

Youth with intellectual disabilities and the right to make choices: Investigating  
the family context to inform a training program

Robyn Saaltink, B.A., B.Ed.

Department of Child and Youth Studies

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Faculty of Social Sciences, Brock University  
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## Abstract

People with intellectual disabilities (ID) are more likely to be victims of abuse and human rights violations than people without ID. The 3Rs: Rights, Respect, and Responsibility project has developed and is testing a human rights training program for adults with ID. The current project was conducted to make recommendations to adapt the 3Rs rights training program to be used with youth with ID and their families. An interpretive phenomenological framework was employed to investigate youth with ID, parents', and siblings' perceptions of their experiences with choice making, an enactment of rights, in the family context. Thematic analysis of interviews revealed that, consistent with previous research, family members consider family values, conventions, and family members' well being when making decisions. A training program should promote a consideration of expanded opportunities for youth with ID to make choices and should be flexible to address individual families' cultures, needs, and desires.

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*Introduction*

*Human Rights and Choice*

“Human rights implies the inalienable entitlement to certain universal natural rights such as food, shelter, a non-threatening physical environment, security, health, knowledge, work, freedom of conscience, freedom of expression, freedom of association, and self determination” (Tarulli et al., 2004, p.164). While international and national documents provide written affirmation that all people are privileged to the same human rights (e.g. The United Nations Convention on the Rights of Persons with Disabilities, 2006), people with intellectual disabilities (ID) have historically and are currently denied many of the opportunities and protections that are espoused in rights documents and typically afforded to non marginalized populations. Therefore, the current project focuses on people with ID and human rights promotion and awareness. More specifically, the current investigation concerns the daily enactment of human rights for youth with ID within the family context.

When it comes to the practical application of human rights within relational systems such as the family, where it is unlikely that rights documents and policies will be consulted and cited as they are in more formal situations involving public institutions, the enactment of rights is often discussed in terms of opportunities for individuals to make decisions and choices in and about their lives (e.g. Ward & Stewart, 2008). While the right to make choices is not specifically outlined in any rights document, it has been suggested that all human rights are built upon the two interconnected values of freedom

and well being (Gerwith, 1996), meaning that values of personal freedom or values of choice and decision making encompass many of the specific rights enshrined in rights documents. The application of a human rights framework to discussions about choice and persons with ID is therefore powerful, “creat[ing] a protective zone around persons and allow[ing] them the opportunity to forward their own valued personal projects” (Ward & Stewart, 2008, p. 298), and can provide guidance and standards in the pursuit of equity in freedom and well being. As such, this study examines choice making for youth with ID in the family context and is underscored by an understanding that everyone has the right to make choices and decisions about their lives.

### *Literature Review*

#### *Human Rights and Intellectual Disabilities*

The history of people with ID is laden with abuse, neglect, and human rights violations. During much of the 19<sup>th</sup> and 20<sup>th</sup> centuries, people with disabilities were typically institutionalized, meaning that people with ID were often subject to unsanitary, overcrowded living conditions. “Patients” in these institutions were typically afforded little, if any, control over their lives (Tarulli & Sales, 2009) and were frequently victims of various forms of physical and psychological maltreatment, including sexual and physical abuse (Sobsey, 1994). Throughout the majority of the 20<sup>th</sup> century, the low value placed on the lives of those with disabilities was evidenced by the eugenics movement, during which people with ID were sterilized, often without their knowledge or against their will, to prevent their “bad genes” from contaminating and threatening the well being of the human race (Watson & Griffiths, 2009). The devaluation of people with disabilities manifested itself in even more extreme measures during World War II.

As a part of Hitler's regime, approximately 90,000 people with disabilities were killed in Nazi Germany (Owen, Griffiths, Tarulli, & Murphy, 2009) because it was widely believed that these "useless eaters" consumed resources without contributing anything to the betterment of society (Watson & Griffiths, 2009). While the denial of the right to bear children and the blatant killing of people with disabilities are perhaps the most striking of human rights violations experienced by people with ID, people with ID have also been denied a multitude of other fundamental human rights throughout history. For example, people with ID have been denied the right to marry, the right to live in the community, and the right to receive life saving medical treatment (Griffiths et al., 2003; Rooke, 2003; Sobsey, 1994; Tarulli et al., 2004).

According to Rioux and Carbert (2003), The United Nations Declaration on Human Rights (1948), which officially recognized that all people, regardless of difference or disability, have the same human rights, marks the beginning of a shift in thinking to a rights based approach to disability. "The human rights perspective means viewing people with disabilities as subjects and not as objects. It entails moving away from viewing people with disabilities as problems towards viewing them as rights holders" (Quinn & Degener, 2002, p.1, as cited in Rioux & Carbert, 2003, p. 2). This shift was further brought to light during the 1960s with the growth of the community living movement, which led to greater community inclusion for people with disabilities. The 1970s showed a rise in the normalization principle (Wolfensberger, 1972), defined as the "utilization of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviors and characteristics which are as culturally normative as possible" (p.28). In other words, there was a growing acceptance of the

idea that people with ID should be able to access the same “normal” opportunities and experiences as those who are non disabled. Furthermore, currently, The United Nations Convention on the Rights of Persons with Disabilities (2006) explicitly guarantees equality of rights for people with disabilities and the Canadian Charter of Rights and Freedoms (1982) guarantees that all individuals are entitled to equal rights without discrimination. These changes in attitude, approach, law, and policy regarding disability led to more opportunities for people with ID to make choices and to have independence (Tarulli & Sales, 2009).

Nevertheless, people with ID continue to be denied basic rights in their everyday lives, such as the right to privacy, the right to parenthood, and the right to make everyday choices (Griffiths et al., 2003; Rooke, 2003; Sobsey, 1994; Tarulli et al., 2004); rights that people without ID may take for granted. Additionally, people with ID are substantially more likely to experience abuse throughout their lifetime than people without ID (Sobsey, 1994). Sobsey and Varnhagen (1988) reviewed the literature on sexual abuse and people with disabilities and conducted pilot surveys with community agencies that support people with disabilities to further explore the relationship between sexual abuse and people with disabilities. Across the studies they reviewed and the surveys they conducted they consistently found that people with ID are at a higher risk of experiencing sexual abuse than people without ID.

More recently, Horner-Johnson and Drum (2006) reviewed studies examining the maltreatment of people with ID published between 1995 and 2005. In the reviewed studies it was found that 11.5 - 28% of children with ID experienced some form of physical, sexual, or emotional/psychological maltreatment, 25 – 53% of adults with ID

experienced sexual abuse throughout their lifetime, and, according to the one study that examined the physical abuse of adults with ID, 67% of adults with ID experienced physical abuse throughout their lifetime. While Horner-Johnson and Drum concluded that further research needs to be conducted to determine more accurate estimates of abuse prevalence, they also concluded that the available research indicates that people with disability likely experience higher rates of maltreatment than people without disabilities and that people with ID likely experience higher rates of maltreatment than people with other disabilities.

### *Causes of High Rates of Abuse*

Current theories of abuse and ID point to multiple, systemic, complex causes of abuse and identify environmental, personal, and social factors as contributors to and predictors of abuse (e.g. Nettelbeck & Wilson, 2002; Sobsey, 1994; White, Holland, Marsland, & Oakes, 2002). Thus, while it is currently believed that the high rates of abuse experienced by people with ID may be partially due to personal characteristics of the victims, it is not believed that these characteristics represent faults that are endemic to specific individuals or to people with ID in general (Nettelbeck & Wilson, 2002). In fact, IQ itself does not predict the likelihood of experiencing abuse. Rather, it has been hypothesized that characteristics of victims with ID that may contribute to abuse are learned due to society's response to disability (Sobsey, 1994). Social interactions that create conditions that may lead to abuse likely arise because of generally accepted beliefs about people with disabilities. Ableism, the belief that people with ID are inferior to people without ID and are incompetent, (Tarulli et al., 2004) and paternalistic attitudes whereby caregivers and people without ID think that they "know what's best" for people

with ID (Schultz, 1996) are prevalent in our society. In such an environment, people with disabilities are perceived as less than fully human (Sobsey, 1994), incapable of making decisions, and unable to handle the rights that most people take for granted, making it easy to justify less than humane treatment that is abusive or that contributes to abuse.

*Compliance.* One consequence of these ableistic perceptions is that overcompliance may be rewarded, both implicitly and explicitly, for people with ID, potentially increasing chances that they will become victims of abuse (Mazzuchelli, 2001). Sobsey and Varnhagen's (1988) review of the literature with regard to abuse and ID highlights the heavy emphasis generally placed on compliance training for people with ID. According to these authors, a review of the *Journal of Applied Behavior Analysis*' cumulative index revealed that, over the previous 20 years, 80 articles were published on the topic of teaching generalization, mostly to participants with disabilities, while only four articles focused on discrimination skills.

Compliance likely continues to be considered an important skill for people with ID, more so than it is for people without ID (Sobsey, 1994). To illustrate, a more recent study examining the nature of staff members' interactions with clients with ID revealed that the most frequent form of communication employed by staff was directive as opposed to questioning or conversational. In other words, as people with ID interacted with their staff, they were given specific directions more often than they were asked questions or engaged in conversations (McConkey, Morris, & Purcell, 1999).

These findings are alarming; when people with ID are taught and rewarded to comply with any request made by any adult and are punished for doing otherwise, they are unlikely to stop a prospective abuser. Accordingly, it has been found that

acquiescence with inappropriate requests predicts abuse (Nettelbeck & Wilson, 2001) and that those who are more compliant have a higher risk of suffering from abuse (Sobsey, 1994).

As Sobsey (1994) points out, the view that compliance is a highly desirable trait for people with ID may be a result of actual elevated occurrences of aberrant behaviour in this population. This, however, appears unlikely because, as also discussed by Sobsey, a Floyd and Phillippe (1993) study investigating compliance rates in children with ID and their siblings revealed that both disabled children and their nondisabled siblings complied with parental requests approximately 80 percent of the time. Although children with ID were found to comply with parental requests an equal percentage of the time, children with ID were given more direct commands than their nondisabled siblings and therefore exhibited both compliance and noncompliance more frequently. Unfortunately, the misleading finding that youth with ID exhibited higher frequencies of noncompliance continues to be cited as evidence that people with ID present behaviour problems and are in need of compliance training (Gavidia-Payne & Hudson, 2002). Thus, the heavy emphasis placed on compliance by people with ID is likely driven by stereotypic and ableistic views rather than from an actual need for compliance training. As mentioned above, these stereotypic views can lead to situations where people with ID are taught and rewarded for complying with the requests of anyone, thereby inadvertently increasing the chances that they will comply with potential abusers.

*Limited skills.* In addition to being trained and reinforced to be overcompliant, people with ID often do not have the specific knowledge and skills needed to defend themselves from abuse. A lack of some protective skills may be due to the nature of a



person's disability itself. For example, some people with ID may lack communication skills needed to defend themselves against abuse (Sobsey, 1994). Many protective skills, however, could be learned through explicit training or, implicitly, through a change in the nature of interactions typically experienced by people with ID. This point is illustrated in a study undertaken by McCabe, Cummins, and Reid (1994) who conducted interviews and had participants complete Sexual Knowledge, Experience, and Needs Scales to compare the knowledge of sexual abuse and related issues of people with ID to people without ID. Results of this study indicated that, compared to the nondisabled population in the study, participants with ID were less likely to know terms associated with abuse, such as rape or incest, and reported being less likely to say no to unwanted touching. Even more alarmingly, 36 percent of participants with ID believed that someone other than themselves should decide whether or not they would engage in sexual activity and the majority of participants with ID reported feeling good or neutral about sexually abusive relationships. In short, the population with ID in McCabe et al.'s study demonstrated little knowledge of their rights, of their sexuality, or of how to make decisions about their own sexuality. It is easy to see how this combination could make a person vulnerable to abuse. McCabe et al. did not attribute their findings to internal characteristics of the participants with ID. Rather, they explained these results by suggesting that, compared to the general public, people with ID tend to have less access to information about their rights, their sexuality, and associated decisions due to pervasive attitudes whereby people feel uncomfortable discussing sexuality with people with ID. If this is the case, a change in such attitudes or a concerted effort to teach

specific protective knowledge and skills could potentially increase the chances that people with ID will stand up for themselves in the face of prospective abuse.

This idea is supported by Sobsey and Varnhagen's (1988) finding that service providers believed that people with ID may be more susceptible to abuse because they do not have enough knowledge about appropriate behaviours or how to defend themselves against abuse. Similarly, it has been hypothesized that people with ID may be more likely to be abused because they do not know that they have the right not to be abused (Mazzucchelli, 2001). Although people with ID are often capable of understanding and asserting human rights, many people with ID have never been taught, either explicitly or implicitly, that they have rights (Sobsey, 1994). This contention is upheld by the research described above, showing that people with ID are often rewarded for compliance and are often not provided with opportunities that would enable them to learn specific skills or knowledge that could potentially help to prevent abuse. Such skills and knowledge, essentially an understanding of fundamental human rights and how to assert them, may be understood and taken for granted by most. The research reviewed here, however, points out that this might not be the case for people with ID. If a person is always rewarded for following directions, how will he/she learn that it is important to discriminate between directions that are acceptable to follow and directions that compromise individual safety and well being? If a person's basic human rights are generally overlooked in his/her interactions with others and are never directly communicated, how will a person learn that he/she has the right not to be abused? Again, a change in everyday interactions and/ or the employment of training programs that

implicitly convey or explicitly teach these specific skills and concepts could help to lower the chances that people with ID will be abused.

### *Systemic Approach to Human Rights Promotion*

As alluded to above, when the high rates of abuse and rights infringements experienced by people with ID and some of the underlying causes are considered, it is easy to see that it is important for people with ID to learn that they have rights and how to exert them. Nevertheless, it is not enough to simply teach people with ID that they have rights. The above-described research suggests that rights violations and abuse are, at least partially, caused by society's response to disability (Sobsey, 1994). If it is accepted that abuse and rights violations are enacted in systemic contexts, it is unlikely that the prevention of abuse and rights violations will be effective if targeted solely at individuals with ID. If people are told that they have rights but their interactions with others continue to indicate otherwise, they may come to believe that rights are nothing more than rhetoric. If staff, caregivers and other people who have relationships with people who have ID do not respect and uphold the rights that people with ID are taught they have, the conflicting messages may lead to feelings of confusion and powerlessness (Sobsey, 1994). Therefore, to be effective, rights must be taught in a context where individual rights will be supported and upheld.

### *Rights Training for People with Intellectual Disabilities*

Despite the importance of systemic rights training for people with ID, little research exists on the development and implementation of human rights training curricula for people with ID (Tarulli et al., 2004). In a rare exception to this trend, Sievert, Cuvo, and Davis (1988) developed and tested a self-advocacy program with eight adults with

mild ID. The goal of the program was to teach adults with ID to determine when their legal rights have been violated and how to appropriately redress rights violations. To do so, trainers used verbal scenarios and written prompts to introduce broad categories of rights. After each broad rights category was taught, trainers presented specific rights that fit within the broad category and conditions that must be present for each specific right. For example, the right to marry is a specific right in the broad category of personal rights. To enact this right, individuals must pay a fee and complete necessary paperwork. Next, trainers would present scenarios demonstrating rights violations and nonviolations for each specific right. Trainers repeated these steps for each specific right and each category of rights being targeted. Throughout the training process and before and after training, trainers presented verbal scenarios and participants were asked to verbally communicate whether a right was violated and to explain why this was or was not the case. In this manner, researchers could evaluate the effectiveness of the training program and participants could practice discerning between violations and nonviolations.

Once rights were taught, participants were taught to redress rights violations. Using verbal, written, and video instructions and scenarios as well as role play rehearsal, participants were taught to use the following escalating steps in the face of a rights violation, as needed to solve the rights dilemma: 1) assert their right to the person violating their right; 2) to talk to the administrative supervisor of the person violating their rights, and/or 3) contact an advocacy agency. Effectiveness of the training was assessed using role plays, both in training sessions and in the community, and *in vivo* testing, for which participants' rights were violated by their caseworker in a natural setting (Sievert, Cuvo, & Davis, 1988).

On the whole, results from the study were promising. Researchers found that participants learned to discriminate between rights violations and nonviolations and were able to redress rights violations during role plays (Sievert, Cuvo, and Davis, 1988). These results suggest that people with ID can learn how to assert their rights if they are taught to do so. Therefore, this study provides a model for a rights training program for people with ID; however, this study does not address the importance of a systemic approach to human rights for people with ID, which, until recently, continued to represent a gap in the literature.

*The 3Rs Project: Rights, Respect, and Responsibility.* To this end, in 2000, researchers at Brock University collaborated with Community Living Welland Pelham (CLWP) to initiate what is now the 3Rs Community University Research Alliance. Researchers affiliated with the 3Rs project are currently developing and testing the effectiveness of a rights training program for adults with ID. The project began in response to Community Living Welland Pelham's desire to take action against the above noted high rates of abuse experienced by people with ID (Owen & Griffiths, 2009). Therefore, in 2001, CLWP, in conjunction with Brock University, developed a human rights statement to solidify standards for practice within their association.

As articulated by Owen et al. (2003), the development of a human rights statement is an important step in upholding the rights of people served by any agency, but will not independently guarantee that the rights of people supported by an agency will be upheld. Therefore, researchers involved with the 3Rs project set out to determine whether any rights in CLWP's rights statement were being violated in daily practice (Griffiths et al., 2003). To do so, a survey consisting of 80 rights items was developed

from both rights documents and focus groups with CLWP's staff and persons with ID. Agency staff and individuals supported by the agency completed the survey. Results revealed that both the adults with ID and the staff felt that people with ID faced rights restrictions within the Association. These perceived rights restrictions covered a broad array of categories and perceptions of the rights being violated differed by respondent group.

While none of the rights identified by staff or people with ID were abusive in nature (Owen & Griffiths, 2009), the Association's administration believed that further steps needed to be taken. As alluded to above, rights are guaranteed to everyone in various charters, policies, and laws, and may be important in communicating to people that they have the right not to be abused (Mazzuchelli, 2001). This led to the next stage in the 3Rs project: human rights training for staff and individuals with ID. In every organization involved in 3Rs human rights training, staff are trained before people whom they serve in order to ensure that individuals with ID are supported when they subsequently learn about and assert their rights. Researchers took this approach in recognition of the importance of a systemic approach to human rights training (Owen et al., 2003). If people with ID within an agency were taught that they had rights, but these rights were not supported or upheld by agency staff, the people with ID may come to feel frustrated and disempowered. A lack of organizational responsiveness to rights assertions could send a message that human rights do not, in fact, exist for them (Sobsey, 1994).

Therefore, 3Rs staff training is conducted with the goal of staff developing an increased awareness of human rights and the skills necessary to deal with rights issues that emerge in everyday practice in a way that addresses the tension between staff

commitments to protect the people they support from harm and to respect their rights (Owen et al., 2003). The 3Rs staff training involves reflecting on human rights issues encountered while working at the agency, and discussions of human rights policies and procedures. To encourage the generalization of concepts taught, training also involves the use and discussion of human rights scenarios that staff might encounter as a part of their jobs. Pre- and post-training tests conducted with CLWP staff who participated in training revealed that, following participation in training, staff were significantly more likely to identify rights violations, to identify the nature of rights violations, and to communicate solutions to rights violations (Owen et al, 2003), suggesting that staff rights training was effective.

In response to feedback and results from pilot studies, the rights training program for adults with ID has changed over time (Owen & Griffiths, 2009). Similar to Sievert, Cuvo, and Davis' (1988) rights training program for people with ID, all versions of the 3Rs rights training program have focused on teaching adults with ID how to discriminate between rights violations and nonviolations and how to redress rights violations (Owen & Griffiths, 2009). Additionally, in recognition of the idea that rights are supported and upheld in social contexts and interactions (Tarulli et al., 2004), the 3Rs rights training programs have all taught the concept of rights with an emphasis on asserting rights in respectful and responsible ways (Owen & Griffiths, 2009). Originally, the training program was largely discussion based. Initial evaluations, however, revealed that the use of print and verbal test scenarios might not be appropriate for all learning styles (Owen et al., 2003). Initial testing using videotaped scenarios revealed that a multimedia approach might better serve a variety of learning styles (Owen et al., 2003).

More recently, 3Rs researchers developed and tested an interactive CD-ROM training program for adults with ID. Results of a study investigating the effectiveness of the CD-ROM interactive training program compared to traditional classroom training indicated that both teaching methods were equally effective in increasing participants' ability to identify and remediate rights violations (Tardif-Williams et al., 2007). This provides support for the idea that, with appropriate training, people with ID can learn complex skills, such as how to assert human rights respectfully and responsibly. Tardif-Williams et al. also found that participants scored higher on tests of rights awareness when videos, depicting realistic rights situations, were used than when verbally presented scenarios were used.

Taking these past findings into consideration, a game based rights training program is currently being used in organizations affiliated with the 3Rs project and studied by 3Rs researchers. The game is designed for use with adults with ID and can be played in small group settings. The game consists of 8-10 two-hour training sessions, comprised of concept teaching, video scenarios with questions and role play rehearsal activities. The first sessions of the training program are conducted with the goal of teaching participants the meaning of the core concepts of rights, respect, and responsibility. Once these fundamental concepts are established, training sessions involve the presentation of videotaped scenarios that illustrate rights situations that could occur in group home or agency settings. After participants watch each videotaped scenario, they must identify whether a rights violation occurred and, if it did, what action could be taken. During some sessions, role play scenarios are also used. For role play scenarios, individuals participating in the training have a chance to watch trainers enact a



rights situation. Participants then state whether a right was violated, and if it was, how the person whose rights were violated could stand up for her/his rights. Following this discussion, the role play is enacted again, with participants practicing carrying out the solution that they suggested. While some sessions focus primarily on rights, as described above, other sessions focus more heavily on respect and responsibility, identifying whether rights were enacted respectfully and responsibly and, if not, how they could have been.

To determine whether the game based rights training program is effective, participants are tested before, during and after training using video scenarios, to which they are asked to respond to questions about rights, respect, or responsibility. These questions are similar to the questions asked in training and are used to determine whether participants can discriminate between rights violations and non rights violations, and if participants can generate solutions to rights violations that are respectful and responsible. Both trained and untrained items are tested to assess for generalization. Participants' rights knowledge is also assessed with *in vivo* probes, for which low risk rights are violated by a research assistant, unknown to the participant, in an everyday situation. *In vivo* probes are conducted to assess whether participants will stand up for their rights in real life situations.

Preliminary results from 3Rs rights training game testing suggest that people with ID can learn complex skills and concepts, such as rights, respect, and responsibility (Tardif-Williams et al., 2007). Currently, however, the program exists only for adults with ID who are affiliated with community agencies that support people with ID. The above described findings from the 3Rs project's investigations, coupled with the

importance of abuse prevention programs for people with ID, provide justification for continued investigation into the effectiveness of the 3Rs rights training programs for other populations. In order to determine what other populations that could be targeted for rights training programs and how the rights training materials should be adapted, research investigating the experiences of other populations of people with ID is described below.

*The 3Rs Project for Families and Family Home Providers*

Another facet of the 3Rs program does not involve rights training, but rather focuses on the rights concerns of families that include a member with ID who lives at home. To explore families' rights concerns, members of the 3Rs team conducted interviews with primary caregivers and family members with ID, ranging in age from less than 9 years of age to over 19 years of age (Tardif-Williams, Tarulli, Robinson, & Owen, 2008). Analysis of the interview data showed that caregivers and youth with ID both believed that having access to the right to make choices was important. Both caregivers and individuals with ID also communicated that they experienced conflict between the desire to make choices and protection from the risks inherently associated with making choices. The interviews revealed that families spoke of valuing autonomy when speaking about rights and choices broadly and generally, but that discussions of the right to self-determination became more nuanced as families spoke more specifically about choices and situations in their own family (Tarulli, Tardif-Williams, Vyrostko, Terreberry, & Bishop, 2006). Analysis also showed that families tended to consider personal and familial moral values when balancing the right to self-determination and autonomy with a desire to protect someone who may be considered vulnerable. This means that focusing solely on rights in the family context without considering negotiations and respect and

responsibility does not reflect the way that families interact. Rather, “the context of family relationships suggests a communicative ethics in which acting autonomously is acting both with respect and responsibility” (Tardif-Williams et al., 2008).

Researchers concluded that these preliminary findings point to the need to further examine how caregivers negotiate the tension between the desire to protect individuals with ID and the desire to uphold the right to make choices and encourage autonomy. Researchers also suggested that preliminary findings indicate a need to raise awareness and promote dialogue about rights in the family context in a manner that acknowledges respect and responsibility as well as the morals and values that come into play when rights are enacted in the family context (Tarulli et al., 2006; Tardif-Williams et al., 2008). To address the needs highlighted in the family interviews, the current project will begin to bridge the 3Rs project for families with the 3Rs rights training research to seek information that will help adapt the rights training program, currently designed for use by adults with ID, to be used by young adolescents with ID and their families. The existing 3Rs rights training program teaches adult participants to stand up for their rights using rights language. For example, in response to being told what to wear, an adult with ID could respond, “I have the right to choose what to wear.” While this approach is useful for adults who are supported by community agencies, it does not reflect the way that rights are enacted in a family context, as acknowledged by Tardif-Williams et al. (2008) and Tarulli et al. (2006). Tarulli et al. discuss the difference in the application of rights in public versus private domains in terms of the codes of ethics that are applied in either domain. An ethics of strangers characterizes the nature of rights when an individual deals with an institution or service (Moody, 1988). In such situations an individualistic

approach to rights is invoked; individuals have to stand up for their rights in the face of potential violations from others. Again, this approach is useful for adults with ID who are served by community agencies. However, “a morality informed primarily by rights deemphasizes need for moral judgment, disregards questions of responsibility and the affective dimensions of human relationships” (Tarulli et al., 2006). In other words, an ethics of strangers and the corresponding us vs them approach to rights are not applicable when looking at rights in the family context because they fail to consider the processes that take place in a family, where relationships among people are complex and framed by emotional attachments. An ethics of intimates is likely a more appropriate way to consider rights in the family context because, rather than conceptualizing rights as us versus them, an ethics of intimates brings to light the existence of negotiations and dialogue among family members (Moody, 1988). No family member acts with complete autonomy; independence unfolds in the context of family morals, with consideration for respect and responsibility. This is not to say that rights are not important in the family; rather, the concept of an ethics of intimates allows for consideration of the idea that rights are enacted together, in a manner where the explicit use of rights language would not be appropriate or natural. Accordingly, as previously mentioned, Tarulli et al. suggest that a rights training program for families would most likely work towards opening up dialogue about rights, respect, and responsibility, instead of teaching people how to identify and redress rights violations in the family context.

Therefore, in order to adapt the 3Rs rights training program for use with families it is important to continue to consider respect and responsibility, but to also address the negotiations and tension between, on the one hand, the desire to protect family members

with ID and, on the other, the desire to promote autonomy and the familial morals and values that influence these negotiations. To gain a better understanding of these issues and to provide further support for the idea that rights for youth with ID are important to study and that the family context is an appropriate system in which to study them, literature examining these areas is described below.

### *Youth with Intellectual Disabilities and Rights Violations*

Research suggests that adapting the 3Rs rights training game for use with youth who have ID would be an important extension for several reasons. Nettlebeck and Wilson (2002) forward the idea that behaviours that increase the chances that a person will experience abuse as an adult are likely learned in childhood and maintained throughout adolescence. Furthermore, similar to Mazzucchelli's (2001) assertion that people with ID may often be victims of abuse because they do not know that they have the right not to be abused, it has been suggested that children with ID experienced abuse in institutions because they were not listened to, meaning that they were not given opportunities to exercise their rights (Cavet & Sloper, 2004). Thus, targeting a rights training program towards youth may serve to decrease the chances that youth who participate will be victims of abuse throughout their lives.

*Rights in the school environment.* Recent studies examining children's everyday experiences reveal that children with ID face rights violations in their daily experiences. The majority of research concerning the rights experiences of children with ID explores rights within the school environment. While Article 12 of the UN Convention on the Rights of the Child (1990) conveys the message that all youth have the right to express their opinions and that youths' opinions should be seriously considered in matters

affecting them, it appears that this right is often violated. For example, Woolfson, Harker, Lowe, Shields, & Mackintosh (2007) conducted surveys and focus groups with youth with ID, aged 9 to 14 years, and found that less than half of the youth reported being asked their opinion about issues that mattered to them at school. Furthermore, they reported that when youths' rights and abilities to make decisions were not taken seriously, youth were sometimes not provided with assistance when it was necessary and were sometimes provided with more assistance than required. Similarly, Lewis et al. (2007) conducted surveys and case studies with youth with ID, aged 11 to 18 years, and concluded that because youth with ID were often not allowed to make choices or to have a say in decision making processes at school, their needs were often not met in this environment. Lewis et al. also commented that youth in their study provided highly thoughtful answers, and that teachers and school staff were often surprised at the extent to which youth with ID could communicate their views. Along this vein, MacArthur, Sharp, Kelley, and Gaffney (2007) investigated the school experiences of 11 to 14 year olds with ID and reported that, when youths' preferences were listened to and seriously considered, resulting school experiences were more appropriate and positive. These studies all point to a similar conclusion: youth with ID are capable of exercising their right to make choices, but this right is often disregarded, at least in school settings. Because children are generally considered vulnerable, this is probably the case for most children, not just children with ID (Davis & Watson, 2000). However, this issue is of particular relevance for children with ID because they may have even less participation in decision making processes than children without ID (Cavet & Sloper, 2004).

*Rights in the family environment.* Tarulli et al. (2006) suggest that rights in the family environment are enacted quite differently than they are within public institutions. A search of the literature on disability and rights reveals that the rights of youth with ID within the family have not been a major research focus. This may be because it is difficult to monitor the nature of rights within family settings (Ochaita & Espinosa, 1997). Nevertheless, some research exists with regard to youth in general and rights in the family that focuses largely on the right to make choices. Studies that have been conducted with regard to youth rights in the family context suggest that many youth are not aware of their rights (Ochaita & Espinosa, 1997) and that youths' right and ability to make decisions are often overlooked. Tomanovic-Mihajlovic (2000) conducted research with the parents of 17 year olds in Yugoslavia. She reached the conclusion that youth are often not given opportunities to make decisions about issues that matter to them, most likely because parents consider youth to be immature, incompetent, and at risk. Tomanovic (2003) also surveyed and interviewed young adolescents and reached a similar conclusion. Although findings suggested that youth in her study participated in family life more than youth were able to participate in family life historically, youth were still frequently discounted from decision making processes because of the overprotective attitudes of parents. Although the above mentioned research took place in Yugoslavia, as previously mentioned, it is likely that children everywhere are denied rights because they are considered to be vulnerable (Davis & Watson, 2000).

Since children with ID may have even less participation in decision making than children without ID, the above mentioned findings may represent more access to rights and decision making than youth with ID experience. This contention is supported by a

recent study investigating choice and decision making of adolescents with ID within the family. Almack, Clegg, and Murphy (2009) interviewed parents of adolescents with ID who reported that, while nondisabled siblings became less dependant on parents with age, disabled siblings faced ongoing dependency. Parents also reported that they tended to make more choices for their children with ID than for their children without ID.

Additionally, researchers investigating self-determination and/or choice making in general, both within and outside of the family context, have consistently argued that both youth and adults with ID make fewer choices and decisions and state their preferences less often than their nondisabled counterparts (e.g. Clark, Olympia, Jensen, Heathfield, & Jensen, 2004; Jenkinson, 1993; Wehmeyer, 2007).

#### *Importance of Studying the Right to Make Choices*

It is apparent that examinations of the practical application of child and youth rights tend to center on opportunities for participation, choice, and decision making in areas that affect youths' lives. This focus on choice seems to reflect the above described nature of rights as they are practiced in the context of close and emotional relationships; while a rights framework lends power to declarations that individuals or groups are privy to certain opportunities or protections (Ife, 2001), appeals to formal human rights are unlikely to be invoked in most day to day relational transactions (Tarulli et al., 2006; Tardif-Williams et al., 2008). Thus, a focus on choice making, framed by the concept that everyone has the right to make choices, versus a focus on rights in general, may better capture the negotiations, conventions, and emotional ties that affect the manner in which ideas enshrined in rights documents are enacted in everyday situations involving personal relationships. In addition to contentions that choice may be well suited to



encapsulate the complexities of rights within the family and that youth with ID typically make fewer choices than youth without ID, a review of the research on the nature of choices that people with ID make and the potential benefits of choice making lends further credence to the idea that the right to make choices is an important one to investigate with regard to youth with ID.

*Benefits of choice.* An examination of the research regarding choices and people with ID indicates that increased ability and opportunity to make choices potentially contributes to many positive outcomes. Neely-Barnes, Marcenko and Weber (2008) examined the relationship between quality of life and the number of choices made by adults with ID. They concluded that making greater choices was associated with having a higher quality of life, as assessed by community inclusion, the degree to which participants' rights were respected, and the nature of participants' relationships. This does not represent an anomalous finding: increased choice, decision making, and self-determination have been found to correlate with a higher quality of life for adults with ID in numerous studies (e.g. Nota, Ferrari, Soresi, & Wehmeyer, 2007), demonstrating the importance of providing opportunities for people with ID to practice making choices.

Studies have also shown that choice may have a positive effect on behaviour. Shogren, Faggella-Luby, Bae, and Wehmeyer (2004) conducted a meta-analysis of studies pertaining to choice making as an intervention to decrease problem behaviour. Results indicated that when both adults and children with ID were taught effective choice making skills and provided with more opportunities to make choices, they tended to engage in fewer problem behaviours. Choice making was an effective intervention for participants of all ages, but the authors found that choice making was particularly

effective when implemented with children, possibly because it served to prevent the development of learned helplessness or contributed to greater feelings of control. This provides support for the idea that it is important to investigate and promote choice making for youth with ID.

Jenkinson (1993) reviewed the literature with regard to choices and people with ID and found that many people with ID have trouble making and articulating decisions and choices, but that this problem can be rectified through experience making choices or training that teaches choice making skills. Similarly, it has been suggested that if people with ID are not taught choice making and associated communication skills, their attempts to assert preferences and choices may be misinterpreted as problem behaviour. For such reasons, researchers have recommended that the skills needed to make and assert choices and decisions should be explicitly taught to children with ID (Clark et al., 2004).

*Choice in the family.* Decision making in the family context is also important to investigate because being able to make choices with the family has been associated with positive outcomes. Researchers investigating rights in the family context have suggested that the right to participate in family and personal decisions is not only a legal right for youth, as outlined in the UN Convention on the Rights of the Child (1990), but is necessary for the development of personal autonomy (Ochaita & Espinosa, 1997). Further, it has been suggested that recognizing and exerting the right to participation within the family is important for youth because making choices within the family provides an opportunity to practice making decisions; a skill that is important for participation in civil society (Tomanovic, 2003; Tomanovic-Mihajlovic, 2000). The family home is the place where most people first learn and practice making choices and

decisions (Lee, Palmer, Turnbull, & Wehmeyer, 2006), meaning that it is a reasonable context within which to discuss and further choice making skills and opportunities.

As important as the choice making in the family is, little research exists in this domain, especially with regard to youth with ID. As Tardif-Williams et al. (2008) and Tarulli et al. (2006) communicated, the issue of rights within the family is far more complex than simply encouraging youth with ID to assert their rights. Rights in the family environment involve consideration of the respect and responsibility that accompany rights as well as negotiations that take place within the family as choices are made. As described below, the research that does exist in this area supports the findings of these 3Rs researchers (Almack et al., 2009; van Hooren, Widdershoven, van der Bruggen, van den Borne, & Curfs, 2005), thereby showing that the enactment of the right to make choices within the family warrants further investigation.

The complexities of the application of rights in the family context are perhaps most tangible when considering individuals with Prader-Willi Syndrome, who usually have mild ID and tend to lack typical satiety responses so that they are prone to overeating which usually leads to obesity, among other health problems (van Hooren et al., 2005). Therefore, to allow people with Prader-Willi complete autonomy over choice and decision making would lead to severe obesity, but to allow people with Prader-Willi no choices would also diminish their quality of life, as described in the above research on the benefits of choice making. van Hooren et al. (2005) conducted interviews with parents and caregivers of individuals with Prader-Willi Syndrome, aged 8 to 38, nine of whom lived in their family home. The interviews revealed that, rather than focusing solely on human rights, parents and caregivers tended to consider the broader context of

an individual's life. For these families and caregivers, freedom for the individual with Prader-Willi was not seen to exist on its own; rather freedom was conceptualized relationally. Individuals with Prader-Willi achieved freedom by acting responsibly, with the support of others.

In summary, caregivers do not focus only on the question whether one should intervene or not. They try to create conditions for living that are acceptable and meaningful for everybody involved. They aim to maintain life by building up a relationship to which acceptance and respect are central. In this relationship a certain amount of independence and responsibility can be developed. In a permanent and stable context of care, in which there is room for creating trust, it is possible to deal with rules in a less rigid way and to look where there is room for choices. This gives way to a life that is characterized by a process of mutual commitment, support, care and shared responsibility. (p. 318-319)

Thus, through their examination of Prader-Willi Syndrome, van Hooren et al. (2005) demonstrated the nuanced nature choice takes in the family context. For the families interviewed by van Hooren et al., decision making was seen to unfold within the context of relationships, with support from others, and with a consistent regard for respect and responsibility. While these issues are brought to the forefront when dealing with the symptoms of Prader-Willi syndrome, these findings are also likely relevant when discussing the right to make choices for people with ID in general.

Through an extensive search of the literature, only one article was found that discussed the complexities of choice making for youth with ID in general in the family context. Almack et al. (2009) interviewed parents of children with ID in their final year

of high school and shortly after high school graduation in order to determine how families negotiated the 'moral terrain' of choice making. Their findings indicated that parents reported experiencing a great tension between wanting to protect their children, who were often seen as being at greater risk of being taken advantage of or of accidental injury or death, and wanting to allow their children the autonomy that official policies and many practitioners who worked with their families seemed to deem to be important. While parents did not want to be seen as overprotective, they also did not want to put their children in situations that were dangerous. As one mother articulated,

So he really wants to be independent and I also think as parents you do hold, you must hold them back because you are just afraid all the time of what might happen. The first time, for about 18 months now of going down to the shops on a Friday and oh it is just horrendous and he has had so many near misses. If he gets in his own world he will just go across the road. You know he's done that a couple of times and neighbours have said 'Oh no Mark' and its as if he doesn't even notice... I have got this friend... she said 'if he got knocked over and killed, isn't that better that he's had a full life and done what he wants to do than you keeping him wrapped up in cotton wool inside the house all the time (pp.292-293)

While some element of risk is inherent in every choice that is made by every person, this quote highlights how these risks may be larger for youth with ID. If 'Mark' got 'knocked over and killed' would he really be better off than if his mother had been more protective? A consideration of this mother's dilemma makes it clear that the link between choice and quality of life is not easy to determine.

Furthering this idea, many of the parents interviewed by Almack et al. (2009) characterized their children with ID as having no sense of the future, meaning that choice could potentially serve to lower their quality of life.

I know all the government guidance says we have to include our children with severe intellectual disabilities in the decision making process... But he wasn't going to make a decision except to stay at home and that wasn't acceptable... He hasn't got the bigger picture and he'll just say what he wants to do at that moment in time. He has no capacity to see that residential college is an opportunity that won't come again... I can't let him sit around at home, stopping me going to work, watching telly and videos all day long, becoming more and more isolated, eating more and more. (p.294)

While this mother acknowledges the importance that is placed on allowing youth with ID to make their own choices, she also implicitly conveys a recognition of the importance of the respect and responsibility that necessarily accompany choice and decision making in the family context. While her son could wake up each morning and choose to spend the day watching TV, this would clearly not be a responsible choice. As shown in this quote, the application of choice without respect and responsibility could potentially lower quality of life. Additionally, it is evident that family members struggle in their decisions of how to apply concepts of rights to their family member with ID.

The issues raised by the work of van Hooren et al. (2005), Almack et al. (2009) and 3Rs researchers (Tardif-Williams et al., 2008; Tarulli et al., 2006) demonstrate that when examining choice in the family context there is far more to consider than a seemingly straightforward analysis of quality of life or behavioural outcomes. Everyone

has the right to make choices and decisions in their lives and choice has been shown to have positive benefits. Despite the potential negative outcomes that come along with choice, the right to make choices is important in the family context. It is necessary to keep in mind, however, that choice and decision making in the family context is a complicated process that involves consideration of all family members along with family morals and values.

Thus, it would be valuable to adapt the 3Rs rights training program for use with youth and their families, but before doing so it is important to look further into the little explored territory of the right to make choices in the family context, to ensure that a training program would be suitable to address families' unique situations. For adolescents without disabilities, research has been conducted on more specific decisions and patterns of decision making. (Smetana, 2000; Smetana & Asquith, 1994). Findings from such studies have consistently shown that both parents and adolescents feel that youth should make autonomous decisions for personal issues, issues that are seen to affect the individual actor only. Both parents and youth also tend to report that parents should exercise authority over moral issues, acts that are considered necessarily wrong because they affect the well being of others, and conventional issues, acts that pertain to agreed upon behaviours that structure the social interactions that take place within social systems. It is suggested that parent-child conflict occurs when parents and adolescents hold divergent views about the jurisdiction of a particular choice. Adolescents tend to interpret multifaceted issues, items that could be seen as personal or conventional, and friendship issues, multifaceted items that relate specifically to friendships, as more subject to personal control than to parental control. Parents, on the other hand, are less

likely to report that these issues fall into youths' personal domain, and are more likely to report that these issues are legitimately subject to parental authority. For prudential issues, issues that concern the health and safety of the individual, parents and adolescents both agreed that parents should have authority, but youth tended to perceive parents as having less legitimate authority in this area than parents did. Thus, conflict reportedly arises for multifaceted, friendship, and prudential items. Of these issues, the least amount of conflict reportedly arises over prudential issues, possibly because parents are not aware of youths' risk taking behaviour (Smetana & Asquith, 1994).

Findings regarding domains of choice making and autonomy for non-disabled adolescents suggest that adolescent decision making is typically structured by concerns for youths' safety and well being, along with consideration of morals and conventions (Smetana, 2000). These results are similar to the broad choice making themes identified by researchers investigating choice making for individuals with ID in the family context. Research about youth with ID and choices, however, has yet to examine how more specific choices are made, a gap that needs to be addressed in order to adapt the 3Rs rights training program for use with youth with ID and their families. More detailed information about the choices that youth with ID make and do not make will give researchers a better understanding of specific content that should be included in a rights training program for families. To this end, the current project will seek to extend on knowledge about choice making themes, as established through prior research, to determine how specific choices unfold in the family context.



*Teaching Choice Making and Decision Making Skills*

The current project looks at rights in the family context with the ultimate goal of obtaining information that could be used to create a rights training program, with a focus on choice making, for youth with ID and their families. Therefore, it is worthwhile to first to look at choice making curricula for youth with ID that have been studied to date in order to determine what areas have been covered, what has been found, and what has yet to be researched. In light of the limited number of decisions that people with ID generally make in their everyday lives and the benefits reportedly associated with increased choice making, some researchers have looked at programs designed to teach people with ID how to make and communicate choices effectively. According to Jenkinson's (1993) review of the literature about choice making for people with ID, most research on choice making and disability has been conducted with people with severe or profound ID. In such studies, adults, adolescents, and, less frequently, younger children with ID are generally taught to choose between 2 or more concrete items to indicate a preference for food, leisure activity, or tasks (Parsons & Reid, 1990; Reid & Parsons, 1991, Stafford, 2005). Results from these studies are generally positive in that researchers report that participants are able to learn to make choices in the desired manner. These positive results, however, are tempered by the fact that most choice studies focus on teaching people with ID how to make noncontroversial choices (Lancioni, O'Reilly, & Emerson, 2006). Possibly because the majority of research in this domain has taken place with people with severe and profound disabilities, for whom both receptive and expressive communication may be challenging, most studies involve teaching participants to choose between concrete items that either are or are

representative of options that are already deemed acceptable and safe by teachers or caregivers. While this approach undoubtedly teaches youth with ID an important skill, it does not represent the complexity inherent in choice making procedures as they take place in the family context, as described by researchers who have examined this dynamic (Almack et al., 2009; Tardif-Williams et al., 2007; Tarulli et al., 2006; van Hooren et al., 2005).

Recognizing the limited research conducted on teaching more complex processes of decision making, Karvonen, Test, Wood, Browder, and Algozzine (2004) looked at programs that effectively taught self-determination skills to youth, with the youngest being in grade six and the oldest being 21 years of age, who had varying levels of ID. Karvonen et al. qualitatively studied six special education classes, all of which were described by students and parents as being successful in teaching self-determination. The curricula used within these classes all shared certain integral features. In each class, teachers explicitly taught self-determination skills by first giving students information about self-determination, by then modeling and role playing self-determination with students, and by then providing students with opportunities to generalize self-determination skills to other people and contexts. Also, several noncurricular factors, when implemented across entire schools, were found to contribute to students' success in learning self-determination skills; programming was found to be more effective when staff provided all students with choices during daily activities and when all staff responded to students' assertions in a consistent manner. It was also determined that programming was more effective given the existence of an impetus person who helped foster a culture where self-determination was supported, when teachers had consistent

expectations for students, and when parents paralleled the programming implemented at school. For example, students were more likely to be more self-determined if their parents afforded them opportunities to make choices, and experience the natural consequences of their choices, at home.

This study contributes to an understanding of the area of concern in the proposed research in that it illustrates that a decision making curriculum taught in an environment where there is consistent, positive support for decision making can increase youths' self-determination (Karvonen et al., 2004). Nevertheless, this study describes programs that take place in classroom and school environments, places where the ethics of intimates may not as accurately describe the nature of interactions between individuals as it would in a family (Moody, 1988). As discussed above, in the family home, choices are made within an ethics of intimates, whereby family members support each other to achieve autonomy. While Karvonen et al.'s research acknowledges the importance of support and opportunities for decision within the family context, they do not discuss potential contributing factors to a family environment where choice making and risk taking are encouraged and supported.

As evidenced by the limited research conducted on rights in the family, encouraging choice making in the family home is more difficult, and certainly more than a matter of implementing curriculum, as could be done in a school setting. The tension between risk and autonomy, and the need to respect family values, morals, as well as other family members makes rights in the family context a more complicated issue. To date, it appears that no choice training program addresses these issues. Given the complex nature and the importance of choice making in the family context, there is a clear need for

further investigation into how the right to make specific choices unfolds within the family context before such a training program could be developed. Additionally, it would be useful to ask families how they would like to learn about the right to make choices in order to open up dialogue about choice making and decision making. An examination of these topics, currently underrepresented or nonexistent in the literature, would give researchers and practitioners practical information that could be used to create a training program addressing families' actual needs, while respecting families' preferences and desires.

### *Researcher's Perspective*

The foregoing literature review introduced the research that informed the current study. At this point, it is necessary to acknowledge the researcher's perspective, which also influenced all stages of the current project. My interest in the fields of education and disability began when I was a teenager. Throughout high school, I was employed by a family to help support their daughter, who was diagnosed as having physical and intellectual disabilities. Following this interest, I worked as a community support worker for adults with ID after completing my undergraduate degree. My job was to support people with ID as they participated in educational and recreational activities at a day program site and in the community. In this position, I gained first hand experience with issues discussed throughout the literature review; I recognized the pressure that is placed on both staff and family members to balance individuals' perceived needs for autonomy and protection and I have seen how families or staff are often blamed when a person with ID chooses something that is considered to be "wrong" or "bad". I have heard about, witnessed, and participated in situations when individuals were stopped from making a

choice or decision for health and safety reasons or because it was believed that the individual's desired choice would not be in their best interest. I believe that these restrictions were enforced with individuals' well being in mind and were not conceived of as true restrictions, but rather as measures that would help to promote a good life. Therefore, issues of rights, choices, and people with ID resonated with me partially because of my work in the disability field. Because of my practical experiences, I feel that I was able to approach this research topic with a deeper understanding and a greater sensitivity to the concerns of all family members and the multiple forces that influence the nature of independence, support, and care within families.

My appreciation for the pressures that are placed on families were also enhanced as I completed a Bachelor of Education and spent a year as a grade 1 teacher. Through teacher training and practice I additionally gained knowledge and experience regarding curriculum design and implementation, an asset when it came to making training program recommendations. Using knowledge of educational theory and practice, I based training program recommendations on desired outcomes, evaluated the practicality of the recommendations, and considered the importance of adapting training program elements to suit different learning styles and abilities. In these ways I am aware that my background allowed me to approach the research process with a practical understanding of the issues and tensions discussed throughout, helping me to plan, interpret, and analyze with greater clarity.

## Method

### *Purpose and Research Questions*

The goal of the current research project was to fill a gap in the literature involving youth with ID and choice making in the family context. Specifically, the project addressed the need to investigate choice making for youth with ID in the family context to gather background knowledge that could inform the development of a rights training program for youth with ID and their families. To do so, the current study focused on investigating the perceptions of family members in families that include a youth with ID with regard to the following questions:

1. How do negotiations about choice making and family members with ID unfold in the family context?
  - a) Interpersonally: How do family members negotiate choices among themselves?
  - b) Intrapersonally:
    - a. How do family members think about choices that they do and do not make and choices that youth with ID do and do not make?
    - b. How does the family member with ID think about choice making in the family context?
2. What barriers prevent youth with ID from making choices?
3. How would a rights and/or choice training program help open up dialogue about choice making and address the issues highlighted through the answers to the first two questions? In particular, how might such a program ultimately change familial awareness of the right to make choices and increase opportunities for youth with ID to make respectful and responsible choices and decisions in the family context?

- a) What content should be included in a rights and/ or choice training program for families with a youth who has ID?
- b) What training format(s) would be useful for a rights and/ or choice training program for families with a youth who has ID?

### *Methodology*

This research project was a qualitative study. Historically and currently, much research about families has been quantitative in nature, although the use of qualitative methods is growing in popularity (Eggenberger & Nelms, 2006). While valuable information can be gained through quantitative methods, quantitative studies on families tend to focus on individual family members' needs, as opposed to the multiple and complex needs of whole families. Because this project focused on an examination of a complex issue, namely the right to make choices for youth with ID in the family context from the point of view of multiple family members, a qualitative approach was an appropriate approach to uncover the rich and nuanced data required to achieve such a goal (Eggenberger & Nelms, 2006).

### *Phenomenology*

The methods for the current project were primarily informed by interpretative phenomenology. Like other qualitative traditions, phenomenology can best be seen as an approach to research rather than a prescriptive set of methods (Giorgi & Giorgi, 2008). Therefore, what it means to conduct a phenomenological study has been interpreted in different ways by different scholars and continues to evolve and change as an approach to research (Laverty, 2003). That being said, phenomenology is consistently described as a mode of research concerned with exploring and illuminating the lived experiences of

people with regard to a phenomenon of interest. “It involves detailed examination of the participant’s lifeworld; it attempts to explore personal experience and is concerned with an individual’s personal perception or account of an object or event” (Smith & Osborn, 2003, p.51).

As alluded to in Smith and Osborn’s (2003) description of phenomenology, interpretive phenomenology is based on a constructivist epistemology (Jones, Torres, and Arminio, 2006). Constructivism is the idea that reality is constructed as people make sense of the world. From a constructivist perspective, an individual object or event does not have an objective meaning; rather people’s perceptions of objects or events give meaning to experiences. There is no ultimate truth; meaning is bestowed upon objects and events as people interpret their experiences. This means that, when employing an interpretive phenomenological framework, researchers work to understand people’s interpretations of their everyday encounters with an event or situation under investigation. Interpretive phenomenological researchers want to know how people perceive their everyday experiences. Furthermore, interpretive phenomenological researchers necessarily recognize that their understandings of others perceptions are also based on interpretation (Smith & Osborn, 2003). Again, researchers’ understandings of participants’ experiences do not represent an ultimate truth; rather, they represent the researcher’s interpretation of participants’ accounts of events.

A phenomenological approach was well suited for the current study for several reasons. The purpose of the study was to investigate families’ experiences with choice and decision making, or the daily enactment of rights. The desire to highlight families’ everyday experiences echoes the overall goal of all phenomenological research: to



understand phenomena as interpreted by those who experience it. Additionally, phenomenology has been described as a useful framework to use “when one is concerned with complexity, process or novelty... Research questions in (phenomenological) studies are usually framed broadly and openly... the aim is to explore, flexibly and in detail, an area of concern” (Smith & Osborn, 2003, p.53). Choices and decisions that take place in the family context present a complex and nuanced issue that required an in-depth investigation, as argued in the first chapter. Thus, this topic required a methodological framework that could lend itself to an exploration of the topic that would result in the collection of rich data. It was decided that phenomenology was a methodological approach that would address this need.

In addition to the conceptual considerations that made phenomenology a clear choice for the current project, phenomenology has been shown to be practically useful in studies that are similar to the current project. For example, Eggenberger and Nelms (2007) used a phenomenological approach in their study of families’ experiences with critical illness. They cited phenomenology as an ideal method for learning about familial experiences because it is a method that allows researchers to focus on the phenomenon as a whole while still allowing room to explore differences in experiences. Also, they felt that phenomenology would give researchers a deeper understanding of the phenomenon in question. The same rationale can be applied to the current study. Phenomenology has also been used to explore family experiences of therapy (Campbell, 2004) and parents’ experiences receiving support for their child with ID (Wodehouse & McGill, 2009). The similarity of the topics under investigation in these studies to the topics that were

investigated in the current study provides further rationale for the use of a phenomenological approach in the current study.

### *Participants*

#### *Sampling*

Purposive sampling was used in the current study. For purposive sampling, researchers select participants based on whether or not they are a part of a specific population under investigation (Cohen, Manion, & Morrison, 2000). Because participants are selected based on predetermined characteristics, purposive sampling is generally used when researchers are interested in conducting an in-depth exploration of a certain topic and are not interested in producing results that can generalize to the wider population. For this reason, purposive sampling is frequently used in phenomenological studies (Smith & Osborn, 2003). Purposive sampling is appropriate for phenomenological inquiry because it is concerned with in-depth examination of a specific population with regard to a phenomenon of interest. Instead of attempting to produce generalizable results, researchers conducting phenomenology attempt to highlight the perceptions of a specific group.

#### *Sample Size*

Also due to the in-depth, rich data that are typically procured from specific populations in phenomenological studies, it is often recommended that sample sizes should be small (Smith & Osborn, 2003). A close analysis of a small number of individuals' experiences can give researchers the information needed to develop an interpretation of the perceptions of a particular group. For this reason, four families were recruited to participate in the study.

*Inclusion Criteria*

As stated above, the focus of phenomenology is on investigating the perceptions of people who have had specific experiences. For the current study, the researcher was interested in examining the experiences of families which included a youth with ID aged 12-21 years. The study was conducted with the assistance of two Associations for Community Living in southern Ontario, meaning that to be eligible for participation families had to receive family support services from one of these Associations. To receive services from either of these Associations for Community Living, youth must be identified as having an ID. From each participating family, at least one parent, at least one sibling over the age of 5, and the youth with ID were recruited to participate in individual interviews. Multiple family members who have different roles in the family were invited to participate with the goal of triangulating the data obtained in this study. “Triangulation is the process of corroborating evidence from different individuals, different types of data, and different methods of data collection” (Stoner, Angell, House, & Bock, 2007, p.27). Through the use of triangulation, researchers can obtain the “validation of convergent results on the one hand, complimented by the inclusion of divergent viewpoints to obtain a fuller picture of the event being investigated, on the other” (Ma & Norwich, 2007, p.212). The insights offered by different family members allowed for the confirmation of themes that are consistent across participants (Stoner et al., 2007). Reflecting differing perspectives, concerns, and ideas, different family members also contributed some dissimilar responses, meaning that a more complete understanding of the matter of interest was obtained throughout the interview and analysis processes (Boland, Daily, & Stains, 2008). For these reasons, the use of

triangulation afforded the researcher a more in-depth understanding of families' experiences with the right to make choices (Banister, Burman, Parker, Taylor, & Tindall, 1994).

To be eligible for participation, siblings had to be at least 5 years of age to ensure that they understood and were able to meaningfully respond to interview questions. The age range of 12-21 years was selected for the youth with ID partially for pragmatic reasons. Originally, in the hopes of recruiting a more homogenous population, youth aged 12-14 years and their families were going to be recruited to participate in the study; however, discussions with Community Living Association staff revealed that such a restricted age range would seriously limit the number of families eligible to participate and would therefore likely lead to recruitment difficulties. Therefore, the age range was expanded. It was decided that participants would have to be at least 12 years of age because the study examined choices. As children grow older, they are typically afforded more independence and more opportunities to make choices (Almack et al., 2009; Tardif-Williams et al., 2008) and differences in choice making opportunities tend to become more pronounced in older children as opposed to younger children (Almack et al., 2009). Consequently, the researcher felt that an examination of the right to make choices in younger children would be less likely to reveal barriers to choice making specific to children with ID. Twenty-one years was selected as the upper age limit because youth with ID usually attend high school until the age of 21. After the age of 21 youth with ID transfer to adult services, meaning that their experiences with the right to make choices would likely differ significantly from youth still in high school. In addition to meeting

age range criteria, youth with ID had to be able to communicate verbally so that they could participate in interviews.

### *Participant Characteristics*

From the first four families that expressed an interest in participating, a total of ten participants, a youth from each family, a parent from each family, and a sibling from two of the families, were interviewed. Youth participants ranged in age from 14 -18 years, all attended high school, and all lived at home with their families. All youth participants had been diagnosed as having an ID, but their specific abilities or diagnoses were not sought out as a part of this study.

In each family it was the mother who volunteered to participate in the parent interview. Because interviews often took place in a common living space, however, other people in the house were sometimes present for portions of the interviews or sometimes overheard portions of the interviews from other rooms. During one mother's interview the father, brother, brother's friend, and brother's girlfriend prompted some of the mother's responses and in another mother's interview the father was present for the majority of the time and offered input throughout the interview. The father who was present for the majority of the interview was asked if he would like to sign a consent form so that his comments could be used as a part of the study, but he declined. As these family members did not complete the consent procedure, their comments were not included in the write up of results.

The two siblings who were interviewed were between 1 and 2 years younger than their sibling who had a disability. In both cases, sibling participants were the only siblings who currently lived at home, but were not youths' only siblings. Siblings from

the two families that did not include a sibling participant were at home during the time of the interviews, but did not express an interest in being interviewed.

To maintain participants' confidentiality, pseudonyms are used throughout the results and discussion sections.

## *Interviews*

### *Semi-Structured Interviews*

All data was gathered through the use of semi-structured interviews. This method of data collection was utilized because phenomenology is concerned with the way that participants understand their experiences (Smith & Osborn, 2003). Semi-structured interviews helped achieve this goal because they involve an interview schedule, for which areas that must be covered are addressed in pre determined questions, but they also allow researchers to adapt the interviews during the interview process. Researchers can change questions in light of participants' responses, can clarify questions if necessary, can skip questions that have already been addressed, and can use unscheduled probes to follow up on themes that may emerge during interviews (Berg, 1998). For these reasons, semi-structured interviews were advantageous in uncovering information necessary to address research questions. The interview guides used for parents, youth with ID, and siblings, can be seen in Appendixes A, B, and C, respectively.

### *Interview content*

Interview questions were determined based on Berg's (1998) recommendations for interview schedule development. Berg suggests listing the broad themes that should be covered by the interview and recording questions that could potentially be used to address each theme. For the current study, the research questions were the themes. Thus,

beginning with a basic outline of the interview guide, all questions were developed in an effort to answer the questions arising from the research questions.

When it comes to filling in the interview outline, Berg encourages researchers to include four types of questions in the interview in order to gain a thorough understanding of the subject matter in question. For the current study, questions of each type were included in the interview guide to serve the purposes outlined by Berg. Essential questions focus on central aspects of the study that must be addressed throughout the interview. For example, in the interview guides for parental interviews in the current study, the question, *is there anything that stops (child's name) from making choices?* is an essential question because it addresses the overall research question of *what barriers stop youth with ID from making choices?* This question is important to ask in all interviews because it will serve to elicit information that is required to answer one of the broad research questions. Extra questions are those that are highly similar to essential questions, but are worded slightly differently to see if more or different information emerges when the question is slightly changed. In the current study, the question *Is there anything that stops (child's name) from having the right to make choices?* is an extra question because it is similar to the above question about barriers to choice, but the slight difference in wording may lead to a more elaborate response or may elicit new or different information. Throw away questions are those that do not help the researcher learn more about the main themes, but are integral to the interview because they may gather demographic information, they may help build rapport between the interviewer and the interviewee or they may lead into essential questions. In the current interviews, questions addressing demographic information serve this purpose. Finally, probing

questions are those that can follow essential or extra questions to encourage participants to elaborate on their stories. For example, *can you tell me about a time when something stopped (child's name) from making a choice?* is a probing question that follows the above mentioned essential question to aid in drawing out a more complete picture from participants.

According to Berg, it is important to tailor question wording based on participant characteristics. It is important to ask questions in such a way that participants will understand questions and will be likely to respond to them. Thus, for the current study, it was determined that three interview schedules would be developed: one for youth with ID, one for siblings, and one for parents. The three parallel interview schedules address the main themes of the research questions, but question wording is slightly different in each interview format in an attempt to reflect the understanding and experiences of different family members.

To enhance the practicality of the research (Cohen et al., 2000), interview guides were developed in collaboration with the Community Living Associations affiliated with the project. As interview guides were drafted, they were sent to the Associations for Community Living so that employees could offer their suggestions and concerns with the interview content and wording. Employees at one Association were concerned that the question wording that was included in an earlier draft would not elicit in-depth responses from families. Thus, in keeping with the idea that wording should reflect participant characteristics, vocabulary was 'softened' in the interview guides. In many places the word 'rights' was removed and the word 'barrier' was often changed to 'things that stop'. Staff also recommended that questions about families' suggestions for potential rights



training program leaders be added into the interviews. Thus, questions addressing this practical issue, not addressed in the original interview guide draft, were included in the final interview guide.

As mentioned above, the final interview guides can be examined in the Appendixes A, B, and C. Questions addressing research questions 1 and 2 are scattered throughout the interviews and questions addressing research question 3 are concentrated at the end of the interviews.

### *Procedures*

#### *Participant recruitment*

Clearance was obtained from the Research Ethics Board at Brock University before any prospective participants were contacted (Appendix D). To begin the recruitment process, family support workers made the initial contact with eligible families with whom they work. Family support workers telephoned eligible families and, using the telephone script seen in Appendix E as a guide, they briefly described the current study and asked if family members were interested in participating. For families that expressed an interest in participating, family support workers set up a time and location for the interviewer to meet with the family or recorded the families' contact information so that the researcher and the family could determine a mutually agreeable time to meet. Family support workers were used in this phase of recruitment in the hopes that a telephone call from someone known to the potential participants would increase likelihood that families would consider participating, as opposed to receiving an impersonal letter in the mail from an unfamiliar sender. This approach was not considered coercive because family support workers will have no direct affiliation with

the study and therefore will have nothing to gain by inviting families to participate. Also, support workers informed families that their decision about whether or not to participate in the study would have no bearing on services that they receive from their Association for Community Living.

### *Setting*

In the initial contact that they made with families, family support workers indicated that families had the option to meet with the interviewer at their family home or in a private meeting room at the Association office. The option to meet in the family home was included for the convenience of families. The option to meet at a Community Living office was included in case some participants did not feel comfortable being interviewed in their family home. Reflecting participants' wishes, all interviews took place in family homes.

### *Consent and Assent*

The interviewer and a research assistant met with the first four families that expressed an interest in participating in the research. Prior to conducting any interviews, the interviewer provided each interested family member with a letter of invitation. See Appendixes F and G for letters of invitation for parents and youth respectively. Parents were given time to read the letter of invitation and the interviewer read the letter of invitation to children and youth. After answering any questions that potential participants had, the interviewer gave each interested parent an informed consent form (Appendix H) and a parental consent form (Appendix I) for potential minor participants. Parents were given time to read the consent forms, ask any questions, and sign the consent forms. Assent forms were read aloud to youth with ID (Appendix J) and their siblings (Appendix

K). Assent forms for youth with ID included comprehension questions that youth were required to answer to maintain eligibility for participation. It was determined that questions could be reread and reworded if youth did not initially understand a question. Following these procedures, all youth answered the questions correctly, demonstrating that they understood their role and rights as participants. After inviting youth to ask questions, youth were given the opportunity to sign assent forms. In order for youth to participate in the interviews, they had to provide written assent and their parents had to provide written parental consent.

### *Interviews*

Sibling, youth, and parent interviews were conducted independently, with one family member being interviewed at a time. This being said, parents and children were given the option to be present at one another's interviews, in an effort to ensure that all participants were comfortable during the interview process. Three out of four youth participants were interviewed in the presence of their parents, and all other participants were interviewed independently. The order of interviews was determined by familial preference. In all families, youth with ID were interviewed first, and parents and/or siblings were interviewed afterwards. Before each individual interview, participants were reminded that they could skip any questions they wished to and that they could stop the interview at any time. The interviewer followed the interview guide for the appropriate family member during each interview. Because the interviews were semi-structured, the interviewer added questions and probes to delve further into themes raised by participants, and omitted questions that were previously addressed. Each interview was audio recorded and, as each interview took place, the research assistant wrote notes,

remarking on anything that could help clarify or affect data analysis. Interviews ranged from approximately 20 minutes to an hour and a half in length. Before recruitment began, it was determined that interviews would be stopped immediately and the interviewer would refer the participant to counseling services if participants appeared distressed. As all participants appeared comfortable during the interview process, it was not necessary to stop any interviews or refer any participants to counseling services.

Upon interview completion, all participants were given a feedback letter, thanking them for their help and reminding them about the purpose of the study (see Appendixes L and M for feedback letters for parents and youth, respectively). Parents were given time to read the letter and the researcher read the letter aloud to youth.

## Results

### *Data Analysis*

#### *Thematic analysis*

Thematic analysis was conducted to illuminate participants' perceptions of their experiences with regard to choice making in the family context. Thematic analysis is frequently suggested as a mode to interpret data obtained in a phenomenological study (e.g. Fereday & Muir-Cochrane, 2006; Giorgi & Giorgi, 2003; Jones et al., 2006). This is because, as stated by Van Manen (1990), "The insight into the essence of a phenomenon involves a process of reflectively appropriating, of clarifying, and of making explicit the structure of meaning of the lived experience" (p.77). By identifying themes that emerge in participants' accounts of events, the structure of participants' experiences can be explored (Van Manen, 1990).

Thematic coding was used “to find repeated patterns of meaning” (Braun & Clarke, 2006, p. 86) in participants’ accounts of their experiences. Before describing the steps followed throughout the thematic analysis, it is important to explain the methods that were used to identify themes. Both inductive and deductive coding techniques were used throughout the analysis process (Fereday & Muir-Cochrane, 2006). For research questions 1 and 2, which are broad research questions relating to choice making in the lives of youth with ID, inductive coding techniques were generally utilized. The analysis process was data-driven for these areas of inquiry; observed themes came from participants’ discussions and not from pre-determined codes or analytic frameworks (Braun & Clarke, 2006; Fereday & Muir-Cochrane, 2006). Deductive coding was also utilized for these questions as themes relating to specific domains of decision making (Smetana & Asquith, 1994; Smetana, 2000) were specifically sought out. Data that fit under each of Smetana’s previously identified domains were intentionally coded for the appropriate domain. In this manner, a theoretical framework was used to identify themes. Additionally, analysis was more deductive for research question 3, a question about family members’ recommendations for both content and format of a rights training program. Transcripts were examined for content that specifically answered this research question and corresponding interview questions (Braun & Clarke, 2006).

It is also necessary to note that all interview data were accommodated throughout the thematic coding procedure. According to Berg (1998) any data that contradict a theme should be included in the analysis because such data may disconfirm a theme, meaning that themes may have to be reworked, or may be indicative of new connections, possibly explained by the particular family’s circumstances or experiences. As evidenced

throughout the write up of results, data that disconfirmed themes in the current analysis were generally explained by the families' life situations.

*Phases of the thematic analysis.* The researcher began the analysis by interacting with all data provided by participants (Braun & Clarke, 2006). This was an important step because phenomenological inquiry is concerned with the overall picture as well as the parts that constitute the whole (Giorgi & Giorgo, 2003). As interviews were conducted and then transcribed, the interview data were heard, recorded, and read.

Next, the more formal coding process began (Braun & Clarke, 2006). Once all interview data were transcribed, the analysis process continued with close readings of the text to establish initial themes (Aronson, 1994). This process was conducted by research question and by participant subset. For example, the researcher began by reading the transcript for each parent interview, looking for themes that corresponded with question 1a). Next, the researcher did the same for each youth and sibling transcript. Once general themes were established for question 1a), the same procedure was conducted for each of the following questions. During these close readings, the researcher took notes on the themes that emerged under each question (Braun & Clarke, 2006).

After initial themes were established for each question and participant subset, the researcher created a file using NVivo software for qualitative analysis. A node, NVivo's terminology for code, was created for each research question. A node for each participant subset was created under each question node. Under each of these participant subset nodes a node was created for each previously identified theme. Focusing on several nodes that fell under one research question for one participant subset at a time, transcripts were reread and data that fit the themes in question were collated under the

appropriate node. Throughout this entire process themes were reworked to focus their clarity and precision as the data were analyzed in detail (Braun & Clarke, 2006).

A great number of nodes resulted from this NVivo coding exercise. To refine the themes, the nodes and corresponding quotes were examined and any redundant nodes were removed or integrated with similar nodes (Aronson, 1994; Braun & Clarke, 2006). The revised themes were further filtered as they were then used to write a point form summary of results for each research question (Appendix N). In synthesizing results for the summary, two overall themes emerged. It became clear that themes corresponding to the research questions fit into the theme of a *desire to protect youth with ID* and/or the theme that, within the family context, *all choices take place within the boundaries of family morals and conventions*. Thus, these themes were further considered and were described at the beginning of the point form summary of results.

Next, the summary of themes was used to develop a more 'readable' summary of results for each participant subset (See Appendixes O, P and Q for parent, youth, and sibling summaries respectively). The key findings for parents, youth, and siblings were written in as straightforward and jargon free a manner as possible. These summaries were then used for respondent validation, a process used to determine participants' thoughts on the validity of researchers' interpretations of their experiences (Stoner et al., 2007). For the purposes of respondent validation, all participating families were contacted by telephone to ask if they would be interested in meeting to review the research findings. Three out of the four participating families were successfully contacted. The three families who spoke to the researcher were interested in learning about the results. Therefore, the researcher set a time to meet with each of these families

in their respective homes. At each meeting, every participating family member was given a written summary of results for their participant subset. Parents and siblings read the results themselves and results were read aloud to youth, with the exception of one youth who was able and interested in reading the results himself. Individually, participating family members were asked if they had any questions and were asked to give feedback on the results. Participants were informed that, if they believed that any of the themes misconstrued their perceptions of their experiences or did not reasonably reflect their experiences, themes and results would be renegotiated. All sibling and youth participants communicated that they felt that the researcher's interpretation of results accurately reflected their experiences. Parents also agreed with the researcher's understanding of results; they did not feel that anything needed to be changed, but, as mentioned in relevant areas in the results section, most parent participants clarified and/or reiterated the importance of some of the ideas presented in the summaries. Thus, following respondent validation, themes did not need to be altered but participants' comments were incorporated into the final write up of results (Aronson, 1994).

The final step in the interpretation of results took place during the writing stage (Braun & Clarke, 2006). In an effort to present results in the most economical and logical manner possible, the point form summary and participant summaries of results were reviewed to further refine themes and to structure results by overall theme instead of by research question. Results were written following the newly integrated and organized themes. Interview excerpts were chosen to support the themes presented in the results section. Excerpts that were determined to clearly capture key concepts of particular



themes and to accurately represent the data set and the theme in question were selected for inclusion in the results write up (Braun & Clarke, 2006).

### *Themes*

#### *Overarching Themes*

Two overarching themes were found to permeate participants' discussions about choices and youth with ID. The concept that *within the family, choices are constrained by family conventions and values* was seen to affect the way that family members perceived choices and decisions to unfold within the family context. As shown throughout the results section, choices are made in negotiation with other family members and choices are necessarily affected by the culture of the family. This is not only true for youth with ID, but is the case for all family members.

The second overall theme, the idea that *choice making for youth with ID was influenced by family members' desire to protect youth*, is connected to the first theme. Whether or not and the extent to which youth were considered to be in need of protection both influenced and was influenced by family values and conventions. Due to the interrelated nature of these two overarching findings, results for both of these themes will be presented together.

#### *Independent Choices*

All participating family members reported that youth with ID make choices with considerable autonomy when family members believe that youth will make a decision that falls within the boundaries of family values and conventions and when the outcome is seen to affect the decision maker only. In response to questions about choices that youth make in their everyday lives, participants' responses included, "He just kind of does what he wants, as long as it's not the wrong thing" (Charlie's mother). "Well, he

doesn't choose anything we don't want him to have, cause he knows my mom won't let him have anything that has fake blood, so, he probably wouldn't choose that" (James' sister). "(I make) the (choices) that try not get me in trouble" (James). In stating that youth make choices as long as they do not make choices that are "wrong," that family members would not want them to make, or that would get them in trouble, participants from all participant subsets communicated a recognition that youth have opportunities to make choices within the family but that these choices are always constrained by the culture of the family.

As mentioned above, there was also a general consensus among participants that choices that youth were able to make independently were personal in nature, meaning that the outcome of the choice impacted youth only. "Usually his choices are just whaddy want for breakfast, what game he's gonna play and what he does at school. And if he's ready or not to go to school in the morning. That's usually it" (Jordan's brother). "Well every morning I wake up at six. You know to come down stairs, fix my hair get dressed and eat breakfast and watch a little bit of TV and put my stuff on before I go to school...[after school I] come home, get changed into my casual clothes and then play on the computer a little bit play that one scramble game on my iPod and I play with my dog..." (Lily). Family members communicated that, for these personal issues, youth often make a choice independently, without consulting anyone, as Charlie articulates here:

Robyn: So let's say it's after school and you're at home and you're trying to pick what to do. How would you pick what to do?

Charlie: I will just go upstairs and wrestle.

Participants also explained that youth often ask parents for things that they want or want to do that fall under the personal domain, and that parents generally say yes.

Robyn: So can you also describe how the decision of what to eat at other times of the day is made? So snacks, dinner, breakfast?

James' Mother: Ahh, he will ask. I usually say yes.

While participants all agreed that youth with ID make personal choices that fall within the bounds of family expectations, reports of the number of independent choices that youth are perceived to make and the frequency with which parents or other family member intervene in decision making differed within and between families. In terms of the quantity of choices that family members believed that youth made autonomously, there was no consistent theme. Siblings' and parents' reports of youths' choice making tended to be in line with one another. Youth, however, differed individually in the extent to which they felt that they made independent choices compared to the extent to which their other family members felt that youth made independent choices. Compared to parents' and siblings' accounts of youths' choice making, some youth reported that they made more choices, one youth reported that he made a comparable number of choices, and one youth reported that he made fewer choices. Between family differences in youths' independent choice making will be explored in the following results for choices that other family members make with or for youth.

### *Choices Together*

All participants provided examples of times when family members made choices that were similar to personal choices in that they did not violate family norms or values but that were different from personal choices in that they did affect multiple family

members. When such choices are made, all affected family members are consulted and their opinions considered in the decision making process.

James: But if I really did want to paint my room, first I'd have to ask my parents, then we'd have to wonder "do we have the money for it"? Do we have the time for it? Where I'm gonna be sleeping in the meantime? Ya um, sometimes me and my sister switch rooms, because sometimes my sister wants a smaller room, sometimes she wants a bigger room, and it really gets really complicated from there. When I was first born I had the original room that I have now, but I think when I was 8 or 10 or something we switched rooms and I think last year we switched our rooms back to the original.

Robyn: ... So, who decides if you're going to switch rooms with your sister?

James: First, me and my sister talk about it and after a long argument about it maybe days or weeks, I'd probably agree to it. Then we'd have to talk about it to our parents, and see if they actually have the time to move everything around, and then, ya, it's just like that, just a big cycle.

In addition to illustrating how all affected family members' preferences are considered in decisions regarding James' bedroom, this example also demonstrates how pragmatics, such as cost and time, are factors in the outcomes of such decisions. Family members also reported accounting for perceived fairness by the practice of taking turns, and family values or conventions, shown in the excerpt below by the practice of "spoiling the kids," when making decisions together.

Well, it's usually like he'd have his week where he'd get to pick what he wanted.

We just kinda take turns. It's usually what he wants and then what they'll watch

and then what Charlie's brother wants and then I'll get my pick and then it goes back to Charlie again cause it's I kinda let him take my turn. You know what, spoil the kids right? (Charlie's mother).

Other choices that are reportedly made together include: deciding where to go out for dinner, deciding where to go on vacation, deciding which sibling will get to use an item such as the computer, and deciding what movie to see as a family.

### *Guided or Negotiated Choices*

All participants reported that youth are guided in their decision making for choices that could be perceived as personal but that may push the boundaries of family norms. Family members described situations when youth with ID were guided to make the 'right' choice, the choice that was perceived to be in youths' best interest as determined by family morals and conventions. Accordingly, guided choices typically take place when family members think that youth are likely to make choices that fall near the outskirts of what individual families perceive to be normal and moral. Often, guidance simply took the form of suggesting or encouraging youth to do something thought to be in their best interest, as articulated here by Jordan's brother.

Usually it's if he goes somewhere it's because he has something to do, he doesn't go for leisurely strolls and, if mom decides that we should go out he'd get in the wheelchair and the two of them'd go for just a ride and walk around the block or something. So if he's going out it's usually for something specific or because mom decided that they could go for a little outside time instead of being in his room all day...He normally agrees but some days he says no. It's usually just, it's his choice, so I don't really know what's behind it. (Jordan's brother)

As Jordan's brother explained, family members may try to encourage youth to make a particular decision, but when the outcome affects youth only, youth are able to make the final choice.

While some participating families described simply suggesting that youth make a particular choice, other participating families described guiding youth through negotiations or discussions, during which family members try to show youth the benefits of making the 'right' choice. For example, in encouraging Lily to dress according to weather conditions, her mother explained the importance of choosing appropriate clothing.

Sometimes she likes to wear, I know uh, it's really cold outside all that and uh she'll wear these really, it's actually, tennis you know like the socks that are really really short and I'll say, "oh honey it's so cold outside." "Oh I'm all right," an I'm like, "You gonna catch a cold." Like she leaves them on but, it's her choice like what are you gonna do she just likes to wear them. (Lily's mother)

By explaining the importance of dressing for the weather, Lily's mother hoped that Lily would align her beliefs with those of her parents, which here dictate that it is responsible to wear larger socks when it is cold outside. In doing so, Lily's mother tried to prevent Lily from making a potentially harmful choice. A similar process was evident with most families in which guidance processes were heavily emphasized. Parents from these families frequently described attempting to influence youths' decisions by trying to make them understand and accept familial values in an effort to protect youth from harm in various areas.

Protection through guidance was particularly apparent in areas relating to social interaction. Parents often communicated that they felt a certain level of stress with regard to the atypical way that youth may present themselves to others, meaning that parents sometimes guide youth to make ‘normal’ choices with regard to personal presentation. As James’ mom articulated,

You know umm he’ll put on a pair of shoes and they could be this big, he’ll say they’re fine. I say James, they’re not like, where’s your toe man? And you know doesn’t really appreciate that things should fit properly perhaps sometimes and that there is you know perception of how people are gonna treat you depending on what you’re wearing or doing like you don’t buy shoes that are too big, you try another pair on that fit more comfortably... But I, I it’s a very conscious effort to, you know, James, you just can’t, you know hold up a pair of jeans, maybe you have to go try them on. Maybe you have to try on three pairs because there is a difference in how they fit and how they’re gonna be more comfortable. You can’t just grab and run, and then there’s reasons why people try things on and stuff. You know he doesn’t really care. You have to, stuff like that, conscious effort.  
(James’ mother)

In the above quote, James’ mom acknowledges that clothing choice is important for practical reasons, specifically comfort, but that clothing choice also affects the way others will treat James. She expresses concern that, if James chooses clothes that are perceived to be atypical, other people will react to him differently than they would if he dressed in a more socially normative manner. While James’ mother does not specifically indicate here whether she thinks that James’ clothing choice will be linked to social

acceptance or rejection, her reported efforts to have her son understand the ramifications of clothing choice, her efforts to encourage her son to purchase and wear properly fitting clothes, and her distress over James' lack of social acceptance, expressed numerous times throughout the interview, suggest that she believes that, in wearing non-normative clothing, James may be more likely to be rejected by peers. The issues illuminated in the above quote, namely a concern about youths' propensities to make choices that fall outside social norms and a concern about the corresponding possibility of social rejection, led some parents to report seeking to protect youth by attempting to influence youths' choices in this area.

Most parents also described attempting to persuade youth to interact with peers in a socially normative manner, as they sometimes worried about their potentially non-normative friendships. Sometimes this was because youth were not very social and did not have many friends. For example, Lily's mom explained,

Sometimes she has a hard time with friends. It's just that uh, she's very mature and sometimes the kids that, what they do is, she'd rather stay alone. And she's not one to have too many friends over, once and a while here and there, she likes her space at home to be her own space. This is my domain. There's few friends but, sometimes I say you have to uh, not everyone's gonna be perfect, she doesn't expect everyone to be perfect, but there's some little quirks that you have to accept in friends. As long as they're not embarrassing you or, but she just... I dunno, it's just really, it's encouraged but I don't know what else to do. But the social, great with adults, great! But, she has a few friends at school but she limits herself. Which maybe she'll always be like that, there's not much ... She's happy



that way. I mean that's her choice I can't really, I try talking to her, but maybe that's her choice, and maybe she's not one... I'm not saying you have to have 20 friends I'd rather her have 3 good ones than 20 that ..you know...but in time it will expand, but she's 15 now...

Although Lily's mother says that Lily is happy, she worries because Lily is 15, an age when teens are typically more social. By encouraging her daughter to be more social, Lily's mother tries to protect her daughter from behaving in ways that are considered to be atypical. Sometimes, parents also described guiding youths' social decision making in terms of the way that youth interacted with peers as they wanted to encourage youth to interact with friends in a normative way.

I always try to explain to him, I have friends for different reasons. I don't have one or all my friends are not just to go out for lunch with Saturday afternoon, I have different friends for different reasons. One I like going to the movie with, one I go for lunch with, so you have to pick and choose why you like your friends and you do the things that you like to do with them. You can't force them to do things that you wanna do. So, he's usually pretty good that way. (Charlie's mother)

Here, Charlie's mother concluded that, because of her guiding explanations, Charlie interacts with others in a way that is in line with her conceptions of appropriate behaviour. As evidenced by other interview extracts above, however, youth do not always choose to follow parents' recommendations. An examination of youths' accounts of guided choice making reveal that this may depend on the extent to which youth internalize the values espoused by other family members. For example, James discussed

how, in making the decision of when to take gym, he did not accept his parents' rationale that taking the gym in the summer would be beneficial.

James: Well, I'm not going for into the summer, it's my summer, I don't wanna do 20 more days of school. Ya, and, going and guessing if I had to switch one of my classes that would probably require a little bit of paperwork and I just wanna avoid all that.

Robyn: Ok. so you decided to take it next year then?

James: Yup.

Robyn: And so did you make that decision all on your own or did you have other people helping you make that decision?

James: Uhh, my parents wanted me to do it in the summer because, "Ohh its 5 days you can get the credit very easily", I'm like "nooo"...

Robyn: (laughing)

James: Especially my sister because she wants to be all by herself and do whatever without me bugging her or her bugging me, so (trails off)

Robyn: Ok, so, they wanted you to do it in the summer, and how did you let everyone know you wanted to do it in the fall? How did that happen?

James: Well, I after a sort of argument thing, I finally told them I'm just gonna do it next year it'll just be easier, I won't have to waste my summer or do lots of paperwork, so ya, and it was sold very easily.

On the other hand, in making a similar decision, Lily did seem to internalize family values and therefore made the decision that her parents felt would be in her best interests.

Lily: Oh, the choice of summer school. Oh, see I want or see mom wanted me to take summer courses... Would like to take summer courses. I'm like, "Ok, why?" She said because you know, you do it, it's more easier in the school time, cause in school time it's harder. An summer school I'm like, "OK, why not?" Plus I can could get more, more classes I guess after that. Cause once I took it I get a credit an I could do more opportunities then.

Lily's Mother: Ya, cause you get a credit, then you move onto something else.

Robyn: ... OK, so are you going to do summer school?

Lily: Ahh, I did it last year.

Robyn: Oh, last year

Lily: With gym. Cause I didn't take gym the year before. I It was cut.... So I took it last year. It was alright. It was good. At least I got my mark, which is the main thing. And I'm taking careers and civics this summer coming up for a month.

R: OK, perfect. That was a good example.

Y: And plus it will give me something to do, you know.

In this case, Lily's communications reveal that she accepted the ideas forwarded by other family members, meaning that she was content to follow her parents' recommendations when making a decision. This reinforces the concept that, while parents often reported making an effort to guide youths' decision making, they tended to recognize that they should not explicitly make choices for youth in the areas that they were trying to influence. As such, an acceptance of family values and norms appeared to be one

determining factor in the likelihood of whether or not youth would comply with parental wishes.

When discussing influencing youths' decision making, some parents explained that they felt a greater need to guide youth with ID versus their other children. As discussed above, this was likely due to a perception that youth were in greater need of protection because they did not necessarily understand or follow familial values and norms with regard to making respectful and responsible decisions as readily as their siblings might.

It's just, I dunno if it's choices, but with my other son and my other daughter, I didn't have... I didn't have to guide them. Like they pretty well knew the difference between right and wrong. With Charlie you have to explain everything all the time" (Charlie's mother).

This, however, varied by family and by specific situation within families. In other instances parents explained that guiding children's decision making was a natural thing to do and was, "... same like I'd do for [James' sister]" (James' mother).

In further support of the idea that siblings usually received less guidance because they were more likely to follow familial norms, analysis of sibling interviews revealed that siblings did tend to assert a belief in the values forwarded by parents. In fact, siblings often seemed to internalize values to such a degree that they described themselves as aligned with parents in efforts to guide youth to adopt familial values.

James' Sister: He usually takes more time in getting something off, like if he's used to wearing his boots, when it starts getting warmer outside, it'll take us a long time to tell him to stop wearing his boots or if its if it's summer and he's

wearing his shoes then we'd have to tell him to take off his running shoes and put on his boots. He just gets used to something.

Robyn: ... For example if it started to get warm out and he still wanted to wear boots how would the decision be made if he was gonna wear boots or not?

James' Sister: We have to start getting him to wear running shoes like, when we're going outside to do something he'd just go get his boots on and I'll tell him to get his running shoes on and argue for a couple seconds and then he would go get his running shoes on.

### *Expectations for Respect*

Many of the decisions that parents or siblings reportedly guide, as discussed above, or make, as discussed below, for youth centre around issues of responsibility, as determined by family conventions and values. Issues of respect, on the other hand, seem to unfold based on expectations established by parents and generally accepted and followed by youth and siblings.

Robyn: OK... so for Jordan can you describe how decisions of how to treat other family members are made? ...So in terms of if you guys disagree about something?

Jordan's Brother: I think he, pretty much just, gets just normal opinions just like any other person would, just like that person seems a little, mean to others so I won't be as nice to them. Or just, doesn't talk to anyone at all.

Robyn: Are there any rules in your house about how you treat the other people in the family, or...

Jordan's Brother: Not really, it's sorta just an accepted, treat them nicely they're family. He occasionally makes jokes with the other people, like he has, I'm With Stupid, shirt and pretty much as a joke he'll stand next to a lot of people.

As shown in the above conversation with Jordan's brother, all participants communicated that their family holds general expectations instead of rules about how to treat other family members or other family members' belongings. Also articulated by Jordan's brother, all family members internalized these expectations and therefore felt that they were important and reasonable to follow. Even James, who expressed the greatest level of dissatisfaction with rules and guidelines set out by his family, communicated the importance of showing a degree of respect for other family members. In speaking about arguments he said, "We try to avoid them at all, all, all. But if there's no way out of it, we try to make it as nice as possible". Because family members tended to accept and therefore follow guidelines for respectful behaviour, parents did not report having to make choices for youth in areas of respect, but sometimes reported discussing the importance of respectful behaviour with youth.

### *Parents' Choice*

Analysis revealed that all family members tended to believe that parents exercised a greater degree of authority over a range of issues that fell outside of youths' personal domains. Some participants expressed an understanding that parents made these decisions to stop youth from making choices that could be perceived as straying too far from what family values and conventions determined to be typical and safe. Parents were also described as sometimes making choices for practical reasons. Examples of areas in which family members communicated that parents reportedly make choices for youth

include: going out alone, determining what time to come home, establishing standards of cleanliness for their bedroom, doing homework, managing money, deciding what to wear, and deciding when to go shopping. Parents were only described as having to intervene in choice making in many of these areas when youth made or wanted to make choices that were out of line with family values or conventions.

While all participants recognized that parents had more authority in these areas, parental decision making was conceptualized differently by each participant subset. Youth with ID tended to provide straightforward examples of areas where parents had the final say in decision making. They explained how they often asked their parents or their parents often told them what to do in these areas without engaging in much discussion as to why parents made the choice. This is evidenced in the following exchange with Charlie.

Charlie: I wanted to go to the Wal-Mart store by myself or go to the (store) by myself.

Robyn: OK, so who did you want to tell about that? Your mom?

Charlie: MmmmHmm.

Robyn: So did you tell her?

Charlie: Yes and she said no.

Similarly, during a discussion about grocery shopping, Jordan communicated that his mother makes the final decision on items to purchase at the grocery store.

Robyn: So you choose those things? Do you ever want something at the store but you're not allowed to get it? (pause) Your mom says no?

Jordan: (moves hand side to side)

Robyn: Sometimes she says that? And then what happens if she says no?

Jordan: (pause). I just put it back.

Finally, in discussing the cleanliness of his bedroom, James asserted:

James: After a long half hour argument it'd either be, I'd probably either do it now or wait a few minutes and do it later. In the end I'd still do it anyway.

Robyn: Ok, so if you had the choice all on your own, do you think your room would be tidy or messy?

James: I probably wouldn't be able to go inside the room. It'd probably be so bad.

In all of the above examples, participants with ID demonstrate an understanding that parents have the final say on certain issues. As shown in the following exchange with James' sister, siblings sometimes similarly described parents as decision makers who tell youth to make the correct choice.

Robyn: ...So is James ever stopped from making a choice?

James' Sister: Umm, yes sometimes yes because sometimes he wants to go play the computer or Wii when he has to do his homework, so my mom tells him he has to do his homework and they kinda argue for a second and then he goes and does his homework for half an hour.

In contrast to youths' accounts, however, siblings were more likely to describe parental decision making as being less straightforward. Instead of simply stating that youth were unable to make a choice, sibling participants often used language like "influenced" to discuss the way that parents exerted a measure of authority over youths' decision making. For example, in response to a question about how James decides to take or buy his lunch, James' sister responded, "Well, I think my mom kinda influences



that 'cause my brother doesn't honestly care and my mom said ok, we'll just make your lunch instead of spending money on buying something at school." This explanation is quite different from James' understanding of the same topic:

Robyn: So who gets to decide if you take money to school or if you bring lunch from home?

James: My parents, and even though it's my-y-y money, I think that's a little bit annoying that even though something is actually yours, you don't actually have proper control over it. Like, money.

Robyn: Ok so have you talked to your parents about this before? Deciding what to take to school for lunch?

James: Yes, but they always try to change the subject when I'm about to win the argument.

James and his sister provided the most obvious example of siblings reporting a less authoritarian version of parental decision making, but this trend surfaced throughout sibling interviews. In addition to using guidance type language when discussing areas in which other participants felt that parents made choices for youth, siblings also described decision making in these areas as being more flexible and less parent controlled than other participants described. For example Jordan and his mother explained that Jordan's mother always chooses his clothes.

Robyn: OK. Great. Umm... Can you tell me about how you choose what you're going to wear everyday?...

Jordan: I don't.

Robyn: OK, so your mom chooses your clothes?

Jordan: Yes.

Robyn: OK, so how does that go? Does she put them out for you to see?

Jordan: Yes.

Robyn: OK, and do you always like what your mom chooses?

Jordan: Yes.

Robyn: OK, so you always just put them right on?

Robyn: You've never said I don't wanna wear this today I wanna wear something else?

Jordan: (pause)

Jordan's Mother: No. I don't think so. He's very compliant.

In contrast, Jordan's brother explained that, while his mother is the primary decision maker in terms of Jordan's clothing choices, Jordan does in fact have some input into the clothing he wears.

Robyn: ...Can you tell me about how Jordan chooses what he's going to wear everyday?

Jordan's Brother: Usually it's just set out on the bed by mom in the morning and then once he puts it on if there's something wrong with it she'll just tell him to go back and fix it.

Robyn: And it sounds like he's always, like if somebody asks him to go change and gives a reason he's always OK with going and changing. So he never would be like no I wanna leave this on?

Jordan's Brother: No, it's more of just the, if it's pretty simple and he'll do it he'll manage to do it by himself, so, he'll just say OK and go do it. He won't even say OK he'll just go do it.

Robyn: And do you think that there's anything that would help him to choose what to wear?

Jordan's Brother: not really just looking at all the clothes he might be able to pick what shirt he wants that day 'cause there are certain things about shirts, like some that have just a small stain on the arm, he'll decide that he doesn't wanna wear that one and he'll pick a different one.

Robyn: OK so that happens sometimes then?

Jordan's Brother: Mmmhmmm. There's one shirt he has that has a bleach stain on the shoulder and he said that he doesn't wanna wear that shirt anymore 'cause of the stain.

Robyn: OK, so then he just told your mom that or told you that and then your mom doesn't put that one out anymore, is that?

Jordan's Brother: pretty much. Er it's just an around the house shirt for when he's not goin out.

Again, this conversation demonstrates how siblings interpreted parental decision making as less absolute than other participants did. The two conversations regarding Jordan's clothing choices also illustrate how parent conceptions of choice making in areas where parents were deemed to have more authority tended to be closer to youths' conceptions. Like youth, parents gave examples of issues for which they made the final decision. Unlike youth, however, parents also explained why they made these decisions.

In some cases, parents cited making choices for youth to ensure that youths' actions stayed within the boundaries of family and social convention. For example, Charlie's mother said, "sometimes if we want to go out for dinner, he'll come down with his suit pants on and a white shirt and it's like, nooo, you don't have to get that dressed up. But sometimes I'll let him go in it." Although choosing what to wear was an area in which youth generally exercised considerable independence, Charlie's mother communicated a concept echoed by all parents; youth only make this decision when they make normative choices. When youths' choices defy convention, as defined by parental conceptions of cultural and familial norms, parents have the final say. Conversely, when youth are perceived to make normative choices, parents are less likely to intervene.

*Physical health and safety.* By making choices for youth to make sure that they conduct themselves in ways that are in line with familial conventions and values, parents also explained that they sought to protect youth from harm. To this end, parents exerted authority over youths' actions when youth were perceived as in need of protection for physical health and safety reasons. This is evident in the following excerpt of a conversation with Jordan's mother:

Jordan's Mother: ... And then also like I say you if don't tell him it's time to do something to a degree, I have to tell him to go to bed. That's what that [comment about Pirates of the Caribbean was about] because he'll stay up till 3 o' clock in the morning.

Robyn: Really, and he can just stay awake that long?

Jordan's Mother: Well what happens is he can manage to go to school that day, then the next two days he's home. He sleeps on average, needs about fourteen hours sleep. The physical things.

Parents attempted to keep youth physically healthy and safe by making a variety of other choices for them as well. Some parents told youth what to do in terms of personal hygiene (e.g. face washing, showering, brushing teeth) and some parents made decisions for youth about where and when to go out alone. Here, Charlie's mother explains why she chooses what activities her son can participate in: "he'd like to play hockey, but I don't want the violence. I think that little kids would get broken bones if he was thrown into the boards so I don't want him to play hockey."

#### *Parent-Youth Conflict*

Given the emphasis placed on protecting youth from harm, it is not surprising that the two items of parent-child conflict that were mentioned throughout the interviews focused on issues of physical health and safety. These conflicts arose when youth did not comply with parents' wishes in these areas. Specifically, Lily's mother described conflict occurring because of Lily's refusal to take a vitamin, something that Lily's mother believes is important for maintaining physical health.

Oh I'll tell you one, that's why she didn't want to bring it up, is to take a vitamin in the morning that's no choice, sorry, it's healthy, yeah, cause you don't always eat well and you know and being a teenager and women and everything else you go through in a month. Ever since they were little so, to me that's not a choice, no, but she's getting better but I know a couple times she refused and I said no you have to take it there's no choice in this matter, you know it's health, you

know, she's a good eater, I'm a good eater yeah but it doesn't matter a vitamin has more in it too. (Lily's mother)

The other item of conflict occurred when Charlie "took off" on his own without letting anyone know where he was going.

Cause he took off a few times. And he was on, I don't know if you know this area. Well, he was someplace, that would probably take a normal person 2 hours to walk. But he went.... And that's what I said is pretty scary. (Charlie's mother)

Neither youth participant involved in these conflicts would discuss them, possibly indicating that youth are aware of the importance placed on following rules or directions established to promote and maintain health and safety. Charlie said, "I took off a long time ago on my bike, but I don't want to talk about it". And, when prompted by her mother to talk about vitamins, Lily responded, "no one needs to know that. K, it's a little too personal". Youth appeared to be embarrassed or uncomfortable discussing situations in which they violated familial conceptions of prudent behaviour. As both Charlie and Lily were interviewed in the presence of their parents, it is unclear whether they were unwilling to discuss the conflicts in front of the person with whom the conflict occurred or whether they were unwilling to discuss the matter in general.

### *Reasons to Protect Youth*

Just as there was variation between families in reported quantity of guided decision making, there was variation between families in the reported range and frequency of choices that parents make for youth. The extent to which parents intervened in youths' choices seemed to depend on parents' conceptions of the likelihood that youth would make responsible choices that stayed within the bounds of family norms and

ensured youths' safety. Parents often articulated that they felt that they needed to limit youths' choices because of youths' characteristics.

A major area of concern for most parents, in terms of youths' personal characteristics, was a perceived lack of flexible and complex decision making skills needed to effectively make decisions. The concept that youth are in need of protection because of an inability to responsibly manage the complexities that are a part of many everyday situations was discussed in terms of different skills, varying by families' personal situations. Many parents did not give youth opportunities to make autonomous choices to do with going places alone because they were concerned that youth would not be able to defensively and effectively solve problems that might arise while they were out.

Ahh, you go to a stop sign and then you stop, and then you step out on a curb. Cause everybody else is gonna obey that stop sign. The concept that the next driver, may not obey the law, cause that's what they do. You go to a stop sign, you stop, and then you step out. You know and that's the way everything is.

He's trusting.... You know a lot of decisions we do make for him... and a lot of it is we're still teaching him how ta... (Jordan's mother)

As Jordan's mother expressed with regard to traffic safety, many parents believed that youth were not capable of applying knowledge to safely navigate less than perfect conditions, meaning that parents felt that they had to make decisions for youth.

Youth were also closely supervised because parents thought that they were more likely to be taken advantage of by others, again because of a lack of flexible and complex decision making skills. Some parents worried that youth did not understand the moral

complexities of “right versus wrong” or did not have the confidence or self-advocacy skills to stand up for themselves or their beliefs. Many of these issues are prevalent in the following conversation with Charlie’s mother.

Robyn: ... Is there anything that you see as stopping Charlie from making choices?

Charlie’s Mother: Other people taking advantage of him. And that seriously bothers me. I think that he would make the right decision if put in front of him, choose this or this. If the two ones were the right answers he would be able to tell you what he wanted preferred something else, but to make a choice on his own, no. It just depends on what you give him a choice to do. Like I don’t think that he would choose to do something bad, but I think that if the other person told him, well there’s something in it for you if you do, that he might get swayed into doing something that’s wrong.

Robyn: And has that happened at all?

Charlie’s Mother: No, it’s something I’m more concerned about and gets into more kids that are his age. He, for instance, he wanted to be down the street at Chris’ house, Chris was having a party with his friends, but they all said, you know, you gotta go home it’s 9 o’ clock, your mom is there, you gotta leave, but he really wanted to stay there, cause they were gonna party. And it’s like, they knew that he wasn’t able to say because he’s not old enough. Not that he’s not old enough, he’s not mature enough to stay, and they kinda know that so that to me, it’s always beneficial to have a friend like that, who will just say, you know, time to go home, instead of saying oh you act like a baby or whatever. Or he,



cause most of the kids he hangs around with don't have disabilities, and for them to accept him for who he is is pretty special. There's not many people around who would do that. And especially when this other boy's a year older than him and he's in grade 11 and he tells his friends oh that's my buddy leave him alone kind of thing, and now they're all friends with Charlie, cause they realize, he's not a bad kid, he just struggles with his learning.

Robyn: OK, so it's more like if they see something that's not appropriate for Charlie then they would

Charlie's Mother: Tell him.

Robyn: Stop him from being able to do that.

Charlie's Mother: ... Meeting up with the right kinda people. Cause there are bad people out there with any situation. That's, that's gonna get him in the end.

Hooking up with somebody who's trying to convince him to do wrong things.

Like he knows it's wrong, but he'll wanna do it anyway, and he's gotta learn, can't do that. That's why always the constant supervision with him. He doesn't really have a chance to do whatever he wants whenever he wants to do

Because of Charlie's perceived immaturity, his mother, with assistance from his friends, stops him from being able to make choices that are considered appropriate for other youth his age. As is evident in the above conversation, parents said that youth are often stopped from making choices because they are perceived to be vulnerable or highly likely to make morally unsound choices.

In addition to worrying that youth may be taken advantage of due to a lack of understanding or ability with regard to standing up for right versus wrong, parents

sometimes felt that youth lacked more specific skills, such as an understanding of the true value of money, that made them more susceptible to being taken advantage of by others. Again, discussion with Charlie's mother brought this issue to light.

Money. He doesn't really make choices with money. He doesn't really know the value of it. So to me like if he says oh can I have a dollar for my potato chips at school I can give it to him, but if he had 20 dollars, he wouldn't make that choice not to spend it, it'd be gone and he would give it away too, he's done that. Cause he doesn't understand the value of money and I had to work to get that and he just gives it to his friends, and that's where I get worried about people taking advantage of him cause give me 5 bucks, I'm keeping it.

Here, the perceived lack of a specific skill, namely money skills, means that parents more heavily control decisions surrounding this issue.

Because many youth were thought to lack the skills needed to flexibly solve problems, parents described a greater need to protect youth versus their siblings. However, when parents did believe that youth possessed these skills, it appears as though they were more likely to provide opportunities for autonomous decision making. For example, Lily's mother often described guiding her choices, but rarely described stopping her from making a choice altogether.

I think she... she seems to be the type that she would listen... Yeah she has a pretty quiet uh crowd too, whether or not, I can't see anything really happening, it's the movies and, you know, she knows how to act right and not cause any trouble and all that, you know, but, I'm not there but I would assume she would listen to the ideas and I know if there was something being said that

she didn't want to do she'd go oh no, I'm not doing. It's funny because, OK this won't be a long story. She told me the other day she was at her locker and, and the girl's cardigan fell and, she went to elementary school with her, and she said, "Hey Lily you wanna pick that up for me?" and she goes, "No I don't have time for that, or you". And I thought good for you, don't have anybody tell you what to do. This girl doesn't talk to her at all.... And the other one, that was with her said, "Well that wasn't very nice what you said Lily". And she goes, "well I don't really care what you think". Like I always taught her, like you know, she said, "I would have picked it up for Andrew, he's in a wheelchair, or if I seen somebody with a lot of books mom, that I know, even if I don't know, and they're coming into the school, and I'll open a door, like a teacher or even a grade 12 student, maybe, you know, like, they're packed with all these subjects and that, I would help somebody. But to tell me to pick up a cardigan," she said, "I don't think so"... No, because, because of the disability you can't come out and say hey people might take advantage of you, but if you teach her, different ways, right, from the cardigan to tell you what to do if you don't want to do it you're not gonna do it. You know what I mean, don't take her for a fool. (Lily's mother)

In contrast to Charlie's mother's concerns, Lily's mother is confident that their daughter knows right from wrong and that she would stand up for herself and what she believes in. Because she has reportedly internalized family values and learned the skills needed to be able to make safe choices, Lily is not in need of protection in the same way as Charlie. One way of conceptualizing these different perspectives is that Lily's parents have protected Lily by encouraging and teaching her to advocate for herself and to

understand issues perceived to be prudential concerns. Because she is now able to protect herself from being taken advantage of or making morally unsound choices, her parents do not feel that they have to protect her, or keep a close watch on her, in the way that other parents might.

Some other participating parents also reported attempting to teach youth skills needed to conduct themselves more safely and appropriately in areas perceived to pose a threat to youths' well being. In addition to promoting self-advocacy skills, some parents also described attempting to teach youth social skills that would enable them to conduct themselves in a more normative manner around others, as described in the section on guided choices. Until parents believe that these skills are mastered, however, it appears as though they continue to express concern about youths' decision making abilities.

#### *Other Barriers to Choice Making*

Siblings and youth both communicated that youths' personal characteristics may inhibit the number of choices that youth make in the family context. In terms of personal barriers to choice making, one youth brought up the issue of age,

Well, something silly like, oh having a boyfriend, but I'm too young type thing? Right?... I'm not ready for it or, and all that. And in fact... [I'd] Probly [like it to be] the parent's choice cause, you know, the age of dating. It's not appropriate age for dating, but I'm not really into that kind of stuff" (Lily).

While only Lily identified her age as something that inhibited her from being able to make a choice, most youth interviewed acknowledged that they lacked skills needed to access specific choices.

Charlie: Well my mom gets up with me, but I'm trying to know if I can just go up by myself and then go out the door by myself and they will stay in bed. Like I'm getting a little bit confused on that. Like I'm a big boy, so I may wanna get up by myself and they stay in bed.

Robyn: Ohh, so you're wanting to be able to get ready... do everything on your own in the morning...

Charlie: Mmmhmm.

Robyn: ... So, you, but you don't do that yet?

Charlie: No

Robyn: So are you still practicing to be able to do that?

Charlie: Yes

Robyn: So what sorts of things do you need to practice?

Charlie: To get an alarm clock.

Robyn: Ohhh

Charlie's Mother: And to get up in the morning when it goes off.

As shown in the above conversation, youth sometimes wanted to be able to do something independently, in this instance get ready for school, but sometimes recognized that they lacked the skills needed to do so, in this example using an alarm clock to wake up.

Although youth did acknowledge that there were things about themselves that stopped them from being able to make choices, they did not discuss personal characteristics to the extent parents did. Unlike parents, youth did not identify as many personal issues that acted as barriers to decision making and they did not connect their personal traits to a need to be protected.

Similar to parents, siblings discussed some of youths' characteristics as barriers to choice making, but did not expand on these issues in terms of a need for protection.

Robyn: ...Um, so would you say that James is allowed to make choices as much as you are?

James' sister: I think we make about the same amount of choices. Um, I might make a little more choices cause at school I have a lot of different groups of friends, so I might have to choose which one to hang out with at certain times. But um, other than that I don't think we have any other different choices like we both have to choose what to eat in the morning, or choose what to do after school.

Robyn: So with your family you'd say you have about the same number of choices that you make?

James' Sister: Yes

Here, James' sister explained that James is able to make as many choices as she does, but that, because of his personality, James has fewer opportunities to make choices in his daily life. As alluded to in this excerpt, siblings did not convey a message that youth were ever stopped from making choices by other family members; rather, they seemed to believe that barriers to choice making were a natural consequence of a youth's personality or disability related characteristics. Here, this thinking is clearly articulated by Jordan's brother.

Robyn: OK, ummm so is Jordan able to make choices as much as you are?

Jordan's Brother: No he is limited to simple stuff just like breakfast. He doesn't have any wide variety of what he does in the day, so it's limited down to pretty much a straight choice of this or that throughout the day.

Robyn: And then is that, I know that some of that is because you guys do that and then it's easier for him to make choices, but is there anything else that you think stops him from making as many choices as you?

Jordan's Brother: usually just his ability to make the choices. That's really all that I feel that stops him from making more choices.

*External barriers.* In keeping with their belief that youths' characteristics were the main inhibitor of choice, siblings did not identify any other barriers to choice making, either within or outside the family. Siblings did, however, suggest that youth might sometimes be stopped from making choices at school or in social situations, but were not certain about this as they said that they did not see youth in these situations. This is illustrated in James' sister's response to a question about whether James is ever stopped from making choices. "... Maybe during school, uh maybe he wants to go and sit somewhere at a lunch table and somebody else says you can't sit there because he's not like, welcome there or because they're saving a spot for somebody. Or, maybe he doesn't have enough to do something he was planning on doing, but, I don't know". James' sister's hesitancy to confirm whether James is stopped from making choices at school was echoed in Jordan's brother's interview as well, indicating that siblings may be aware that youth are not always able to make choices that they would like to outside of the family home, but that they are not aware of the exact way that this affects youths' lives.

In contrast, parents and youth identified a number of factors, external to youths' characteristics, that prevented youth from being able to make choices outside of the family home. All youth mentioned some form of external barriers to choice, but, as with barriers to choice that youth perceived to exist within the family, youth did not bring up





many external barriers and usually did not reflect on potential reasons for the existence of the barriers. Most youth reported that they are sometimes stopped from making choices in interactions with people from outside their family. Interactions with peers or teachers were sometimes described as difficult because youth did not feel as though others listened to them. In discussing classmates who took his pencil case from him James said,

Words aren't really effective on people these days. It's um I'm surprised that any of them ever did actually graduate grade 8. They all, if they if they were give it back I bet that if they would they would probly eat all my stuff. (James)

The frustration conveyed in James' experience was evident in other youths' accounts of their interactions with others. Jordan did not express a frustration with the way that others listened to him, but, in recognition that personal characteristics also influence interactions with people outside of the family, Jordan stated that it is sometimes hard to tell people what he wants or needs.

Robyn...When is it hard for you to tell people what you want? Or to let people know what you want?...

Jordan: (pause)

Jordan's Mother: What about school? Or someone that's not mommy or [your brother]?

Jordan: Questions

Robyn: Questions at school? So if you have a question to ask your teacher, that's hard for you?

Jordan: Yes

Robyn: And can you tell me about a time that you wanted to ask your teacher but it was hard?

Jordan: (pause)

Jordan's Mother: Like the other day I had to go get you at school? What did you ask your teacher?

Jordan: If I could go home.

Robyn: And was it hard for you to ask your teacher?

Jordan: Yes.

In addition to the possibility that others would not listen or that it would be difficult to articulate requests outside of the family home, some youth also gave examples of policies and rules at school that constrain their choices.

Well actually, they were surprised that I I wanted to explain to them that we should help, we should help animals too cause animals is part of God's creation. Cause community service get to help with people and people who are need and, but we have to follow theses rules but what I said is helping animals is made from God too. So we should help animals too then just people. Cause people can be very picky and cruel. Animals can't tell you if you're being cruel or not. They go through a lot worse than people. And and abuse and (mom whispers something) Exactly, I am an animal lover and I totally respect about what that kind of environment for animals. And I don't really like you know like their their fur on the clothing you know like their print of their fur on it? I don't like that, I think that's animal cruelty. And I don't like how they use animals their products, I think that's another way of animal abuse too... But then she said oh you can't do

that. You can't really help. You know you gotta follow the rules and all that I'm like OK. I'm really disappointed but that's but you know, if I wanna graduate I have to follow the rules of Community Service. (Lily)

As evidenced in Lily's anecdote, even when youth are able to communicate effectively with others, policies and rules may prevent them from making certain decisions at school.

While policies and rules at school would likely constrain the choices that all students are able to make, not just students with disabilities, parents were critical of policy and practice in both schools and society in general with regard to persons with disabilities. As such, parents emphasized heavily the role of external barriers to choice making for youth with ID. Many parents reported that, at school, youth with ID are not given the support necessary to access the same opportunities as most youth without ID. For example Jordan's mother explained that Jordan was homeschooled for a number of years and was unable to exercise the option to attend public school because

The school was unsafe. The school was huge, it was unsafe, they would not offer, they would not give me an aid. Full time. For him. Umm he had to share an aid with 6 other kids. Right, well how far d'you think he'd get? He's the kid who gets lost in the classroom. You know I've always stayed very involved and if he put his, when he was in middle school, if he put his hand up, to ask for something, he would leave it up for a half hour. Until the teacher got around to him. It's just, everybody else draws the attention and Jordan doesn't and kinda sits back and doesn't ask.

While Jordan's mother was the only interviewee who decided to home school her son, her concern that Jordan was not adequately supported to safely and successfully

navigate academic and personal challenges that arise within a school day was brought up in all parental interviews. Many parents described feeling as though, “In elementary school. It’s just that I felt that, if you do not advocate, like advocate for your child, they just fall between the cracks” (Lily’s mother), both socially and academically. It was felt that youth could “fall through the cracks” because of inadequate measures to promote social inclusion, failure to provide youth with appropriately challenging academic work, and an insufficient focus on teaching youth about topics that would prepare them to make informed decisions. Corresponding with parents individual concerns about youth’s lack of flexible and complex thinking skills, different parents said that the curriculum should be more comprehensive in areas concerning money, sexual knowledge, and interpersonal safety. “But there are you know things that I wish would have been taught or when he was younger I had more of a say. Um, you know, stranger danger’s my peeve” (Jordan’s mother).

Further, parents expressed frustration that, not only were their children not given the support and knowledge needed to make choices, parents were often not supported in their attempts to advocate for their children.

I’ll never go to school meetings by myself anymore. It took me years to learn but I’ll never do it (laughs). Oh god no. No, awful... I go with a rep, actually a representative from the Autism society. And I and I used to be on the Special Education Committee and I would go with other parents but for me to go as a parent after years I just I would not go by myself. It was too hard. So umm the chapter in (city) has a placement ahhh a girl from Family Children Services

actually, and she goes and advocates on behalf of, which changes the whole dynamic of the meeting. (James' mother)

Participants' dissatisfaction with the school system is particularly striking given that interview questions were primarily directed towards choice making in the family context. One parent even reinforced her disappointment with her son's educational experiences by discussing the issue at length during the member checking phase of the research. Evidently, parents felt strongly enough about the lack of support and ensuing negative consequences that they broached the topic with little or no prompting.

With comparable spontaneity, most parents also described a general lack of societal support for families that include a member with ID. According to parental reports, a lack of support in multiple areas prevents families and youth from having opportunities to learn skills or acquire tools and resources that would help youth to be able to make additional choices. For example, one parent explained that a medical misdiagnosis stopped her family from being able to access autism support and training services.

We only found out he was autistic, last year... Cause we had no idea what was wrong with him. We knew about physical things, but there was definitely something that wasn't right. And that's when they diagnosed him with PDD. So everything he's learned and everything he's done, we have developed ourselves.

We had none of this Autism training" (Jordan's mother)

Another parent discussed the challenge of accessing funding that people with ID are entitled to.

Oh, ya, well right from day one when you've got a kid that's got special needs, the funding is there, most of the time. But there's a lot of people that have kids way elder than me that don't know the funding is there and they don't know that. That they could for that had access to that. Cause it's not given to you in a book... Tryin to get wheelchairs and things like that. Ya like we're pretty lucky. We don't need the diapers, and the Depends, and the wheelchairs, and the aids and stuff, there's people out there that need em. That their spouses are working 2, 3 jobs tryin to get the wheelchair for the kids, meanwhile there's grants and there's funding out there available to help these kids which there's a lot of times they, they just don't know that they're there. And I know somebody who was working for (an association)... and he's actually one of the head guys for the funding, but he didn't know that there was ahh, oh, what is it called? Oh, Ontario Support Disability Program? But it's geared to income and you're allowed to apply for it. But he's been workin for the agency for years, helping em, didn't know anything about it. But it's, it's miscommunication. Like Doctors don't even know. Like if you've got a kid, the mom doesn't get a book saying this is how you take care of your child. You learn from experience and by other people's mistakes and hopefully you can learn that way. But they don't give you a book. Like if somebody was born with mongoloidism they don't give you a booklet from the hospital saying you know what, you're going to need some help, there's funding available. There's this that can help you out. There's this, this, and this. It's all, it's not all readily available in a book. (Charlie's mother)

Charlie's mother described the additional challenges that families may face because of the difficulty in locating information regarding funding and supports for people with disabilities. The obstacles that she described would prevent youth with ID from being able to learn the skills or access the supports needed to have many of the opportunities afforded to youth without ID. Additionally, as described by Charlie's mother, a lack of communication between families and various service providers also places considerable constraints and stress upon entire families. Only Lily's parents did not identify any external barriers or stressors beyond the barriers created in the school system. As questions did not directly address external barriers to choice making, it is not possible to ascertain whether Lily's family recognized barriers beyond those encountered at school or not.

### *Enabled Choices*

Recognizing that systemic and personal factors make it more difficult for youth to make choices, all families reported making adaptations to enable youths' decision making. For example, understanding that Lily better comprehends the implications of decisions when given practical experience or when possible outcomes and alternatives are demonstrated with the use of visuals, her father took her golfing to ensure that she could make an informed decision about whether or not to join her school's golf team. "So again, it's a visual thing.... He made her decide it, and if she wanted to, OK like.... She's like, 'Oh ya, that's not easy'." (Lily's mother)

Lily's parents were glad that Lily decided not to join the golf club, but, instead of telling her not to join, they gave her the experience that she needed to make the choice on her own. Siblings often reported making such adaptations to facilitate choice making

alongside parents. Because Jordan was not diagnosed with Autism until the age of 18, his family was never provided with autism materials or training. Therefore, his mother reportedly developed comparable materials and techniques on her own, allowing Jordan to make more decisions than he would have been able to in the absence of such materials. Jordan's brother explained how, along with his mother, he implements these techniques.

Usually it's, any choice he needs to make he really needs to think about, so we pretty much keep down any of the choices just to a couple things. So like if he wants mac and cheese for dinner or hamburger, just simple questions like that, just takes a while to think. That's usually it... He usually (pause) doesn't, like we usually just have to ask do you want this and he'll say yes or no or we already know he doesn't eat it so we just offer him pizza pockets of macaroni and cheese.

Using language such as 'we' to describe how adaptations are made for youth, siblings seemed to perceive themselves as co-facilitators of choice making alongside parents. As evidenced by the examples given here, family members tended to facilitate choice making for choices that would be perceived as personal choices. In helping youth to make these choices, family members also helped to ensure that the choices would stay within the realm of family morals or conventions, for example by presenting only family acceptable alternatives for food or by helping to show youth why joining the golf team might not be in their best interest.

### *Independence*

Despite parents' reported attempts to teach youth skills needed to make choices and parent and siblings reported adaptive measures to enable choice making, most youth participants reported wanting greater independence. Some youth said that they wanted to



be able to make more choices currently, either by communicating a desire to make more choices in general, “like I would like to have more say in the choices I make, especially at home, because most of the time I don’t really have the choice to do something and I would like to have more choices” (James), or by stating a desire to make specific choices. Only one participant reported attempting to reconcile the desire to make more choices with the current constraints on choice making. Charlie stated that he wanted to get a job and explained the steps he was taking to learn the skills necessary to obtain employment.

Charlie: Get a job.

Robyn: So how did you decide where you’re going to get your job?

Charlie: At (pizza restaurant).

Robyn: And how did you choose to try and get a job at (pizza restaurant)?

Charlie: Call him. And ask him.

Robyn: So was it your idea?

Charlie: Yes.

Robyn: So then you called him? And what did he say?

Charlie: We’re trying to look that into... I talked to him at the store.

Robyn: And what did he say?

Charlie’s Mother: When you talked to one of the workers you kept asking all kinds of questions. How much you’d get paid, do you get free pizza. When you were talking to the girl when we picked up pizza?

Charlie: Ya

Charlie’s Mother: Remember all the questions you were asking?

Charlie: Oh, ya.

Charlie's Mother: So what did the lady do with the pizza box for you? What did they set up?

Charlie: A pizza box!

Charlie's Mother: Ya that you have to what?

Charlie: Work!... practice.

Robyn: So you've been practicing?

Charlie: Yup

Robyn: And then once you've practiced enough you can get a job there? That's how it works?

Charlie's Mother: That's what he's hoping.

Some youth additionally or alternatively reported wanting to be able to make more choices in the future. For example, some youth reported wanting to be able to eventually choose where to live, choose where to go on vacation, choose where to work, and/or choose where to go to college. "Oh, like career wise.... Ya, like where I wanna live, how I live my life, er" (Lily).

Like all choice making processes that take place in the family context, a desire for independence appeared to be influenced by family morals and conventions. Those who reported being less interested or not interested in currently making more choices communicated a high degree of acceptance of family conventions and values. In other words, youth who did not want to make more choices expressed an understanding and acceptance of the reasons why they could not make more choices with autonomy. For example, Lily picks her own clothes, but her mom has a say in her final decision when they are shopping. This is because, "sometimes mom helps me with different styles and

certain age appropriate clothes for me” (Lily). In making this statement, Lily communicated an acceptance of the perception that she would be likely to choose clothes that may not be “age appropriate” and she therefore accepts a lower degree of autonomy in deciding what types of clothes to buy. An acceptance that they were not old enough to make certain choices and that they possessed physical limitations which stopped them from making certain choices were also communicated by youth who did not express a current desire to make more choices.

Both siblings interviewed also reported accepting family norms and values. This is illustrated in the following excerpt from James’ sister’s interview. “Well, we go to a movie or go to a restaurant it’s always with family cause like we’re not old enough to go hang out with our friends and go to a movie or something.” James’ sister seems to accept the belief that she and her brother are not old enough to partake in certain activities without parental supervision. In accepting such values, siblings did not see limitations on youths’ choices as problematic and did report that youth would benefit from increased independence. Conversely, youth who did report wanting to make more choices appeared to be more willing to break outside of family norms and conventions that structured choice making opportunities.

### *Recommendations for a Training Program*

#### *Content*

*Siblings.* In keeping with siblings’ reported acceptance of family norms and siblings’ reported beliefs that youth with ID are not stopped from making choices, siblings did not make many recommendations for the content of a training program about choices and youth with ID. When asked about their recommendations for a training

program, siblings communicated that youth already make their own choices with competence and autonomy.

If it's, if it helps him get through daily life like the choices that he makes, and they're said on a simple level, it's pretty much, he can make the choices and they're his choices, not like we're pushing any answers onto him. (Jordan's brother)

Similarly, James' sister articulated that James might already know everything he needs to know about making decisions.

... James already knows that he should be respectful and thoughtful about decisions that he makes. But with some things, he just doesn't know, but we're kinda young so it's OK, but he's kinda good with making choices, cause we know what's good and what's bad and that's pretty much all we need to know about making a choice. (James' sister).

In stating that, because of their age, it is unproblematic that she and her brother do not know about making all choices, James' sister is again demonstrating an acceptance of family conventions and values. This acceptance of family norms was also evident in the only sibling recommendation for training program content that youth, as well as themselves, could learn about making "better decisions".

Robyn: ... So then, um, what you're thinking then, and correct me if I'm wrong, is that um, you don't think your family could benefit from a choice making program?

James' sister: Well, I guess in some ways, just not that I know of, because we make the right choices and we don't make any bad choices, but there are some

things we could use to make better decisions. But the choices that we choose are not bad, but they're not always the best choice. (James' sister)

*Youth.* Likewise, youth did not provide many examples of items that should be included in a training program to help them to be able to make more choices. Only one youth, James, conveyed dissatisfaction with the constraints on the choices he currently makes. He stated that he would welcome more opportunities for discussion that could lead to more choice making in the family context. "I would like to have more choices and I think a program would be very good for that" (James).

*Individualized.* All parent participants and one youth participant emphasized the importance of a training program being individualized according to the ability, age, and interests of the youth who would be using the training program. "So they'd have to have a lot of the same videos, but different categories for different age groups. They wouldn't be able to do like just one video for everybody with special needs, cause all the special needs are different" (Charlie's mother). Parents communicated that tailoring the training program to meet the needs of specific individuals and their situations would help ensure that the program would be effective. In keeping with the importance of individualized programming, training program recommendations tended to reflect each individual's perceived needs, explaining variations within broad categories recommended for inclusion.

*Flexible and complex decision making skills.* Given parents' concerns with youths' perceived lack of ability to apply specific skills in flexible ways, it is not surprising that parents thought that youth would benefit from learning or practicing flexible and complex decision making skills in a variety of areas. Parents felt that youth

would benefit from practice or instruction in areas in which parents expressed a desire to protect youth. Accordingly, most parents expressed a conviction that it would be important for youth to learn about safety skills in a way that transcends a basic understanding of rules. A deeper understanding of safety issues would help youth learn how to utilize judgment to make sound choices when presented with complex safety issues.

Traffic safety. Um, dealing with public in general cashiers, um it's OK to ask a police man for directions um a lot of what you wanna call the safety issues is where I see it. Ya, you know ah, they're all taught their signs you know the skull and crossbones and all that like they know that but it's just like you don't go in there. They don't understand why not to go in there. And that's, you know, um, they tend to teach to this level and I really think they need to be taught to think about, not just because they were told not to go in there or that's poison, it's like to make the choice or the reason is not taught to them when they're young.

(Jordan's mother)

Within this area, other specific suggestions for issues to address included teaching an understanding of what to do if something unexpected occurs on a routine trip outside of the house.

... He was riding his bike over there, and he came back and and he couldn't get there. I was like "what happened?" right. He goes, there was a barrier up like a sawhorse type thing. Over, I mean not crossing the whole thing, just over one section right. But he saw that and turned around and came back. Figured he couldn't go past it. You know what I mean? Like, and, he was well beyond the

age of rationalizing that out, but he wasn't. And it's just that's like wow (whispers), you know, ummm, so training yes, practical experiences, maybe even throwing curves up when like doing practical experiences and just unexpected you know, cause you always train for the expected and if all of a sudden you throw something unexpected in, they have no practice, no experience, no, and then the panic sets in they don't know how to respond, you know? (James' mother)

James' mother discussed the importance of helping youth to understand how to respond effectively when something unexpected occurs with regard to a relatively benign situation. Other parents discussed a similar concept, but with reference to situations that more clearly linked to safety issues.

Ya, cause something happened to me, I'd want him to be able to trust his brother to go with him, I'd want him to be able to trust Sarah to go with him. Like, I would want that in case something ever happened, but how do you teach him it's the right time to go or the wrong time? Cause my son and I could be in conflict and he could be I don't know somebody who'd just come out of a jail, and you know, gotten into trouble. Maybe you don't want him to go with him. What do you give him a password, or to tell him yes you do? Cause there's too many scenarios that could happen that you'd want to keep him safe and then you do everything that you can and can anyway. (Charlie's mother)

As she explained that she would feel more comfortable if Charlie was able discern between safe and unsafe circumstances under which he could potentially get into someone's vehicle, Charlie's mother alluded to the relevance of training youth to be able to adapt and apply their knowledge to a variety of situations.

Some parents recommended that a training program include a focus on flexible thinking with regard to more specific skills addressed in conversations about the need to protect youth. For example, multiple parent participants addressed the issue of money skills. According to parents, a training program should go beyond the money recognition skills that youth learn at school to be effective. For example, Charlie's mother highlighted the relevance of training youth about the importance of checking to ensure that cashiers return the proper change.

Cause you don't want people to take advantage of. Normal people will take advantage of normal people. But if they can get away with, you know, getting money offa him they're goin a do it. Even when it comes to going to a grocery store like er the corner store they have suggested that we give him a calculator so that he can figure out if they're giving him, but how do I know that he's going there that he pressed the right button. Like, that's the hard part. Like I could teach him here but how do I know? Like I can't go back into put it back on the history so I know what he did when he was there. Unless I talk to somebody up at the store. And they check it and make sure that he knows what he did and they make sure that OK, there's the 25, 35, 37 cents back. Unless they're willing to do that with him and get him used to doing it that way. But if he goes to another store and they don't know him they're not gonna do. They're like here's your change. And he's too trustworthy. (Charlie's mother)

Some parents also suggested that youth should learn about the "true value" of money and about how to budget.



Another specific skill set that parents felt would be beneficial to include in a training program centers around clothing choices. Some parents stated that youth could benefit from learning about wearing clothes that are appropriate for the season and buying clothes that fit properly and appropriately.

If you show her, if you just tell her, oh no, no that doesn't suit you or whatever, but if you show her why or how, I told her to, if you teach them to, when you try on clothes, if you don't have anybody there, bend your elbows, make sure there's room, look in the mirror, if someone shows you those tips, if you're by yourself when you're shopping you remember them, you know, and different fabric, if you're buying all cotton then remember to buy it a little loose or don't put it in the dryer. (Lily's mother)

As parents also believed that youth should be protected in areas concerning social interactions, it follows that many parents reported that youth would benefit from an increased facility with social skills.

Mmmmm Well, ya, I guess umm like, how do you choose to stick up for yourself, you know? At what point do you, you're allowed to stand up and it's actually important that you're allowed to? And how do you stand up for yourself? You know? When it's hard ahh verbally to express yourself, under pressure, you know, ummm, you know one day, actually I think it was the day you phoned, he had his pencil case in tech class, which is a very loud class, it's noisy sometimes, you know it's annoying for him, and he goes, those students are just as bad as the ones as ahh my elementary school he said right you know? Or can behave just as bad because I donno because there's, there's a bit of a distance there, my students,

you know it's not my buddies or friends, it's, it's kind of odd how he sees the social structure, you know? It's different, right? (James' mother)

In addition to learning about interacting with same age peers in general and learning about how to self-advocate with peers, parents suggested that youth could learn about making and choosing friends.

*Self-advocacy skills.* All parents mentioned the importance of self-advocating in the presence of peers, as noted above, and/ or the importance of self-advocating in other situations. As evidenced in the above except from James' mother's interview, parents thought that youth should learn about how and when to stand up for themselves or what is considered to be "right". Some parents also suggested that youth could benefit from an understanding that it is appropriate to ask questions or ask for help when they need it.

Robyn: Umm, so are there any choices that we haven't talked about, choices that would be important to learn about that maybe would be in a program about choices or rights?

Jordan's Mother: Well, I really think a lot of, they need to be told that (pause) they can say something if they don't feel it's right. Like if there was something I could put him in or start teaching it would be it's all right to stand up for yourself.

Umm, if you want something it's OK to ask other people for it.

Some parents also suggested that a training program should include skills that would help youth to be effective self-advocates. Such items included: "scenarios trying to build her confidence up" (Lily's mother), an understanding of rights and how to access them and an understanding that it is not necessary to self-advocate alone.

I think just as umm as the kids get older I err the same as the adults, what are their actual rights... as far as renting as far as this or that or if you buy something that's broken you can bring it back, you need to have your bill, you need to have your receipt. There's a standard procedure and stuff, but you do have the right to do something and you also have a right to find help to get it done too. You know you don't have to be by yourself to do this. (James' mother)

*Skills to enable future choices.* Working to increase complex problem solving and self-advocacy skills could potentially prepare youth to make more choices, both currently and in the future. Both parents and youth also highlighted skills that youth should learn to specifically enable them to make more choices in the future. For example, Lily's parents discussed the importance of organization skills for future choices.

Lily's Mother: Ya, to plan, to organize what you're gonna do. Like you know she has a calendar, she's always writing things down or she's to remind herself. So like a daytimer. You know, a dayplanner. To let them know what they're doing er. I mean even ourselves we go grocery shopping, we make a list. And uh, I mean that's just a normal thing to do. So making a list of Monday, Tuesday, Wednesday, what's to be done. And then that way, when you're out on your own, you know. Bills come in on certain days. Circle those days. Your cable or somein. It's always the same. Your cable, Bell Canada, gas bill. It's usually they'll tell you the due date so when you get it, circle the date on your calendar so then you know its due so then you can plan. Right. Basically like I mean almost everybody does. You know rent is due at the end.

Gillian: Do you think that's something we should train now, or something for a training session that you should wait till they're a little older to do, or?

Lily's Mother: Well... Ya, even now ya... The bill paying part might be for training later. But even just organizing your everyday ahh example tests. Mark it down. Like she marks it down, she has an agenda for school. They'll tell her project due, she'll write it down. So carry those skills over till when adult, training.

Other skills that parents thought should be included in a training program to enable future choices included: budget management skills and knowledge of rights, as mentioned above.

Youth did not forward examples of transferable skills that they felt were important to learn for future choices; rather they said that they wanted to learn how to make specific choices when they were older. Different youth said that it would be helpful to learn the skills needed to be able to rent an apartment, choose where to go on vacation, choose where to work, choose where to live, choose to go to college, and choose to have a relationship. To illustrate:

Lily: I think that's really important. So I know which is a which is a good road for me, which is a not good road for me. Well I well I, not just career, but I was thinking like in life, like where I wanna live or what to do if someone try to break in the house.

Robyn: Ya, that is really important.

Lily: Or how to pay the bills and how how,

Lily's Mother: Cleaning.

Lily: Cleaning.

*Format*

*Visuals.* Most participants from all participant subsets expressed an interest in the use of videos or video games for a training program, with video games being the option that participants showed the most interest in. Participants believed that videos or video games would be effective learning formats because they would suit youths' visual learning styles, as shown here in Lily's response to a question about the way that she would like to learn about making choices, "I usually have a a vision.... a visual, in front of me". Participants also believed that video games or videos would be effective learning tools because they would interest youth.

I like the video game concept because that's what most of the kids are into now.

Ya you know you could give him a video game, that's where he learned to read.

Ya you know that's how he learned to read umm by reading what they say and stuff like that. Um, it needs to be appropriate to them. (Jordan's mother)

One parent also suggested that a training program could capitalize on youths' visual learning styles by using pictures to remind youth about the steps to follow when completing tasks independently.

So she's learning as we go shopping, so I think it is important to teach her that, cause she can comprehend that, you know, but if someone even couldn't, but got a list and they could read it or someone point it out it's a good learning tool, you know by the washing machine, white cotton, not dryer, hang. You know, something, or with a hanger, yeah like that's how they were taught to talk like

with the pictures, picture exchange, a little binder, say they wanted a water or cookie they would come to me with a picture. (Lily's mother)

*Role play.* Some parents suggested using role play in a training program to provide youth with opportunities to practice solving problems that could occur in everyday scenarios. One parent commented that the use of role play could be effective for teaching youth about making respectful and responsible choices because it would allow youth to explore problem solving strategies in a low stress, third person format.

Sure you can play and drama's always a great way to do it because even with a costume, so they can practice but it's not necessarily themselves again. You know take that pressure off again cause that pressure is, you know, it's hard, but you start learning that you know so and so came over because and said something because they felt uncomfortable cause you weren't you know, doing that face to face with your own face would be hard, I would think. But with a costume or doing it in a third party type of scene, whatever, it would be, I think more easily absorbed, you know. (James' mother)

Some parents also communicated that it would be important to provide balance with role plays, training different types of situations and discussing the purpose and outcomes of roles plays to ensure that youth do not overtrain for a certain outcome and/or do not become overly frightened or desensitized to issues brought up in the drama exercises.

Cause you don't want them to be scared to go with somebody, especially if they're hurt, and they need help. You don't want them to be scared of everybody. So I don't know if role playing to that extent's really gonna help them. I think it might hurt them. Unless you tell them, you know what, one day we are going to

have a practice like the fire alarm. We're gonna see how we're gonna make out when that fire alarm goes off, where are you gonna go and how would you get outside? And do that. Say maybe on Thursday when you go to the store, something's gonna happen. You'd have to tell them. It just kinda depends what kind of degree that kid's operating at. And you would have to do that. You would have to tell them that this is gonna happen and we just wanna know if the situation as for real and it wasn't an exercise, to see if he could get out safely, exactly what you would do. (Charlie's mother)

*Natural opportunities for choice.* Some parents emphasized the effectiveness of providing youth with opportunities to practice making respectful and responsible choices in their everyday lives. While it was reported that all youth make personal choices with their families, two parents discussed the deliberate use of natural opportunities for practice. One parent suggested that this could be an effective technique with regard to making healthy food choices.

... Also giving them the choice of, putting certain things out on the table and giving them the choice of what they want to have. So they wanna have celery instead of carrots, or he'll want grapes instead of the apple, then it'll all be laid out for him. Cause, if you've got things in the cupboard, they won't go get it. It's like if you're peeling apples for an apple pie, you'll probably rip your mom's apples off all the time, but you wouldn't go peel your own. But if it was out there in front of them, I think that them seeing it, as well as them knowing that it's there, will help them better.... like putting them in a clear plastic bag instead of a

brown paper bag. They wouldn't think to look past that plastic bag, they wouldn't care. (Charlie's mother)

Lily's parents described how they regularly employ similar techniques in providing their children with opportunities to exercise responsible choice making skills in their daily lives. In the excerpt below Lily's mother explains her rationale for keeping bowls of candy out in the house.

Sometimes she can get into a lot of the sweets, so I tell her, you know, try to relax on the sweets and, you know, cause then you'll spoil your dinner and it's not always good to eat a lot of chocolate. I'm just trying to teach her that it can be there but kinda have some self control which is hard, it is, but you know I say, like, have one a week or whatever. Cause I want to teach them that you can have things out cause everybody does.... and everyday and they're growing up, like you know what I mean, like, and people have bowls all over their house, like candies out. And you don't have to eat it every second. It's just there for people to have when they come over, or even yourself, but you don't have to eat them all, you know, it's, it's self control too, ya, which you know, you can develop though, I mean, it's the same as, I'm trying to teacher her if you have money, you can't spend it all. It's nice to have and you really want this and that but put some way for next time, so then, when you do go you'll have some, you know, don't have to spend it all. If you start with something like that, self control, you can control other things too you know?... And that's the stuff there's never to young to start, like, I mean, that's why I have it out, and I tell Lily's brother too, don't eat a lot of it, once in a while and he'll come and he'll have one. Because you know, if, if you



don't expose it and you hid everything then when it is out they'll want it all at once, you know what I mean, so it should be out for people who are over.... No, I, I just think if you teach them little things like that it will help for down the road.

(Lily's mother)

As discussed above, compared to other youth participants, Lily reportedly makes more independent choices, is stopped from making choices less often, and her parents report more trust in her judgment. This suggests that, at least for Lily, the practice of providing opportunities for youth to make decisions and mistakes in the family home is effective in encouraging autonomous respectful and responsible choices.

*Convenience.* One parent stressed that a training program should be readily available and quick and easy to implement to ensure that it is actually used.

James' Mother: I think just keeping it like keeping it really simple and not like the game is great, but a game is a game you and ummm, for the point of what you're trying to teach like keeping the focus and the stress down and because computers are such a comfortable thing for many people with Autism or Asperger's or many other issues umm and options is nice and if you just have to push a button instead of actually having to do something, you know you may think and play around more with the scenarios. Then having to play a game where you're trying to win something, do something, there's a bit of a different focus. But I also like the cards too, because again it's just a simple.

Robyn: that would be neat too cause it could be something you could just pull out and then do a few and then put them away.

M: Well exactly, it doesn't have to be like 2 hours.

*Training the whole family.* Some parents indicated that a training program would be most effective if it incorporated the entire family. The rationale for including the entire family included: to ensure that all family members take responsibility and ownership for the training, thereby relieving mothers of the pressure that is typically placed upon them for implementing all training and programming, and/ or to ensure that the entire family has an understanding of the concepts and ways of thinking covered in the training program.

But it's just i it's overwhelming and I and I think you know I think something like this is needed, but it should be more inclusive of the whole family. And cause parents are burnt out. And like I said, the kids are only gonna take in whatever they're gonna take in, but at least have part and parcel of the whole process, you know.... I think my last point is just for everything that I have learnt over the past 11 years with dealing with this and the province and everything else, that it would be a nice change to instead of just training one person or whatever, m make it a whole family thing. You know don't, you know. And there's no reason why not to. There's no reason. So instead of putting the sole onus on one person or another, just it's all a group thing. Unless the person doesn't want it. If they wan it just solo then fine. But give the option perhaps. (James' mother)

Some of the other families did not state whether they would want a training program to incorporate the entire family.

### *Trainer*

Participating family members tended to stress the importance of a potential trainer's personality. It was generally emphasized that an ideal trainer would be someone

trusted who could connect and communicate effectively with youth. Different participants suggested that different people would meet these requirements. Some participants asserted that staff from an association that supports people with ID or staff from the 3Rs project would make an ideal trainer because “they’re really nice people so it would be kind of ok to learn from them” (James’ sister) or because such staff are perceived to be experts in the area. “Because who would know it better than (pause). You know what I mean than first hand because you’ve been training doing that and (the association)’s been trained...” (Lily’s mother).

Some youth identified specific people from outside the family home whom they know, respect, and have positive relationships with as potential trainers. Extended family members or family friends were recommended as ideal candidates to fill this role.

Because I cause I I just admire Aunt Lena and she admires me a lot and I think cause she raised three kids, three girls, and I really liked her, because she, we can actually connect. Cause we’re really emotional, we’re really like, same type of person. Or the other person I would choose, that’s my choice, is in Toronto which is mom’s best friend. In Toronto ya. She’s pretty cool, but she likes to keep it, you know, so I won’t get in trouble type thing. Ya she she’ll she, one time she tell me, “Oh, Lily if there’s anything you don’t want to tell your parents you should just tell me. I won’t say anything to your parents”. You know, “I’ll be your guardian angel or something like that”. (Lily)

Some parents similarly believed that someone from outside the family home would be an effective trainer, but did not identify the specific relationship that a trainer should have with the family. Parents suggested that someone from outside the family home would

make a good trainer because it would help to relieve parents of some pressure typically placed upon them and youth may be more likely to listen to someone other than a parent.

You know sometimes it's better for these kids to look at it from another aspect outside the home. I don't think the home environment is the best place for kids to learn things like that. Cause they learn so much anyway from the parents, they get to the point, pff I hate listening to you. But when they hear it from other people they seem to listen a little bit better. (Charlie's mother)

Conversely, citing the importance of having a close relationship with and knowledge of youth, participants from Jordan's family believed that Jordan's mother would be a good trainer if Jordan was to learn about making choices.

Robyn: Would you want your mom to teach you?

Jordan: Yes.

Robyn: You would want your mom to teach you?

Jordan: (nods)

Robyn: Maybe somebody else's mom who's taught their family about making choices. Would you want someone like that?

Jordan: No.

Robyn: You just want your mom?

Jordan: (nods)

Robyn: How come?

Jordan: Medical condition.

Jordan's mother also expressed that she would be a good trainer, but she communicated that any parent of a youth with a disability would be a good trainer.

I think a parent would be a good teacher because we understand our own kids but also too you could teach another one because you understand (pause) there's a certain kind of person that can deal with special needs people. So it has to be somebody, but it doesn't have to be somebody that's trained it's somebody that just can comprehend and accept and be there.

Other participants asserted that meeting with one or multiple family members from other families that include a youth with ID could be beneficial to discuss choice making issues and learn from one another and/ or to provide a social support or social network.

Well maybe like, if we had a group of families talk to each other about how they make decision, they could bounce ideas off each other and also if the kids actually had a say in it, not just the parents just gabbling on about how they could make their child's life worse or anything like that. If everyone in the family had their fair share of talking then that'd be nice. (James)

Despite some participants' interest in learning from or meeting with members from another family, other participants were not interested in meeting with other families and some participants did not state whether they would like to meet with other families.

## Discussion

### *Balancing Protection and Autonomy*

A key purpose of the current study was to build on Tardif-Williams et al. (2008) and Tarulli et al.'s (2006) analyses of choice making that takes place in families that include a youth member with ID by broadening the focus to include sibling, youth, and caregiver perspectives and by asking questions about specific choices that youth make

within the family. The findings derived from discussions with family members in the current study are similar to the results obtained in the *3Rs Project for Families and Family Home Providers* and other research investigating familial choice making when a family member has an ID (Almack et al., 2009; van Hooren et al., 2005). Similar to the findings in previous research, family members in the current study reported balancing a perceived need for youth to be protected from harm in various areas with youths' desire for independence or a recognized need to allow youth more independence.

Ya I can stop (choosing his clothes for him) (laughing). Um, I need to give him more independence on a lot of that stuff, but matching colours or that, that that's just not there. You know I'd have to make sure everything was the same colour.... Or if I give him a shirt and it's too short and he comes out, well he put on what I gave him. He will, he doesn't understand that if his belly's hanging out that's not a shirt that fits him anymore. And I have to make him go back and find a bigger shirt. And so the the getting dressed the concept that's not there...

(Jordan's mother)

One parent's narrative resounded particularly closely with Almack et al.'s observations that parents of individuals with ID are not only caught between a desire to protect and a desire to encourage autonomy for youths' own well being, but are additionally pulled in both of these directions by societal expectations of parents in general, and especially parents with children with ID.

You know, I used to think when he took off like that, what would, they, police officers think of me personally, trying to be his mom, knowing he's been gone that long and me out there searching for him. They'd go right, how come she

didn't know he was gone in the first place? You know what I mean? And that's not the truth because I knew where he was going, but I didn't know that he was going to continue to go. (Charlie's mother)

That parental expectations for youth are grounded in and influenced by societal expectations was also conveyed as parents explained that they often tried to influence or tried to stop youth from making choices that would be perceived as abnormal by others. This is consistent with previous research, which has repeatedly revealed that mothers of children with disabilities tend to take measures to ensure that their children appear to be "normal" (McKeever & Miller, 2004). McKeever and Miller interpreted mothers' tendencies to dress their children with disabilities in "normal" or fashionable clothes in terms of the low value that is typically afforded to people with disabilities, suggesting that mothers manipulate their children's appearance in an effort to signal their children's worth. With regard to the current study, parents' tendencies to protect youth from making choices that would mark them as different could be interpreted in this light. Parents explained that youth often experienced undesirable exclusion in social and educational realms because of their disabilities. Possibly, these parents concerned themselves with youths' physical and social presentations in an effort to have others recognize youths' value, thereby combating the consequences of social perceptions.

### *Interconnected Choices*

The idea that, in negotiating the tension between protection and autonomy, parents and siblings tried to guide youth to make choices that are normative, "right", or less potentially harmful is also in line with findings from the 3Rs project (Tardif-Williams et al., 2008; Tarulli et al., 2006). Themes of guidance also support previous

findings that, within the family context, the well being of all family members, conventions, and morals are considered throughout decision making processes. This means that decisions are never made in isolation and are rarely made with complete autonomy (Tarulli et al., 2006). Generally, results indicate that these interdependent decision making procedures apply to all family members, not just to youth with ID. When decisions affect multiple family members, all affected family members are reportedly included or considered in the decision making process. Additionally, while siblings reported guiding youths' decisions alongside parents, other family members acknowledged that parents sometimes persuade siblings to make choices that reflect family morals and conventions in instances when they are perceived to be likely to make choices that fall outside of these boundaries.

It's normally my sister who has a hard time with this choice because my parents are like "No, you can't wear that" well, I guess that's probably with a few other girls, but, well, with me it's just, "wear this, do whatever". (James)

Given the interconnectedness of family members and the care and concern that family members hold for one another, family members tend not to consider their rights in opposition to one another (Tarulli et al., 2006). Parents make choices for children, family members make choices together, and family members are guided in their decision making; all processes that are described as natural and normal. Nonetheless, analysis suggested that family members interfere more often with the choices of youth with ID than with those of other family members. Family members justified this interference by explaining that youth were more likely to make choices that fell outside of the bounds of



family conventions and values, and were thus in greater need of protection than their siblings who were not identified as having a disability.

### *Domains of Choice Making*

The assertion that choice making for youth with ID follows a generally typical yet more restricted pattern is further supported by research regarding adolescents, parents and specific domains of decision making. As found in families of non-disabled adolescents, participants in the current study reported that youth with ID make personal choices, such as what to eat for a snack, with considerable autonomy. Youth usually follow parental rules or wishes for acts that could be seen as conventional issues, such as doing chores (Smetana, 2000; Smetana & Asquith, 1994). Participants in the current study also communicated that parents hold and family members follow expectations for respectful behaviour. This suggests that findings from the current study are congruent with findings from previous research, which indicates that parents hold and family members follow expectations for items that are perceived to be moral issues (Smetana, 2000; Smetana & Asquith, 1994). It is not possible to draw definitive conclusions with regard to the moral domain, however, as the moral domain includes behaviours or intentions to harm others and transgressions such as lying, stealing, or aggressive acts, behaviours which participants in the current study tended not to explicitly discuss but which could be interpreted as falling under the umbrella of expectations for respectful behaviour. Also like non-disabled adolescents investigated by Smetana and her colleagues, family members in the current study communicated that they often make decisions together with youth with ID for issues that could be considered multifaceted, or overlapping the boundary between personal and conventional issues, such as keeping personal space tidy.

Additionally, parents in both the current study and Smetana's studies were found to regulate youths' actions in terms of perceived prudential issues, or issues concerning health and safety.

Although it appears as though both families that include an adolescent with ID and families that include a non-disabled adolescent follow the same general framework for choice making, familial reports in the current study indicate that youth with ID may make fewer independent choices than their non-disabled siblings did at the same age or currently do at younger ages. In other words, youth with ID are afforded a narrower range of personal choice, meaning that fewer choices are seen as legitimately subject to youths' control. This is similar to evidence that, compared to adolescents from European American families, adolescents from minority families are more restricted in what is perceived to fall under their personal domains (Smetana, 2000). Within minority families, adolescents make fewer choices and more issues are subject to parental control. It has been hypothesized that this may be because of a perceived greater need to protect minority youth. Lending credence to this hypothesis, parents in the current study sometimes explicitly stated that the reason that youth make fewer choices is because they are likely to make choices that could result in emotional or physical harm.

#### *Parent-Child Conflict*

Youth did not explain that they needed to be protected, but they did tend to convey an acceptance that they should follow parental wishes in areas that parents described youth as being in need of protection. The contention that youth with ID in the current study generally accept parental authority is supported in family members' discussions of conflict. It has been suggested that within family conflict occurs when

adolescents interpret an issue as personal and parents interpret the same issue as falling in a domain that is legitimately under parental jurisdiction (Smetana & Asquith, 1994). In the current study, parents and siblings reported no or very little conflict between youth and other family members, and only one youth participant consistently reported conflict and dissatisfaction with the independence he had in terms of choice making. This suggests that most youth in the current study endorsed parents' authority over the broad range of parental controlled issues. This finding should be interpreted cautiously, however, as the youth participant who described minor conflicts as consistently occurring over issues that his parents controlled was the only youth who was interviewed independently. If other youth participants had been interviewed without the presence of their parents it is possible that they would have expressed more conflict and dissatisfaction with regard to choice making opportunities in the family context.

While siblings did not acknowledge the existence of any real conflict, two of the parent-youth dyads did provide evidence that parent-child conflict occurred over prudential issues. During discussions about choices that youth have a difficulty making or wish that they could make, both parents prompted youth to discuss the conflict items, namely a desire to not take a vitamin and a tendency to travel far distances unannounced and unsupervised. Both youth avoided talking about these issues, stating that they did not feel comfortable or that they did not want to talk about the items. Possibly, this supports the hypothesis that youth would be more likely to discuss conflict if they were interviewed independently, without the presence of parents. Parents, however, did discuss the above mentioned items, communicating that parent-child conflict occurred

when youth did not or did not want to follow parental rules for prudential acts, or acts that parents felt were important in maintaining youths' health and safety.

... That's why she didn't want to bring it up, is to take a vitamin in the morning that's no choice, sorry, it's healthy, yeah, cause you don't always eat well and you know and being a teenager and women and everything else you go through in a month. Ever since they were little so, to me that's not a choice, no, but she's getting better but I know a couple times she refused and I said no you have to take it there's no choice in this matter, you know it's health, you know, she's a good eater, "I'm a good eater," yeah but it doesn't matter a vitamin has more in it too.  
(Lily's mother)

Lily's mother interprets the act of taking a vitamin as a prudential act, but her narrative implies that Lily may consider the decision of whether or not to take a vitamin a personal issue, suggesting that parent-youth conflict does occur over differing interpretations of issues (Smetana & Asquith, 1994).

### *Protection*

The finding that the one reported area where true conflicts arose was over prudential issues stands in contrast to findings reported by Smetana (1989; 1994), who found that adolescents and parents report relatively few conflicts as arising over prudential issues. She suggests that this may be because parents are less likely to know about youths' risky behaviour compared to other types of behaviours. It is possible that prudential conflicts may be more likely to arise between youth with ID and their parents because parents of adolescents with ID may have a heightened awareness of their children's risky behaviours. As discussed in the literature review, prevalent ableistic

and paternalistic attitudes and beliefs create an environment where compliance is highly valued for people with ID and people with ID are given more explicit directions instead of opportunities for independent decision making (Sobsey, 1994). The emphasis placed on compliance and instructions suggests that the behaviour of those with ID is highly monitored, more so than the behaviours of their non disabled peers or siblings would be. This is not to say that the parents of people with disabilities hold stereotypic views towards their children, but a pervasive belief that people with ID are incompetent and at risk, combined with a reported lack of social support and a belief that parents are solely responsible for ensuring youths' safety and well being (Almack et al., 2009) would likely foster an environment where close monitoring would be natural.

Additionally, ableism has contributed to a system where, not only are the actions of those with disabilities more closely scrutinized, but, when assessing competence or appropriate behaviour, people with ID are often held to a higher standard than people without ID (Davis & Watson, 2001). Therefore, parents may be more aware of youth with ID's risky behaviour because they are more likely to define youth with ID's behaviours as unsafe, while they may define the same behaviour as appropriate for someone without a disability. This is suggested in the following excerpt from a conversation with Charlie's mother, about the times when Charlie "took off" on his own.

Robyn: Oh wow that must have been scary.

Charlie's Mother: Ya especially when you know he works at a grade 1 level, you don't want him out. Especially one time he had no shirt on. Outside, middle of summer.

Although Charlie was 11 or 12 years old at the time, his behaviour was seen as riskier than it would be for many 11 or 12 year olds, as he is perceived to be “at a grade 1 level.”

### *Readiness for Independence*

Some parents repeatedly stated that youth were developmentally younger than their chronological age. “Um, the fact that he’s behind, he’s not age appropriate thinking in a lot of stuff” (Jordan’s mother). Other parents did not; when participating in member checking, James’ mother made a point to say that James does have the maturity level of same age peers, but that his maturity level may not always be recognized in interactions with others. This statement, however, still insinuates that James may be in greater need of protection, not because of his own “age appropriate thinking” but because of others’ reactions to his behaviour that strays from the norm, as discussed throughout the results section. The perception that youth with ID’s chronological age is not accompanied by the same developmental milestones as most youth of the same age or that milestones achieved by youth with ID may manifest themselves differently than they do for youth without ID may also partially account for the restricted range of choices that are afforded to them.

The content of adolescents’ personal jurisdictions, in terms of choice making, is culturally determined (Smetana, 2000). Typically, more items are defined as legitimately subject to youths’ control as they age, meaning that older, versus younger, adolescents tend to make more independent choices. As such, age has been found to be a powerful marker for the expectations and perceptions placed on people in general (Montepare & Zebrowitz, 1998). In the current study, however, age was not found to be a significant determinant of choices that youth were described to make independently, possibly

because youths' perceived personal characteristics were often cited as a barrier to choice making. This meant that Jordan, who at 18 years of age was the oldest youth participant, reportedly made fewer choices than the rest of the youth participants. If the zone within which youth make personal decisions is culturally defined, perhaps dominant conceptions of disability, which emphasize vulnerability and risk and employ a discourse where chronological age does not match the age of developmental abilities, negate the social markers that typically indicate when children and youth should be afforded increasing levels of independence. The tendency to seek markers other than chronological age does not need to be problematic, as youth may need to learn certain skills before they can do certain acts with a reasonable degree of safety. This finding becomes problematic, however, as people with ID are likely closely monitored and held to a higher behavioural standard than people without ID. Given the absence of cultural markers and the lofty behavioural standards set for people with ID, how will caregivers know when youth with ID can or should exercise more independence? This question should be addressed in training programs targeted at families and is something that is worthy of pursuit in future research.

This issue was partially addressed in some of the adaptations that families discussed using to facilitate youths' choice making.

But I know that we're planning on, when we sell this house, to buy like a duplex with a self contained apartment that we can get to to help him, to see what kind of transition he would need to be able to go on his own. Or, even if that, even if that's even a question, so. (Charlie's mother)

Charlie's family plans to provide Charlie with an opportunity to live semi independently, which would allow them to assess whether he would be able to eventually live on his own. Because Charlie's parents may not feel that Charlie has the skills needed to live independently at the age when most adolescents or young adults move out of their family homes, this tactic will allow them to use behavioural markers to determine when, or if, Charlie will be able to live away from his family. In a sense, Charlie's parents will be replacing cultural markers with their own assessments of Charlie's preparedness for independence in a specific area. Given that Charlie will be highly monitored in this stepping stone to autonomy, it would be relevant to examine how parents who use such techniques would determine readiness for independence. Most people are irrational decision makers, including 'typically developed' adults who are generally assumed to make competent and economical decisions (Jacobs & Klaczynski, 2002), meaning that, if anyone's living habits or decision making capabilities were closely scrutinized, it would be easy to find areas in which they could be more responsible.

Although developmentally normative milestones and corresponding increasing levels of independence are generally not applied to youth with ID in the current study, conversations with participating family members suggested that most youth tend to be very aware of "age appropriate" norms and tend to be highly motivated to follow these developmental expectations.

Umm, that bit about grade 12, what grade you're in. Last year he was 12. Well, he knows grade 12 you graduate (pause) but they're allowed to stay till they're 21. And then one day he came home, he goes, you graduate in grade 12 right? I says yes, in the United States. In Canada you go to 12B, 12C. I try to make it so he'll



understand why everyone else his age graduated and he didn't. He's very clued in on age appropriate. At 18 you're supposed to do this, at 17 you're supposed to do this. And he will not do it before, he will not do it after. Ya, I, I, I, it's a very distinct, like he will not. (Jordan's mother).

Perhaps a desire to present themselves as though they were reaching these desired, "age appropriate" levels of independence led two of the youth participants to state that they made more choices than their parents' or siblings' reports suggested. It may also be a driving force for some youths' desire for more current autonomy. "Like I'm a big boy, so I may wanna get up by myself and they stay in bed" (Charlie).

Most youth, in their desire for increased independence or their desire for "age appropriate" interactions with others either currently or in the future, communicated that they wanted to fill roles that they or their family members would value. According to social role valorization, people's perceptions of themselves or others are largely influenced by the roles that they are perceived to fulfill (Wolfensberger, 2000). The role of a person with a disability is typically afforded a low value, while the role of older brother, employee, or college student, roles that youth communicated a desire to hold, are typically afforded a higher value. As some youth indicated that these were roles that they were working towards or wanted to learn more about, this again justifies the use of a training program to teach youth about making choices that can enable them to fulfill personally and socially desirable roles.

### *Siblings' perceptions*

By seeking siblings' views of their experience having a sibling with a disability, the current study addressed an area where there exists a paucity of research. Sibling

perspectives are rarely examined (Stalker & Connors, 2004) and it appears as though siblings' perspectives on youth with ID and choice making has never been studied.

Although siblings were not specifically asked about their role in terms of their relationship with their brother or sister with ID, siblings volunteered information in this area, thereby contributing to the dialogue about the role and psychological well being of siblings of youth with ID. One recurring theme that emerged throughout sibling interviews was the concept that siblings accepted familial values espoused by parents. Entrenched in this belief set, siblings explained that they helped parents to encourage or teach youth to make 'good' choices and to implement adaptations to enable youth to make decisions. That siblings perceived themselves in a helping role is consistent with previous findings that indicate that the siblings of brothers or sisters with disabilities often take on a care giving role, even when siblings are younger than the family member with a disability, as was the case in the current study (Stoneman, 2005). Additionally, it has been suggested that siblings' views about a brother or sister with a disability are influenced by parents' attitudes and beliefs towards their child with a disability (McHale, Sloan, and Simeonson, 1986), possibly explaining why siblings helped youth in the manner deemed acceptable and important by parents.

The implications associated with this caregiving role have been the subject of some academic and professional debate. Siblings in the current study did not communicate negative feelings about their helping roles and they sometimes expressed interest and pleasure in helping youth in certain areas. In response to a question about who decides when James goes shopping, his sister said,

Me and my mom. Cause um, my mom is the one who tells him he needs to go get some longer pants or a new shirt or something. But I usually come cause I like to go shopping and I'm good at consulting with what works and what doesn't work, or the quality of something. So it's usually up to me and my mom cause he doesn't really care but he doesn't really want to do it.

In contrast, much of the early literature and some of the more recent literature concerning siblings of children or adolescents with disabilities has shown that siblings who take on a helping or care giving role are subject to a host of negative psychological consequences such as feelings of anxiety or guilt (Lamorey, 1999). More recent studies, however, have tended to yield more positive results, often finding little to no difference between siblings of disabled or non disabled youth or positive outcomes for siblings, such as increased empathy (Newman, 2002; Stalker & Connors, 2004; Stoneman, 2005). When siblings do experience negative outcomes, it has been suggested that they might be caused when family functioning in general is harmful or when they feel overburdened in their caring role. Conversely, when siblings are supported and recognized for their contributions they are more likely to perceive their jobs as necessary and shared with parents (Lamorey, 1999) and "children who develop high quality sibling relationships are able to acquire and enact roles that are pleasing to both children and that accommodate the siblings' disabilities" (Stoneman, p. 341, 2005). This may explain siblings' experiences in the current study. Parents, siblings, and youth described sibling-youth relationships in generally positive terms and descriptions of siblings' responsibilities could not be described as so burdensome as to classify them in the 'young carer' role that is associated with many negative outcomes. If family relations had been more stressful for participants

or sibling and youth participants had more hostile relationships, perhaps siblings would not have been found to be such willing helpers.

Most findings regarding siblings' perceptions are in line with findings from a Stalker and Connors (2004) study, one of the few identified studies examining the experiences of the siblings of children or youth with disabilities. While sibling-youth relationships were generally positive in the current study, they were not conflict free. Siblings, parents, and youth all reported that youth and siblings negotiate with each other, tease one another, and have minor arguments, as most siblings do (Stalker & Connors). Accordingly, despite acknowledging their guiding roles, siblings in the current study tended to describe their siblings with disabilities and their relationships with them as 'normal'. In both studies, youth with disabilities were more frequently described in terms of their personality characteristics than they were described in terms of their disability.

Despite siblings' depictions of normal youth and normal relationships, participants in both the current study and the Stalker and Connors (2004) study identified that youth were unable to do certain things or make certain choices because of disability. Disability and the perceived consequences of disability were not described in negative terms, however, and were rather stated as though they were simply facts of life. The sense that youths' disabilities and ensuing consequences are natural may partially explain why siblings in the current study did not conceive of youths' current levels of choice and independence as being problematic.

Siblings in Stalker and Connors' (2004) study did, however, identify others' negative reactions towards disabled youth as problematic. On the other hand, siblings in the current study hinted that others' reactions to youth may lead to decreased decision

making for youth, but did not make any conclusive remarks on this issue. As articulated by siblings themselves, this is likely because siblings did not attend the same school as youth and rarely saw them in public or social situations, meaning that siblings were unsure of youths' experiences outside of the family home. Possibly because they were more aware of youths' experiences outside the family home, youth, and to a greater degree, parents gave numerous examples of times when people, policies, and procedures presented barriers to equity, independence, and choice making for youth with ID.

### *Implications*

#### *Justification for a Choice Making Training Program*

The foregoing results provide further justification for the development and use of a choice training program for youth with ID and their families. Most obviously, parents and youth with ID both identified areas in which youth are currently stopped from making choices because of a perceived lack of skills and areas in which youth could learn to make choices, should be able to make choices, or want to make choices. Siblings, on the other hand, did not conceive of youths' current level of independence as problematic and did not forward any suggestions in terms of content that should be included in a rights or choice training program for youth with ID. This, however, does not detract from the relevance of a training program, but rather points to the next reason why a training program is justified. Youths' personal domains are culturally defined (Smetana, 2000), and are determined by family morals and conventions. In a system where youth with ID are often perceived as functioning at a lower developmental stage and as having a corresponding greater need of protection, they will not have as many decision making opportunities. The use of a training program to open up discussion about and exploration

of youths' interests in making choices and ability to make choices may prompt reevaluation of the range of decision making options that should or could be available to youth. In this way, a training program could lead to a new consideration of youths' capabilities and best interests, potentially enabling all family members to see previously unconsidered abilities and possibilities for independence. Finally, as alluded to in the second point of justification for a training program, families' experiences are influenced by external pressures, policies, and practices that structure decisions that youth with ID can make both internally and externally to the family home. Opportunity for discussion of and experience with choice making would not only allow families to renegotiate practices within the family home, but could also help families to question practices and advocate for youth outside of the family home. While parents already described doing so, this would be especially relevant for siblings, who were generally unaware of choice making barriers external to youths' personal characteristics, and for youth who were described as needing to learn to self-advocate. This is not to say that siblings, who conveyed the perception of youth in a normal light, and youth, who communicated being generally content, should participate in a program designed to teach about the current negative impact of disability on participation. Rather, it is to say that through discussion and practice youth and siblings could become aware of more opportunities for choice, some of which they may have to advocate for. As some youth already described self-advocating or advocating for specific choices, this is not an unreasonable expectation.

#### *Training Program Purpose*

Thus, based on literature and participants' accounts, it is proposed that the overall purpose of a training program should be twofold:

1. To enhance familial understanding of:

- a) youths' choice making abilities and desires
- b) possibilities for overcoming barriers to choice making, both internal and external to the family home.

2. To help youth learn skills needed to make choices that they want to make.

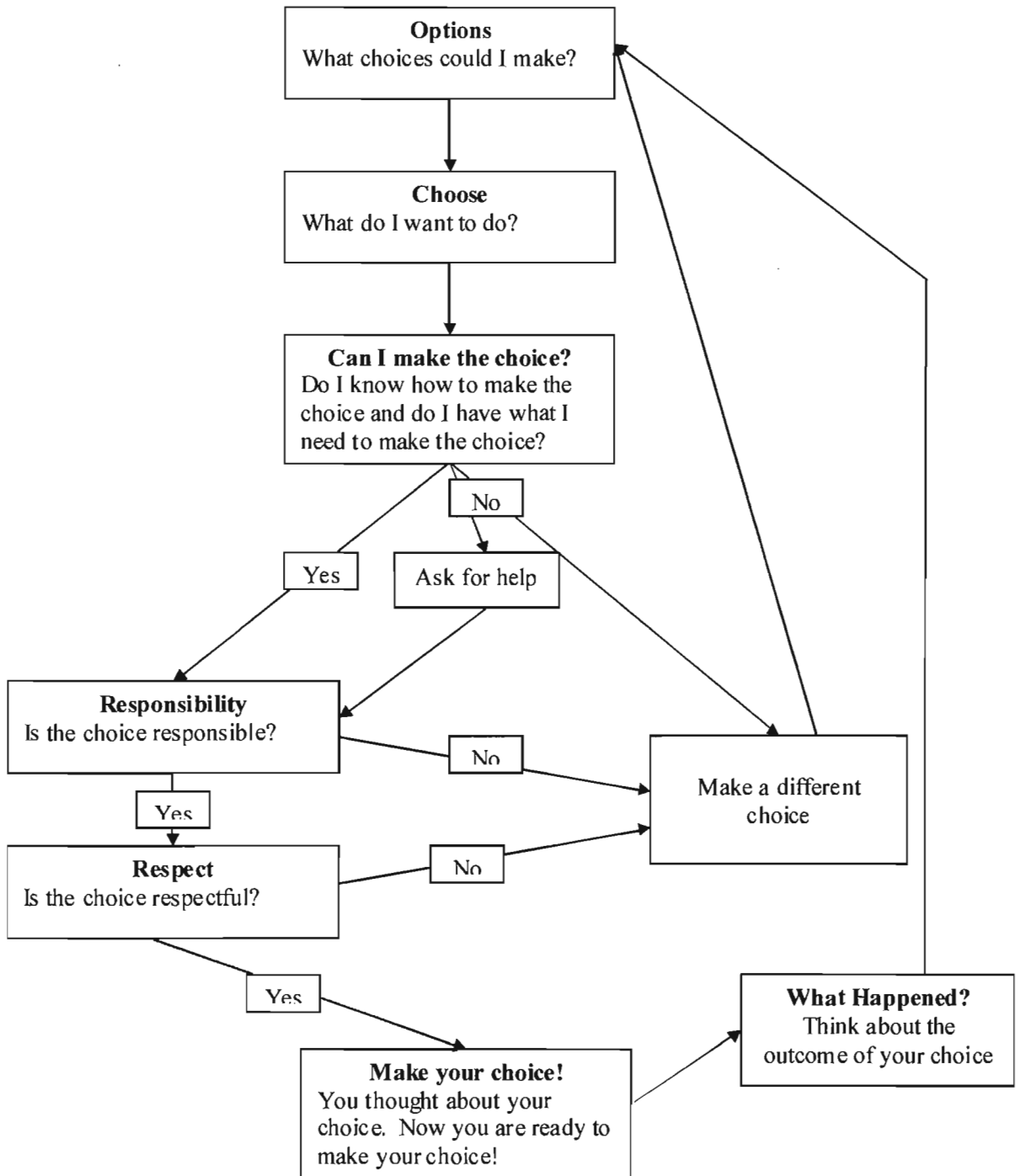
In pursuing these goals, it is hoped that a training program could result in the expansion of youths' personal domain and could open family discussion and consideration of youths' readiness for new levels of independence and valued roles.

### *Training Program Structure*

As specifically mentioned by some and alluded to by all participants, to be effective a training program should address the unique objectives, interests, abilities, beliefs, and learning styles of individuals and families who will be using the training program. It was also suggested by one parent that a training program would need to be convenient and easy to implement to ensure that it was actually used by families. To allow for flexibility, it is suggested that the core feature of a training program be a standard decision making procedure that would be taught and practiced by all participants. The proposed decision making procedure is shown in Figure 1. The decision making procedure could be learned and applied in a multitude of ways and would therefore meet training program goals while addressing the individual needs of different families.

The following example, showing the thought process for the choice of what to do after school, demonstrates how the procedure depicted in Figure 1 may be applied to any decision. The process begins at the top with the first question, *What are my options?* Responses could include: *I could do my homework, I could watch TV, or I could go to the*

Figure 1. Flowchart depicting decision making procedure.





*store*. Having answered the first question, the arrow is followed and the second question is considered, *What do I want to do?* Choosing from one of the three options, it is decided that *I want to watch TV*. Following the arrow, the questions in the third box are posed. *Do I know how to make the choice and do I have what I need to make the choice?* The answer here could be, *yes, I know how to use the TV* and *yes, I can use the TV because no one else is watching it right now*. Because the answers were *yes*, the *yes* arrow on the left side of the chart would now be followed to the question *Is the choice responsible?* *Yes, the choice to watch TV is responsible because I have no homework tonight*. Again, the *yes* line would be followed to next question, *Is the choice respectful?* *Yes, the choice to watch TV is respectful because nobody else is in the TV room, so I won't be bothering anyone*. At this point, the *yes* line would be followed to the final box, where the decision would be made and carried out.

Alternatively, the path through the flowchart would have been different had the answer to any one of the questions been *no*. For example, if the answer to *Do I know how to make the choice and do I have what I need to make the choice?* was *no, I do not know how to turn on the television*, it would have been necessary to choose between the two *no* lines and either make another choice or ask for help. If the answer to either of the respect or responsibility questions was *no*, then the *no* lines would again be followed, indicating the need to make another choice.

The feedback loop, pointing from the final *Make your choice* box to the *What happened?* box to the beginning *Options* box, is included in recognition of the importance of reflection about the outcomes of decisions. After making choices during training or in real life, youth may be encouraged to consider and/or discuss the consequences of their

decision. In turn, the outcomes of youths' decision may affect their perceived options and the perceived respectfulness and responsibility of the options the next time a decision is made.

In this manner, the choice making guideline could be applied to any choice that family members want to learn about or discuss. Such an approach would not only be beneficial due to its adaptability, literature on teaching complex skills suggests that teaching a generic procedure that can be followed to solve everyday complex problems could be effective. As discussed in the literature review, Sievert, Cuvo, & Davis (1998) successfully taught adults with disabilities a series of steps to follow to assert their rights and redress rights violations. Additionally, it has been stated that adolescents in general would benefit from learning metacognitive strategies to enable them to make 'good' decisions when they would otherwise be prone to making 'poor' or risky ones (Jacobs & Klacsynski, 2002).

The choice making framework also addresses issues brought up during interviews with family members. Including the option to *ask for help* ensures that youth will have opportunities to learn skills needed to be able to make specific choices. Also, the necessity of making respectful and responsible choices was included to reflect the nature of rights, or more personally and softly stated, autonomy or choice, in the context of the family. "... Children... dwell in a tangled web of reciprocal responsibilities, strong emotional ties and conflicting aspirations. In short, they live in families, social entities that are not easily deconstructed by the individualistic thrust of human rights discourse" (Newman, p. 619, 2002). As suggested by Newman, the 'us versus them' mentality invoked by the discourse of rights is relevant in the public sphere, but makes little sense

for interactions that take place within a family (Freedom & Weijer, 1999; Tarulli et al., 2006), where pitting individuals' rights, preferences or decisions against one another would be both unnatural and unproductive. Family members in the current study described caring for and protecting youth with ID as well as working within the limits of familial norms and values to promote and enable choice making for youth. These family processes should be both built upon and acknowledged. The respect and responsibility components were included to ensure that the bounds of familial norms and values, while they may be questioned and stretched, are acknowledged and respected throughout the training process.

Parent participants consistently promoted the value of safety and protection. As discussed throughout the results, this was because youth were perceived as being at a greater risk of making unsafe decisions or being taken advantage of by others. The responsibility component specifically addresses the importance of safety, as part of being responsible is making decisions that are safe, a tenet that should be emphasized throughout the training program.

#### *Training Program Procedure*

Before the procedure can be used, foundational concepts needed to meaningfully follow the decision making steps should be established, as foundational concepts are taught in the 3Rs rights training program for adults. The concepts that *rights means being able to make choices about our lives* and that *making a choice or a decision means being able to pick something about our lives* should be introduced and understood. While the proposed training program will focus on choices, the concept of rights should be taught to introduce the idea that everyone has the right to make choices and decisions

about their lives. Once this notion is established, the focus will shift to making choices in respectful and responsible ways to reflect the interdependent and value laden nature of rights, or choices in the family. Therefore, the meaning of respect: *respect comes along with making choices. It means thinking about your choices and how they make you and other people feel*; and responsibility: *responsibility comes with making choices. It means answering to yourself or someone else for the choices that you make* should also be taught. As in the 3Rs training program for adults, these concepts should be taught with the use of definitions and examples.

After the core concepts and the relationships between them are understood, the choice making procedure can be introduced. For both the concepts and the choice making procedure, a variety of instructional options should be made available to participants. Concepts and procedures could be taught by a rights trainer, by a parent in the participating family, by a parent from another family that has participated in rights training, through the use of role play scenarios, flash cards with sample scenarios or discussion items, a video, or a video game. Different participants in the current study expressed interest in different training options, meaning that having multiple options available would ensure that all families participating in training may feel comfortable and all participants' learning styles may be met.

It is recommended that a more visual, straightforward diagram be used to teach youth the choice making procedure. For example, as the procedure entails five questions that must be answered or preconditions that must be met to make a choice, the visual of a hand could be used, with one question or precondition written and illustrated in each finger. Youth could also be taught to hold up one finger as the corresponding step is

completed, meaning that they will be able to make the choice when they have all fingers out. In this way a tactile prompt, that youth could use when making decisions in the absence of the visual, could be incorporated.

Youth with ID and families should have ample opportunities to practice using the choice making procedure. All interested families would ideally be provided with a choice training kit, from which they could choose choice training components that suit their specific needs. As with the introductory training components, the kit could include practice opportunities in the form of discussions, role plays, videos, or video games. Training sessions could be led by a parent, a parent of another youth with ID, a rights trainer, or could be self-directed. Each option should include choice making scenarios, options for families to create their own choice making scenarios that they see as important to discuss or practice, and options for youth to practice or discuss choices that they want to be able to make. The choice making procedure should be followed during all training sessions.

The training program kit should also include suggestions for ways that the choice making procedure could be incorporated into everyday life, a recommendation that stems from both participant suggestions and previous research. As discussed in the results section, some parents in the current study emphasized the importance of purposefully allowing youth to practice making decisions in real situations. Similarly, having opportunities to make choices in everyday life was found to be an important component in successful programs teaching self-determination to children and youth with disabilities (Karvonen et al., 2004). If families display the choice making visual in key areas around the house, it can be referenced as youth work through everyday decisions.

As choices made within a family setting are interconnected and made relationally, it is recommended that all family members participate in at least some aspects of training. The importance of a systemic approach to rights, or in this case choice, training (Sobsey, 1994) was discussed throughout the literature review. In fact, Karvonen et al. (2004) found that self determination training, often taking the form of decision making training, was found to be more effective when a culture of self determination was fostered and when teachers and parents had consistent expectations for children and youth. Through the proposed training program, it is hoped that a culture where individual desires and opportunities for decision making will come to be valued as family members take part in the training program together. If family members develop an awareness of choices that youth with ID can and want to make and ways that they can be supported in making them, consistency and opportunities that are important in generalizing choice making skills may be fostered.

Karvonen et al. (2004) also found that decision making skills were more readily learned when they were not only consistently applied in one setting, but when they were applied and supported across settings, specifically at school and at home. Thus, the proposed choice making framework and associated activities should ideally be implemented in multiple arenas of youths' lives. If the framework was understood and utilized at school, at the community organization that supports youths' families, and anywhere else where participants spend substantial amounts of time, youth could be consistently supported in their attempts to make choices. Engaging the broader systems within which youth interact would help ensure that youth will be supported as they

attempt to make choices internally and externally to the family system, thus avoiding feelings of frustration or powerlessness (Sobsey, 1994).

### *Limitations and Future Research*

#### *Training Program*

The training program itself has two key limitations. Allowing for flexibility and working within family norms and values is at once a necessity a strength and a weakness of the proposed training program. It is hoped that, in discussing and practicing decision making, familial bounds will stretch to allow for the consideration of a broader range of possibilities for youth with ID to make choices. At the same time, a stretching of youths' personal jurisdictions may be more likely to occur in families that already value choice making and autonomy, meaning that the training program may not enable any meaningful choice making for youth if it is used in families where overprotective values may be the norm. This weakness is inescapable because, just as youth have the right to make choices, family members have the right to embrace any morals or parenting approach that they wish to, providing that they are not abusive. As such, the interconnected nature of choices and rights in the family means that family members tend to look out for one another's well being but family members are also necessarily affected and constrained by dominant familial beliefs. This first limitation, however, may be somewhat irrelevant due to another limitation. Any family that would encourage the use of a choice training program is likely not a family that would be opposed to choice making for youth with ID. This implies that families who could most benefit from engaging in dialogue about choices will likely choose not to do so.

Another limitation is that the proposed training program does not address the major external barriers to choice making that were brought up by so many participants. There are benefits to attempting to open up new possibilities for choices within the family and it is possible that youth will carry an increased facility and confidence with choice making into their interactions with the public. Family members, however, already seemed to value youth and perceive youth as 'normal' and most youth seemed relatively comfortable advocating for themselves within their family. On the other hand, reports revealed the existence of exclusionary policies and practices that colour youths' social and educational experiences external to the family. These identified community restrictions may possibly serve as a limitation to the potential generalization of the training outside the family setting.

### *The Study*

Procedures used in the current research also present several limitations. As previously mentioned, most youth were interviewed in the presence of at least one parent. Parental presence was sometimes helpful. Because of their close relationships with youth, parents easily explained difficult questions and provided prompts when youth were unable to think of responses to questions. On the other hand, parental presence may have affected the nature of some of youth's responses; supporting this hypothesis, youth sometimes looked at parents to question whether they were allowed to convey certain information, especially information regarding instances when parents may have stopped youth from making a choice. When conducting future research in this area, it would be beneficial to interview youth independently.



While participants from four families were interviewed, only two siblings participated in the study. Having more sibling participants would have resulted in access to a broader range of experiences and therefore a more comprehensive understanding of siblings' perceptions. Future studies in this area should involve the recruitment of more sibling participants, especially as their perspectives seemed markedly different from youth or parent's perspectives.

Family support workers recruited families to participate in the current research. Support workers purposely contacted families whom they thought would be interested in participating in a study about rights and choices. After being contacted, participants were able to decide whether or not they wished to volunteer to participate in the study. Knowing that the current study concerned youth with ID and choices, it is unlikely that highly controlling or abusive families would be recruited or would volunteer to be interviewed. Thus, the current sample was probably biased in terms of the quantity of choices and independence available to youth participants. Results from the current study should be interpreted with this in mind, as it is likely that participant experiences represent more openness and independence than may be typical.

The sample is also biased because, as criteria for participation, all youth had to be able to communicate verbally and understand both the assent procedure and the interview questions. It is probably easier for youth who are able to complete such tasks to assert their independence than it would be for youth who have more difficulty with such tasks. This is a point worthy of consideration in future studies. Choice making procedures for youth who use limited verbal communication should be examined.

Due to temporal constraints, the participant sample presents another limitation. In an attempt to understand how choice making in youth with ID compares to that of non-disabled youths' choice making, reports of youths' experiences were compared to reports of siblings' experiences and previous research about choice making for adolescents in general. While this approach garnered useful data, the study design would have been stronger if a typically developing comparison group had been included. To gain further insight into the experiences of youth with ID compared to same age peers without ID future research should include a comparison group of matched families that do not include a member with ID.

As stated above, the experiences of youth with ID in the current study were compared to the experiences of non-disabled adolescents who participated in research about domains of decision making (Smetana, 2000; Smetana & Asquith, 1994). While Smetana's domains provided a useful framework for comparison, the data gathering and analysis methods used in the current study differ from the methods used in research conducted specifically on decision making domains. To further investigate the manner in which domains of choice making apply to youth with ID, Smetana's data collection and analysis methods should be applied to families that include a member with ID.

In addition to directions already suggested for future research, a logical next step for the research agenda on choice making for youth with ID in the family context would be to develop, implement, and test a choice training program for youth with ID and their families. Doing so would allow researchers and families to determine the effectiveness of choice training for youth with ID in the family context and to further refine the choice training process.

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## Appendix A

**Interview Guide: Parents***Introduction – Background Information*

I want to start by letting you know a bit more about the project that I am working on. The study that I am doing is a part of the 3Rs project, which stands for Rights, Respect, and Responsibility. For the 3Rs project, researchers from Brock and staff at community associations (such as Community Living Welland-Pelham), have been developing and testing a rights training program for adults with ID. The rights training program uses a board game and aims to teach adults with ID how to assert their rights in respectful and responsible ways.

For my project, I am looking to interview families to discover information that will help researchers create a rights training program for families that include a child with ID. The goal of the rights training program would be to help families to teach youth with ID to understand their rights as they enter into adulthood. To do so, a rights training program for youth with ID and their families would likely focus on making choices in everyday life. Everyone makes choices and I understand that the choices that people make and the way that they make them change over time and with age. I am conducting interviews because I want your input about what should be included in a rights training program for youth with ID and their families.. I want to find out from you what sorts of issues you think would be important to include in a training program about choices. I want to learn about choices that \_\_\_\_\_ makes and about areas that you think that \_\_\_\_\_ might be able to make choices more effectively, respectfully, and responsibly. This information will help me know what to include and what not to include in the rights training game.

I want to remind you that your participation is voluntary. If you feel uncomfortable or if you do not wish to continue for any other reason, you can pass on any question and you are free to stop the interview at any time without penalty.

Do you have any questions before we begin?

*Demographic questions*

I am going to begin by quickly asking you some general questions about you and your family.

What is your full name?

What is your child with ID's full name?

What is your relationship to \_\_\_\_\_ (e.g. mother etc.)

How old is \_\_\_\_\_?

What grade is \_\_\_\_\_ in?

How many people live in your family home?

How are they related to \_\_\_\_\_? (e.g. 1 sister, 1 grandparent, 2 parents)

How old are \_\_\_\_\_ siblings?

### *General Choice Questions*

Thank you very much. Now, I am going to ask you about the choices that \_\_\_\_\_ makes with your family.

\*\*\*\* Note: Italics are prompts that can be used if necessary.

\*\*\*\* Items can be changed, elaborated on, or clarified if necessary. Items can be removed if they have been answered by previous questions.

What choices does \_\_\_\_\_ make in his/ her everyday life?

Can you describe a time when \_\_\_\_\_ made an everyday choice?

- *for example the last time \_\_\_\_\_ chose what to wear, what to take for lunch, what to do with a friend, what music to listen to, how to decorate his/ her room etc.*

Are there any choices that \_\_\_\_\_ has difficulty making? If so, which ones?

- *Why do you think that these choices may be difficult for \_\_\_\_\_ to make?*
- *Can you think of any specific changes that could make these choices easier for \_\_\_\_\_? (e.g. practice letting others know opinion, allowing more time to make these choices, increased awareness of the right to make choices etc.)*

Can you describe a specific time when \_\_\_\_\_ had difficulty making a choice?

How does \_\_\_\_\_ let people know what he/ she wants?

Are there times when it is easy for \_\_\_\_\_ to let people know what he/ she wants?

- *What about these choices or situations makes it easy for \_\_\_\_\_ to express what he/ she wants.*

Can you describe a time when it was easy for \_\_\_\_\_ to let someone know what he/ she wanted?

Are there times when it is difficult for \_\_\_\_\_ to let people know what he/ she wants?

- *what about these choices or situations makes it difficult for \_\_\_\_\_ to express what he/ she wants?*
- *Can you think of changes that would help make it easier for \_\_\_\_\_ to express what he/ she wants?*

Can you describe a time when it was difficult for \_\_\_\_\_ to let people know what he/ she wanted?

Is \_\_\_\_\_ able to make choices as much as his/ her brother/ sister?  
If no, why not?

- Is there anything that stops \_\_\_\_\_ from making choices?
- *E.g. personal characteristics (e.g. shy etc.), factors in the community, safety concerns etc.*
  - *Can you tell me about a time when (factor that stopped choice making) stopped \_\_\_\_\_ from making a choice?*

Are there any choices that \_\_\_\_\_ cannot or does not make for any reason?

- *why or why not? (environmental reasons, social reasons, personal reasons)*

What would need to change so that \_\_\_\_\_ could make more choices?

- *What would help to remove some of the barriers, restrictions, or things that stop \_\_\_\_\_ from making choices?*
- *For example, \_\_\_\_\_ would be able to make more choices about what to eat if \_\_\_\_\_ made healthier choices,*

*\*\*\*\* If the issues of rights, respect and responsibility have not come through naturally in the answers to the above questions, ask the following respect and responsibility questions*

Do you feel that \_\_\_\_\_ makes choices respectfully? Taking his/ her feelings and the feelings of others into account?

Can you describe a time when \_\_\_\_\_ made a choice respectfully?

Can you describe a time when \_\_\_\_\_ had a hard time making a choice respectfully?

Do you feel that \_\_\_\_\_ makes choices responsibly?

Can you describe a time when \_\_\_\_\_ made a choice responsibly?

Can you describe a time when \_\_\_\_\_ had a hard time making a choice responsibly?



Do you feel that \_\_\_\_\_ knows that he/ she has the right to make choices?

Is there anything that stops \_\_\_\_\_ from having the right to make choices?

- *e.g. can \_\_\_\_\_ access the same activities in the community as his/ her brother/ sister or as other children; does \_\_\_\_\_ have the same choices at school as his/ her brother/ sister or as other children?*

Can you describe a time when something stopped \_\_\_\_\_ from having the right to make a choice?

\*\*\*\*

Can you describe how everyday decisions are made in your family?

- *everyday decisions include things such as what to wear, what to do during free time etc.*

Can you give an example and describe how a recent everyday decision was made?

Are there any decisions that you think would be important to include in the rights training game? Any specific choices that you think it would be important for \_\_\_\_\_ to practice making respectfully and responsibly?

### Specific Choice Questions

Now I am going to ask you about specific choices, ones that are made with your family and ones that \_\_\_\_\_ may make on his/ her own.

For \_\_\_\_\_, can you describe how the decision of what to wear is made?

What are specific aspects about this choice or specific scenarios that you feel would be helpful to include in a game about making respectful and responsible choices?

- *for example, do you think that it is important for \_\_\_\_\_ to practice politely letting someone know if there is something he/she does not like to eat while at a friend's house? Do you think that it is important for \_\_\_\_\_ to practice negotiating with other family members when deciding what to watch on TV?*

\*\*\*\* repeat this question after each of the following questions.

For \_\_\_\_\_, how is the decision of what to take for lunch made?

Can you describe how the decision of what to eat at other times of the day is made?

For \_\_\_\_\_, can you describe how the decision of who to spend time with is made (e.g. friends, family members etc.)?

For \_\_\_\_\_, can you describe how the decision of what activities (e.g. sports clubs) to join is made?

For \_\_\_\_\_, can you describe how the decision of what to do during free time at home is made?

When various family members are participating in an activity together, such as watching TV or playing a game, can you describe how the decision of what to play or to watch is made?

### Final Questions

Now I will ask you some final questions to see if there is anything that has not been mentioned that you think would be important to include in a game based training program that helps teach how to make choices respectfully and responsibly.

Are there any specific choices that have not been mentioned that you think would be important to include in a rights training program?

- *are there any choices that you think would be important for \_\_\_\_\_ to learn about that we have not talked about yet?*
- *why do you think these choices are important to learn about?*

Are there any specific scenarios that have not been mentioned that you think would be important to include in a rights training program for youth with ID and their families?

*- For example, if \_\_\_\_\_ often fights with his brother/ sister when deciding on a movie to watch, you might think that it is important for \_\_\_\_\_ to practice choosing a movie with another person. If \_\_\_\_\_ always gives his dessert away to other students at school but would really rather keep it himself, you might think it is important for \_\_\_\_\_ to practice asserting the right to choose to eat his/ her own lunch.*

Are there any specific skills that you think should be included that would be helpful in learning to make respectful and responsible choices?

*- For example, choosing appropriate clothes for the weather, choosing to watch TV only after homework is complete, staying calm if somebody has a different opinion about what game to play etc.*

The 3Rs rights training for adults consists of a boardgame format that involves video scenarios, role plays, and verbal scenarios about rights, respect, and responsibility. Another version of the rights training program used an interactive computer game format for which participants watched scenarios, answered questions about the scenarios, and received feedback, all on the computer. Do you think that any of these formats/ techniques would be helpful for teaching about rights with families?

- *can you think of any other training formats that might be effective for use with your family or other families?*
- *Why do you think that these formats would be effective?*

We are thinking of using role play, puppets, and verbal scenarios as ways of practicing making choices respectfully and responsibly in different situations. Can you think of any other teaching methods that should be included in the training program?

If your family was participating in a rights training program, who would you like to lead the rights training sessions?

- *would you prefer other parents who have a child with ID to facilitate the rights training program? Would you prefer to have rights educators from the association lead a rights training program? Or, would you prefer to have a combination of people lead rights training sessions? Or, would you prefer to have someone else lead training sessions?*
- *Why would you most like \_\_\_\_\_ to lead rights training sessions?*

Thank you so much for your help. The information that you gave will be a big help when we develop the game. If you think of anything that you would like to add to your comments, feel free to contact me and let me know! Also, if you have any other questions at any time I would be happy to answer them.

## Appendix B

**Interview Guide: Youth with ID**

I want to start by letting you know more about the project that I am working on. I am trying to find out information that can be used to make a rights training program that can be used by youth with ID and their families. The training program will have questions and activities that will help youth with ID to practice making choices in respectful and responsible ways. Do you know what respect means? (If no – it means thinking about your choices and how they make you and other people feel). Do you know what responsible means? (if no- (comes with making choices) it means answering to yourself or somebody else for the things that you do and the choices you make. E.g. If you are supposed to meet your friend, it is responsible to tell them if you can't meet them anymore. If it is cold outside it is responsible to wear clothes that will keep you warm like a coat and a hat. If you borrow money from a friend it is responsible to pay your friend back before you spend money on candy etc.)

I want to interview you and your family so that you can help me find out what would be important to put in a rights training program. I want to know what choices you make and what choices you think that you could use more practice making. The information that you give me will help me to know what sorts of choices would be important to put in a rights training game.

I want to remind you that your participation is voluntary. This means that you can stop the interview at any time or you can decide not to answer any question that you don't want to answer. If you feel uncomfortable, you should let me know and you can skip the question that makes you uncomfortable or you can stop the interview. If you do this, you will not be in any trouble and nothing bad will happen to you.

Do you have any questions?

Demographic questions

I am going to begin by quickly asking you some quick questions about yourself.

What is your full name?

How old are you?

What grade are you in?

General Choice Questions

Thank you! Now I am going to ask you questions about choices that you make with your family.

\*\*\*\* Note: Italics are prompts that can be used if necessary.

\*\*\*\* Items can be changed, elaborated on, or clarified if necessary. Items can be removed if they have been answered by previous questions.

Do you know what rights are?

Rights means being able to make choices about our lives. Everybody makes choices. What choices do you make when you are with your family?

- *at home?*
- *everyday?*

Can you tell me about a time when you made a choice?

If you want something, how do you let people know? How do you let people know what your choice is?

- *e.g. how do you let someone know if you want to wear your favourite shirt, how do you let someone know if you want to play a game with them, how do you let someone know if you want to go to your friend's house?*

When is it easy for you to let someone know what you want?

Can you tell me about a time when it was easy for you to let someone know what you wanted?

When is it hard for you to let someone know what you want?

Can you tell me about a time when it was hard for you to let someone know what you wanted?

Sometimes it is easy to make choices. When is it easy for you to make choices?

- *what choices are easy for you to make?*

Can you tell me about a time when it was easy for you to make a choice?

Sometimes it is hard to make choices. When is it hard for you to make choices?

- *What choices are hard for you to make?*

Why do you think these choices are hard to make?

Can you tell me about a time when it was hard to make a choice?

Are you ever stopped from making a choice? When?

- *Are there choices that you are not allowed to make?*
- *Are there choices that you wish you could make but you can't? Why can't you?*
- *Are there choices that you can't make that you do not want to make? How come?*

Can you tell me about a time when you were stopped from making a choice?

\*\*\*\* *If the issues of rights, respect and responsibility have not come through naturally in the answers to the above questions, ask the following respect and responsibility questions*

Making choices respectfully means thinking about your own feelings and the feelings of other people. Do you think that you make choices respectfully?

Can you tell me about a time when you made a choice respectfully?

Can you tell me about a time when you had a hard time making a choice respectfully?

Making choices responsibly means answering to yourself and other people. Do you feel that you make choices responsibly?

Can you tell me about a time when you made a choice responsibly?

Can you tell me about a time when you had a hard time making a choice responsibly?

\*\*\*\*

### **Specific Choice Questions**

Thank you! Now I am going to ask you some questions about how some different choices are made in your family.

Can you tell me about how you choose what you are going to wear everyday?

Is there anything that would help you to choose what to wear?

- *for example, would it help you to practice choosing clothes that go with the weather (e.g. boots in the winter, T-shirt in the summer?)*

Can you tell me about how you choose what to take to school for lunch?

Is there anything that would help you choose what to take for lunch?

Can you tell me how you choose what to eat at other times of the day?

- *snacks*
- *breakfast*
- *dinner*

Who do you like to spend time with? Can you tell me about how you choose who to spend your time with?

Is there anything that would help you choose who to spend time with?

Do you play any sports? Do you belong to any clubs? Do you do any other activities?  
Can you tell me about how you choose what sports/ clubs/ activities you join?

Is there anything that would help you choose what activities/ sports/ clubs to join?

What do you like to do when you have free time? Can you tell me how you choose what you do during your free time?

Is there anything that would help you to choose what to do during your free time?

Does your whole family ever do an activity all together (e.g. watch TV, watch a movie, go to a restaurant, play a game etc.)? Can you tell me about how your family chooses what \_\_\_\_\_ (movie to go to, game to play etc.)?

### **Final Questions**

Thank you! Your answers are a big help. I have a few more questions for you. I am going to ask you some questions to find out if there are other choices that you think are important to learn about.

Are there any choices that we have not talked about that you would like to be able to make or to learn more about?

Is there anything else that you would like to learn about that would help you to make choices?

When we teach adults about rights, we use a boardgame that has videos and uses talking and acting to help adults learn about and practice making choices. Do you think that these sorts of things would help you to learn about how to make choices respectfully and responsibly?

- *why?*
- *Can you tell me more about how \_\_\_\_\_ would be helpful?*

Another way that researchers have taught adults about rights is by using a video game for which the adults watch a video on the computer and answer questions about the video on the computer. Do you think that a computer program could help you to learn about choices?

- *Why?*
- *What would a useful computer program be like?*

Can you think of anything else that might help you to learn about making choices?

- *e.g. puppets, pictures etc.*
- *What helps you to learn new things at school (e.g. watching a friend, someone helping you etc.) or at home?*

If your family was going to learn about choices and rights all together, who would you want to be your teacher?

- *A rights teacher, a mom or dad who has a child with ID, somebody else?*
- *Why do you think \_\_\_\_\_ would be a good teacher for you and your family?*

Thanks again for all of your help. The answers that you gave me will help give me information that can be used to make a training program that is useful! If you think of anything else that you want to tell me or if you have any questions, please let me know.



## Appendix C

*Interview Guide: Siblings*

I want to start by letting you know more about the project that I am working on. I am working as part of a bigger project, the 3Rs project. For the 3Rs project, researchers are using a board game to teach adults with ID about their rights. I am interviewing families to find out information that will help us make a training program that will help teach youth with ID and their families about rights. The game will have questions and activities that will help youth with ID to practice making choices in respectful and responsible ways. This is important because everyone has the right to make choices.

I want to know what choices \_\_\_\_\_ makes and what choices you think that \_\_\_\_\_ could use more practice making. The information that you give me will help me to know what sorts of choices are important to put in a training program.

I want to remind you that your participation is voluntary. This means that you can stop the interview at any time or you can decide not to answer any question that you don't want to answer. If you feel uncomfortable, you should let me know and you can skip the question that makes you uncomfortable or you can stop the interview. If you do this, you will not be in any trouble and nothing bad will happen to you.

Do you have any questions?

*Demographic questions*

I am going to begin by quickly asking you some general questions about you and your family.

What is your full name?

What is your brother/ sister with ID's full name?

What is your relationship to \_\_\_\_\_ (e.g. brother etc.)

How old are you?

What grade are you in?

*General Choice Questions*

Thanks! Now I am going to ask you questions about choices that \_\_\_\_\_ makes.

\*\*\*\* Note: Italics are prompts that can be used if necessary.

\*\*\*\* Items can be changed, elaborated on, or clarified if necessary. Items can be removed if they have been answered by previous questions.

We all make choices. What choices does \_\_\_\_\_ make in his/ her everyday life?

Can you tell me about a time that \_\_\_\_\_ made an everyday choice?

- *for example the last time \_\_\_\_\_ chose what to wear, what to take for lunch, what to do with a friend etc.*

Are there any choices that \_\_\_\_\_ has a hard time making? If so, which ones?

- *Why do you think that these choices may be hard for \_\_\_\_\_ to make?*
- *Can you think of any specific changes that could make these choices easier for \_\_\_\_\_? (e.g. practice letting others know opinion, allowing more time to make these choices, increased awareness of the right to make choices etc.)*

Can you tell me about a time when \_\_\_\_\_ had a hard time making a choice?

How does \_\_\_\_\_ let people know what he/ she wants?

Are there times when it is easy for \_\_\_\_\_ to let people know what he/ she wants?

- *With these choices, why it is easy for \_\_\_\_\_ to let people know what he/ she wants?*

Can you tell me about a time when it was easy for \_\_\_\_\_ to let someone know what he/ she wanted?

Are there times when it is hard for \_\_\_\_\_ to let people know what he/ she wants?

- *What about these choices or makes it hard for \_\_\_\_\_ to let people know what he/ she wants?*
- *Can you think of changes that would help make it easier for \_\_\_\_\_ to let people know what he/ she wants?*

Can you tell me about a time when it was hard for \_\_\_\_\_ to let people know what he/ she wanted?

Is \_\_\_\_\_ able to make choices as much as you are? If no, why not?

Is \_\_\_\_\_ ever stopped from making a choice?

If yes, why is \_\_\_\_\_ sometimes stopped from making a choice?

Can you tell me about a time when \_\_\_\_\_ was stopped from making a choice?

Can you think of some changes that would help \_\_\_\_\_ to be able to make more choices?

- *For example, \_\_\_\_\_ would be able to make more choices about what to eat if \_\_\_\_\_ made healthier choices*

\*\*\*\* If the issues of rights, respect and responsibility have not come through naturally in the answers to the above questions, ask the following respect and responsibility questions

Making choices respectfully means thinking about your own feelings and the feelings of other people. Do you think that \_\_\_\_\_ makes choices respectfully?

Can you tell me about a time when \_\_\_\_\_ made a choice respectfully?

Can you tell me about a time when \_\_\_\_\_ had a hard time making a choice respectfully?

Making choices responsibly means answering to yourself and other people. Do you feel that \_\_\_\_\_ makes choices responsibly?

Can you tell me about a time when \_\_\_\_\_ made a choice responsibly?

Can you tell me about a time when \_\_\_\_\_ had a hard time making a choice responsibly?

Having rights means being able to make choices about our own lives. Has \_\_\_\_\_ ever been stopped from having the right to make choices?

Can you tell me about a time when \_\_\_\_\_ was stopped from having the right to make a choice about their life?

\*\*\*\*

### **Specific Choice Questions**

Thank you! Now I am going to ask you some questions about how some different choices are made in your family.

Can you tell me about how \_\_\_\_\_ chooses what he/she is going to wear everyday?

Is there anything that would help \_\_\_\_\_ choose what to wear?

- *for example, would it help \_\_\_\_\_ to practice choosing clothes that go with the weather (e.g. boots in the winter, T-shirt in the summer?)*

Can you tell me about how \_\_\_\_\_ chooses what to take to school for lunch?

Is there anything that would help \_\_\_\_\_ choose what to take for lunch?

Can you tell about how \_\_\_\_\_ chooses what to eat at other times of the day?

- *snacks*
- *breakfast*
- *dinner*

Who does \_\_\_\_\_ like to spend time with? Can you tell me about how \_\_\_\_\_ chooses who to spend your time with?

Is there anything that would help \_\_\_\_\_ choose who to spend time with?

Does \_\_\_\_\_ play any sports? Does \_\_\_\_\_ belong to any clubs? Can you tell me about how \_\_\_\_\_ chooses what sports/ clubs/ activities to join?

Is there anything that would help \_\_\_\_\_ choose what activities/ sports/ clubs to join?

What does \_\_\_\_\_ like to do when he/she have free time? Can you tell me how \_\_\_\_\_ chooses what to do during free time?

Is there anything that would help \_\_\_\_\_ to choose what to do during free time?

Does your whole family ever do an activity all together (e.g. watch TV, watch a movie, go to a restaurant, play a game etc.)? Can you tell me about how your family chooses what \_\_\_\_\_ (movie to go to, game to play etc.)?

### **Final Questions**

Thank you! Your answers are a big help. I have a few more questions for you. I am going to ask you some questions to find out if there are other choices that you think are important to learn about.

Are there any choices that we have not talked about that you think would be helpful for \_\_\_\_\_ to make or to learn more about?

Is there anything else that you think that \_\_\_\_\_ could learn about to help him/ her make choices?

When we teach adults about rights, we use a boardgame that has videos and uses talking and acting to help the adults can learn about and practice making choices. Do you think that these sorts of things would help \_\_\_\_\_ to learn about how to make choices respectfully and responsibly?

Another way that researchers have taught adults about rights is by using a video game for which the adults watch a video on the computer and answer questions about the video on

the computer. Do you think that a computer program could help \_\_\_\_\_ to learn about choices?

- *Why?*
- *What would a useful computer program be like?*

Can you think of anything else that might help \_\_\_\_\_ to learn about making choices?

- *e.g. puppets, pictures etc.*
- *what helps \_\_\_\_\_ learn new things at home or at school?*

If your family was going to learn about choices and rights all together, who would you want to be your teacher?

- *A rights teacher, a mom or dad who has a child with ID, somebody else?*
- *Why do you think \_\_\_\_\_ would be a good teacher for your family?*

Thanks again for all of your help. The answers that you gave me will help researchers be able to make a training program that is useful! If you think of anything else that you want to tell me or if you have any questions, please let me know.

## Appendix D

*Research Ethics Board Ethics Clearance*

DATE: July 13, 2009

FROM: Michelle McGinn, Chair  
Research Ethics Board (REB)

TO: Frances Owen, Child & Youth Studies  
Robyn Saaltink

FILE: 08-360 OWEN/SAALTINK  
Masters Thesis/Project

TITLE: Human Rights Education for Youth with Intellectual Disabilities and Families

---

The Brock University Research Ethics Board has reviewed the above research proposal.

**DECISION: ACCEPTED AS CLARIFIED**

This project has received ethics clearance for the period of **July 13, 2009 to May 31, 2010** subject to full REB ratification at the Research Ethics Board's next scheduled meeting. The clearance period may be extended upon request. *The study may now proceed.*

Please note that the Research Ethics Board (REB) requires that you adhere to the protocol as last reviewed and cleared by the REB. During the course of research no deviations from, or changes to, the protocol, recruitment, or consent form may be initiated without prior written clearance from the REB. The Board must provide clearance for any modifications before they can be implemented. If you wish to modify your research project, please refer to <http://www.brocku.ca/researchservices/forms> to complete the appropriate form Revision or Modification to an Ongoing Application.

Adverse or unexpected events must be reported to the REB as soon as possible with an indication of how these events affect, in the view of the Principal Investigator, the safety of the participants and the continuation of the protocol.

If research participants are in the care of a health facility, at a school, or other institution or community organization, it is the responsibility of the Principal Investigator to ensure that the ethical guidelines and clearance of those facilities or institutions are obtained and filed with the REB prior to the initiation of any research protocols.

The Tri-Council Policy Statement requires that ongoing research be monitored. A Final Report is required for all projects upon completion of the project. Researchers with projects lasting more than one year are required to submit a Continuing Review Report annually. The Office of Research Services will contact you when this form *Continuing Review/Final Report* is required.

Please quote your REB file number on all future correspondence.

MM/an

Research Ethics Office

Brock Research, MC D250A-1

Brock University

500 Glenridge Avenue, St. Catharines, ON L2S 3A1

Phone 905-688-5550 ext. 3035

Fax 905-688-0748

Email: [reb@brocku.ca](mailto:reb@brocku.ca)

[http://www.brocku.ca/researchservices/Ethics\\_Safety/Humans/Index.php](http://www.brocku.ca/researchservices/Ethics_Safety/Humans/Index.php)

## Appendix E

**Telephone Script****Part A: Greeting and Small Talk**

Greet the family in the manner that you normally would.

**Part B: Invitation to Participate:**

I am calling about a research project that I thought you might be interested in. The research is being done by researchers at Brock University in affiliation with a large project about human rights and people with intellectual disabilities called the 3Rs Project: Rights, Respect, Responsibility. The current study is about families and the choices that people with intellectual disabilities (ID) make in their everyday lives. The goal of the research is to gather information that will one day help researchers create a program that will help family members work together to teach youth with ID about making choices so that they understand their rights as they become adults and possibly move out of their family home. The principal investigator is hoping to interview families, who have a family member with ID, to find out this information. Do you think that you and some of your family members might be interested in being interviewed for this project?

If no – Thank them for their time and say goodbye.

**Part C: More Details about the Interviews**

If yes- Great! I will tell you a bit more about the project then. Robyn, the principal investigator, will be conducting interviews with the help of a research assistant. If you choose to participate in the interviews, she will come to your home or you can choose to meet with her in a private meeting room at Community Living Welland-Pelham. She would like to interview at least one parent, one sibling, and one child with ID from each family who participates, but if more or less family members want to participate then that would be OK too. She will interview one family member at a time and each interview will be about one hour long. Just so you know, your decision to participate or not will not affect your services from Community Living (Welland Pelham or Port Colborne-Wainfleet) in any way. Are you interested in participating in these interviews?

If no – Thank them for their time and say goodbye.

**Part D: Booking the Appointment**

If yes – Excellent! Thank you! Now we just need to set up a time for Robyn to meet with you to explain the study further and conduct the interviews.

Would you like to meet at your home or at Community Living Welland Pelham?

Answer: \_\_\_\_\_

When would you like to meet? The researchers are able to schedule interviews (list dates and times)

Answer: \_\_\_\_\_

Thank you so much for agreeing to help out with this research. Robyn will really appreciate it! Reconfirm date, time and place that were scheduled for the meeting and say goodbye.



Appendix F

**LETTER OF INVITATION**

**Principal Student Investigator:**

Robyn Saaltink  
MA Candidate  
Department of Child and Youth Studies  
Brock University  
[rs08tc@brocku.ca](mailto:rs08tc@brocku.ca)

**Faculty Supervisor:**

Frances Owen  
Associate Professor  
Department of Child and Youth Studies  
Brock University  
905-688-5550; [fowen@brocku.ca](mailto:fowen@brocku.ca)

May 13, 2009

Dear (parent's name),

This letter is an invitation to consider participating in a research project entitled *Human Rights Education for Youth with Intellectual Disabilities and Families*. I am conducting this research as part of my Master's degree in the Department of Child and Youth Studies at Brock University under the supervision of Professor Frances Owen. This letter will provide you with more information about the purposes of the study and what each family member's involvement will entail, should they decide to take part.

The purpose of this study is to find out about the choices that youth with intellectual disabilities make in their everyday lives. The information and suggestions provided by families will be used to help researchers understand the sorts of issues that families believe should be included in a choice training program for youth with ID and their families. This research is important because it will provide background information that will help researchers make recommendations about material that should be included in a training program that could help youth with ID understand what their rights are as they enter into adulthood and become more independent.

Although it would be beneficial to have all family members involved in the study, participation for each member is completely voluntary. Each family member should make their own independent decision as to whether or not they would like to be involved.

Further, as this study involves minors, only children with parental permission and minors who themselves agree to participate (in addition to their parent's permission) will be included in the study. All participants are free to withdraw their participation at any time; parents and/or the child may withdraw the minor's participation at any given time.

If a family member does choose to be involved, she or he will have an interview with me and a research assistant or the faculty supervisor that will last approximately one hour. Depending on your family's preference, the interviews will be conducted independently or with family members together. Your family will also have the option to choose to have the interviews take place at Community Living Welland Pelham or at your family's home. Each family member may decline to answer any of the interview questions if they so wish. The research assistant or faculty supervisor will take notes

during the interview and the interviews will be audio recorded to facilitate the collection of information. Later, interviews will be transcribed for analysis.

This research is being conducted as a part of the 3Rs Project: Rights, Respect, and Responsibility and is being conducted at Community Living Welland Pelham.

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

If you have any questions or if you wish to participate in this study, please contact me using the contact information provided above.

Thank you,

Robyn Saaltink

**This study has been reviewed and received ethics clearance through Brock University's Research Ethics Board (file # 08-360]**

Appendix G

**LETTER OF INVITATION**

**To be read aloud**

**Principal Student Investigator:**

Robyn Saaltink  
MA Candidate  
Department of Child and Youth Studies  
Brock University  
[rs08tc@brocku.ca](mailto:rs08tc@brocku.ca)

**Faculty Supervisor:**

Frances Owen  
Associate Professor  
Department of Child and Youth Studies  
Brock University  
905-688-5550; [fowen@brocku.ca](mailto:fowen@brocku.ca)

May 13, 2009

Dear (child's name),

This letter is an invitation to participate in a research project. The title of the research project is: *Human Rights Education for Youth with Intellectual Disabilities and Families*. I am doing this research project as part of my university degree in the Department of Child and Youth Studies at Brock University, where I work with Professor Frances Owen, my supervisor. This letter will give you some more information about the study.

The purpose of this study is to find out about the choices that young people with intellectual disabilities make everyday. The information that you give us will give us information that could be used to make a training program that would help teach families about choices.

Your participation in the study is voluntary. This means that you get to decide if you want to participate in the study or not. You and your mom or dad both have to agree that you will participate before you can be a part of the study. Also, if you decide to participate and then change your mind, you can stop being a part of the study at any time. If you decide to drop out of the study you will not be in any trouble.

If you decide to be a part of the study, I will interview you (with or without your other family members) with the help of a research assistant or my supervisor. The interview will take about one hour. The research assistant or my supervisor will take notes during the interview. The interview will be tape-recorded and we will later type out what you say during the interview. If you do not feel comfortable or you do not like some of the questions that I ask you during the interview, you can decide not to answer those questions. You will not be in any trouble if you decide to skip a question.

This research should be helpful because information that you and other people give us during interviews could be used to make a rights training program for youth with intellectual disabilities and their families. The information you give will be used to help researchers understand how they could help people with intellectual disabilities learn to make choices respectfully and responsibly.

This research is part of the 3Rs Project: Rights, Respect, and Responsibility at Community Living Welland Pelham.

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

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

Thank you,

Robyn Saaltink

**This study has been reviewed and received ethics clearance through Brock University's Research Ethics Board (file # 08-360]**

## Appendix H

**Consent Form: Parents**

**Project Title:** Human Rights Education for Youth with Intellectual Disabilities and Families

**Principal Student Investigator:**

Robyn Saaltink  
MA Candidate  
Department of Child and Youth Studies  
Brock University  
[rs08tc@brocku.ca](mailto:rs08tc@brocku.ca)

**Faculty Supervisor:**

Frances Owen  
Associate Professor  
Department of Child and Youth Studies  
Brock University  
905-688-5550; [fowen@brocku.ca](mailto:fowen@brocku.ca)

**INVITATION**

You are invited to participate in a research study about human rights and intellectual disabilities. The goal of this study is to gather information so that researchers can make recommendations that could inform the development of a program that will help youth with ID understand their rights as they enter adulthood.

**WHAT'S INVOLVED**

As a participant, you will participate in an interview (with or without other family members present) about the right to make choices with regards to your child with an intellectual disability in the family context. The principal student investigator will conduct the interview with the assistance of a research assistant or the faculty supervisor. During the interview, the research assistant or faculty supervisor will take notes. Additionally, the interview will be audio recorded and later transcribed for analysis. The interview will take approximately one hour.

Researchers will analyze the information from the interviews to make recommendations about what should be included in a rights training program for youth with ID and their families.

Once data is analyzed, the principal student investigator may contact you again to ask if you are interested in providing feedback about the results.

**POTENTIAL RISKS AND BENEFITS**

Possible benefits of participation in the interview include providing necessary background information required to design and test a rights training program for youth with intellectual disabilities and their families. A rights training program could help families teach their child to understand their rights as they enter into adulthood.

Participating in an interview about rights and rights infringements with regards to your child and your family may be distressing. If you feel upset or stressed, you are free to skip any questions or to stop the interview at any time, without penalty. Additionally, you will be provided with contact information for support services at Community Living Welland Pelham, who will be able to provide you with counseling if necessary.

**CONFIDENTIALITY**

Participants will not be named and no identifying information will be given in any communication of the results of the study.

Data collected during this study will be stored in a locked cabinet in a locked room at Brock University. Access to this data will be restricted to members of the research team, including the principal student investigator, the faculty supervisor, thesis committee members (Donato Tarulli and Christine Tardif-Williams), and research assistants.

Five years following study completion, all data will be destroyed.

Confidentiality will only be broken if it is required by law. This means that if you tell researchers about abuse or about hurting yourself or someone else, researchers will have to report this information.

**VOLUNTARY PARTICIPATION**

Participation in this study is voluntary. If you wish, you may decline to answer any questions or participate in any component of the study. Further, you may decide to withdraw from this study at any time and may do so without any penalty.

**PUBLICATION OF RESULTS**

Results of this study will be included in Robyn Saaltink's Master's thesis, may be published, and may be presented at conferences and training events. Feedback about this study will be available in the winter of 2010. A feedback letter will be given to all participants when interviews are complete. If you request a summary of results from the principal student investigator, the principal student investigator will provide you with a summary of results upon study completion. If you have questions about results at any time, you are encouraged to contact the principal investigator.

**SECONDARY USE OF DATA**

The information that you provide during the interviews might be reanalyzed at a later date. If your information is going to be used for purposes other than described here, you will receive a letter letting you know about the new research.

**CONTACT INFORMATION AND ETHICS CLEARANCE**

If you have any questions about this study or require further information, please contact the Principal Investigator using the contact information provided above. This study has been reviewed and received ethics clearance through the Research Ethics Board at Brock University. If you have any comments or concerns about your rights as a research participant, please contact the Research Ethics Office at (905) 688-5550 Ext. 3035, [reb@brocku.ca](mailto:reb@brocku.ca).

**CONSENT FORM**

I agree to participate in this study described above. I have made this decision based on the information I have read in the Letter of Invitation and the Consent Form. I have had the opportunity to receive any additional details I wanted about the study and understand that I may ask questions in the future. I understand that my I may withdraw this consent at any time.

Name: \_\_\_\_\_

Signature: \_\_\_\_\_

Date:

\_\_\_\_\_

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

## Appendix I

**Consent Form: Parental Consent for Minors**

**Project Title:** Human Rights Education for Youth with Intellectual Disabilities and Families

**Principal Student Investigator:**

Robyn Saaltink  
MA Candidate  
Department of Child and Youth Studies  
Brock University  
[rs08tc@brocku.ca](mailto:rs08tc@brocku.ca)

**Faculty Supervisor:**

Frances Owen  
Associate Professor  
Department of Child and Youth Studies  
Brock University  
905-688-5550; [fowen@brocku.ca](mailto:fowen@brocku.ca)

**INVITATION**

Your child is invited to participate in a research study about human rights and intellectual disabilities. The goal of this study is to gather information so that researchers can make recommendations to inform the development of a program that would help youth with ID understand their rights as they enter adulthood.

**WHAT'S INVOLVED**

As a participant, your child will participate in an interview (with or without other family members present) about choice making in the family context. Your child with an intellectual disability will be asked about their everyday experiences making choices. If applicable, your other child(ren) will be asked about choices in the family context, especially with regards to their sibling with an intellectual disability. The principal student investigator will conduct the interview with the assistance of a research assistant or the faculty supervisor. During the interview, the research assistant or faculty supervisor will take notes. Additionally, the interview will be audio recorded and later transcribed for analysis. The interview will take approximately 1 hour.

Once data is analyzed, the principal student investigator may contact your family again to ask if you are interested in providing feedback about results.

Information gained from the interview will be used to make recommendation that could help create a rights training program for youth with ID.

**POTENTIAL RISKS AND BENEFITS**

Possible benefits of participation in the interview include providing necessary background information required to design a rights training program for youth with intellectual disabilities and their families. A rights training program could help youth with intellectual disabilities understand their rights as they enter into adulthood.

During the interview, your child will be asked questions about choices with regards to your child with ID and your family. This may be distressing. If your child feels distressed, he/ she is able to skip any question or to stop the interview at any time without penalty. Additionally, your family will be provided with the contact information of support services at Community Living Welland Pelham, who will be able to provide counseling if necessary.



**CONFIDENTIALITY**

Participants will not be named and no identifying information will be given in any communication of the results of the study.

Data collected during this study will be stored in a locked cabinet in a locked room at Brock University. Access to this data will be restricted to members of the research team, including the principal student investigator, the faculty supervisor, thesis committee members (Donato Tarulli and Christine Tardif-Williams), and research assistants.

All data will be destroyed five years after study completion.

Confidentiality will only be broken if it is required by law. This means that if your child tells researchers about abuse or about hurting yourself or someone else, researchers will have to report this information.

**VOLUNTARY PARTICIPATION**

Participation in this study is voluntary. If your child wishes, they may decline to answer any questions or participate in any component of the study. Further, you or your child may decide for your child to withdraw from this study at any time and may do so without any penalty.

**PUBLICATION OF RESULTS**

Results of this study will be included in the principal investigator's MA thesis, may be published, and may be presented at conferences and training sessions. Feedback about this study will be available in late summer of 2009. A feedback letter will be read to your child following interview completion. If you and/ or your child requests a summary of results from the principal student investigator, the principal student investigator will provide you and/ or your child with a summary of results when this study is complete. If you and/ or your child have questions about results at any time, you are encouraged to contact the principal investigator.

**SECONDARY USE OF DATA**

The information that you provide during the interviews might be reanalyzed at a later date. If your information is going to be used for purposes other than described here, you will receive a letter letting you know about the new research.

**CONTACT INFORMATION AND ETHICS CLEARANCE**

If you and / or your child have any questions about this study or require further information, please contact the Principal Investigator using the contact information provided above. This study has been reviewed and received ethics clearance through the Research Ethics Board at Brock University. If you and/ or your child have any comments or concerns about your rights as a research participant, please contact the Research Ethics Office at (905) 688-5550 Ext. 3035, [reb@brocku.ca](mailto:reb@brocku.ca).

**CONSENT FORM**

I agree for my child participate in this study described above. I have made this decision based on the information I have read in the Letter of Invitation and the Consent Form. I have had the opportunity to receive any additional details I wanted about the study and

understand that I may ask questions in the future. I understand that my child may withdraw this consent at any time.

Child's Name: \_\_\_\_\_

Parent's Name: \_\_\_\_\_

Parent's Signature: \_\_\_\_\_ Date:

\_\_\_\_\_

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

## Appendix J

**Assent Form**  
To be read aloud

**Project Title:** Human Rights Education for Youth with Intellectual Disabilities and Families

**Principal Student Investigator:**

Robyn Saaltink  
MA Candidate  
Department of Child and Youth Studies  
Brock University  
[rs08tc@brocku.ca](mailto:rs08tc@brocku.ca)

**Faculty Supervisor:**

Frances Owen  
Associate Professor  
Department of Child and Youth Studies  
Brock University  
905-688-5550; [fowen@brocku.ca](mailto:fowen@brocku.ca)

**INVITATION**

You are invited to participate in a research study. The goal of this research study is to find out information about the choices that young people with intellectual disabilities make.

**WHAT'S INVOLVED**

As a participant, you will participate in an interview (with or without your other family members). You will be asked questions about making choices with your family. I will ask you the interview questions with the help of a research assistant or my supervisor. The interview will be taped recorded and one of the researchers will write down important things that they notice during the interview. Later, researchers will listen to the recording and write out your answers. The interview will be about one hour long. Information from the interview will be used so that researchers can understand about the choices that young people with intellectual disabilities make. The information about the choices that young people with intellectual disabilities make can be used to help make a program that can teach young people about choices. Later, a researcher might call your family to see if you are interested in talking about the results from the study.

Q1: What will you be asked about during the interview?

---

**POTENTIAL RISKS AND BENEFITS**

A good thing about being interviewed is that you will be giving researchers information that they need to learn about the right to make choices. The information about choices can be used to help make a training program that could teach people about the right to make choices.

Some of the questions in the interview may be upsetting. If you feel upset, you can stop the interview or you can skip questions that make you upset. You will not be in any trouble if you do this. Also, you will be given the information of support services at Community Living Welland Pelham, who will be able to help you if you feel upset after the interview.

Q2: What can you do if you do not like one of the interview questions?

---

### **CONFIDENTIALITY**

All of the information that you provide will be kept confidential. This means that your name will not be put on any of the things that we write about this research. The information we get during this study, like the tape recordings and the notes we take, will be stored in a locked cabinet in a locked room at Brock University. Only members of the research team, including me, my supervisor, other professors helping out with this project (Danny Tarulli and Christine Tardif-Williams), and research assistants will be able to see your personal information.

Confidentiality will only be broken if the law says we have to. This means that if you tell researchers about abuse or about hurting yourself or someone else, researchers will have to report this information.

All data will be destroyed five years after the study is finished.

Q3: Will anyone other than the research team be able to see your personal information?

Q4: If you tell the researchers about abuse, will the researchers keep it a secret?

---

### **VOLUNTARY PARTICIPATION**

Participation in this study is voluntary. This means that you get to decide if you want to be in this study. You can only be a part of this study if you and your mom or your dad say that it is OK for you to be in this study. You do not have to answer any questions that you don't want to. You can stop being a part of this study at any time. You will not be in any trouble for stopping.

Q5: Will you be in any trouble if you decide to stop the interview?

---

### **PUBLICATION OF RESULTS**

We will tell people about the things that we find out from this study. We will tell people what we find out from this study by giving presentations and by writing about the study. When the interviews are finished, I will read you a letter letting you know when the study should be finished. If you tell me that you want to know what we find out from this study, I will give you a summary of results when this study is finished. If you have questions about results at any time, you can contact me.

### **SECONDARY USE OF DATA**

The information that you give us might also be used for other research. If this is going to happen, you will get a letter letting you know about the new research.

**CONTACT INFORMATION AND ETHICS CLEARANCE**

If you have any questions or if you want to know anything else about this study, you can contact me. The information to contact me is at the top of this form. This study has been reviewed and been approved by the Research Ethics Board at Brock University. If you have any comments or concerns about your rights as a research participant, please contact the Research Ethics Office at (905) 688-5550 Ext. 3035, [reb@brocku.ca](mailto:reb@brocku.ca).

**WITNESS STATEMENT**

I have witnessed the presentation of information and the request for consent for participation in the study and I believe that \_\_\_\_\_ fully understands the nature of his/ her involvement in the study and was not coerced in any manner.

Witness Name: \_\_\_\_\_

Witness Signature: \_\_\_\_\_ Date: \_\_\_\_\_

**ASSENT FORM**

You understand that you are agreeing to participate in a research study about choices that you make.

You understand that you will be asked questions about choices.

You understand that the information that you give might also be used for other research too.

You understand that the interview will be tape recorded.

You understand the information that was read to you in the letter of invitation and in the consent form.

You understand that you can stop being a part of the study at any time.

You understand that you will not be in any trouble if you decide to stop being a part of the study.

Name: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Thank you for your help with this project! Please keep a copy of this form.

## Appendix K

**Assent Form: Siblings**  
To be read aloud if necessary

**Project Title:** Human Rights Education for Youth with Intellectual Disabilities and Families

**Principal Investigator:**

Robyn Saaltink  
MA Candidate  
Department of Child and Youth Studies  
Brock University  
[rs08tc@brocku.ca](mailto:rs08tc@brocku.ca)

**Faculty Supervisor:**

Frances Owen  
Associate Professor  
Department of Child and Youth Studies  
Brock University  
905-688-5550; [fowen@brocku.ca](mailto:fowen@brocku.ca)

**INVITATION**

You are invited to participate in a research study about human rights and intellectual disabilities. The goal of this research study is to find out about that choices that young people with intellectual disabilities make with their families. This information will be used to help researchers understand about the sorts of things that would be important to put in a training program for youth with intellectual disabilities and their families.

**WHAT'S INVOLVED**

As a participant, you will participate in an interview (with or without your other family members). You will be asked questions about choices and rights that your brother or sister makes. I will ask you the interview questions with the help of a research assistant or my supervisor. The interview will be taped recorded and one of the researchers will write down important things that they notice during the interview. Later, researchers will listen to the recording and write out your answers. The interview will be about one hour long.

Information from the interview will be used to help researchers understand about the sorts of things that would be useful to put in a training program that would help teach youth with intellectual disabilities about their rights.

Later, researchers might call your family to see if your family wants to talk about the results.

**POTENTIAL RISKS AND BENEFITS**

A benefit of being interviewed is that you will be giving researchers information that they need to make a training about the right to make choices. A training program could help young people with intellectual disabilities learn about their rights.

Some of the questions in the interview may be upsetting. If you feel upset, you can stop the interview or you can skip questions that make you upset. You will not be in any trouble if you do this. Also, you will be given the information of support services at Community Living Welland Pelham, who will be able to help you if you feel very upset after the interview.

**CONFIDENTIALITY**

All of the information that you provide will be kept confidential. This means that your name will not be put on any of the things that we write about this research. The information we get during this study, like the tape recordings and the notes we take, will be stored in a locked cabinet in a locked room at Brock University. Only members of the research team, including me, my supervisor, other professors helping out with this project (Danny Tarulli and Christine Tardif-Williams), and research assistants will be able to see your personal information.

Confidentiality will only be broken if the law says we have to. This means that if you tell researchers about abuse or about hurting yourself or someone else, researchers will have to report this information.

All data will be destroyed five years after the study is finished.

**VOLUNTARY PARTICIPATION**

Participation in this study is voluntary. This means that you get to decide if you want to be in this study. You can only be a part of this study if you and your mom or your dad say that it is OK for you to be in this study. You do not have to answer any questions that you don't want to. You can stop being a part of this study at any time. You will not be in any trouble for stopping.

**PUBLICATION OF RESULTS**

We will tell people about the things that we find out from this study. We will tell people what we find out from this study by giving presentations and by writing about the study. When the interviews are finished, I will read you a letter letting you know when the study should be completed. If you tell me that you want to know what we find out from this study, I will give you a summary of results when this study is finished. If you have questions about results at any time, you can contact me.

**SECONDARY USE OF DATA**

At a later date, the information that you give us might be used for other research. If this is going to happen, you will receive a letter letting you know about the new research.

**CONTACT INFORMATION AND ETHICS CLEARANCE**

If you want to know anything else about this study, you can contact me. The information to contact me is at the top of this form.

This study has been reviewed and received ethics clearance through the Research Ethics Board at Brock University. If you have any comments or concerns about your rights as a research participant, please contact the Research Ethics Office at (905) 688-5550 Ext. 3035, [reb@brocku.ca](mailto:reb@brocku.ca).

**ASSENT FORM**

You understand that you are agreeing to participate in a research study about choices that you make.

You understand that you will be asked questions about choices that your family makes.

You understand that the information that you give might also be used for other research too.

You understand that the interview will be tape recorded.

You understand the information that was read to you in the letter of invitation and in the consent form.

You understand that you can stop being a part of the study at any time.

You understand that you will not be in any trouble if you decide to stop being a part of the study.

Name: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Thank you for your help with this project! Please keep a copy of this form.



## Appendix L

*Feedback Letter: Parents*

Principal Student Investigator  
 Robyn Saaltink  
 MA candidate  
 Department of Child and Youth Studies  
 Brock University  
[rs08tc@brocku.ca](mailto:rs08tc@brocku.ca)

Faculty Supervisor  
 Frances Owen  
 Associate Professor  
 Department of Child and Youth Studies  
 Brock University  
 905-688-5550, ext. 4807  
[fowen@brocku.ca](mailto:fowen@brocku.ca)

Date

Dear *(Insert Name of Participant)*,

I would like to thank you for your participation in the study *Human Rights Education for Youth with Intellectual Disabilities and their Families*. As a reminder, the purpose of this study is to learn more about the choices that youth with intellectual disabilities make. The information collected during interviews will help researchers understand how to develop a rights training program designed to help teach youth with ID about how to exert the right to make choices respectfully and responsibly.

Please remember that any data about yourself as an individual participant will be kept confidential. Once all the data are collected and analyzed for this project, I plan on sharing this information through conferences, publications, and training events. If you are interested in receiving a summary of results from this study or if you have any questions or concerns, please contact me using the contact information given above. Once all data is analyzed, I may contact your family to ask if you are interested in providing feedback about the results.

As with all Brock University projects involving human participants, this project was reviewed by, and received ethics clearance through Brock University's Research Ethics Board (file #: 08-360). If you have any pertinent questions about your rights as a research participant, please contact the Brock University Research Ethics Officer (905 688-5550 ext 3035, [reb@brocku.ca](mailto:reb@brocku.ca)).

Thank you,

Robyn Saaltink  
 Principal Student Investigator

Appendix M

*Feedback Letter: Siblings and Youth*

To be read aloud

**Principal Student Investigator**

Robyn Saaltink  
MA candidate  
Department of Child and Youth Studies  
Brock University  
[rs08tc@brocku.ca](mailto:rs08tc@brocku.ca)

**Faculty Supervisor**

Frances Owen  
Associate Professor  
Department of Child and Youth Studies  
Brock University  
905-688-5550, ext. 4807  
[fowen@brocku.ca](mailto:fowen@brocku.ca)

Date

Dear *(Insert Name of Participant)*,

Thank you for participating in the study *Human Rights Education for Youth with Intellectual Disabilities and their Families*. You have been a big help! The information that you gave me during your interview will help me to learn more about the choices that youth with intellectual disabilities make.

Please remember that any personal information that you gave me will be kept confidential. If you are interested learning more about the results of this study, or if you have any questions or concerns, please let me know. Later, I might call your family to see if you are interested in talking about results.

As with all Brock University projects involving human participants, this project was reviewed by, and received ethics clearance through Brock University's Research Ethics Board (file #: 08-360). If you have any pertinent questions about your rights as a research participant, please contact the Brock University Research Ethics Officer (905 688-5550 ext 3035, [reb@brocku.ca](mailto:reb@brocku.ca)).

Thank you,

Robyn Saaltink  
Principal Student Investigator

## Appendix N

*Point Form Summary of Thesis Themes*

## Thesis Themes

**Overall Themes**

\*\*\* These themes are informed by and inform all other themes

**Overall Theme 1:** Choices take place within the context of family morals/ values/ respect/ responsibility

- When family members make decisions they tend to consider family morals, conventions, pragmatics, and other family member's well being.

**Overall Theme 2:** Protection

- Family members seek to protect youth from:
  - o Social rejection
  - o Emotional harm
  - o Physical safety issues
  - o Being taken advantage of
  - o Falling outside social norms
  - o Failure
- Goes hand in hand with a consideration of family member's well being

\*\*\* These overall themes play out differently for different family members

**Parents**

- Protection issues are most salient for parents
  - o Parents describe fear/ worry about items they seek to protect youth from
- Parents describe protecting youth because of:
  - o A perceived lack of complex thinking skills
  - o A perceived lack of social skills
  - o Youths' tendencies to make choices that may fall outside of norms
- Youths' tendencies to make choices that may fall outside of norms brings in issues of family moral/ values/ respect / responsibility
  - o Parents describe wanting youths decisions/ choices to stay within framework (i.e. make morally sound choice, make family and socially normative choice)

**Youth**

- Youth communicate a recognition that family moral/ values/ respect/ responsibility tend to structure thoughts about and the practice of decision making
- Youth communicate that they should comply with family expectations to do with conventions or values
- Youth do not specifically mention their own safety/ the need to be protected from harm, but they do recognize that they have to comply with items that parents discuss as issues of protection

**Siblings**

- Siblings indicate a general acceptance of family norms and values
- Siblings describe supporting and providing accommodations for youth to help them stay within accepted boundaries
- Siblings describe negotiations where family members consider family morals, conventions, pragmatics, and other family member's well being
- But, siblings do not specifically express fear or worry about youth or a specific need to protect youth

### Themes Addressing Specific Research Questions

#### Question 1a) How do family members negotiate the right to make choices amongst themselves?

##### Theme 1a) 1. Youth make personal choices as long as they fit within the framework of family morals/ values/ respect/ responsibility

- 1-y → reports being able to make less choices than mom reports
- 2,3-y → report being able to make more choices than moms' report
- 4-y → reports same amount of choice as mom (but less than brother)
- this theme connects to overall themes because what is interpreted as personal (and therefore what is interpreted as area that youth can make choice) is dependant on family members interpretations of need to protect and youths' ability to make choices that meet family morals/ values/ conventions

#### Parents

- Parents report that youth make personal choices as long as they fit within framework of family morals/ values/ respect/ responsibility(all)
  - o I.e. youth make choices as long as parents do not perceive choices as posing a threat to safety or well being and as long as choices do not violate family norms
- e.g. what to eat, what to wear, what to do in spare time, how to decorate room (all)
- flexibility on issues within boundaries of family expectations (all)
  - o 'they choose whatever they want as long as they make the right choice'
- some youth make more personal choices than others; quantity may be partially determined by the perception that youths' choices will stay within boundaries (see barriers)
- parents report that youth generally ask for what they want or just do what they want within this domain

#### Youth

- Youth report making personal choices as long as they fit within framework of family morals/ values/ respect/ responsibility (all)
- e.g. what to eat, what to wear, what to do in spare time, how to decorate room (all)
  - o youth report that they often ask parents if the can have/ do something and parents generally say yes
- flexibility on issues within boundaries of family expectations (all)
  - o e.g. 1-y: summer course; 2-y: sharing food that belongs to someone else; all: what to have for dinner if dislike main course)

#### Siblings

- Siblings report that youth make personal choices as long as they fit within framework of family
  - morals/ values/ respect/ responsibility (all)
  - e.g. what to eat, what to wear, how to spend free time (both)
  - flexibility on these issues within boundaries of family expectations
  - number of choices based on personal characteristics (i.e. physical limitations, sensory issues, safety knowledge, perceived ability to process choices) which influences the domain that decisions are seen to fall under (like parents; see barriers)

- siblings report that youth tell/ask/ just do what they want for choices that fall under the personal domain

**Theme 1a) 2. With the exception of personal decisions, which are seen to only affect youth without breaking the boundaries of family morals/ values, family members often make decisions together, with negotiation and/ or support**

\*\*\* these decisions necessarily vary based on the conventions/ morals of each family

**Theme 1a 2.a) Decisions that affect multiple family members are made together/ negotiated based on family members' likes, dislikes, morals/ conventions, perceived fairness, pragmatics etc.**

#### **Parents**

- Parents report that decisions that affect multiple family members are made together/ negotiated based on family members' likes, dislikes, morals/ conventions, perceived fairness, pragmatics (including previous behavior) etc.
  - o E.g. watching TV together, going to the movies together, negotiations between brother/ sister over room or computer etc., what to eat, where to go on vacation

#### **Youth**

- Youth report having a say (along with other family members) in decisions that affect themselves as well as other people in their family
  - o E.g. how to decorate their room (parents might have to pay), where to go for dinner as a family, what to watch on TV as a family,
- Youth report family members accounting for likes, dislikes, pragmatics etc.

#### **Siblings**

- Siblings report that decisions that affect multiple family members are made together/ negotiated based on family members' likes, dislikes, morals/ conventions, perceived fairness, pragmatics
  - o E.g. which sibling gets to use an item (TV, computer), where to go for dinner, when to go shopping together etc.
- Siblings report that affected family members all have a say in the outcome

**Theme 1a 2.b) Family members communicate that parents have the final say on a range of issues that fall into domains other than personal (conventional, moral, multifaceted, prudential, and friendship domains)**

#### **Parents**

- Parents report that they have expectations about moral issues (respect and responsibility, which are generally followed
- Parents report having the final say on numerous issues that are seen to fall outside youths' personal jurisdictions (i.e. issues that are seen to be outside boundaries of safety, norms, conventions)
  - E.g. hygiene, clothes, 'partying' at a friend's house, chores, going out on own
  - Parents often cite making the final decision in an effort to protect youth (for reasons described under overall protection theme)
- Parents say that youth ask for what they want within these domains
- Parents may make more choices for youth vs. siblings, see barriers for some reasons why parents report that this occurs (youth make choices that may fall outside of convention,

youths' perceived age is lower than actual age, parents may perceive youth to lack skills needed to make informed choices etc.)

### Youth

- Youth report a general acceptance of expectations about decisions that may fall under moral domain
  - o E.g. Treat other family members with respect, do not hurt other family members, treat other family members' belongings with respect (all)
  - o When asked if there are rules about treating other family members, some youth say yes (\*but they only say yes when asked specifically, otherwise this is described as general guidelines/ expectations that are followed)
  - o Even when youth describe some dissatisfaction with some moral expectations, they also communicate an understanding of the importance of 'being nice' to other family members
- Youth ask parents/ parents ask or tell youth about items that may fall under conventional, multifaceted, prudential, and friendship domains
  - o E.g. going somewhere alone, time to come home, money, cleaning room, chores
  - o One youth acknowledged the use of boundaries in recognition that his sister was often stopped from making choices about her clothes but 'that's probably the same with most girls'
  - o Youth do not overtly discuss safety concerns, but they do tend to communicate that parents have the final say in issues that parents discussed as safety concerns (comes up with all participants except one)

### Siblings

- Siblings report a general (both siblings and youth) acceptance of expectations about decisions that may fall under the moral domain (primarily respect issues)
  - o Siblings communicate that family members treat each other with respect, and that this is understood and accepted by all family members
- Siblings give some examples where parents have the final say on issues that fall outside boundaries of family norms/ values or where parents make decisions for practical reasons
  - o E.g. what to where (if choice pushes boundaries), to go shopping for new clothes, to do homework
  - o But, siblings do not describe youth being stopped from making choices/ parents having final say as much as youth or parents do
  - o Siblings use language like 'influenced' to describe how parents make choices for youth, or give examples where a parent may make a choice but there is room for negotiation/ room for youths' opinion within the choice
  - o Siblings also describe themselves as sometimes 'influencing' alongside parents
- Siblings do not describe safety concerns or the need to protect as affecting choice making, although they do describe parents having a strong say or the final say in issues that parents may have described as protection issues
- 

### Theme 1a 2c) Negotiations/ guidance occurs for items that may push the boundary of safety or family norms

#### Parents

- Parents guide youth to make the 'right' choice (i.e. the choice that is seen to be in youths' best interest or is most in line with family morals/ values
- E.g. having friends over, healthy eating habits
- Parents often describe guiding youth to make choices to protect youth (for reasons described under overall protection theme)
- Parents make suggestions/ try to show youth benefits of 'right' choice, but sometimes recognize that the decision is ultimately up to youth (especially re: social issues)

- Parents sometimes report ‘bribing’ youth to make the right choice
- While some parents report guiding youth more vs. sibling, some parents communicated that guiding their children to do the conventional/ moral thing is normal/ natural; ‘I would do the same for (sibling)’

**Youth**

- Youth give examples of being guided to make the ‘right’ choice (i.e. the choice fits within boundaries of family morals/ values and that is seen to be in youths’ best interest)
  - o E.g. age appropriate clothing, courses to take at school, bed time, making choices is easier when I’m ‘getting paid’, try to make choices that don’t get them in ‘trouble’
- There may be some flexibility on these issues because they may still be personal choices, although parents attempt to guide youth to a particular decision

**Siblings**

- As described in theme 1a2b) siblings communicate that negotiations take place over items that may push boundaries
- Siblings provide examples of youth being guided to make the ‘right choice’
- In describing choice making/ guidance processes, siblings sometimes say ‘we’, referring to themselves and parent(s), indicating that they likely perceive themselves to also be in a guidance/ influencing role with regards to decisions for youth (i.e. siblings and parents guide youth to make the ‘right choice’)

**Theme 1a 2d) Family members provide support to enable/ support decision making for youth (maybe this should go with making personal decisions)**

**Parents**

- parents report using adaptations to facilitate choice making for youth
  - o e.g. timer to make transitions easier, communication cards, activity to help youth understand choice etc.

**Youth**

- report using available supports/ resources to make choices (not always at home)
  - o e.g. supportive staff member at school, guidance/ coaching from parents, magnet board, communication cards

**Siblings**

- siblings sometimes report making/ using adaptations to help enable/ facilitate choice making for youth (more so with 4-s; 1-s reports more guidance vs. adaptations – this is in line with what parents and youth reported for these families as well.)
- as with guidance, siblings tend to use the term ‘we’, indicating that siblings and parents both make adaptations

**Question 1 b) how do family member think about the right to make choices with regards to the family member with ID?**

**Theme 1b 1.Conflict**

### Parents

- Parents describe feelings of tension when youth makes choice but parents worry that choice falls outside convention
  - o struggle between 'y's choice' and wanting to keep youth within boundaries of family conventions/ protect youth from falling outside conventions
  - o sometimes parents allow youth to stick with choice, sometimes parents attempt to 'guide' youth (as described above, sometimes parents have final say
  - o this is especially salient with issues concerning youths' social life and clothing choices
- Parents don't describe much interpersonal conflict between family members, they tend to describe differing opinions in terms of negotiations (as described under guidance and family decision making together)
- Parents sometimes describe conflicts between siblings, but this is interpreted as normal sibling teasing/ arguing
- Parents give examples of parent/ child conflict arising over prudential issues
  - o E.g. taking off alone, not taking vitamins (these are issues that youth would not describe)

### Youth

- Youth acknowledge the existence of conflict when they are not able to make a decision that they want to make (i.e. believe or act as though something should fall under personal jurisdiction but parents want to retain control because of concerns re: other domains) (all)
  - o E.g. watching a movie late, going somewhere on own, keeping room clean, how to treat other family members, taking vitamins
- Youth interviewed without parents describe far more actual conflict and feelings of conflict than youth interviewed with parents
  - o Most youth described little conflict, more negotiations and acceptance of family norms as reasons for not making decisions
- Some youth would not discuss issues of conflict (found out about conflict from parents)
  - o These issues would very much be considered protection issues (taking vitamins, taking off on bike alone)

### Siblings

- Siblings do not describe conflict as being an issue within household
- Instead siblings tend to describe any area of disagreement in terms of
  - o Negotiations
  - o Minor Arguing
  - o Teasing
- these minor conflict like scenarios are described as 'normal' or like sibling themselves or 'anyone' would do
- these minor conflict like scenarios tend to arise when youth want to do something that sibling wants to use
  - o e.g. use the computer
- or when sibling or parent wants youth to do something that he does not want to do
- e.g. clean room, youth does not like the shirt mom chose

## Theme 1b 2. Independence

### Parents

- Parents communicate both a desire/ reasons to continue to protect youth as well as reasons to promote/ measures to promote independent choice making/ autonomy
- Parents are particularly concerned about social and safety issues
- Social:
  - o Some parents worry that youth may be taken advantage of by peers or others



- Self Advocacy: Some parents worry that youth will not stand up for themselves or for the 'right' choice, but parents from one family believe that youth will stand up for themselves
- Parents also sometimes worry about youths' non normative friendships (described above), youths' lack of social skills, and corresponding lack of social acceptance
- Safety: Youth are perceived to be at a greater risk than siblings because of
  - Youths' perceived age is lower than chronological age
  - Youth may have shown a lack of safety skills in the past (past experience)
  - Parents may not believe that youth have flexible thinking skills needed to safely navigate real life situations
    - E.g. when to get in someone's car, when to cross the road, right from wrong, how to get to someone's house when the usual route is blocked, money sense, understanding of time
  - physical/ medical concerns may be cause for safety concerns
- At the same time, all parents are taking some measures to encourage autonomy
  - All parents/ families report making accommodations to enable youths' choice making
  - Some parents are teaching youth skills needed to address areas of concern (social and safety)
    - E.g. self advocacy skills, social skills
  - some parents describe knowing that 'it's their choice' and allowing youth space to make choice even when it is an area of worry (this is especially evident in social concerns)

### Youth

- Most (3) youth describe wanting some form of greater independence/ to be able to make more choices
- Some youth reported wanting more choices currently/ being stopped in the family from making choices that they want to be able to make
  - E.g. explicitly say want more choices, want more control of money, to stay out late, to buy what want at store
  - One youth specifically describes how he is working towards more choices (external to family home) – practicing to get a job, practicing to get up on own
- Some youth report wanting to make more choices in the future
  - E.g. to choose where to go on vacation, to choose where to work
- one youth does not report wanting to more independence
- like amount of conflict, desire for more independence/ choice currently may depend on acceptance of family norms
  - those who are less interested in making more choices currently report accepting family norms/ reasons for current level of choice making
    - e.g. recognition of physical limitations, expressed acceptance of 'age appropriate' or 'old enough'
    - others do recognize existence of family norms/ values as inhibiting choice making, but are more willing to break outside of them (for some items)

### Siblings

- Siblings do not communicate that youth should/ would benefit from more choice making or independence
- Siblings report that youth are not stopped from making choices at home, and that barriers to choice making are a natural consequence of personality or disability related characteristic (see barriers)
- Siblings also seem to accept family norms and suggest that youth do as well, which is possibly why siblings do not see a need for further choice making/ independence

### Question 3: Barriers

**\*\*\*As with all themes, issues that are perceived to stop youth from making choices are framed within the context of family morals/ values**

**- as described above, youth make choices within the context of respect and responsibility as defined by families, and parents tend to have the final say on issues that are seen to fall outside personal domain**

**- parents tended to identify more barriers than youth or siblings did**

#### Theme 31. Personal Characteristics

##### Parents

- flexible and complex decision making skills: some parents say that youth may not have flexible and complex decision making skills needed to navigate real life scenarios and therefore needed to make decisions
  - o youth may know basic rules of traffic safety, but may not know that other may not follow rules and that youth should therefore exercise caution beyond rules and therefore may not be able to go out on own
  - o youth may know basic steps to follow to go somewhere, but may not know how to deal with any problems that may arise on the way and therefore may not be able to go out on own
  - o youth may not understand the complexities of right from wrong, and therefore need additional supervision
  - o youth may not know the 'real value' of money and therefore may not be able to manage sums of money
  - o social scenarios (see social skills)
  - o because youth do not have these skills, parents describe having a greater need to protect youth
- physical: Physical issues may stop youth from being able to make choices
  - o e.g. go out on own (need wheelchair), what to wear (sensory)
  - o because of these physical issues, youth cannot make these choices because they are dangerous or defy convention
- lack of interest: parents report that youth are not interested in certain areas, and therefore do not make choices in these areas
  - o e.g social (to have friends over etc.)

##### Youth

- Youth sometimes explained that their personal characteristics stopped them from making choices
  - o age
  - o need more practice
  - o physical or medical condition

##### Siblings

- Siblings sometimes explained that youth are stopped from making choices because of their personal characteristics
  - being stopped is generally described as a natural consequence of youth's condition
    - o physical or sensory issues
    - o difficult to consider many options

#### Theme 32) External

##### Parents

- Lack of external support
  - o Some parents report that youth may not be supported at school (inclusion)

- Some parents report acting as an advocate for youth at school otherwise youth will ‘fall through the cracks’
    - Some parents report a general societal lack of support to family that would help access choices
      - E.g. misdiagnosis, not aware of funding, pressure on parents,
  - Lack of self advocacy skills: Parents report that, at home or with the family, youth tend to ask for what they want or need, but that youth may lack self advocacy skills when interacting with other people and therefore may be stopped from making a choice
    - Youth may not stand up for themselves when other people are ‘teasing’ them
    - Youth may not ask vocalize when they have a question
    - Parents worry that youth will not stand up for their knowledge of right s wrong
    - All parents describe self advocacy skills as important knowledge to include in training program
    - Some families make suggestions to youth about how to self advocate, while others are more explicitly teaching and supporting youth to stand up for themselves
      - More teaching tends to be associated with less worry about this issue
  - Social Skills
    - Youth may want to be friends with people who do not want to be friends with them
    - Youth may experience social rejection
    - Going hand in hand with self advocacy skills, youth may not stand up for themselves in social scenarios
  - Fear or lack of confidence (self efficacy): This tends to be external to family home
    - Some parents report that youth may be uncomfortable in social scenarios
      - Therefore do not have many friends
      - May not ask for what need/ stand up for themselves
    - youth may need need reassurance before attempting something new/ something that they are not sure that they can do
      - ‘if not sure of self will not make choice’

### Youth

- external to family home
  - youth reported that it is sometimes hard to ask people outside of the family for what they want
  - other people might not listen
  - sometimes policies or rules stop youth from being able to make a desired choice

### Siblings

- youth “might” be stopped from making choices outside of family home
  - not sure because do not attend the same school as youth

### Theme 33) Prior experience

#### Parents

- parents describe prior experiences as affecting current choice making
  - if youth behave in a way that is unsafe or does not follow convention → less choice in this area currently (opposite may be true if youth show respect and responsibility)
  - if youth experience rejection, may feed into lack of confidence (esp. with social)

## Appendix O

**Principal Investigator:**

Robyn Saaltink  
 MA Candidate  
 Department of Child and Youth Studies  
 Brock University  
[rs08tc@brocku.ca](mailto:rs08tc@brocku.ca)

**Faculty Supervisor:**

Frances Owen  
 Associate Professor  
 Department of Child and Youth Studies  
 Brock University  
 905-688-5550; [fowen@brocku.ca](mailto:fowen@brocku.ca)

**Family Feedback: Parents**

**Human Rights Education for Youth with Intellectual Disabilities and Families (REB #: 08-360)**

**How Do Choices Take Place in The Family Context?**

**Personal Choices:** Parents communicated that youth make choices about personal issues, issues that are seen to affect only the youth. Parents suggested that youth make these choices as long as the choices are safe, and as long as youth follow parent/ family expectations for behaviour and for how to treat other people or other people's belongings. Examples of personal choices that youth make include: what to wear, what to eat, what to do in free time, and how to decorate room.

**Choices that Affect Multiple Family Members:** Parents communicated that decisions that affect multiple family members are made together. Family members who will be affected by the outcome of the decisions tend to have a say in these decisions and family members often negotiate amongst themselves to reach the final decision. When making these choices, parents communicate that family members consider: family members' likes/ dislikes, perceived fairness, the practicality of the decision (e.g. cost, outcomes of previous decisions), family expectations for behaviour and family expectations for how to treat other people in the family. Examples of such choices include: What to watch on TV together, negotiations between siblings about who will get to use a particular room or particular item (e.g. computer), where to go for dinner, and where to go on vacation.

**Choices Other Than Personal Choices:** Parents communicated that they tend to have the final say over all non-personal issues. In other words, parents reported that they have the final say over issues related to respectful and responsible behaviour, safety, and other family norms or conventions. Examples of areas where parents have the final say include: hygiene, 'partying' at a friend's house, chores, and going somewhere independently. Parents often described making choices in these areas in an effort to protect youth for reasons such as: youth may make a choice that falls outside social conventions, youth may not have skills needed to make an informed choice, and youth's maturity level may be lower than their chronological age.

While parents may have the final say, parents suggested that youth tend to ask for what they want in these areas.

**Guidance:** When discussing choices that may be seen as personal choices, parents often described negotiating with youth or guiding youth to make the ‘right’ choice. In such cases, parents tended to describe making suggestions or trying to explain the benefits of the ‘right’ choice to youth. Parents reported that, although they do attempt to guide decision making, they do sometimes recognize that the decision is ultimately up to youth. Examples of such decisions include: wearing appropriate clothes, trying a new activity, taking a particular course at school, and socializing with peers.

**Support:** All parents gave examples of ways that they make adaptations to enable or support youth to be able to make choices. Examples of adaptations include: using a timer to transition between activities, communication cards/ board, giving youth an opportunity to try an activity before making a choice about it, using a walkie talkie to give youth an opportunity to go out alone, and visually showing youth choices.

**Conflict:** Parents did not describe major conflicts as occurring within the family context. Rather, parents described negotiations taking place between family members or normal teasing or arguments taking place between siblings. When conflict did occur between parents and youth it tended to be over safety issues. Some parents described conflict occurring when youth made or wanted to make a decision that parents felt was unsafe or unhealthy (e.g. biking a far distance without permission, not taking a vitamin). Parents sometimes described worrying when youth made personal decisions. Parents described worrying when youth made personal decisions that parents did not feel were in the youth’s best interests. Parents described this as occurring most often with social issues.

**Independence:** Parents communicated some reasons why they make decisions for and/ or protect youth. The range of issues that parents expressed wanting to protect youth from included: social rejection, emotional harm, failure, decisions that may fall outside social norms, being taken advantage of, and physical safety issues. At the same time, all parents described taking measures to promote youths’ independence. All parents reported making adaptations to enable youth to make choices (described above), some parents reported teaching youth skills needed to make more choices (e.g., self advocacy skills, social skills), and some parents described recognizing that ‘it’s youths’ choice’ even though they may worry about the outcome (this is especially relevant with social issues).

### **Barriers: What Stops Youth From Making Choices?**

**In The Family Context: Youths’ Personal Characteristics:** Parents explained that youth are sometimes stopped from making choices because of their personal characteristics. Examples of personal characteristics include:

- **Flexible and Complex Decision Making Skills:** Some parents communicated that youth may not have the problem solving or decision making skills needed to effectively deal with complex situations. Examples of such skills include: how to deal that problems that may crop up in an everyday situation, youth may know traffic safety rules but may not know that other people may not

always follow traffic safety rules, youth may not understand the true value of money, youth may be too trusting and/or may lack social skills.

- Physical: Some parents explained that physical issues may stop youth from being able to make choices. Examples include: being able to go out independently, being able to choose own clothing
- Lack of interest: Some parents communicated that youth do not make decisions when they are not interested in particular choices. Many parents believed that youth may not be interested in being more social.

**Outside Of The family Context: Lack of External Support:** Some parents reported that youth were not able to make many decisions because of a lack of external support. The range of these issues included: lack of support from staff at school, misdiagnosis, lack of information available about funding or programs, and multiple demands on parents with regards to supporting youth.

**Outside Of The family Context: Self-Advocacy Skills:** Parents explained that, at home, youth ask for what they want. Some parents expressed concern that youth may not do the same outside the family home. The range of these issues included: youth may not stand up for themselves when teased, youth may not let others know when they have a question, youth may not let others know when they need help, and youth may not stand up for the ‘right thing’. On the other hand, some parents were confident that youth would stand up for themselves.

**Outside Of The family Context: Social:** Some parents expressed concern that youth did not have strong social skills and that youth may therefore: experience social rejection, make friends with the ‘wrong’ people, and/or may not stand up for the ‘right’ thing when with peers.

**Outside Of The family Context: Fear or Lack of Confidence:** Some parents said that youth may not make certain decisions due to fear or lack of confidence. Some parents explained that youth may be uncomfortable in social situations and therefore may not stand up for themselves or ask for things they need or want. Some parents communicated that youth may need reassurance before they will do something new or something that they are unsure that they will succeed at.

**Prior Experience:** Some parents explained that youth may or may not be able to make certain choices based on previous outcomes. In some cases youth made an unsafe choice or were unable to show effective problem solving skills. In some cases parents think that youth may have experienced rejection, which may also affect their confidence.

### **Training Program Content**

**Individualized:** Most parents suggested that a training program about the right to make choices would have to be individualized. Parents communicated that program content and format would be different for different families depending on youth’s abilities, age, and interests.

**Flexible and Complex Decision Making or Problem Solving Skills:** All parents communicated that youth could benefit from learning flexible and complex decision making skills in various areas. The range of areas included:

- **Safety Skills:** Most parents reported that youth could benefit from learning safety skills in a way that goes beyond simply following rules. Specific suggestions for areas to address includes: knowing when it is OK to get in the car with someone, knowing what to do if something unexpected occurs on routine trip outside of the house (e.g. normal route is blocked), understanding that not everyone follows traffic safety rules and that extra caution is sometimes needed, understanding when it is OK to talk to strangers.
- **Social Skills:** Some parents suggested that youth would benefit from learning about social skills. Examples of areas that parents said could be useful for youth to learn about include: general interactions with same age peers, understanding that not everyone wants to be friends, knowing how to choose good friends, knowing how to stand up for what is right when with peers.
- **Money Skills:** Some parents suggested that youth would benefit from developing an understanding of money beyond what is covered at school. Some suggestions include: understanding how to budget, understanding the ‘real’ value of money (i.e. that somebody had to work for money), to not simply trust cashiers and to understand how to check for proper change.
- **Clothes:** Some parents suggested that youth could benefit from learning about wearing clothes that are appropriate for the season and buying clothes that fit properly and appropriately.

**Self Advocacy Skills:** All parents communicated that it is important for youth to learn self advocacy skills. Issues that parents described as being important included: youth learning how and when to stand up for themselves, youth learning how to stand up for what is right, youth understanding that it is OK to ask questions or ask for help when they need it.

Some parents also suggested that youth could benefit from training on issues that would help youth to be effective self-advocates. Such issues included: building confidence, understanding that help is available and it is not necessary to advocate alone, learning to take/ keep documentation as proof of past interactions, and an understanding of rights (for funding and supports).

**Skills to Enable Future Choices:** Some parents suggested that youth would benefit from learning other skills that would help them be more independent in the future. Suggestions included: organization skills, budget management skills, and knowledge of rights (mentioned above and the right to rent an apartment).

### **Training Program Format**

**Visuals:** Most parents suggested that videos or video games would be effective because they would suit youths’ visual learning styles and these formats would interest youth

**Role Play:** Some parents suggested using role play to act out scenarios that could occur in everyday life. Parents' comments on this issue included: role play may be effective in helping youth to actually practice solving problems that could occur in everyday life, role play may be effective because acting in a 'role' or in the third person would create a low stress situation for youth to practice making choices and solving problems, and it is important to balance the use of role plays to ensure that youth do not end up overly frightened or desensitized to issues that could occur in everyday life.

**Natural Opportunities for Choice:** Parents communicated the importance of allowing youth to practice making choices in their everyday lives. Examples included: Allowing youth access to candy so that they can learn to eat it responsibly, displaying snacks in clear containers or bags so that youth can see healthy choices.

**Convenience:** Some parents suggested that it would be important for a training program to be quick and easy to implement to ensure that it is actually used.

**Whole Family Together:** Some parents suggested that the training program should incorporate the entire family while other families did not state whether or not they would want a training program to incorporate the whole family.

### **Trainer**

**Trainer Should Be Able to Connect/ Communicate with Youth:** All parents stressed that an effective trainer would be someone who would be able to connect and communicate with youth about the issues in the training program.

Some parents believed that someone from outside the family home would be most effective. Reasoning included: An expert from community living or the 3Rs project would have the best knowledge of issues, youth may absorb more information when it is presented by someone other than parent, parents already have enough pressure, and another parent of someone with a disability would be able to understand youth.

Some parents believed that youth's parent should deliver the training because they would best understand youth.

**Meeting With Other Families:** Some parents believed that meeting with other families would be helpful in terms of social support. Some parents did not think that meeting with other families would be helpful. Some parents did not state whether they thought that meeting with other families would be helpful.



## Appendix P

**Principal Investigator:**

Robyn Saaltink  
 MA Candidate  
 Department of Child and Youth Studies  
 Brock University  
 rs08tc@brocku.ca

**Faculty Supervisor:**

Frances Owen  
 Associate Professor  
 Department of Child and Youth Studies  
 Brock University  
 905-688-5550; fowen@brocku.ca

**Family Feedback: Youth  
 Human Rights Education for Youth with Intellectual Disabilities and Families (REB  
 #: 08-360)**

**How Do You Make Choices?**

**Personal Choices:** Youth said that they make choices about themselves. Youth said that they make choices as long as the choices are safe and as long as they are respectful and responsible when they make their choices. For these choices, youth said that they sometimes ask their parents for what they want and that they sometimes just do what they want. Some of the choices that youth said that they make are: what to wear, what to eat, what to do in spare time, and how to decorate their bedroom.

**Family Choices:** Youth said that people in their family sometimes make choices together. Youth said that people in their family make choices together when they are trying to decide about something that matters to everyone or that matters to more than one person. Some of the choices that youth said that people make or should make together are: Where to go for dinner, what to watch on TV, where to go on vacation, and how to decorate room if parents have to pay. Youth said that when family members make these choices together they usually think about what people like, what people don't like, and what they will have to do to make the choice.

**Other Choices:** Youth said that they usually try to be nice, or not to be too mean, to other people in their family. Youth also said that they usually try to treat other people's things with respect. Youth said that their mom or dad usually makes rules or decisions about other types of choices like: what time to come home, going somewhere alone, money, cleaning room, doing chores. Youth said that they sometimes ask their mom or dad when they want to make these choices. Youth said that their mom or dad sometimes tell them what to do.

**Guiding Choices:** Youth said that their parents sometimes try to get them to make what parents think is the right choice or the best choice. Some of the things that youth said about this are: that they try to make choices that won't get them in trouble, that it is easier to make choices when they get paid, and that parents try to tell them about things like age appropriate clothing, courses to take at school, and bedtime.

**Help Making Choices:** Some youth said that they use things to help making choices easier. Some of the things youth said that they do are: ask someone for advice or help, use a magnet board, and use communication cards.

**Conflict:** Youth said that they sometimes have conflicts, or disagreements, arguments or fights with their parents when they want to make a choice that their parent does not want them to make. Some of these choices are: watching a movie late, going somewhere on own, not taking vitamin, keeping room clean, and deciding how to treat other family members. Different youth had different things to say about conflict: some people did not want to talk about arguments, some people did not talk about many arguments, but did talk about discussing choices with their parents or other people in their family, and some people talked about a lot of arguments or conflict.

**More Choices:** Some youth said that they wanted to be able to make more choices with their family. Some youth wanted to be able to make more choices now. Some of the choices youth said that they wanted to make or that they were stopped from making are: youth want to be able to stay out later, youth want to have more control of their money, and youth want to be able to buy what they want at the store. Some youth said that they wanted to be able to make more choices when they are older. Some of the choices youth said that they wanted to be able to make when they are older are: choosing where to go on vacation, choosing where to work, and choosing where to go to college. Some youth did not say that they wanted to be able to make more choices.

### **What Stops You From Being Able to Make Choices?**

**Things in the Family:** Like it says on the first page, youth said that their parents sometimes make choices for them or help them to make choices.

**Things Outside of Family:** Most youth said that things outside of their family stop them from making choices. Some of these things are: other people might be mean, other people might not listen, it might be hard to ask someone from outside the family for help or for something youth want, and rules at school may stop youth from making choices.

**Personal:** Youth said that there were things about themselves that stopped them from making choices. Some of the things youth said were: that they were not old enough to make some choices, that they would need more practice before being able to make choices about things like getting ready for school alone or getting a job, and that they could not make some choices because of a medical condition.

### **What Should be In a Rights Training Program?**

**Individual:** Some youth said that a good training program would be different for different families.

**Skills Needed for the Future:** Some youth said that it would be helpful to learn skills that would help them when they get older. Some of the things that youth wanted to learn

to be able to do are: find and live in an apartment, choose where to go on vacation, choose where to work, and choose to have a relationship.

**Other Suggestions:** Different people had different ideas for things that would be helpful to learn about. Some of the things that youth said that they would like to do are: to be able to talk about making and actually make more choices with their family, to be able to practice waking up on own, and to be able to practice skills needed to get a job.

### **What Should a Training Program Look Like?**

**Video Game or Video:** Youth said that a video game or a video would be most helpful in learning to make choices because that's what they are interested in and that's how they learn best.

**Trainer:** Youth said that they would want their teacher to be someone who they know or trust who connects with them. Different ideas for a good teacher include: mom, somebody else's mom, someone they know, trust, and respect and other families.

## Appendix Q

**Principal Investigator:**

Robyn Saaltink  
 MA Candidate  
 Department of Child and Youth Studies  
 Brock University  
[rs08tc@brocku.ca](mailto:rs08tc@brocku.ca)

**Faculty Supervisor:**

Frances Owen  
 Associate Professor  
 Department of Child and Youth Studies  
 Brock University  
 905-688-5550; [fowen@brocku.ca](mailto:fowen@brocku.ca)

**Family Feedback: Siblings  
 Human Rights Education for Youth with Intellectual Disabilities and  
 Families (REB #: 08-360)**

**How do Choices Take Place in the Family Context?**

**Personal Choices:** Siblings said that youth make choices about personal issues, issues that are seen to affect only the youth. Siblings suggested that youth make these choices as long as the choices are safe, and as long as youth follow parent/ family expectations for behaviour and for how to treat other people or other people's belongings. Examples of personal choices that youth make include: what to eat, what to wear, and how to spend free time.

**Choices that Affect Multiple Family Members:** Siblings communicated that decisions that affect more than one family member are made together. Family members who will be affected by the outcome of the decisions tend to have a say in these decisions and family members often negotiate amongst themselves to reach the final decision. When making these choices, siblings said that family members think about: family members' likes/ dislikes, fairness, the practicality of the decision (e.g. cost, outcomes of previous decisions), family expectations for behaviour and family expectations for how to treat other people in the family. Examples of such choices include: deciding which sibling gets to use a particular item (e.g. TV or computer), where to go for dinner, and when to go shopping together.

**Other Choices:** Siblings said that, within their family, there are expectations for treating other family members with respect. All family members usually accept and follow these expectations.

Siblings reported that, sometimes, parents have the final say over choices for youth. Examples of choices where parents sometimes have the final say are: what to wear (if youth is wearing something that is seen as inappropriate), to go shopping for new clothes, and to do homework. Siblings also reported that this does not happen very often. More often, siblings explained that youth and parents discuss or negotiate the outcomes of choices.

**Guidance:** Siblings explained that youth are sometimes 'guided' to make the right choice, a good choice, or the best choice. Siblings described situations when family members (parents or siblings) try to influence youth's decision by making suggestions or

discussing the benefits of a choice. Examples of choices that siblings and/ or parents 'guide' include: to buy appropriate clothes, to have friends over, and to go out of the house.

**Support:** Some siblings reported that family members, including themselves, make adaptations to help youth to be able to make choices. Examples of adaptations that family members make include: offering a few choices and using communication cards. Some siblings reported fewer adaptations and more negotiations and guidance than others.

**Conflict:** Siblings did not describe major conflicts as happening within their family. Instead, siblings reported that family members negotiated with each other, had small arguments, or teased each other. These minor conflicts were usually described as 'normal' family interactions. Disagreements, discussion, or negotiation usually happened when youth wanted to use something that someone else wanted to use (e.g. youth and sibling both wanted to use the computer) or when siblings or parents wanted youth to do something that youth did not want to do (e.g. clean bedroom, wear a shirt that youth does not like).

**Independence:** Siblings did not describe youth as being stopped from making many choices at home. Siblings did not seem to think that youth needed or would benefit from being able to make more choices at home.

### **Barriers: What Stops Youth From Making Choices?**

**In the Family Context: Youths' Personal Characteristics:** Siblings explained that youth are sometimes stopped from making choices because of their personal characteristics. For example: sometimes youth cannot make choices because of physical issues (e.g. it is difficult to leave the house alone, it is difficult to know what clothes to wear) or because they may have a hard time thinking about many options. Also, siblings reported that youth sometimes choose not make choices about things that they are not interested in. Examples of items that youth might not be interested in include: spending time with friends or joining clubs or teams.

**Outside the Family Context:** Siblings said that youth might be stopped from making choices at school or in social situations. Siblings were not certain about this because they do not see youth at school.

### **Training Program:**

**Content:** When asked what should be included in a training program, siblings communicated that they could not think of any items beyond issues already discussed. Siblings reported that youth make their own choices, siblings sometimes reported that youth know about making respectful and responsible choices, and siblings sometimes reported that youth may benefit from learning about making good choices or the best choice.

**Format:** Some siblings said that it might be useful to discuss choice making with other families and some siblings suggested that the use of visuals (i.e. a video or a video game) would help youth learn about making choices.

**Trainer:** Siblings stressed that a good teacher would be someone they know and trust who could connect and communicate with youth. Different siblings suggested that different people would make the best teacher. Examples include: mom, Community Living employees, and other families.