time to express their views and seemed to enjoy sharing

information in quite a lot of detail. As a result, I ran out of time and was not able to ask all of the questions that had been asked of the other two groups, resulting in less data on the topic of course selection.

*Classroom activities.*

Similar to the students without intellectual disabilities, the students with intellectual disabilities also perceived themselves as having few or no decision making opportunities in their classes. For example, students reported that the choir teacher decided which songs would be sung and the math teacher decided which questions a student would do. Some statements demonstrated the perception that it was the educational assistant who was making those decisions. When asking about decision making in woods class, one student said, "Well, Jason (EA) tells me what to do there..." One student spoke fondly of his work experience placement in the school cafeteria. When asked about opportunities to make decisions there, he said, "I just do what they tell me. It's a job thing." This suggested that there was no expectation that he would be allowed to make a decision. Again, similar to the previous group, most students indicated that they did not mind when someone else made those decisions because they liked what they were doing. Similar to students without intellectual disabilities, this group talked about being given some opportunities to make group choices in their physical education classes by voting to determine which activity the class would do that day. However, at least one student did not perceive voting as a decision making opportunity as he said, "the other kids decide". It is possible he believed that his vote did not count or perhaps he did not understand the concept of going with a majority decision, even if you voted for the opposing option. When following up on a comment about changing clothes for gym

class, I asked whether or not they had a choice about changing clothes. One student with quite a significant intellectual disability indicated she did not need to change and another student whose intellectual disability was less severe, said she would fail if she didn't change and did not see it as a choice. I wondered if the rules may be different for different students, based on their individual needs. Similar to the previous group, this group also reported limited choice-making opportunities in foods class, and added a new example, whether or not to eat the food. They also said they could choose what part to play in drama class. One student stated that he would like to have more choices about which food is prepared during foods class and which music is played during choir because he did not like the selected food or songs. It is possible that some students (and maybe some adults) only object to decisions being made for them when they do not like the results of those decisions.

The students with special needs also reported different opportunities for decision making than their non-disabled peers such as being able to participate in a recreational activity of their choice during class time (e.g., ping-pong, weight training). Once again, this would more accurately be described as choice-making as opposed to decision making, therefore offering little or no opportunity for improving decision making skills. It would only be if students purposefully chose to participate in the activity in an unsafe manner that an opportunity for coaching and learning to make better decisions would occur.

*Classroom assignments.*

Some students talked about opportunities they had to make decisions around class assignments or projects such as what a finished product might look like (e.g., choice of design, paint colours and types of finish for woodworking projects, choice of fabric in sewing classes). They talked almost exclusively about classes that were less academic in nature such as woods, sewing and foods. It appeared that the support of student services teachers and EAs allowed students to work on assignments or projects that had been adapted or modified on an individual basis. This may occur in the classroom and/or in the student services area during the time students spend there each day.

*Less structured parts of the day.*

While this group of students reported to have a similar decision making opportunities during class time, they appeared to have fewer decision making opportunities during less structured times of the school day than their peers without disabilities. When talking about the few minutes before classes started, I was reminded by the EAs that most of the students with special needs travel to school on a school bus, and therefore arrive at school only a few minutes before classes start. This limits their opportunities for decision making prior to the beginning of the school day. When students in this group were describing what they did before classes started, two of them specifically mentioned that they look to see if cars are coming when they get off the school bus.

As in most high schools in Manitoba, students are expected to go straight to their first period class, as there is no 'home room' time built into the timetable. During this discussion, one student indicated that he chose to either go straight to his first class in the

morning (if he liked the class) or stopped to talk to other students in the hallway and took his time getting to class (if he didn't like the class). Another student indicated that he did not know what class he had in the morning, so would look for a friend and follow that person to class. One student said she would look to see if her friend was smoking outside the school. Since she did not approve of her friend's choice to smoke, she would purposefully walk away from her friend and go into the school building. This student and all of the other five students with special needs said they went to the student services area prior to moving to their first class or learning activity. From their discussion, it appeared that several students and at least one EA sat together in the student services area in the morning and socialized during this time.

It took a little while for me to get the students with special needs to understand what I meant when I asked about the ten-minute break between classes. After a few prompts and some processing time, the following information was shared. During the ten-minute break between classes, some students indicated that they went straight to their next class. Two students with special needs reported that they would "hang out" with friends in the hallways or outdoors, while others indicated that they would read or "goof off" or "chillax" (a word that is a combination of 'chill out' and 'relax') in the student services area. A student who went to the student services area to read complained that an EA sometimes interfered with her choice of reading materials because they were deemed inappropriate. Two boys, who were friends, reported that every day during the ten-minute break, they went to the school office to talk to the office staff and check on the fish that they had named.

Every student with special needs mentioned that s/he would spend some or all of their lunch periods in the student services area. About half of the students within the groups indicated that they ate lunch in the student services area and stayed there after lunch to read, talk or play games with peers and EAs. The other students indicated that they could decide where to be during the lunch hour. Some chose to eat in the cafeteria and then “do laps”, walking around inside or outside the school. One of the girls said she ate outdoors and then spent the rest of the lunch hour by herself outdoors, or she might come to the student services area. One student from this group indicated that he might go to a friend’s house at times, but usually stayed around the school hanging out with friends, or might check in at the student services area during the lunch hour. He was the only student who indicated that he might leave the school grounds. All of the students in this group reported that they brought their lunch to school almost every day. The student who worked in the cafeteria was given free food to supplement his lunch on the days he worked there. Two of the students said they ordered food in the ‘caf’ at times, and one pointed out that she did not like standing in line. About half of the students indicated that they made their own lunches and were only limited by what food was available in their homes. For the other half, parents made lunch for them reportedly without asking what they wanted. These students reported that they did not mind because they liked what they were given. In contrast, lunch hour seemed to be ‘prime time’ for students without special needs to be making decisions independently, many of which included the risk of making a mistake and learning from it, or at least being allowed the opportunity to explore personal preferences.

After classes, most students with special needs indicated that they went straight home. Many of them traveled to and from school by school bus, and so did not have the option of staying at school to 'hang out', as reported by the students without intellectual disabilities. One boy indicated that he walked home, but had to leave the school before the other students (for behavioural reasons) and so did not hang out at the school. One student mentioned that he was transported to and from school by his foster parent.

### *Special events.*

When special events were held during class time, such as school pep rallies or fund-raising events, almost all students with special needs indicated that they went to watch these events. In contrast to the students without special needs, they did not indicate any awareness of having a choice, but all spoke enthusiastically about such events. Only one of the students indicated that he had participated in a pep rally as he was a member of the school football team. None of the students said that they actually participated in the fundraising events, but some expressed interest in participating some day. I wondered why school staff members saw the value in ensuring that all students with special needs were in attendance, but did not facilitate their participation, allowing them to express their preferences and to learn from the experience of making the decision to participate or not.

### *Co-curricular activities.*

Talking with the students with intellectual disabilities about opportunities to make decisions requiring longer-term commitments, such as co-curricular activities and course selection, was relatively challenging. Students appeared to not understand what I was

asking or would forget about longer-term decisions, unless their involvement was current or very recent. The first question dealt with involvement in co-curricular activities where there was a significant difference in the number who participated between this group of students and those without intellectual disabilities. Two of the students talked about participating in co-curricular athletics, one of whom was part of the school football team. He appeared to be a confident, socially adept young man. In fact, one staff member referred to him as a 'poster child' for the school's inclusive special education program. When asked about getting started in football, he stated, "My mom was kind of cautious about this. At first she did not want me to play football. Then she kind of gave in and let me." Another student participated in track and field. One of the EAs who had worked with her was also a track and field coach and provided supervision and support as needed. A third student indicated that she had been part of the school musical and had attended practices after school as required. Two of these same three students indicated involvement in organized groups/activities outside of school, and two additional students talked about doing lawn care work for clients after school with one of their fathers.

I later learned from the staff that they willingly went out of their way to make it possible for students with special needs to participate in co-curricular activities. This information made me curious about the significant difference in levels of co-curricular participation. Is it that this option is not specifically offered to students with special needs and they miss the opportunity? Are they not able to or not interested in making the longer-term commitment that is required? Are they and their parents aware that co-curricular participation is a possibility? It seems that the students with special needs are

missing out on this low-risk decision making opportunity that is substantial in that it requires a longer-term commitment.

*Course selection.*

The student services department head indicated that students with special needs participate in their IEP meetings, and are encouraged to have input in deciding what courses they take and what they would like to do for work experience. At this age level in Manitoba, the IEP process becomes an Individual Transition Planning (ITP) process where the planning team is expanded to include individuals from appropriate Adult Services agencies (i.e., Vocational Rehabilitation or Supported Living). For more information, see Manitoba Education, Citizenship and Youth (2008). It appeared that students in the focus group only remembered their participation in an IEP meeting when they were prompted. Even in response to a prompt, one of the students said, “It was a long time ago”, as he paused to recall the meeting. The meeting had actually taken place about a month before the focus group. This made me wonder what else might have been forgotten and why, and what impact the challenges with memory may have on the development of decision making abilities.

Almost all students in this group indicated that they got to choose their courses without limitations being placed on them by parents or teachers. In most cases, students talked about participation in classes that are less academic in nature (e.g., foods, woods, choir, etc.). In addition, students talked about having opportunities to go to the weight room or to play ping-pong as part of their class schedule; options that did not appear on the class schedules of the students without intellectual disabilities. All of the students in this group reported that they worked in the student services area for at least one period

per day. The work they described ranged from getting extra help with assignments from their classes to working on tasks specific to their individual strengths and needs.

None of the students with intellectual disabilities mentioned a connection between the classes they were in and their post-school plans or career goals. Career plans were not part of the prompt questions for any of the student groups as the focus of the study is decisions made during the school day or school year. However, one of the students in the mixed group mentioned two long-term goals in other contexts. The first was to work in a particular kind of retail store (i.e., Anime Store), but indicated that her work experience choices were being limited by the fact that there was no store of that kind in Winnipeg. This same student was also quite emphatic about the fact that she had chosen not to smoke “because it kills you and people will forget what a wonderful person you were when you die”. Further comments related to post-school or career plans may have been limited by the fact that I ran short of time with the group comprised exclusively of students with intellectual disabilities. It is also possible that students forgot about connections they may have made during their IEP or ITP meetings.

### ***Friends.***

During the focus groups, I observed that many of the students with special needs talked about support staff as if they were friends. One example of this included the two boys who went to chat with the office staff during break times. Other examples came up during discussions about "hanging out in the student services area" during less structured times, particularly first thing in the morning. The image created by the discussion was EAs and students sitting around having coffee and sharing conversation before classes began. The banter and informality between EAs and students during the focus groups

certainly supported my perception of a friendship type of relationship between students with special needs and the support staff. None of the students actually used the term “friend” in relation to an EA, but made comments referring to EAs such as, [when I get to the student services room in the morning], “I bug James” or “I go to talk to Andy...he’s a great guy”.

There were only two examples where peer friends were mentioned. Two of the boys in the second group were very close friends at that time, and even jokingly referred to themselves as “twins”. I was told during one of my subsequent visits to the school (a few weeks later) that the “twins” were no longer friends, and in fact, were not even speaking to each other. The boy referred to as the ‘poster child’ made several references to seeing friends in the hallway and through his co-curricular involvement (i.e., friends without special needs). There was no reference of the influence of peer friends on decision making.

### **Data from School Staff**

Data were collected through two adult focus groups and an interview at the same Winnipeg high school where the student data were collected. The first group was comprised of five teachers and the second of five EAs. The interview was with the school administrator who had primary responsibility for student services in that school.

Each session began with participants viewing the graphic records from the three student focus groups as they entered the room, prior to beginning our conversation. I then initiated the discussion with a brief ‘walk through’ of the organization of the graphic records, asking participants to compare the graphic records of the students with and

without intellectual disabilities. I next began asking participants to explain any similarities or differences that they noted between the two sets of student data, prompting them to include any factors that may have come into play (e.g., student characteristics, environmental factors, other factors). Throughout the sessions, I shared relevant information from my analysis of similarities and differences between the student transcripts in order to prompt further discussion.

As described in chapter III, following data collection, within-case and cross-case analyses were completed through a process of coding and sorting using MS Excel spreadsheets. Data were sorted based on staff observations and discussion about similarities and differences between the data from students with and without intellectual disabilities, an exploration of perceived reasons for these differences with a focus on factors that may have had an influence on the perceived similarities and differences, and some analysis that came about during the discussion. Information in this section is organized according to themes identified during analysis, which roughly coincide with the parts of the school day and school year used in the student section. One theme, 'role of adults', evolved outside the scope of the focus questions. This topic arose unsolicited during both staff focus groups and has a connection to research outlined in the literature review in chapter II. For these reasons, I chose to include it in my findings.

An overview of the staff data is provided in Table 4, and is expanded upon in the text following.

**Table 4**  
**Overview of data from teachers, administrator and EAs**

<b>Part of school day/year</b>	<b>Teachers</b>	<b>Administrator</b>	<b>EAs</b>
Limited choices or not real choices in class	<ul style="list-style-type: none"> <li>• Students have very few opportunities to make real decisions</li> <li>• Tend to give either/or choices with one unattractive alternative that most students would not consider</li> </ul>	<ul style="list-style-type: none"> <li>• Students with and without intellectual disabilities (ID) appear to have similar opportunities for decision making during class time</li> <li>• Decision making opportunities appear to be more closely connected to the subject area and teacher than class composition</li> </ul>	<ul style="list-style-type: none"> <li>• Tend to give either/or choices with one unattractive alternative that results in compliance in most cases</li> <li>• Students with ID appear to have more options during class time</li> </ul>
Level of participation	<ul style="list-style-type: none"> <li>• Able to offer no explanation for why level of participation did not come up during discussion with students with ID</li> <li>• Most students see connection between marks and tests or written assignments but not between marks and attendance or participation in class</li> </ul>	<ul style="list-style-type: none"> <li>• Level of participation may not have come up in discussion with students with ID because flexibility is built into their schedule based on their needs</li> </ul>	<ul style="list-style-type: none"> <li>• Both students with and without ID sometimes ‘zone out’ in class; likely just didn’t come up in discussion with students with ID</li> <li>• Many students with and without ID do not make connection between level of participation and marks until they see progress report</li> </ul>

**Table 4 (cont.)**

<b>Part of school day/year</b>	<b>Teachers</b>	<b>Administrator</b>	<b>EAs</b>
Awareness of decision making opportunities	<ul style="list-style-type: none"> <li>• Did not come up</li> </ul>	<ul style="list-style-type: none"> <li>• “Some students define freedom as doing whatever you want” so any limitations might be perceived as being told what to do and not as a decision making opportunity</li> <li>• Some students would not consider skipping class as a decision making opportunity because they would not want to disappoint a parent or teacher or would be afraid to get into trouble</li> </ul>	<ul style="list-style-type: none"> <li>• Students with and without ID sometimes do not recognize decision making opportunities because of a negative attitude on or the decisions are more abstract or staff or parents do not identify a decision making opportunity as such</li> <li>• part of role of EA is to guide students with ID through decision making opportunities</li> </ul>
Flexibility in assignments	<ul style="list-style-type: none"> <li>• Tend to allow more flexibility for students with ID and ‘at risk’</li> <li>• Have the option of modifying program for students with ID</li> <li>• Wondered why they did not offer more flexibility for all students</li> <li>• When more flexibility was offered, students tended to do more than expected</li> <li>• Some subject areas allow more flexibility</li> </ul>	<ul style="list-style-type: none"> <li>• Did not come up</li> </ul>	<ul style="list-style-type: none"> <li>• Students with ID have a lot of choice-making opportunities because “we’re also helping them to be able to make choices, and make good choices.”</li> </ul>

Table 4 (cont.)

Part of school day/year	Teachers	Administrator	EAs
Less structured parts of school day	<ul style="list-style-type: none"> <li>• Students with ID spent time in student services area during breaks and lunch and have limited decision making opportunities before/after school due to perceived need for supervision to ensure safety of individual being supervised or safety of others</li> <li>• Students with ID have more supervision when first enter high school; gradually reduce supervision as student can handle more freedom</li> <li>• Most students with ID travel to/from school on school bus or transported by caregivers therefore were unable to choose to arrive early or stay later than the school bus permitted</li> </ul>	<ul style="list-style-type: none"> <li>• Students with ID spending time in student services area during lunch-similar to gr. 9's or French Immersion students who eat lunch together in classrooms; they go where they feel comfortable, to be with people with whom they have a connection</li> <li>• Safety was the biggest issue for students with ID during less structured times; coming into grade 9, provided with increased supervision upon entry which may gradually decrease as the student demonstrated more independence</li> <li>• Many students with ID were permitted movement breaks as needed as opposed to on school schedule whereas students without ID are generally expected to wait until the scheduled school break</li> </ul>	<ul style="list-style-type: none"> <li>• Students with ID spent time in or at least 'checked in' at student services area during breaks and lunch due to perceived need for supervision for safety reasons</li> <li>• The main factor involved was trust; could they trust that the student was not going to hurt someone or get hurt or run off</li> <li>• Some students with ID followed schedules that were more fluid and were permitted breaks as needed as opposed to on school schedule</li> <li>• EAs did their best to supervise students with ID who wanted to go elsewhere and/or be with students without ID during these times (e.g., gym, outdoors)</li> <li>• Most students with ID travel to/from school on school bus and so were unable to choose to arrive early or stay later than the school bus permitted</li> </ul>

**Table 4 (cont.)**

<b>Part of school day/year</b>	<b>Teachers</b>	<b>Administrator</b>	<b>EAs</b>
Less structured parts of school day (cont.)		<ul style="list-style-type: none"> <li>• Age is a factor in that students without ID in grades 9-10 are fully timetabled and start getting spares in grades 11-12; many have access to a vehicle and choose to leave the school during spares or other less structured times; students with ID are expected to stay at the school</li> <li>• Most students with ID travel to/from school on school bus as do students without ID who live a far from school</li> <li>• Students without ID are more likely to have access to a vehicle to get together with friends outside of school hours; students with ID likely do not have that option</li> </ul>	
Special events (e.g., pep rallies)	<ul style="list-style-type: none"> <li>• Students with ID may be more aware of events than those with ID due to adults (i.e., EA's and student services teachers)</li> </ul>	<ul style="list-style-type: none"> <li>• Students without ID have access to cars and can choose to slip out of special events unnoticed whereas students with ID do not have access to cars</li> </ul>	<ul style="list-style-type: none"> <li>• Students with ID enthusiastic about attending special events; news spreads quickly</li> <li>• Some students with ID unable to attend due to sensory</li> </ul>

**Table 4 (cont.)**

<b>Part of school day/year</b>	<b>Teachers</b>	<b>Administrator</b>	<b>EAs</b>
Special events (cont.)	<ul style="list-style-type: none"> <li>available to ensure they do not miss opportunities</li> </ul>		<ul style="list-style-type: none"> <li>needs; all others would be expected to attend</li> </ul>
Co-curricular activities	<ul style="list-style-type: none"> <li>Arrangements would have to be made for students with ID to participate but between teachers, EAs and parents, 'there's lots of possibilities'</li> <li>Accommodations are sometimes needed for a wide range of students and teachers made those accommodations on a regular basis</li> </ul>	<ul style="list-style-type: none"> <li>All co-curricular activities are supervised by staff members who are responsible to ensure that the needs of all participants are met</li> <li>Teacher supervisor would consult with student services dept. head about needs of students with ID</li> <li>If needed, EAs could be compensated for time spent supporting co-curricular involvement of students with ID</li> </ul>	<ul style="list-style-type: none"> <li>Arrangements would have to be made for students with ID to participate; parents would need to be involved</li> <li>EAs had been compensated for time spent supporting co-curricular involvement of students with ID</li> </ul>
Course selection	<ul style="list-style-type: none"> <li>Some students without ID (or their parents) chose certain courses like Pre-Cal in order to 'keep options open' even if the student was failing that course or had no interest in a career related to that field</li> </ul>	<ul style="list-style-type: none"> <li>Course selection for students without ID influenced by plans for post-school, parents and desire to "keep options open"</li> <li>Student with ID-more flexibility because they are not entering post-school programs that have course requirements</li> </ul>	<ul style="list-style-type: none"> <li>Course selection is "probably the biggest choice" students without ID make in high school</li> <li>Not aware of students with ID complaining about limited course options</li> </ul>

Table 4 (cont.)

Part of school day/year	Teachers	Administrator	EAs
Course selection (cont.)	<ul style="list-style-type: none"> <li>Sometimes students had to give up a course they were more interested in due to this</li> </ul>	<ul style="list-style-type: none"> <li>Students with and without ID show pattern of more varied options in gr. 9-10 and narrower in higher grades</li> </ul>	
Friends	<ul style="list-style-type: none"> <li>Did not come up</li> </ul>	<ul style="list-style-type: none"> <li>Not uncommon for students without ID to choose courses based on what friends are taking; students with ID course selection facilitated by student services staff in consultation with students and parents; not usually based on friends' choices</li> <li>Students with ID sometimes perceived EAs as friends because they spend more time with EAs than teachers</li> <li>Similar to the fact that some students without ID connected strongly with certain teachers too</li> </ul>	<ul style="list-style-type: none"> <li>Students without ID very much influenced by their friends</li> <li>Students with ID did not know how to interact with others and did not have appropriate social skills ("it's all about them")</li> <li>Did not mention a role for EAs in improving this</li> </ul>

**Table 4 (cont.)**

<b>Part of school day/year</b>	<b>Teachers</b>	<b>Administrator</b>	<b>EAs</b>
Role of adults	<ul style="list-style-type: none"> <li>• Students with ID have more adults available to support them (i.e., EAs, student services teachers)</li> <li>• Additional adults can support students with ID in decision making process and help to adapt or modify classroom assignments</li> <li>• Students without ID do not have that level of support available to them</li> </ul>	<ul style="list-style-type: none"> <li>• Did not come up</li> </ul>	<ul style="list-style-type: none"> <li>• Emphasized the importance of teacher involvement related to acceptance and inclusion of students with ID, their participation in classes and opportunities to make decisions in those classes</li> <li>• As EAs, they were happy to provide support and assistance to the teachers, but needed guidance and direction from them</li> </ul>

**Data from teachers.**

Three classroom teachers and two professional student services staff members participated in the teacher focus group. The data were collected as outlined in the previous section using the agenda and questions in Appendix F as a guide. Throughout the session, I shared information from my analysis of the student transcripts in order to prompt further discussion.

***Limited choices or not real choices in class.***

When the teachers looked at the graphic records from the three student focus groups and started to share their thoughts, one of the first themes that emerged was the fact that adults do not give students many ‘real’ decision making opportunities during the school day. Most teachers in the group expressed concern about this. As one teacher stated with concern, “We turn out good little soldiers.” They talked about their tendency to give students choices that are very limited such as choosing between two books or giving choices that are not really choices, such as doing an assignment or not passing. The teachers observed that most students would not see doing an assignment or not as a choice for a variety of reasons, including incongruence with their own goals or not wanting to disappoint their parents or teachers. In actuality, doing an assignment or attending school is a decision that students make each day, and there are some students who decide to not do the work or to not attend. These are the kinds of decisions that are not really intended by the school system. These are also decisions that have consequences that could impact a student throughout their adult life.

***Level of participation.***

Level of participation was another topic that the teachers found engaging. From the data from students without intellectual disabilities, it was observed that students did not always connect their decisions regarding level of participation with the marks they got on their progress report or report card. This was not a surprise to the teachers as they were aware that students were sometimes surprised by their marks. Teachers perceived that most students saw a direct connection between marks and written assignments or tests, but did not always see the connection between marks and their decisions to attend or not or whether or not to participate in class activities. When teachers were told that level of participation came up only in a very limited way in discussion with students with intellectual disabilities, they were not able to offer any explanation. I wondered about the possibility that as students with intellectual disabilities often receive report cards that are based on modified curriculum outcomes and/or are more anecdotal in nature, the impact of their decisions related to level of participation may not be as obvious to parents or school staff.

***Flexibility in assignments.***

The teachers' views of choice or decision making opportunities related to assignments were quite different when comparing students with and without special needs. The teachers reported they tended to allow students with special needs and students considered 'at risk' more flexibility and more decision making opportunities than students without these needs when it came to assignments. This increased flexibility was used to increase motivation and allow students the opportunity to do a version of the assignment that is more harmonious with their individual strengths and needs. It was

interesting to hear teachers question why they do not offer more flexibility in assignments for all students. Further, teachers noted that when they gave students guidelines but allowed more flexibility in their assignments, students tended to “run with it” and sometimes did much more than would have been expected. Teachers clearly saw the benefit of allowing flexibility in assignments for these students. However, they reported that sometimes students reacted quite differently to a flexible assignment. In some cases, students would spend so much time worrying and trying to guess what the teacher wanted that they had a lot of difficulty even starting the assignment. Factors that came up during this discussion were student confidence and teachers needing to convince students that it is “okay” to write about something they knew a lot about instead of wondering what the teacher “really wanted”. The teachers’ discussion did not include comments indicating an understanding of the importance of decision making opportunities in the lives of all students in order that they can learn about their own strengths and preferences or that they can learn to make better decisions with practice. It was more focused on providing students considered at risk or those with special needs with enough latitude that they had the opportunity to enjoy success with the assignment.

Teachers discussed that there was the option of modifying the content or format of the assignment for students with intellectual disabilities, whereas that is not an option for students without intellectual disabilities. In Manitoba, modification refers to a process whereby school teams (including student and parents) may choose to change the number or content of the outcomes that an individual student with an intellectual disability needs to achieve in order to receive credit for a course (Manitoba Education, Citizenship and Youth (2006). The teachers in the focus group perceived this as providing them with

greater freedom to negotiate assignments with students, suggesting that they may not have a clear understanding of the intent of modified and adapted programming.

Teachers pointed out that some subject areas offer “more opportunities for creativity” than others. For example, it was perceived that a subject like language arts offers more opportunities for teachers to be flexible than subjects that have right and wrong answers like math.

Finally, teachers observed that many students without intellectual disabilities are focused on getting their high school credits in order to graduate, and often just want to know what they have to do in order to get those credits and are not looking for alternative assignments or tasks. The students considered at risk or those with special needs were thought to be more likely to ask if they can do something different, something they are more interested in. They also have adults available to support them in determining appropriate options and following assignments through to completion.

#### *Less structured parts of the day.*

I shared with the teachers that many students with intellectual disabilities reported that they went to the student services area during less structured parts of the school day, such as lunch hour and break times, and wondered why that was the case. The teachers reported that they believed the reasons would be individual. Some students were expected to be there because they required supervision by the EAs. The main reason for this was reported to be safety. In some cases, the safety of the student being supervised was the main concern (e.g., students who may get lost or may walk into the street). For other students, it was their behaviour that resulted in the need for supervision. This included students for whom direct supervision was recommended by the justice system and

students who tended to get themselves into difficulties. Level of disability was part of it, but not the only consideration. The level of trust appeared to be the bigger factor; trust that a student would remain safe or that other students would remain safe around that student. It seemed that opportunities to make decisions during less structured times was seen as a privilege, conditional upon school staff judging that the student was ready. This would fit with the 'duty of care' argument presented in the literature review but would not fit with the perspectives that individuals need to take risks and need to make decisions and fail in order to learn to make better ones. Some may argue that the students deemed to require more supervision have made poor decisions in the past, the result of which was increased supervision.

When asked if age or gender had anything to do with limiting choices, it appeared that gender was not perceived as a factor. Age was only seen as a factor as it related to the amount of experience a student had in the high school setting. Students have more supervision and more limits placed on them when they are new to the school. They would then be given more freedom as they demonstrated their ability to handle it. It was pointed out that all students, including the ones who went to the student services area because they required supervision, were offered opportunities to go other places (e.g., gym, outdoors) with EA supervision.

When I shared the marked difference between after-school decision making opportunities reported by students with and without intellectual disabilities, once again, teachers were not surprised. They perceived that it came down to the need for supervision, once again. Many of the students with special needs traveled to and from school by bus; therefore they did not have the choice of staying after school. A small

number walked to and from school or got a ride from their parents and would be supervised by school staff until they were 'handed over' to parents or caregivers.

*Special events.*

The teachers perceived that the students with special needs were as aware, if not more aware, of co-curricular opportunities and special events offered through the school as the students without intellectual disabilities. This was because the students with special needs had many adults (i.e., EAs and student services teachers) available to ensure that they did not miss out on opportunities if they were interested. The students without intellectual disabilities had to rely on intercom announcements, classroom announcements or friends for this information, and sometimes missed it.

*Co-curricular.*

When it came to co-curricular involvement, the teachers made it clear that "anything is possible" and provided an example of a student with special needs being involved in the musical. This was possible because one of the EAs committed to staying after school and supported the student during rehearsals until the student was able to participate with only the regular supervision provided by the teacher(s) involved. At that point, another student from the cast was enrolled as a 'buddy' to assist as needed. The teachers also emphasized that arrangements would have to be made for students with special needs to participate in co-curricular activities but that "between para's [EAs], parents and teachers, there's lots of possibilities". They perceived that the most challenging circumstances were those involving students where there was a legal requirement for supervision. One of the teachers clarified that accommodations

sometimes needed to be made for a wide range of students, not only those designated as having intellectual disabilities, and that teachers made those accommodations on a regular basis. In addition, the freedom and choices offered students without special needs were also limited, at times, due to their behaviour.

*Course selection.*

When introducing the topic of course selection, I shared the idea of students without intellectual disabilities and their parents feeling the need to ‘keep their options open’, and a lively discussion ensued. This was something that many of the teachers had encountered related to their students, as well as their own children. It appeared that students would stay in certain courses in an effort to keep their options open, even if they were failing (e.g., Pre-calculus math). Students and parents seemed to use this reason to sign up for certain courses, even though the student’s interests did not include a career where ‘Pre-cal’ or a similar course was required. Students were often forced to give up a course they really enjoyed (e.g., woodworking) because it did not fit into a timetable that included ‘Pre-cal’. This led to a discussion of summer school. Teachers questioned why some courses were not offered in the summer so that students would have more course options available to them. Generally, students can only take a summer school course if they have already attempted the course during the regular school year, and did poorly. The teachers understood that this was because summer school is only three weeks long, so students needed to already be familiar with the material, but still questioned whether it had to be this way. They were questioning the decision making limits placed on students without intellectual disabilities by the structure of the school timetable and the summer

school timeline. The topic of course selection as it relates to students with intellectual disabilities did not come up in discussion with the teachers.

***Role of adults.***

A perceived difference noted by the teachers between students with and without special needs was that the students with special needs have additional adults available to them (i.e., EAs and student services teachers). Teachers observed that these adults can spend the time needed to spell out possibilities more clearly, and to adjust those possibilities to make them more suitable to individual students' interests and needs. These additional adults are also available to 'walk students through' the decision making process and support them as they make decisions. It was opined that students without special needs do not have that level of support available to them. The students without special needs who are already able to make decisions and are not worried about taking decision making risks enjoy having opportunities and thrive on them. Students who need that support but do not have it available to them would prefer to be told what to do, or to be given an "either/or choice" because it is easier for them than dealing with broader decision making opportunities.

**Data from administrator.**

The administrator viewed the graphic records from the three student focus groups prior to beginning our discussion. I began by asking him to share his observations of similarities or differences in the graphic records of the students with and without intellectual disabilities. I then prompted him to explain similarities or differences that he noted, based on the outline in Appendix F. Throughout the session, I shared information

from my analysis of the student transcripts in order to prompt further discussion. Once again, information is organized according to themes identified during analysis.

Comparisons are drawn between the data from the administrator and data from other sources.

***Limited choices or not real choices in class.***

Unlike the teachers, the administrator made no comments related to the number or quality of decision making opportunities in the classroom. However, the administrator did observe that students with and without intellectual disabilities showed similarities in opportunities for decision making during class time. He observed that decision making opportunities related to class activities appeared to be more dependent upon the subject or curriculum and the teacher than on the composition of the class. He also observed that both groups of students talked about foods classes, and the fact that students would like more say in what they cook. That request had come up in other forums as well. He perceived that the challenge in allowing students more choice is that the food needs to be purchased on a weekly basis for all foods classes, and what gets cooked depends upon what gets ordered.

***Level of participation.***

When discussing the subject of students choosing their level of participation in class, the administrator provided choir as an example where this may occur. Students with or without intellectual disabilities may choose to just move their lips and not sing, therefore choosing their level of participation without making it obvious.

I commented on the fact that the topic ‘level of participation’ did not come up when talking with the students with intellectual disabilities as it did when talking with students without disabilities, and wondered why this was the case. The administrator wondered if this might be because students with intellectual disabilities have more flexibility built into their programming. For example, if they need a break to walk around during class time, that is usually considered part of their programming. A student may actually be choosing to not participate at that particular time, but it is not seen that way.

*Awareness of decision making opportunities.*

I shared my observation that students are not always aware that they are making decisions and that they often do not perceive decision making opportunities as such. In response, the administrator made the statement, “I think some kids might define freedom as doing whatever you want”. He went on to explain that when a student with this belief is given an assignment with some limitations, it might be perceived as being told what to do and not as a decision making opportunity.

Similar to the discussion with the teachers and the students without intellectual disabilities, the administrator also observed that some students would never consider skipping a class because they would not want to disappoint a parent or a teacher or would be afraid that they would get into trouble. These students do not perceive attending school as a choice, even though it is a decision they are making every day. The administrator said that he sometimes reminds students that they are making the choice to be at school.

*Less structured parts of the day.*

When looking at the graphic records, the administrator observed that the students with special needs went straight home after school, whereas other students tended to have many choices during that time. The administrator pointed out that there are other students who also travel to and from school by bus, and generally head straight home as well; this was not exclusive to the students with special needs. He stated, "...Depends on where you live or how you get home – that kind of makes the choice for you..." The administrator agreed that the students with special needs likely have a smaller range of options available to them after school since the majority of them do not drive cars, while many of their peers without disabilities have access to vehicles and are able to drive to meet up with friends.

It was also noted that there was a difference between students with and without special needs during the lunch hour. The students without special needs appeared to have more places to go during the lunch hour, whereas the students with special needs tended to go to the student services area. He pointed out that this is not unlike other groups of students in the school. For example, the grade nines tend to eat lunch together in a grade nine classroom, and may have the option of some activities in those rooms after they finish eating since several teachers leave their classrooms open over lunch hour. Another example of such a group is the French Immersion students, who also tend to "hang out" together at lunch hour. His belief was that the students go to the student services area because they feel comfortable there. It is their home base. They know that when they go there, they will find people with whom they have a connection.

With regard to the ten-minute break between classes, it was pointed out that many of the students with intellectual disabilities need to take periodic movement breaks, which may or may not coincide with the ten-minute break between class periods. It is not uncommon for the students with intellectual disabilities to be permitted to go for a walk in the hallway during class time. In contrast, students without intellectual disabilities are generally expected to wait until the ten-minute break. However, they also may occasionally be permitted to take a short break from the classroom if needed, depending upon what is happening in the class at that time.

When talking about students with special needs being directly supervised during less structured parts of the school day, the administrator commented that safety is the biggest issue. He explained that they are alerted by the sending school during transition meetings if a student coming into grade nine has a history of running off or of other unsafe behaviours so that increased supervision can be arranged. When this is the case, supervision is provided at the beginning of the school year, and as the student demonstrates more independence, the direct supervision may be reduced gradually. He described a process where a student might be given opportunities to practice navigating the school with an adult beside, then with the adult behind, then with adults watching at each end of the route, and so on until the student can navigate the school independently, which is the goal. This could be described as gradual fading of supports and would be supported by the 'duty of care' argument outlined in the literature review in chapter II.

According to the administrator, age is a factor when it comes to opportunities for decision making in that students without intellectual disabilities in grades nine and ten are fully timetabled and do not have any spares. By grades eleven and twelve, they tend to

get spares, and therefore have more freedom. If students have spares before or after lunch, they end up with two hours in the middle of the day to use as they choose. Many students without special needs have access to a vehicle by this age, and may choose to leave the school during spares. The students with special needs are expected to stay at the school. This demonstrates a significant difference in the expectations for students with and without intellectual disabilities and supports the observation that the students with intellectual disabilities did not mention that they had spares. It appears that students without intellectual disabilities are expected to demonstrate growth in their ability to make responsible decisions during less structured times as they get older, even though there was no mention of teaching or coaching decision-making strategies or processes related to use of less structured time. This may also suggest that students with intellectual disabilities are not expected to demonstrate this same growth as they get older.

### *Special Events.*

When asked about level of participation at pep rallies and fundraising events, the administrator indicated that there were a number of factors at play for the students without special needs. For example, if the event is scheduled near the end of the school day, some students will leave in their cars without being noticed. The students with special needs would not have this option.

### *Co-curricular.*

When asked about opportunities for participation in co-curricular activities outside of school hours for students with special needs who require direct supervision, the administrator pointed out that all activities are supervised by the staff members who

organize them, and it would be the responsibility of the teacher supervisors to ensure that the needs of the students are met. Most times, the teacher supervisor would consult with the student services department head to gather information about a student's needs. If an EA is required outside of school hours, they would negotiate a way to compensate them for their time to ensure that all students have the opportunity to participate. This perspective matched closely with the perspective shared by the teachers who stated that "anything is possible" regarding co-curricular activities for students with intellectual disabilities.

### *Course selection.*

When discussing course selection, the administrator observed that students with special needs tend to have more flexibility "because they may not be going to specific types of programs that have required courses". He went on to explain that course selection for students without special needs is influenced by their plans for the future and their parents. If students are planning to enter a particular faculty or program of studies after high school, they often need certain courses during high school in order to meet entrance requirements. This matched well with the data collected from students without intellectual disabilities.

Similar to the teachers' discussion, the administrator went on to suggest that students who do not have a definite plan for their future will often select challenging courses in the math or science field in an effort to "keep their options open". It sometimes happens that a student's plan for the future does not match that of his/her parents and so they end up taking courses because their parents want them to, limiting options even further. The fact that there are sixteen to seventeen courses required to meet graduation

requirements results in students only having thirteen to fourteen options over their high school career.

The administrator noted that students with and without special needs show a pattern of exploring a broader range of options in grades nine and ten, and then narrowing down options in grades eleven, twelve and beyond based on post school goals and individual interests. The administrator added that many students with special needs stay in school until age 21 but did not discuss a connection between high school courses and post school plans for students with intellectual disabilities.

This suggests a striking difference in perception of the contribution of the school system toward the life-goals of students with and without special needs. Is it possible that participants perceived a stronger connection between high school courses and post-school plans for students without special needs than for those with special needs?

### ***Friends.***

The administrator indicated that it was not uncommon for students without special needs to make decisions around course selection based on what their friends were taking. For students with special needs, the course selection process is facilitated by the teachers in the student services department in consultation with the students and their parents. For this reason, the administrator indicated that he generally did not see students with special needs choosing courses based on the choices of their friends or peers.

I shared my observation that some of the students with special needs appeared to have something of a friendship with some of the EAs. The administrator was not surprised by this as he explained that the EAs are with specific students for larger parts of the school day than the teachers. In addition, the EAs are sometimes required to provide

physical supports to some students that are quite personal in nature. The administrator drew a comparison to some students without special needs connecting strongly to certain teachers, seeing them as friends. This was not mentioned during discussion with students without intellectual disabilities.

### **Data from EAs.**

The EAs began by viewing the graphic records from the three student focus groups prior to beginning our session. Just as I did with the teachers, I initiated the discussion by asking them to compare the graphic records of the students with and without intellectual disabilities, and to explain similarities or differences that were noted between the two groups of students. Throughout the session, information from my analysis of the student transcripts was shared. Unlike the teachers or administrator, the EAs immediately connected information recorded on the graphic records with certain individual students with intellectual disabilities, even though there was no identifying information included on the graphic records. This demonstrated how well they knew the students.

At the end of the session, the EAs expressed appreciation for including their perspectives in my study. Only one the EA participants indicated that he/she had participated in a focus group before this experience. It occurred to me that this is another group whose voices are often left out of educational research. Once again, the summaries that follow are organized according to themes identified during analysis, and comparisons are made between the data from the EAs and data from other sources.

***Limited choices or not real choices in class.***

Similar to the conversation with the teachers about giving choices that are not real choices, the EAs mentioned that they sometimes give students with special needs choices like: “you can either not change for gym and lose marks or change and get your two marks, your choice”. They indicated that students sometimes choose to lose the marks, but most often just comply with the request.

After viewing the graphic records of the three focus groups, one of the EAs stated, “I think special needs kids have more fun” and went on to observe that they seemed to have more options and activities available to them during class time.

***Level of participation.***

In agreement with the teachers, the EAs observed that many students with and without intellectual disabilities do not make (or acknowledge) the connection between level of participation and their marks until they get a progress report, or even a week or two prior to the end of a semester when teachers are going over marks with them; then they make frantic attempts to “make up the time”.

When I mentioned to the EAs that making decisions related to level of participation did not come up in discussion with the students with intellectual disabilities, they supposed that it “just didn’t come up” and explained that the students with intellectual disabilities do sometimes “zone out” in class or choose to “mouth the words” instead of singing during music classes, just like the students without intellectual disabilities do.

*Awareness of decision making opportunities.*

The EAs opined that both students with and without special needs sometimes “zone out” in class or demonstrate a negative attitude and may miss decision making opportunities offered by the teachers. When this happens the student then goes on to believe that the teacher did not offer any options.

The EAs indicated that the students without intellectual disabilities got many decision making opportunities each school day, but that many times the students did not perceive those as decisions. This is similar to the suggestion by the administrator that students may not interpret a decision making option as such. EAs suggested that sometimes this was because the decisions or choices were more abstract, or they were not pointed out as decision making opportunities by the teachers. One EA reflected back to when she was in high school and shared the following: “thinking back to when I was a kid, I would have probably said the same thing. My mom makes me come to school...I wouldn't have thought of that as a choice then, I would have thought of it as if my mom catches me at home in the afternoon I'm gonna be in really big trouble.” In contrast, the decision making opportunities that the students with special needs have tend to be more concrete (described as “cut and dried choices”). The EAs saw it as part of their role to help guide the students with special needs through those choice-making opportunities.

*Flexibility in assignments.*

When discussing decision making in general terms, the EAs perceived that students with special needs have a lot of choice-making opportunities. One of the EAs stated, “...we give them choices for everything because we're also helping them to be able to make choices, and make good choices”. It was interesting that the perception that

teaching decision making was part of their role came up in discussion with EAs but not the teachers or administrator. The EAs did not comment on flexibility in assignments for students without intellectual disabilities as they tend to have relatively little involvement with this population.

*Less structured parts of the day.*

When I shared my observation that the students without disabilities had choices about when to arrive and leave school each day, the EAs immediately shared that most of the students with special needs traveled to and from school on the school bus, which limits their opportunities to make decisions about the time before and after school. This is the same immediate response that came from the teachers and was mentioned more softly by the administrator. None of the staff participants suggested that the students with special needs who traveled by school bus may have other options for transportation to and from school. It appeared that it simply had to be that way.

I shared with the EAs that there appeared to be a difference between the students with and without special needs with regard to the ten minute break between classes, and that it was difficult to get some students with special needs to understand what I meant by the “break”. In congruence with the response of the administrator, the EAs pointed out that the schedule for students with special needs was more fluid in that students were permitted to have breaks as needed or as they completed a task, and that it did not necessarily coincide with the ‘ten-minute break’ between classes. It is likely that this flexibility is available due to the presence of EAs to supervise students when they are in need of a break. The EAs were not surprised that this group of students had difficulty expressing what they did during the ‘ten-minute break’.

When talking about lunch time, I mentioned that many of the students without intellectual disabilities reported that they did not eat lunch during lunch hour while almost all students with special needs indicated that they did eat lunch at school. The EAs wondered if the difference was having a place to eat lunch. They indicated that the cafeteria at the school was very small, given the student population, and that many students simply did not have a place to sit down and eat. In contrast, the students with special needs could come to the student services area to sit down and eat lunch. Another perceived difference was that many of the students with special needs had parents who made lunch for them, and referred to the daily “gourmet lunch” of one student, whereas the other students would have to make their own lunches. They wondered if this had an impact on eating habits.

Similar to the views of the teachers and administrator, the EAs pointed out that most of the students with special needs had to be supervised; therefore they were expected to at least ‘check in’ at the student services area during the lunch hour. If students were interested in going to the gym or outdoors to “hang out” instead of staying in the student services area, the EAs did their best to accommodate those requests. None of them could remember a time when a student was told ‘no’ to such a request or suggestion, indicating “we always figure a way to do it” and pointed out that it was part of their jobs to encourage such interactions between students with and without disabilities. Facilitating opportunities for the students with special needs to be with the students without special needs was mentioned by both the teachers and EAs as part of the role of the EAs. Unfortunately, none of the staff mentioned that coaching students toward

increased independence, therefore requiring less supervision, as another potential role for an EA.

I shared that students without special needs appeared to have a lot of freedom during less structured times, and some chose to simply wander anywhere they wanted and do nothing in particular but hang out with friends. My question was could the students with special needs do this? The immediate response was “not by themselves”. They then explained that, for safety reasons, some students had to be supervised more closely, and that those were the ones that they would accompany to places upon request. Other students had more freedom, and were just expected to “check in”. When I asked what factors were considered when determining this, they agreed strongly that age and gender had little relevance. The main factor identified was trust...could they trust that the student was not going to go and hit someone or jump in front of a bus or run off? This thinking was clearly harmonious with the perspectives of the administrator and teachers. All were very concerned about the safety of the students with intellectual disabilities and appeared to equate safety with supervision.

### *Special events.*

When discussing special events such as pep rallies, spirit week and fundraising events, I asked how students found out about such events. The EAs said it was usually during announcements or through ‘eavesdropping’ in the hallways and indicated that once one person in the student services area mentioned it, the information “spread like wildfire”. It was reported that the students with special needs are generally quite enthusiastic “to go and be with every other kid in the school”, so the EAs end up taking one or more groups, or most often, all of the students with special needs to such events.

I pointed out that some students without intellectual disabilities reported that they chose to wander around in the school yard or leave the school ground altogether during pep rallies or similar events, and asked if the students with intellectual disabilities could do that. The answer was a definitive “no”. They indicated that it was unlikely that students without special needs wandered around the halls because the teachers were patrolling and would notice that. Some of the students with special needs were unable to attend such events due to their sensory needs (i.e., over-stimulation) and would stay in the student services area, but the rest would be expected to attend. The administrator mentioned that sometimes students without special needs would “slip out” unnoticed and leave the school during special events. The students with special needs tend to be supervised quite closely by the EAs and so would be unable to ‘slip out’ unnoticed. Once again, it appears that increased supervision limits opportunities for decision making and eliminates the opportunity to make an error and learn from the experience.

### *Co-curricular.*

When it came to the discussion of involvement in co-curricular activities, the EAs concurred with teachers and the administrator in sharing how arrangements had been made for some students to participate in activities outside of school hours with the supervision of an EA. At times, the EAs were compensated for that time, with time off. They were the first group to point out the main challenge in this, which I believe may result in limiting such opportunities. It was difficult to provide coverage for all students during the school day while their colleagues take compensatory time. Like the teachers, the EAs perceived that parents also needed to be involved when students with special needs wanted to participate in co-curricular activities.

There appeared to be a strong willingness to make necessary arrangements, and examples were cited by all three groups where this had been done. For some reason, however, a relatively small number of the students with intellectual disabilities involved in my study reported involvement in co-curricular activities compared to the students without intellectual disabilities who participated. If school staff are willing to make arrangements for any student's participation, the disparity between the groups is curious. The only possibility raised in discussion was the challenge of providing coverage for all students with special needs when EAs needed to take compensatory time during the school day.

### *Course selection.*

The EAs identified course selection as “probably the biggest choice” students without intellectual disabilities make during high school. They were not aware of students with intellectual disabilities complaining about limited options for courses. It was apparent that EAs had little involvement in the course selection process.

### *Friends.*

The EAs were very aware of the differences between students with and without special needs in regard to friends. They quickly observed from the graphic record that the students without special needs seemed to be very much influenced by their friends. This seemed to support their own observations which were summed up in the following statement, “non-special needs...they just want to hang out with their friends”. In contrast, they observed that most of the students with special needs did not appear to know how to interact with others. One of the EAs described a scene where several students with

special needs are sitting together in the student services area, each doing or talking about different things (i.e., one planning a wedding, one reading a book or magazine, one talking on a cell phone and one talking to the group). This was described as happening all at the same time. Another EA summarized by saying, “that's true, they don't interact with each other but they're...put together”. The EAs observed that many of the students with special needs did not have appropriate social skills, and tended to be self-centered where “it's all about them”. Even though the EAs were aware and appeared to have a good understanding of these behaviours, none of them mentioned a role EAs might have in helping students learn the missing social skills so that they could be more socially appropriate. I see a wonderful opportunity for EAs to model and coach these students in the development of appropriate social skills, especially if they interact so frequently with them that the students view them as friends.

### ***Role of Adults.***

The EAs were the first group to talk extensively about how important teacher involvement was in the opportunities the students with special needs have to be accepted, to participate fully in classes, and to make choices and decisions in those classes. They indicated they were very happy to provide whatever support and assistance that was needed, but wanted guidance and direction from the classroom teachers. The EAs shared several examples of classes where the teacher was interested and involved in planning for the students with and without special needs, as well as examples where this was not the case. If the teacher did not take an interest in the students with special needs, the impact was felt by both the students and the EAs.

The EAs also observed that when a teacher did not make an effort to include the students with special needs in their classes, the students without intellectual disabilities did not make that effort either. They described times when they, as EAs, attempted to facilitate the inclusion of their charges into class activities, mostly with limited or no success unless the teacher was also modeling and supporting this. They did not believe that the students with intellectual disabilities could necessarily be fully included all day, every day, but that the students should be included for whatever period of time they could handle or whatever part of a class that was appropriate for them.

They did not blame the teachers, but wondered if they were getting enough pre-service opportunities to experience working with students with special needs. They observed that at least some of the teachers they considered to be more inclusive of all students had experience with individuals with special needs within their families or through volunteer experiences prior to becoming a teacher.

### **Conclusion.**

In this section, I outlined information and specific examples obtained from three student focus groups including students with and without intellectual disabilities, two adult focus groups including teachers and EAs and an interview with a school administrator. I also highlighted similarities and differences in the perceptions of the groups. In the next section, I will briefly review the process in which I compared the data from all six data sources and outline the three key themes that were identified as a result of this analysis.

### **Common Themes across All Groups**

As explained in chapter III, once I completed within-case and cross-case analyses of the student and staff data separately, I used the two spreadsheets that contained summarized data from all six data sources, the spreadsheet sort function, as well as my memos and contact summary sheets to complete a key theme analysis based on the summarized data. This resulted in the identification of three main themes: structure of the system, role of adults and safety. It appears that each of these three can facilitate or limit opportunities students with and without intellectual disabilities have to make decisions during the school day and school year.

#### **Structure of the system.**

The structures of the school system were identified as factors that frequently limit decision making opportunities of students during the school day and school year. Structures had an influence on decision making opportunities throughout the school day, including the time immediately before and after school. The two main structural limitations that became apparent are transportation to and from school and the high school credit system. These affected the students with and without intellectual disabilities quite differently.

#### ***Transportation.***

All participants recognized that students without intellectual disabilities experienced more decision making opportunities immediately before and after school than students with intellectual disabilities. The students without intellectual disabilities who were interviewed reported that they had choices about how to get to and from

school. These included taking a transit bus, walking, skateboarding or getting a ride from family or friends. These options allowed them flexibility around what time to arrive at school in the morning and what time to leave at the end of the day. Many students without special needs chose to arrive early and/or stay late so that they might "hang out" with friends or get involved in an activity. These time periods permitted them to make real decisions independently, and to build social connections with peers.

Most of the students with intellectual disabilities who were interviewed traveled to and from school by school bus, therefore eliminating flexibility in arrival and departure times. Those who traveled by private vehicle or walked also had arrival and departure times that were determined by the system, as students were reportedly "handed" from adult to adult. It was clear that arrangements would be made for students with special needs to participate in co-curricular activities, and examples of such arrangements were shared. However, having the system determine daily arrival and departure times eliminated the informal opportunities for decision making and socializing enjoyed by the students without special needs. It was pointed out that there were some students without special needs who were also transported by school bus because of the distance they lived from the school, and therefore would experience similar limitations. However, it is possible that many of these students could arrange to travel via public transit or with family or friends if so desired. I suggest it is also possible for at least some of the students with special needs who travel to and from school by school bus to also learn to travel via public transit or with friends. Perhaps action is being taken toward this, but it was not mentioned by any of the staff participants.

***High school credit system.***

Another structural limitation discussed was the high school credit system. The credit system was perceived as impacting decision making opportunities for students in three different areas including (a) class time activities, (b) assignments and (c) course selection.

***Impact of credit system on student decision making during class time.***

It was clear from all data sources that the teacher made the decisions related to what went on in the classroom. Both teachers and the administrator indicated that some subject areas seemed to lend themselves to more decision making opportunities than others (e.g., language arts provided more opportunities than math). However, it was also indicated that some teachers provided more decision making opportunities by nature of their teaching style, regardless of the subject they were teaching. These factors seemed to impact students with and without special needs similarly in that students perceived that they had few decision making opportunities related to what happens in the classroom other than whether or not to participate and whether or not to attend.

***Impact of credit system on student decision making related to assignments.***

The second area limited by the credit system was decision making related to assignments and projects. This area seemed to impact students with and without special needs quite differently. Teachers perceived they could offer less flexibility and fewer opportunities for decision making around assignments and projects for students without special needs because of the need for them to meet the criteria for obtaining credit for their courses. For students with special needs, teachers said they tended to offer a wider

range of options for assignments and projects. In fact, they were even willing to negotiate projects and assignments based on what the student with special needs requested or suggested. An explanation for this was that students could receive a modified (M) course designation, and therefore did not have to meet the same criteria for obtaining credit. This automatically permitted more flexibility. They also tended to offer more flexibility in assignments for students considered to be 'at risk', citing the need to motivate them. These students were not eligible for "M" designated courses, yet teachers still found ways to offer these students more choices. In discussion, teachers wondered why they did not offer more decision making opportunities to all students related to assignments, acknowledging that students often performed better on assignments where they had more options. Teachers did not raise the issue of the importance of student decision making in relation to their growth and development toward adulthood as a reason to offer more decision making opportunities but were interested in the research when I summarized it briefly for them.

***Impact of credit system on student course selection.***

The third area influenced by the credit system was course selection. Once again, students with special needs were reported to have much more flexibility and less adult influence in the course selection process than students without special needs. It was explained that students without special needs had to obtain thirty credits in order to graduate. In addition, many had to meet certain requirements in order to enter their chosen post-secondary education programs therefore further limiting their course options. Even students who did not have a clear career path would have their choices limited by the perceived need to 'keep their options open' and tended to take the most challenging

courses. Students without intellectual disabilities and professional staff also agreed that parents had a significant influence on course selection for most students, and in some cases, may have used the opportunity to guide their teens through a decision making process.

In contrast, it seemed to be assumed that the students with special needs were not going on to postsecondary education and therefore did not need to be concerned about meeting entrance criteria. In addition, they had the option of staying in school until they were 21 years old which allowed them more time to participate in their preferred options and to obtain credits. As a result, students with special needs had the option of incorporating recreation and leisure activities into their school day. Some of the students talked about going to the weight room or playing ping-pong during class time. When I asked the administrator about weight training being an optional course, he indicated that it was for credit and that the students received some instruction around nutrition and health as part of the weight training program. In addition, work experience opportunities were also available to the students with special needs in order to obtain their credits. For example, one student participant worked in the school cafeteria. This was considered to be one of his classes. This additional flexibility results in a different school experience for the students with special needs than that of the students without special needs. When looking at the graphic representation of the student focus groups, one of the EAs summed it up by stating that it looked like students with special needs had a lot more fun at school.

The discussions seemed to suggest a striking difference in the perception of the contribution that the school system may make toward the life-goals of students with and

without special needs. It appeared that participants perceived a stronger connection between high school courses and post-school plans for students without special needs than for those with special needs, particularly those students without special needs planning to pursue post-secondary education. An exception to this might be work experience, when treated as course credit and connected to the post-school goals of a student. One student bemoaned the fact that she could not get work experience in an Anime store because none existed in Winnipeg. Her goal was to work in that type of store. In my experience, school staff members try to place students in work experience placements that match their interests and goals. However, this is extremely challenging due to the limited availability of such placements and the fact that schools, school divisions and adult service agencies sometimes compete for them. Therefore, it is not uncommon for students to be placed in work experience placements that are not related to their interests or goals, once again weakening the connection between the high school experience and the post-school goals and dreams of students with intellectual disabilities.

### **Role of adults.**

It appears that the role of adults can either facilitate or limit the decision making opportunities experienced by students with and without intellectual disabilities during the school day. The role that adults play was raised during discussions around decision making related to (a) classroom activities, (b) classroom assignments, (c) co-curricular activities, (d) participation in special events and, (e) friendship.

There was general agreement from all participants that students with and without intellectual disabilities had very limited opportunities to make decisions related to

activities during class time. Decisions about what happens in the classroom on a day to day basis were clearly the responsibility of the teacher. At times, students had some limited opportunities to make decisions such as voting on what game to play during a physical education class, choosing between two songs in choral class, or deciding which jobs to do or what condiments to use during a foods class. The teachers in the focus group wondered aloud why they did not offer more opportunities for students to make decisions during class time. They readily admitted that when they did offer choices, the choices were limited, and in fact, often were not even “real choices” (e.g., doing an assignment or not passing). EAs reported offering similar choices such as “changing into your gym clothes or losing marks”. Conversely, the presence of EAs allowed the students with special needs much more freedom to enter or leave the classroom during class time, or to participate in different activities or tasks than other students, based on individual needs.

Students, teachers and the administrator all observed that level of participation in class, doing an assignment or not, attending school or not were not perceived as choices by many students for a variety of reasons. Some of these included incongruence with a student’s personal goals or not wanting to disappoint parents or teachers. One student summed it up by saying, “I don't really see it as choice. I file it as best strategy.” Students who think in this way have already made the decision to participate in their schooling. It was also acknowledged by the students without special needs and all of the adults interviewed that some students do make these choices and are willing to suffer the consequences as they choose to not participate or to not attend. This is likely not a decision making opportunity that the school system ever intended. It is most concerning

that many students making these high risk decisions are doing so without the opportunity for adult guidance or coaching as they go through the process of decision making.

The EAs emphasized the critical role of the teacher in modeling acceptance of all students, orchestrating opportunities the students with special needs to participate fully in classes, and in providing opportunities for students to make choices and decisions in those classes. The EAs also emphasized that they were very happy to provide whatever support and assistance that was needed during classes, but their ability to provide appropriate support really depended upon the guidance and direction they received from classroom teachers.

In discussing classroom assignments and the difference in decision making opportunities available to students with and without intellectual disabilities, it was pointed out that the additional adult support available to students with intellectual disabilities and those considered to be 'at risk' (i.e., student services teachers, EAs) allowed for assignments and projects to be individualized according to the specific strengths, interests and needs of each student. This additional adult could help facilitate the negotiation around the assignment or project, and could also provide direct support as the student worked on the adapted or modified assignment or project.

If a student with special needs who required more support than could be provided by the teacher supervisor wished to participate in a co-curricular activity, this was sometimes facilitated by adjusting the hours of an EA to provide necessary support outside of regular school hours. The specific role of the EA would vary depending on the needs of the student or students involved. Generally, the EA support would be faded out as the student gained independence and confidence, and responsibility for the student

would be transitioned to the teacher in charge of that particular co-curricular activity.

Two examples were shared of situations where the staff member in charge of the activity was able to take full responsibility for all participants, including the one with special needs, right from the start, and additional EA support was not required. The students involved were more independent, requiring little or no one-on-one support.

The EAs indicated that part of their role was to facilitate inclusion. For this reason, and because the students with special needs got very excited about opportunities to be with all the students in the school, the EAs encouraged and facilitated the presence of students with special needs at school wide special events such as pep rallies and fundraising events. According to the students, their participation in such events was not facilitated, however. Students without intellectual disabilities would have to depend on school announcements or their friends to find out about these events. Some would miss the information and, therefore, the event, while others saw it as a decision making opportunity and chose to be somewhere else.

A clear difference between students with and without special needs emerged during discussions around friendships, and the role that adults played in this area of the students' lives. As already discussed, students without special needs appeared to have more opportunities during less structured times to make decisions and these decisions were frequently influenced by peers considered to be friends. It appeared that adults (in the school and at home) had a role to play in helping students consider other factors when making decisions. For example, if students wanted to change sections or courses based on a desire to be with their friends, adults may point out the importance of meeting entry criteria for postsecondary education in comparison to being with friends. Decisions made

by the students with special needs did not appear to be influenced by peer friendships. In fact, the EAs even questioned whether or not some of the students with special needs actually had friends in the same way as their non-disabled peers. They observed that when the students with special needs were together as a group, they did not appear to have conversations on common topics but instead each talked about their own individual interests. There was no discussion around what role they or other adults could play in facilitating such conversations and teaching appropriate conversational skills. It was obvious during the student focus groups that the students with special needs treated some of the EAs as if they were their friends. This was not surprising, given that the students with intellectual disabilities spent a lot of their unstructured time with the EAs, and in some cases, depended upon EAs to meet their physical needs. It was observed by the administrator that some students develop a friendship with some teachers as well. However, this did not come out in discussion with the student focus groups.

### **Safety.**

Every one of the adults interviewed was in agreement about the importance of safety for all students in the school. Students with special needs also seemed to have a heightened sensitivity to safety rules as two of them specifically mentioned watching for cars when crossing the parking lot in the morning. For the adults, the need to keep students safe was translated into the need for supervision. It was clear from the comments of all adults interviewed that the students with special needs were perceived to require more supervision than the students without special needs in order to keep all students safe. The need for increased supervision ended up limiting the decision making opportunities of the students with special needs. For example, almost all of the students

with intellectual disabilities who participated in the study were expected to be in the student services area during the lunch hour. The few students who did not need to remain in the student services area were expected to check in at the student services area from time to time during the lunch hour. For students without special needs, lunch hour offered the freedom to choose where they wanted to be and with whom. It appeared that these students were perceived as not requiring supervision over the lunch hour in order to remain safe.

All of the adults interviewed indicated that the goal for all students was to work toward increased independence as they got older. Younger students without special needs are fully time-tabled, therefore having less unstructured time. By grade eleven, students without exceptional needs have the opportunity to have 'spares' in their timetables, therefore allowing more opportunity for independent decision making, even though there was no mention of instruction or guidance to develop these decision making skills. It was just expected that they were better able to manage more unstructured time as they got older. When students with special needs are new to the school, they tend to be supervised more closely and this supervision is gradually lessened as the students gain confidence and experience in their new setting. At the same time, the adults in the setting are gaining confidence that the students can keep themselves reasonably safe. It was reported that experience in the setting was a primary factor in determining the level of supervision a student required. It was clear that the level of trust adults had in student with intellectual disabilities and other special needs significantly influenced decisions about level of supervision. Age, gender, and cognitive ability were reported to have little if any influence.

## **Summary**

In this chapter, I have summarized the data obtained from students with and without intellectual disabilities and have compared and contrasted the perceptions of the students who participated in the three student focus groups. This data was collected and analyzed in response to the first two research questions identified in this study. In addition, I summarized the data obtained from teachers, EAs and an administrator and then compared and contrasted these perceptions. This data was collected in response to the third research question identified in this study. Finally, three major themes were identified as common across most or all of these six data sources as follows: structure of the school system, role of adults and safety.

## **Chapter V: Summary and Discussion**

In this chapter, I begin by restating the research questions. Then I briefly review the major methods used in the study and summarize the results. The main section of this chapter provides a discussion of my results as they connect with previous studies. I close chapter V by outlining the limitations of my study and suggest areas for future research.

### **Brief Summary of Study**

In this study, I explored the range of opportunities for decision making during a typical school day or school year perceived by high school students with and without intellectual disabilities from one Manitoba high school. After I completed a preliminary analysis of the data from the students, professional staff and EAs from the school had the opportunity to see and hear about the comparative results. During focus groups and an interview, they were asked to explain any similarities or differences, as well as to explore the personal characteristics, environmental factors or other factors that may have had an influence on the similarities and differences.

As explained in chapter III, this study was an exploratory qualitative study that was conducted in three phases. The first two phases were focused on gathering data related to the first two research questions and the third phase was focused on the third research question. Participants in this study were students and staff members from a high school in one suburban school division in Winnipeg, Manitoba. I relied on data collected through five focus groups and one interview that I facilitated and audio-recorded. The student focus groups were also recorded graphically by a graphic facilitator. During the

first two phases of the study, high school students with and without intellectual disabilities provided perspectives of their opportunities to make decisions during the hours they are at school. In the third phase of the study, I shared the graphic record and a preliminary analysis of the results of the first two phases with members of one focus group made up of teachers, another of EAs, and with a school administrator in an interview format. Adult participants were asked to comment on the similarities and differences in opportunities for decision making reported by students with and without intellectual disabilities, and to explore possible reasons for the similarities and differences.

As indicated in chapter III, I then completed within case and cross case analyses of the data collected through the five focus groups and one interview, followed by a key theme analysis of the summarized data. These processes resulted in the identification of three major themes including (a) structure of the school system, which included transportation and the impact of the high school credit system; (b) the role of adults working in the school system; and (c) the issue of safety. I observed that each of these themes has the potential to increase or decrease decision making opportunities for students with and without intellectual disabilities.

## **Discussion**

I propose that the three themes identified in the data (a) structure of the school system, (b) role of adults, and (c) safety, are not distinct but intertwined. The adults who work in the school system have the ability to facilitate or limit opportunities that students have to make decisions during the school day and the school year within the structure of

the school system. Furthermore, facets of the structure of the school system and the adults who work there have opportunities to influence the impact of safety concerns on decision making opportunities for students.

### **Safety and role of adults.**

I will begin by discussing the issue of safety. In my study, concerns about safety appeared to have a more significant impact on decision making opportunities for students with intellectual disabilities than those without. It was clear through discussion with all adult participants that safety of all students is of paramount concern. This concern appeared to be even more heightened in relation to the students with special needs, to the point where it even came up in discussion with the students themselves. It did not, however, enter the discussion with the students without special needs. I certainly do not want to downplay the importance of keeping students safe. However, I question whether the concern for safety is sometimes taken further than necessary, to a point where it becomes a barrier to student development.

This is not new thinking. In 1972, Perske wrote about the ‘dignity of risk’ in relation to individuals with intellectual disabilities, stating that “to deny any person their fair share of risk experiences is to further cripple them for healthy living”. At that point in history, individuals with intellectual disabilities who had been institutionalized were being relocated into mainstream society. There was great concern about the safety of these individuals as they made this transition, as well as concern about the safety of the community at large. As we know, most of these concerns turned out to be unfounded.

In my study, one of the most striking differences between the students with and without intellectual disabilities is found in the decision making opportunities that

occurred during the less structured times at the school day (i.e., before and after school, lunch hour, 10 minute breaks and spares). These were the times that the students without special needs had the most freedom to make decisions about where they would be, with whom, and what they would be doing. There were few, if any, limits placed on their decision making opportunities during these times, and they were not directly supervised or even supervised at all. The decisions they made during these less structured times were more influenced by their friends than by the adults in the school system. Interestingly, neither the adults nor the students without special needs mentioned concerns about their safety during these less structured times. The teachers did mention that some students without special needs had to be supervised due to their behaviour, implying that these students may start off without supervision until they demonstrated that they were not trustworthy.

In contrast, when I pointed out this difference and asked the EAs if the students with special needs could wander around where they wanted and hang out with friends during less structured times, their immediate response was "not by themselves", followed by an explanation that some students needed to be supervised more closely for safety reasons. The teachers concurred with this and also mentioned that some students needed to be supervised for their own safety and some needed supervision in order to keep other students safe. When the same difference was pointed out to the school administrator, it was observed that the students with special needs generally did not have vehicles to drive and so did not have the same freedom as the students without special needs during less structured times. The administrator also explained that students without intellectual disabilities in grades 11 and 12 have spares. If the spare is scheduled just before or after

lunch hour, these students have two hours in the middle of the day where they are free to choose what they want to do, where and with whom. None of the students with special needs who participated in this study mentioned that they had a spare in their timetable.

All adults agreed that age and cognitive ability factored only minimally in determining the need for supervision. The factor reported to have the most influence was whether or not adults perceived that the students could be trusted. The other influential factor reported was the amount of time and experience a student had in that school setting. I suggest that these two factors are actually one and the same as it is implied that the adults in the system need to determine whether or not a student with special needs is “trustworthy” (i.e., could navigate the school without getting lost or wandering onto the street, could move about without harming self or others) and, in turn, determine the degree of supervision perceived to be required. It was reported that the students with special needs would start off with a higher level of supervision, which would be reduced gradually as the adults judged the student was ready.

It is well-established that a reduction in opportunities to practice decision making experienced by the students with special needs results in reduced opportunities to improve their decision making competence. This increased supervision (as compared to students without special needs) also results in reduced opportunities in another area of their personal development. Less structured times are when students without disabilities develop and nurture friendships with peers and practice their social skills. They generally do this outside the direct supervision of adults. Most go through a stage where they insist on this. Many parents of teenagers share the experience of causing their son or daughter to be angry with them by being too close when he or she is with friends or peers. Students

with intellectual disabilities were reported to be in relatively close proximity with adults throughout the school day.

The EAs observed that the students with special needs did not seem to know how to interact with each other appropriately and that many did not seem to have same aged friends. It was also observed that the students with special needs appeared to perceive the EAs (who are paid to be with them) in a friendship role. This is in keeping with the research done by Giangreco et al. (2005) and Giangreco and Doyle (2007) who reported on inadvertent detrimental effects of unnecessary EA proximity which included interference with peer interactions and insular relationships.

***Balancing duty of care with importance of decision making opportunities.***

Limiting decision making opportunities based on estimation of trustworthiness by school staff is supported by the “duty of care” argument cited by Smyth and Bell (2006) and supported by Bannerman, Sheldon, Sherman and Harchik (1990), which suggested that caregivers must balance decision-making autonomy with “duty of care”. Smyth and Bell expressed concern that when individuals with cognitive disabilities are given too much decision-making autonomy, they may end up experiencing harm due to their limited ability to make appropriate decisions. They also cite (a) past experience of choice, (b) lack of knowledge and (c) level of cognitive ability as factors that may reduce the likelihood of making good decisions. The counter argument to this position comes from the research in decision making theory and practice, as well as from the self-determination literature. These bodies of research make a strong case that the only way individuals get better at making decisions is by having the opportunity to make decisions and failing. Experiencing the negative consequences of the decision (outcome feedback)

combined with coaching from someone with more knowledge and experience (verbal feedback) allows individuals to evaluate their decisions and learn from them (Berry and Broadbent, 1984; Byrnes, 1998; Byrnes, Millar and Reynolds, 1999).

These two positions appear to be at opposite ends of the spectrum in the impact each would have on decision making opportunities for individuals with intellectual disabilities. However, using the limited research on decision making that is based on children, Byrnes (1998) added an intermediate perspective. Byrnes suggested that young children and those who are not highly self-regulated (which may include individuals with intellectual disabilities who have not yet reached a high level of self-regulation) benefit from being “other regulated” (p. 53), or in other words, receiving guidance from others who are more self-regulated in their decision making capacity. It is the responsibility of the person(s) providing the guidance (those with ‘duty of care’) to gradually transfer more and more decision making responsibility as those in their charge demonstrate increased self-regulation. This does not mean waiting until every decision is a successful decision since even the most self-regulated decision maker makes poor decisions at times. As discussed in the literature review, the self-regulation aspect of decision making is that when an error occurs, the decision maker examines the negative outcome feedback of the unsuccessful decision, evaluates (ideally with the guidance of a more competent decision maker) and adjusts accordingly so that the next decision in a similar context will more likely be positive and/or the individual has access to more strategies to use when making his/her next decision. Wehmeyer and Schwartz (1998) supported the idea of “other regulation” when writing about the misinterpretation of self-determination as completely independent performance. They acknowledged that individuals may begin

their journey toward self-determination in different places along a continuum. Regardless of individual starting points, the focus should be on providing adequate opportunities to practice so that every individual can become as self-determined as possible.

I suggest it would be beneficial for school staff, students with special needs and their parents to discuss the importance of decision-making practice, opportunities to experience the consequences of poor decisions, and the importance of moving from being “other regulated” toward increased self-regulation in the personal development of children and youth. It is important that all parties involved have a basic understanding of what is needed in order for individuals to become more successful decision makers and the importance of balancing this with ‘duty of care’. It is also important to consider decision making opportunities and degrees of supervision experienced by same aged peers with and without special needs (perhaps during less structured parts of the school day) in that conversation, in order to have natural points of reference. When students with special needs enter the high school in grade 9, the team might consider a period of direct observation and/or data collection so that the initial need for supervision or “other regulation” during less structured times is based on evidence for each particular student with intellectual disabilities. Goals/outcomes related to decision making, plans for providing ongoing guidance in decision making, and plans for ongoing assessment could then be established for working toward decreasing “other regulation” and increasing self-regulated decision making at school and at home.

### ***Role of EAs.***

As indicated in the literature review, one of the most common supports provided to students with special needs in inclusive or segregated classrooms, is an EA for part or

all of the school day. Giangreco et al. (2005) advised that we should not assume the need for EA support based on appearances or labels, but should first contemplate adapting the school environment and taking into consideration alternatives to EA support such as peer supports and support/instruction by professional educators.

From the perspective of individuals with intellectual disabilities, Broer, Doyle and Giangreco (2005) found that the presence of a EA interfered with opportunities to (a) make friends, (b) to have a girlfriend or boyfriend, (c) to sit at the back of the room with the other kids, (d) have conversations with friends, and (e) to be independent in certain classes or during certain times of the day when they did not need support. A common experience reported in that study was that participants got frustrated with the constancy of EA support saying that they felt embarrassed or like they had a babysitter.

Based on the data from my study, it appears that EAs are already playing an important role in facilitating interactions between students with and without intellectual disabilities by helping to ensure that requests to take part in school activities made by the students with special needs during less structured times were accommodated. None of them could remember a time when a student's request was refused and pointed out that it was part of their jobs to encourage interactions between students with and without disabilities. EAs were also reported to help facilitate decision-making opportunities around student assignments and projects, and to help students follow through on those decisions.

EAs could play a more extensive role in helping students build skills in decision making and self-advocacy. However, a better understanding of this potential role is required by the EAs and, more importantly, by those who supervise or direct them, as

demonstrated by the story about Mark included in the introduction of my thesis. As part of the student support team, EAs could help determine the true level of risk involved in allowing a student to make a particular decision. They could assist students to understand the consequences and dangers associated with certain options. If teachers were teaching decision-making steps or processes, EAs could help to reinforce that information. EAs could also help provide the scaffolding that students with intellectual disabilities would need in order to improve their decision-making competencies. The EAs themselves noted that the students with special needs did not seem to know how to nurture friendships or to have conversations using appropriate social skills, but did not mention a role for themselves in helping to facilitate that.

Based on my study, I concur with Broer, Doyle and Giangreco (2005) who recommended future research on topics such as the effect of EA support on social relationships and self-determination. I would add decision-making opportunities to this list. Further, in congruence with Broer et al., I would encourage studies that solicit input from students with disabilities.

### **Safety and structure of the school system.**

The structures of the school system contribute to the extreme concerns related to safety of students through policies and guidelines developed to avoid the possibility of being found legally liable if a student ever met with harm during any school sanctioned activity. While the number of actual court cases is relatively small, the legal concern remains heightened. For example, the Manitoba School Board Association (formerly known as the Manitoba Association of School Trustees or M.A.S.T.) has a link on their website entitled "risk management" which includes further links to manuals, guidelines

and checklists to help school divisions identify and manage risk. They even have a link to a document called *Risk Management at a Glance for Manitoba Schools*.

In my experience, this heightened legal concern is passed on to the adults who work within the school system, often without the opportunity to learn the background information and actual intent of the policies and guidelines related to safety. This results in responses that range along a continuum from mild to extreme concern. I believe that it is the individual human interpretation or perception of this information that often results in barriers to decision making opportunities for students. I suggest that this could be another area for future research. Once again, I do not want to negate that there is risk associated with many things in life, including offering students with special needs opportunities to make decisions. However, I suggest that adults in the school system, jointly with parents and students, need to candidly consider level of risk when reviewing the need for supervision of individual students during the less structured times of the school day or whether or not to provide students with certain decision making opportunities.

Schloss, Alper and Jayne (1993), as cited in Wehmeyer et al. (1998), outlined four levels of risk associated with choices or decisions. The first level involves some potential for immediate risk but little possibility for long-term harm to self or others; the second level is mild immediate risk and minimal possibility of long-lasting harm; the third level is moderate possibility for long-lasting harm to self or others; and the fourth level involves almost certain personal injury. The reality is that the vast majority of choices and decisions in day to day life fall within the first two levels of risk. The nonspecific statements made by school staff when discussing the need for supervision of the students

with special needs during less structured times made me wonder if “these relatively low levels of risk are overemphasized and used to curtail the opportunities students have to make choices and decisions” (Wehmeyer et al., 1998, p. 126).

***Transportation, structure, safety and role of adults.***

The transportation to and from school for students with special needs was identified as a structural barrier that inhibited opportunities for these students to make decisions and to socialize with peers before and after school. I question whether the topic of transportation would also fit under the topic of safety. Most students without intellectual disabilities traveled to and from school in a variety of ways such as public transit, rides from parents or friends, walking, skateboarding, etc. Some students without special needs reported that they made decisions about their mode of transportation on a daily basis. The majority of students with special needs reported that they traveled to and from school on a designated school bus. I expect that this would be similar in most high schools across the province. Who makes this decision and on what basis?

I wonder what might happen if school staff, parents and students openly examined the reasons that individual students with special needs are transported by school bus in areas where students without special needs typically are not. I then challenge teams to examine the balance between the actual level of risk involved in other modes of transportation with the potential benefits of offering individual students with special needs the same choices regarding traveling to and from school as are enjoyed by students without special needs (e.g., more opportunities to practice decision-making, more opportunities to socialize). Would all the students with special needs currently transported by school bus continue to be transported in this way? Pumpian (1996)

submitted that if professionals honestly examined our reasons for many of the decisions we make on behalf of students, we would realize that the reasons are often associated with convenience or scheduling, costs or the desire to protect them from failure. I would add perceived protection from harm to this list.

### **Structure of the school system and the role of adults.**

As outlined in Chapter II, Field and Hoffman (2002) developed a set of nine quality indicators for promoting self-determination in educational settings. One of these indicators states: “Students, families, faculty, and staff are provided with opportunities for choice”. Another quality indicator is: “Students, families, faculty, and staff are encouraged to take appropriate risks” (p. 117). Field and Hoffman explained that members of the school community “need to be encouraged to take calculated risks” and “to celebrate and/or learn from the results of their actions” (p. 118). I believe that classroom teachers have the power and the opportunity to teach decision making skills, to provide students with decision making opportunities, and to encourage appropriate risks within the current structure of the school system. School administrators can support, encourage and model this in their schools with both staff and students. In my study, it was reported that EAs and student services personnel already support classroom teachers and students with exceptional needs in broadening their decision making opportunities. It is possible that this role could be expanded even further.

### ***Decision-making during class time.***

Students with and without special needs reported very limited decision making opportunities related to classroom learning activities. The opportunities they mentioned

such as voting on what game to play during physical education class or choosing what condiments to use during foods class would be described more accurately as choice making. During the focus group, teachers wondered out loud about why they did not offer more decision making opportunities to students. They labeled the choices they frequently offered students as "not real choices" because the options were not equally desirable. The structure of the school system was perceived to put some limits on decision making opportunities because students needed to achieve their credits in order to graduate. Some courses were perceived to allow more flexibility than others due to the nature of the content (e.g., language arts courses permitted more flexibility than math).

However, it was also pointed out that decision making opportunities varied according to individual teaching styles, even when two teachers were teaching the same course. This suggests that the role of the adult (teacher) has at least as much of an impact on decision making opportunities as does the structure of the school system. How do teachers decide how much flexibility they will offer their students? This topic also has potential for future study. It was clear from all sources that the teacher is in charge of what happens in his or her classroom. The EAs supported this as they told me that they did their best to encourage and facilitate inclusion and to offer choices, but they perceived that their impact was dependent upon the support and direction provided by the classroom teacher. School administrators could improve the quality of the school environment by providing decision making opportunities for staff and students, and encouraging calculated risk. Wehmeyer, Kelchner and Richards (1996) stated, "If interventions to promote self-determination are to succeed, we must also alter the environments within which people with mental retardation live, work, and play to allow

greater choice and control and examine the attitudes of service providers, educators, families and others who interact with them” (p. 641).

***Decision making and assignments.***

All adult participants in my study perceived that the students with special needs have more decision making opportunities related to classroom assignments and projects than did the students without special needs. Once again, the structure of the high school credit system was mentioned in connection with this. Teachers reported they could offer students with intellectual disabilities more flexibility in their assignments because they could modify courses for them. In Manitoba, this means that teachers can change the number or content of the outcomes that a student with intellectual disability is expected to achieve (Manitoba Education, Citizenship and Youth, 2006, Glossary). At the high school level, these students would receive an *M* designation on their transcripts for any course that has been modified. Further, teachers reported that the additional adults (e.g., student services teachers and EAs) were available to help with the negotiation process and to assist the student to complete the modified project or coursework as required.

Teachers also indicated that they offered similar flexibility in assignments to students considered to be ‘at risk’. They said that this flexibility helped to motivate these students. The ‘at risk’ students are generally not eligible for having their programs modified, so the negotiated assignment would be seen as differentiating instruction (D.I.) which is defined in the glossary of the *Appropriate Educational Programming: Standards for Student Services* (Manitoba Education, Citizenship and Youth, 2006) as “a method of instruction or assessment that alters the presentation of the curriculum for the purpose of responding to the learning diversity, interests and strengths of pupils”.

Teachers in Manitoba are not only permitted, but are expected to differentiate their instruction, as well as their classroom assignments and projects in response to the diversity of students' interests, strengths and needs. A document entitled *Success for all Learners: A Handbook on Differentiating Instruction* was published in 1996 to support teachers in their efforts (Manitoba Education and Training, 1996). In the *Middle Years Assessment Grade 7 Student Engagement Support Document for Teachers* (Manitoba Education, Citizenship and Youth, 2007), it states, "Supporting the development of student engagement involves...listening to 'student voices' in classrooms and schools and providing choices in how students demonstrate their understanding." This sets up the expectation that educators engage students in decision making related to their projects and assignments and allow them to have a say in what goes on in their classrooms and schools.

During the student focus groups, I observed that student participants with and without special needs were more enthusiastic and more engaged when they talked about assignments or class activities where they were permitted decision making opportunities. This seemed to be true even when the decisions were limited to the final appearance of the project or assignment. Just as the teachers wondered aloud why they did not offer more decision making opportunities for all their students, I wonder the same thing. It appears that decisions a teacher makes related to differentiating their instruction for one or all students is based more on his or her individual knowledge, skills and beliefs than on the structure of the school system since the system not only allows, but encourages the use of D.I. in all Manitoba classrooms. An interesting topic for further exploration may

be inviting teachers to reflect upon their reasons for offering or not offering decision making opportunities to the students they teach.

***Decision making and course selection.***

Another area where students with special needs appeared to have more decision making freedom than those without special needs was related to course selection. Once again, teachers and the administrator both cited the structure of the high school credit system as one reason why choices for students without special needs were more limited. It was explained that students without special needs were expected to complete 30 credits in order to graduate from high school and often needed to meet requirements for postsecondary programs. Another structural difference pointed out was that students with special needs could stay in school until they were 21 years old and so had more time in their schedules to complete credits for graduation. This meant that they were able to select more optional courses including work experience, and participate in recreation and leisure activities during the school day. One of the EAs observed that the students with special needs seemed to have more fun at school than the students without special needs.

In actuality, according to the Manitoba Public Schools Act (2009), all students have the right to attend school until the last school day of June in the calendar year in which they turn 21 years of age, not only students with special needs. In fact, even after they have met graduation requirements, a student of any age can return to school to complete up to four additional credits according *Public Schools Enrolment and Categorical Grants Reporting 2010/2011* (Manitoba Education, 2010). Given this, why is it that only the students with special needs choose to have 'more fun in school' and stay longer? If a student without special needs chooses to stay past the age of 18, it is

generally because they are working toward gaining credits that they missed in the past or upgrading marks in order to meet entry requirements for a post-secondary program. They are not seeking optional recreation and leisure courses. How much are students with special needs benefiting from remaining in school beyond the time that their same age peers graduate?

The structure of a system beyond the school system is a factor here. In Manitoba, students with special needs that require more extensive support as adults typically are expected to stay in school until the age of 21 because funding to support them post-school is not available from the Family Services and Consumer Affairs Department until they reach that age. Generally, this means that community supports are not available to them either. This issue continues to be a topic of discussion among government departments and stakeholders and has been for many years. Perhaps it has become 'normal' and accepted by the adults who work within both systems, and so it is assumed that students with special needs will remain in school until they turn 21, whether they benefit from it or not. The data from my study suggests that students with special needs have more decision making opportunities when it comes to course selection. However, they lose out on an important life decision that students without special needs make; that is when to leave the school system and transition to their adult lives.

### **Limitations**

Although this study provides information that contributes to several bodies of research, there exist some limitations that must be considered in examining its implications. The first and most obvious limitation is that I ran out of time during the

focus group comprised exclusively of students with intellectual disabilities and was unable to discuss the last question, related to course selection, with them. This is unfortunate in that it limited my data on course selection and its connection to post-school planning for individuals with intellectual disabilities. Another limitation is that this qualitative study involves a relatively small sample size, drawn from only one high school in one particular province in Canada. The participants were selected through a process of theoretical sampling, which is consistent with qualitative research. For these reasons, the results cannot be generalized to other settings. The analysis may have benefited from having samples re-coded and analyzed by someone who was not involved in the collection of the data. However, I did get feedback on my methods from the chair and members of my thesis committee prior to starting the process of data collection. In addition, I sought and received feedback from my committee chair at two points in time as I worked through the analysis.

### **Areas for Future Research**

I suggested several areas for future research in my discussion section that may help support educators and administrators who would like to offer more decision making opportunities to their students.

In my study, it was clear that educators were very concerned about the safety of all students in their charge, and particularly those with intellectual disabilities. This resulted in a reduction in freedom and decision making opportunities enjoyed by students with intellectual disabilities. It would be helpful to find out if parents of students with intellectual disabilities shared the same concerns and perceived the same risk factors as

did educators. To take that one step further, an examination of the impact of parent concerns and perceptions on educator actions would also add to this research. A relevant action oriented study may be to have a researcher work with a school/parent/student team to help them learn about and address the issue of balance between risk and decision making opportunities or between duty of care and decision making practice. It would be useful to find out whether increasing the team's understanding of levels of risk and the importance of opportunities to make decisions and take calculated risks, results in increased decision making opportunities for students. Another topic related to safety would be to explore the perception and interpretation of adults in the school system of policies and guidelines related to safety and risk compared to the actual intent of those policies and guidelines. A clarification of the intent may free educators to offer more decision making opportunities.

Related to this, another potential area for further research is to talk with teachers about how they decide how much flexibility to offer students. This could be related to decision making opportunities during less structured times of the school day, and therefore connected with safety concerns. This could also be related to decisions that teachers make regarding the amount of flexibility they offer students when it comes to classroom assignments and activities.

A final area of research suggested in my discussion was the effect of EA support on social relationships and self-determination, including decision-making. It would be ideal if this research was based on the perspectives of students with disabilities.

## Conclusion

I began my thesis research with two purposes in mind. The first was to compare the perceptions of students with and without intellectual disabilities regarding their opportunities to make decisions in the high school setting. The second purpose was to obtain initial explanations from involved staff members for any differences in the perceptions of these two groups of students. I found out that there is a difference in the perceptions of the two groups of students. The perceived differences were verified by staff participants, who also provided their perceptions of possible reasons for the differences.

The most striking difference in decision making opportunities between students with and without intellectual disabilities was during less structured parts of the school day. The data showed that the adults demonstrate a strong need to keep students (and especially students with special needs) safe. In order to do that, they provide supervision to the point where it limits the opportunities that students have to make decisions. Since students have limited opportunities to make decisions, they have less opportunity to grow in their decision making competence. Therefore, they continue to be perceived by adults as lacking competence for making effective decisions and so continue to need to be protected.

It is particularly concerning that this is happening in the school system given the results of a study by Smith, Morgan and Davidson (2005) where they concluded that once adult status is attained, availability of decision making opportunities remains relatively static as there is a plateau in the trajectory toward the end of adolescence.

When students are permitted few if any decision making opportunities during their school years, the impact on their lives can be significant. All those who participated in this study talked about the limited opportunities that all students have to make 'real decisions' or 'real choices' during the structured parts of the school day. For some students, there may only be one real decision they perceive they can make, which is whether or not to participate, or to what degree to participate in their school experience. The students who do not regard participation or non-participation as a decision but, instead as "best strategy", are students who have actually decided to participate for reasons such as their own personal goals or not wanting to disappoint parents or teachers. Educators and students without intellectual disabilities also said that there are students who decide to not participate in their school experience by skipping classes or even dropping out of school. These actions seem to carry pretty harsh consequences given that it is the only decision making opportunity those students may perceive. I wonder what opportunities they had to practice with scaffolding from competent decision makers before making such life-altering decisions.

Three major themes identified in the analysis of my data were safety, role of adults and structure of the system. Each of these can limit or extend decision making opportunities for students. The adults who work in the school system have a significant role to play in mediating the effects of the structure of the school system, and the effects of safety concerns, on the opportunities that students have to make decisions during their time at school. As with so many situations, it is people who can make the difference. The teachers in my study wondered why they themselves did not offer more decision making opportunities to their students. This indicates the realization that they have that ability.

The EAs indicated a willingness to support the teachers, and it was reported that the EAs and student services teachers already did support decision making opportunities currently offered to students. The administrator can support teachers and EAs by offering decision making opportunities to school staff and encouraging them to take calculated risks.

According to Powers et al.(1996), “few experiences are more empowering than communicating respect and trust for someone’s decision making skills” (p. 263).

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## Appendix A

Dear \_\_\_\_\_,

My name is Barb Melnychuk and I am a student at the University of Manitoba. I am doing a research project for my Masters degree. In order to do the research, I need approximately 20 volunteer students to participate in some discussion groups. Your teacher gave me your name, as someone who may be a good candidate for my project. Please share this letter with your parents or caregivers.

The purpose of this research project is to find out if there is a difference in the opportunities to make decisions at school between students with and without disabilities. If there is a difference, I will explore possible reasons for that difference.

Each student who volunteers for the study will participate in one group discussion. The groups will meet at the school during school hours. Each group will meet one time for 60-90 minutes. Students will be asked questions about the opportunities they have to make decisions at school.

For purposes of protecting privacy, the school division, school, and study participants will be referred to only with invented names when the study results are reported. Only those who participate in the study may request a summary of the data. The data will be destroyed at the end of the study.

Students who participate in the study will get to choose a thank you gift at the end of the study, either a Gift Card/Certificate for a movie or for a free lunch at your school cafeteria.

If you are interested in participating in a discussion group about making decisions at school, or if you have further questions, please contact me in one of the following ways.

Telephone: XXX-XXXX extension XXXX or e-mail: XXXXXXXXXXX@XXXX.XXX or

Tear-off sheet below and return to your school office.

---

Attention: Barb Melnychuk, Researcher, University of Manitoba

I am interested in participating in one of your discussion groups about decision making. Please send me the consent forms to complete and return to you.

Name or student (please print):

Signature of student:

Signature of parent:

## Appendix B

### Consent Form-Parent

**Research Project Title:** Decision Making by Youth With and Without Intellectual Disabilities: A Comparison of Perceptions

**Researcher(s):** Barbara J. Melnychuk

I am a graduate student at the Faculty of Education, University of Manitoba, and this research project is for my thesis.

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what participation by your son/daughter will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully.

#### 1. Purpose of the Research

As students in high school have increased opportunities to make decisions as they get older, the purpose of this research project is to find out if there is a difference in the opportunities to make decisions at school between students with and without disabilities, from the perspectives of the students. If there is a difference, I will explore possible reasons for that difference, from the perspectives of the staff.

#### 2. What is expected of students who participate?

Each student involved in the study will participate in one focus group discussion. The focus groups will meet at the school during school hours. Each focus group will meet one time for 60-90 minutes. Students will be asked questions about the opportunities they have to make decisions at school. The researcher may need to contact participants once more after the focus group session in order to get clarification if needed.

#### 3. Benefit and Risk

**Benefit:** Individuals who participate in research studies often find the experience interesting and beneficial to their personal growth. In addition, staff members who participate may find that the experience causes them to reflect upon their current practice.

**Risk:** The focus groups will take place within the school environment, therefore the risk is no greater than the participants experience in the normal conduct of their everyday lives. With the permission of their teachers, students who participate will miss 60 to 90 minutes of class time on one occasion (i.e. approximately one class period).

**4. How will information be recorded?**

All sessions will be audio-recorded with a small digital recorder. During student focus groups, an assistant will also make 'picture notes' in order to help participants follow the discussion more easily. This is formally called "graphic facilitation". Near the end of the session, the helper will check with participants to make sure that the 'picture notes' are accurate.

**5. Confidentiality**

For purposes of protecting privacy, the school division, school, and study participants will be referred to only with invented names when the study results are reported. At the beginning of each Focus Group, the researcher will establish ground rules. One of these rules is that what is discussed in the group stays in the group. The researcher will work with participants to ensure they understand this concept.

Only Ms Melnychuk and her advisor, Dr. Lutfiyya, will have access to the original information collected through the focus groups. The graphic facilitator will only have access to the 'picture notes' during the session. After that, the information will be kept in a locked, secure location in Ms Melnychuk's home. Ms Melnychuk will transcribe, code, combine and analyze the student responses before the results are reported. It is possible that direct quotations will be used in the report. If this is necessary only invented names will be used.

After the thesis has been completed, all original information collected through the focus groups will be destroyed.

**6. Withdrawing from the Study**

You may choose to withdraw from the study at any time by talking to Ms. Melnychuk in person, by phone or by e-mail. If you choose to withdraw, I will 'black out' any responses made by you during the focus group session and it will not be used in the analysis.

**7. Would you like a copy of the results?**

The results of the study will be made public in the winter of 2008-09. Please indicate below if you would like a copy of the summary of results sent to you when it becomes available.

Yes, please send a copy of the summary of results to me as indicated below:

Name (Please print): \_\_\_\_\_

Send the summary home from school with my son/daughter

Mail to the following address (include postal code):

\_\_\_\_\_

By e-mail to: \_\_\_\_\_

No, I do not wish to receive a copy of the summary of results

**8. Thank You Gift**

Students who participate in the study will be given a choice of thank you gift at the end of the study. They may choose either a gift card for a movie or a gift certificate for a free lunch at the school cafeteria.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and that you, as a parent/legal guardian, agree to allow your son/daughter, \_\_\_\_\_ to participate in a focus group. In no way does this waive your legal rights nor release the researcher or involved institutions from their legal and professional responsibilities. You are free to withdraw your son/daughter from the study at any time without prejudice or consequence. The continued participation of your son/daughter should be as informed as your initial consent, so please feel free to ask for clarification or new information at any time.

Your son or daughter will receive an assent form to complete. Your support in assisting him or her to understand and complete the form is very much appreciated.

Principal Researcher: Barbara J. Melnychuk

XXX-XXXX

XXXXXXXXXX@XXXX.XXX

Advisor: Dr. Zana Lutfiyya

XXX-XXXX

This research has been approved by the Education/Nursing Research Ethics Board. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Secretariat at XXX-XXXX, or e-mail xxxxxxxx\_xxxxxx@umanitoba.ca. A copy of this consent form has been given to you to keep for your records and reference.

Name of Student (Please print): \_\_\_\_\_

Name of Parent or Name and Title of Legal Guardian (Please print): \_\_\_\_\_

\_\_\_\_\_  
Signature of Parent/Legal Guardian

\_\_\_\_\_  
Date

\_\_\_\_\_  
Researcher's Signature

\_\_\_\_\_  
Date

## Appendix B (cont.)

### Assent Form-Student

#### Sample Assent Form to be Typed on Institutional Letterhead

**Research Project Title:** Decision Making by Youth With and Without Intellectual Disabilities: A Comparison of Perceptions

**Researcher(s):** Barbara J. Melnychuk

This assent form, a copy of which will be left with you to review, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information. Please feel free to have someone you trust, read this form with you.

#### 9. Purpose of the Research

The purpose of this research project is to find out if there is a difference in the opportunities to make decisions at school between students with and without disabilities. If there is a difference, we will explore possible reasons for that difference.

#### 10. What is expected of students who participate?

Each student involved in the study will participate in one group discussion. The groups will meet at the school during school hours. Each group will meet one time for 60-90 minutes. Students will be asked questions about the opportunities they have to make decisions at school. The researcher may need to contact participants once more after the group session in order to get clarification if needed.

#### 11. Risk

As the discussion groups will take place within the school environment, the risk is no greater than you normally experience in your everyday life.

#### 12. How will information be recorded?

All sessions will be audio-recorded with a small digital recorder. The sessions will also be recorded in picture form in order to help participants follow the discussion more easily.

**13. Confidentiality**

Only the researcher, her assistant and advisor will have access to the original information collected through the discussion groups. The responses provided by students will be coded and combined for purposes of analysis before they are reported. This will help ensure that students remain anonymous in the report. If it is necessary to refer to the response of a particular student, an invented name will be used.

For purposes of protecting privacy, the school division, school, and study participants will be referred to only with invented names when the study results are reported. At the beginning of each Discussion Group, the researcher will establish ground rules. One of these rules is that what is discussed in the group stays in the group.

**14. Only those who participate in the study may request a summary of the data. The data will be destroyed at the end of the study.**

Please indicate below if you would like a copy of the summary sent to you when it becomes available.

- Yes, please leave a hard copy of the summary of data for me to pick up at the school
- Please send an electronic copy of the summary of data by e-mail to:

\_\_\_\_\_

- No, I do not wish to receive a copy of the summary of data

**15. Thank You Gift**

Students who participate in the study will receive a thank you gift. Please choose which gift you would like to receive.

- Gift Card/Certificate for a movie
- Gift Certificate for a free lunch at your school cafeteria

**Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and that you agree to participate in a discussion group. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and /or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information at any time.**

Principal Researcher: Barbara J. Melnychuk  
XXX-XXXX  
XXXXXXXXXXXX@XXXX.XXX

Advisor: Dr. Zana Lutfiyya  
XXX-XXXX

**This research has been approved by the Education/Nursing Research Ethics Board. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Secretariat at XXX-XXXX, or e-mail xxxxxxxx\_xxxxxx@umanitoba.ca. A copy of this consent form has been given to you to keep for your records and reference.**

\_\_\_\_\_  
Participant's Name (Please print)

\_\_\_\_\_  
Participant's Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Researcher's Signature

\_\_\_\_\_  
Date

## Appendix C

### Agenda/Questions

### Student Focus Groups

Entry, fill out and wear name tags, get a beverage if you wish

#### Introduction

- Welcome and thank you for agreeing to participate
- Introduce self, Bonnie and students
- Project on decision making-this is the second phase of a 3 phase project; I met with one group of students last week and will meet with 2 groups this week
- What we say will be recorded on tape and on paper
- How focus groups work
  - I will ask you some questions (focus questions) and you will take turns letting me know your opinion about what I ask
  - 3 rules
    - Everyone is encouraged to speak freely, one at a time
    - No right or wrong answers
    - What is said in the group stays within the group (discuss what this means and its importance)

Talk about decision-making-what it means and some examples and non-examples

- Act as a “causal agent”-cause something to happen, “free from external influence or interference by an adult”

- Identify examples of decisions; smaller day-to-day decisions (breakfast, clothes, go somewhere, talk to someone); big decisions (deciding to get my M.Ed., changing jobs, buy a car)
- Invite participants to tell about a decision they made at home this morning; other.

My project is about opportunities or chances that students have to make decisions at school; distribute copies of student timetables for reference

1. Ask students to ‘walk the researcher’ through a typical school day from the time students arrive on the school grounds until the time they leave, thinking about what decisions they make at each point-Probe How decisions are made and Who else makes them
  - a. How did you get to school today? Did you decide how or when?
  - b. Think back to the moment you arrived on the school grounds-got out of parent’s car or off the bus or walked onto school property...are there any decisions you get to make?
  - c. Class time (i.e. upon entry to the classroom; during class-assignments, activities, while teacher is talking; group work; independent work; as class ends); look at timetable and think of all of your subjects
  - d. Breaks between classes, lunch hour-cafeteria, spare periods, after last class-prior to leaving the school
2. Ask students about participation in co-curricular or extra-curricular activities and decision-making opportunities related to these (i.e. student government,

sports teams, inter-murals, music or drama program activities, yearbook, other clubs or committees)

3. Ask students about participation in special events and decision-making opportunities related to these (i.e. assemblies, school dances, spirit week, pep rally, drama or music productions, fundraisers, other special events)
4. Ask students about participation in course selection or program of studies, IEP goals, work experience placements and decision-making opportunities related to these
5. Review what we have recorded (graphic record). Did we miss anything? Are there other times you get to make decisions during the school day? Are there any other places/locations in the school that offer opportunities to make decisions?
6. Do you have any advice for people at school about the decisions you get to make?
7. Are there any additional comments you would like to add? Or questions you would like to ask?
8. Thank students for their participation and explain how I will get their thank you gifts to them.

**Appendix D**

Transcript Codes-Final  
Student Focus Groups

<b>Code</b>	<b>Part of School Day</b>
AC	After classes (end of day)
ADV	Advice
BC	Before classes (beginning of day)
BR	Break between classes
BIGC	Bigger decisions-course selection
BIGF	Bigger decisions-friendships
BIGC	Bigger decisions-long-term goals
BIGOUT	Bigger decisions-participation in clubs, groups, teams, etc.outside of school
CAF	Cafeteria
CC	Co-curricular activities (outside school hours)
CCC	Co-curricular activities (during class time)
CT	Class time
LT	Lunch time
SECT	Special event during class time
SELT	Special event during lunch time

<b>Code</b>	<b>Type of Decision</b>
CAC	Classroom activities
CAS	Classroom assignments
CIR	Circumstances
CS	Course selection
FE	Food or eating
FR	Friends
HE	Help or seeking help
LFT	Leisure or free time
LP	Level of participation
LOC	Location
LS	Life style
LTG	Long term goals
OUTAC	Activities in organizations outside of school
RE	Responsibility
SAF	Safety
SOC	Social/social skills
TR	Transportation or travel to and from school
WES	Work experience selection

<b>Code</b>	<b>How to Make Decisions</b>
HA	Availability
HE	Effort
HF	Fun
HFR	Friends
HGR	Group
HI	Interests/preferences
HIN	Information
HLP	Level of participation
HLT	Long term goals
HO	Other options
HS	Success
HSOC	Social
HSOM	State of mind
HT	Teacher
HTR	Trust
H\$	Fundraiser/Money

<b>Code</b>	<b>Who Else Makes Decisions</b>
WP	Parents
WT	Teachers
WEA	Educational Assistants
WC	Circumstances
WPD	Previous decision results in certain other decisions made for you
WGR	Group

<b>Code</b>	<b>Limits on Decision Making</b>
LimA	Availability
LimP	Parents
LimT	Teachers
LimEA	Educational Assistants
LimC	Circumstances
LimPD	Previous decision results in certain other decisions made for you
LimGR	Group decision



## Appendix F

### Proposed Agenda/Questions

#### Adult Focus Groups and Interview

Note: Subject to change based on results from Focus Groups A, B and C

Entry, fill out and wear name tags, get a beverage/snack if you wish

#### Introduction

- Welcome and thank you for agreeing to participate in this study
- How focus groups work
  - I will ask you some questions (focus questions) and I would like to hear your opinion about what I ask
  - 3 rules
    - Everyone is encouraged to speak freely, one at a time
    - No right or wrong answers
    - What is said in the group stays within the group (discuss what this means and its importance)

What we say will be recorded on tape for purposes of accuracy of transcription

- Talk about decision-making-how it is defined in the study: big decisions and smaller day-to-day decisions, “causal agent”, “free from external influence or interference by an adult”

My thesis is about comparing the perceptions of opportunities that students with and without intellectual disabilities perceive they have to make decisions at school; this is the third phase of a 3 phase project; I met with three groups of students and will be

meeting with one group of teachers, one group of educational assistants and one administrator

Share graphic records and summaries of within case and cross case analysis of the types of decisions that students perceive they make at school.

1. What is your initial reaction to these results?
2. What do you think of the similarities between the two groups? Why are these results similar?
3. What do you think of the differences between the two groups? Why are these results different?
4. What factors related to personal characteristics of students may come into play? (e.g., level of disability, gender)
5. What environmental factors may come into play? (e.g., opportunities to practice, inclusion, presence of support staff)
6. What other factors may come into play?
7. Are there any additional comments you would like to add? Or questions you would like to ask?
8. Thank group members for their participation and explain how I will get their thank you gifts to them.

Appendix G

<b>Sample of Coded Student Transcript</b>				
<b>Speaker</b>	<b>What was said</b>	<b>Part of Day</b>	<b>Type of decision &amp; How to make decisions</b>	<b>Limits</b>
James	Well there is gym and in gym you get to do a lot of activities and sometimes you get to vote on what you do... so you get some choice and sometimes not.	CT	CAC HGR	Tlim Glim
Barb	So it's a group decision?	CT		Glim
James	Sometimes... but not all the time	CT		Glim
Barb	Do you ever get any individual decision-making opportunities in phys ed?	CT	CAC	TLim
James	Not usually.	CT	CAC	TLim
Barb	Okay. Do you have any spares this semester?	CT		
James	No, I have a full schedule.	CT		
Barb	What about you Jessica? In your other subject areas?	CT		
Jessica	Um... I have English history and we have a fair bit of decision-making in a class... like in creative writing... and in gym we don't get much... like James said it's all in group decisions... and in choir our only decision is pretty much which part you want to sing.	CT	CAC CAS HGR	Tlim Glim
Barb	And in English history, just getting back to that for a moment, what kind of decisions do you get to make in that class?	CT		
Jessica	Usually my teacher will like give us a project and will give us a list of topics and we get to decide which one we want to do.	CT	CAS	
Barb	Okay and do you get any choice in how you do assignments?	CT		
Jessica	Yeah every once in awhile the teacher gives us a few options on how we want to do something.	CT	CAS	
Barb	What might those options be?	CT		
Jessica	Like a while back we had to do this project where we had to do journal entries like we were a soldier in the war and we had to choose how to write them and how to present them.	CT	CAS	

Barb	So what would the choices be?	CT		
Jessica	We could've typed it and put it into a book... we could have handwritten it...one girl in my class actually had this old box that her grandpa used and she put them all in that.	CT	CAS	
Barb	Okay so how you presented the final products was your choice.	CT	CAS	
Jessica	Agreement indicated	CT		
Barb	Okay.... any others?	CT		
Jessica	Not really.	CT		
Barb	You have a spare the semester?	CT		
Jessica	Yeah I have a spare.	CT		
Barb	Do you have some choices or decisions to make during your spare?	CT	CAC	
Jessica	Yeah. Every day I have to decide what I'm going to do.	CT	CAC	
Barb	Okay. So what are the options?	CT		
Jessica	You can go to the library and sit with friends or sometimes I do homework...Sometimes I go to the mall or sometimes I go home...	CT	CAC	Slim
Barb	Okay... so how do you make those decisions?	CT		
Jessica	I just take it day by day. It depends what my mood is that day.	CT	HSOM	

Appendix H

<b>Pattern Coding-Student Data</b>				
<b>FG</b>	<b>Type of Decision</b>	<b>Summary Statements</b>	<b>Limits</b>	<b>Other information</b>
FGA 2009-08-03	CAC	very few DM opps that don't include limitations for students with or without SN	TLIM, SLIM, SCHLIM, CLIM	
FGB 2009-08-04	CAC	very few DM opps that don't include limitations for students without SN; a little more choice during a spare, but still within limits; occasional group DM in PE	TLIM, GLIM	
FGC 2009-08-15	CAC	few DM opps that don't include limitations for students with SN; seem to have more DM opps than students without SN re: sequence of activities due to fewer courses, A, M, I programming (e.g. weight room, ping pong, scheduled time in room 109), individual or small group instruction/support with EA allows more DM opps; occasional group DM like in PE-similar to students without SN; DM in Foods class such as job in the kitchen, what to put on food, whether or not to eat food	TLIM, EALIM, CLIM, MLIM, GLIM	one student indicated that changing clothes for gym was not a choice because you would lose marks if you didn't change, whereas another student with more significant ID did not appear aware that changing for gym was expected; when talking about group DM through voting in PE, one student stated, "The other kids decide".
FGA 2009-08-03	CAS	very few DM opps that don't include limitations for students with or without SN	TLIM, SLIM	
FGB 2009-08-04	CAS	some DM opps around how to present a project or what to do in a project within a given framework; day to day smaller assignments-little or no choices		students appeared to enjoy talking about projects where they had DM opps

FGC 2009- 08-15	CAS	some DM opps around colours and materials to use in projects in various classes-students spoke mainly about option classes that are less academic in nature (e.g. woods, sewing, graphic arts)	TLIM	one student was quite enthusiastic when talking about projects where he had DM opps
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### Appendix I

#### Transcript Codes-Final Adult Focus Groups and Interview

<b>Code</b>	<b>Same or Different</b>
S	Similar between students with and without intellectual disabilities
D	Different between students with and without intellectual disabilities

<b>Code</b>	<b>Part of School Day</b>
AC	After classes (end of day)
ADV	Advice
BC	Before classes (beginning of day)
BR	Break between classes
BIGC	Bigger decisions-course selection
BIGF	Bigger decisions-friendships
BIGC	Bigger decisions-long-term goals
BIGOUT	Bigger decisions-participation in clubs, groups, teams, etc.outside of school
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CT	Class time
LT	Lunch time
SECT	Special event during class time
SELT	Special event during lunch time

<b>Code</b>	<b>Opportunities and Limits on Decision Making</b>
OPP	Opportunities to practice/choice availability
LimA	Availability
LimP	Parents
LimT	Teachers
LimEA	Educational Assistants
LimC	Circumstances
LimPD	Previous decision results in certain other decisions made for you
LimGR	Group decision

<b>Code</b>	<b>Personal characteristics related to opp. for decision making</b>
GEN	Gender
SEVD	Severity of disability/assumption of incompetence
SupSAF	Need for supervision-protection/safety
SupSTRUC	Need for supervision-structure
ATT	Attitude/belief
AGE	Age of student
GOALS	Goals
INT	Interests
EXP	Experience

<b>Code</b>	<b>Environmental Factors related to opp. for decision making</b>
POSS-BN	Presence of the support staff-basic needs
POSS-SAFE	Presence of the support staff-safety
POSS-STRUC	Presence of the support staff-structure
ATT-A	Attitudinal barriers-adults
ATT-P	Attitudinal barriers-peers
SCH	Scheduling
DIR	Directive from "above" (e.g., senior administration, school board)

Appendix J

<b>Pattern Coding-Staff Data</b>					
<b>FG</b>	<b>S/D</b>	<b>Part of Day</b>	<b>Opps/ Limits</b>	<b>Factors</b>	<b>Summary Statements</b>
FGD 2009-08-26	more differences (110) than similarities (92) and small number (6) statements that included both S and D				
FGE 2009-08-24	almost 3x as many comments related to D (204) as compared to S (69)				
IVP 2009-08-24	almost equal number of comments related to D (66) as compared to S (60)				
FGD 2009-08-26	S	CT	SLIM	G/A, NCONN	Students sometimes don't make connection between DM re LP and the marks they get in a course.
FGE 2009-08-24	S	CT	SLIM	G/A, NCONN	"They never realize the repercussions of lack of participation marks until the last week when they get there, this is going to be your current mark"

IVP 2009- 08-24	S	BIGC	OPPS, ALIM, SLIM	STRUC AGE	Not uncommon for students to not get their first choice in courses due to limits in class size, no. of sections, etc. When needed, try to provide each student with best match of courses and teachers; students tend to explore courses more when younger and self-select more preferences as they get older; no spares until grade 11
IVP 2009- 08-24	D	CT	OPPS	AGE	As students w/o SN get older, they have more freedom and usually more spares so more opps to leave the school. This is not usually the case for students with SN.
FGD 2009- 08-26	D	CT, LT, BR	OPPS	AGE	Some students need their first year to become familiar with the school, then they can have more freedom; it more based on experience in the building than actual age.
FGD 2009- 08-26	S	CT	SLIM TLIM	BEH ATTS	Sometimes DM opps are limited by student BEH or ATT
FGD 2009- 08-26	D	Anno uncem ents	EAFac	POSS STRUC	"I'd certainly say that the special needs class probably know more about what's going on in this school than other kids do, cause you're right, you've got so many adults in that room"
FGE 2009- 08-24	S	CT	SLIM	ATTS	Opps for DM in class are sometimes affected by students not listening or 'zoning out' for all students; Opps for DM related to friendships sometimes affected by ATTS or BEH for all
IVP 2009- 08-24	S	CC	SLIM	ATTS	Students with and w/o SN have opps to hear or read announcements but many miss them and miss out on opps for participation