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# Addressing the Needs of Parents with Intellectual Disabilities: Exploring a Parenting Pilot Project

## Abstract

Beginning in the 1960s, the deinstitutionalization movement in North America resulted in people with intellectual disabilities integrating into society, forming relationships, and for some, becoming parents. As parents, additional needs were identified by research and addressed by adaptations in clinical practice. However, few policies and specialized services currently exist for these parents, with none offered within Quebec. A pilot project was developed to address this service gap in the Montreal region. International research and best practices were the stepping stone in the development of a curriculum aimed at supporting parents, the majority mothers, in their parenting role. This project is described and examples of content and feedback from key stakeholders are provided. The qualitative results on the impact of this program format may encourage service providers to develop similar groups to address their multifaceted needs.

Until the 1960s, the majority of people with intellectual disabilities were institutionalized, segregated from the rest of the community, and, because of a fear that procreation would perpetuate the disability, subjected to sterilization. Civil rights activism led to widespread deinstitutionalization in the 1970s, resulting in the re-integration of people with intellectual disabilities into the community (Kempton & Kahn, 1991). The transition was exceptionally difficult for many of this "forgotten generation" for whom very few specialized services were available, including those related to parenting (Tymchuk, Lakin, & Luckasson, 2001). This oversight was further hampered by the widely held belief that people with intellectual disabilities could not procreate due to their genetic make-up and because most had been sterilized (Tymchuk et al., 2001). Yet, despite the lack of specialized services and positive role models, people with intellectual disabilities adopted the values and goals of the broader society, including the desire to form relationships and have children (Feldman, 2002; Tymchuk et al., 2001). As a result, a need emerged for education in social skills, sexual health and reproduction, and protection from vulnerability and abuse. These early initiatives, however, were largely designed to prevent people with intellectual disabilities from procreation, not to support them with parenting skills (Kempton & Kahn, 1991).

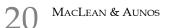
The first phase of research on parenting and persons with intellectual disability began in the 1940s and focused on heredity, as this was the concern at the time (Llewellyn, Mayes, & McConnell, 2008). In 1947, Mickelson determined that intellectual ability was not the sole predictor of parental competence and identified such factors as mental health, marital harmo-

ny, and income as impacting parenting ability (Mickelson, 1947). This discredited the idea that one's IQ was the sole predictor of child outcomes. As societal attitudes changed research redirected its focus to target the need for specialized services. This was considered to be the second phase of research on parenting and intellectual disability (Llewellyn et al., 2008). More recent research has demonstrated that an IQ above 55-60 does not seem to have a direct impact on the parenting skills of those parents who receive support in their parenting role; personal or environmental factors such as stress, parenting style, and perceived child behaviour problems have been found to be more significant (Aunos, Feldman, & Goupil, 2008; Dowdney & Skuse, 1993; Feldman, 2002; Tymchuk & Feldman, 1991). Following these findings the needs of parents with intellectual disabilities were classified into psychosocial needs and psycho-educational needs (McConnell, Llewellyn, & Bye, 1997).

Although there are conflicting views related to defining and measuring parenting adequacy, some parents with intellectual disabilities do face additional challenges to providing adequate parenting care. These challenges include a decreased awareness of basic child care skills, inconsistent parent-child interactions, difficulties in providing a stimulating home environment according to developmental ages, and decision making and problem solving difficulties (Feldman, Case, & Sparks, 1992; Keltner, 1992; Tymchuk, Yokota, & Rahbar, 1990). Children of parents with intellectual disabilities seem to have an increased risk for developmental delay and/or behaviour problems and lower academic success (Feldman & Walton-Allen, 1997; Keltner, Wise, & Taylor, 1999). Some parents with intellectual disabilities experience poor self-concept and poor mental health, social isolation, and high parenting stress levels, which increase when children reach school age (Aunos et al., 2008; Feldman, Léger, & Walton-Allen, 1997; Feldman, Varghese, Ramsay, & Rajska, 2002; Tymchuk, 1991, 1994).

The tendency to focus on parental inadequacy in research has been criticized for omitting the past and present environmental factors that also influence parenting, which reduces opportunities to identify those factors that promote adequate parenting abilities (Tymchuk, 1992). This need for a contextual perspective on the family, community, and social systems of parents with intellectual disabilities marked the third phase of research in this area (Llewellyn et al., 2008). In addition to the challenges parents with intellectual disabilities face individually, they also encounter systemic challenges, as they are also more likely to encounter worker biases that lead to unsupportive attitudes from service workers regarding their ability to parent (Aunos & Feldman, 2002). Furthermore, they are less likely to receive support from experienced professionals due to a paucity of specialized services to parents with intellectual disabilities, including resources and trainings for professionals working with these parents (Aunos & Feldman, 2002; Aunos & Feldman, 2007; Booth & Booth, 1993; Clayton, Chester, Mildon, & Matthews, 2008; McConnell et al., 1997; Wolfe, 1997). They are also subjected to stigmatization, as they are more likely to have their children removed from their care following involvement with child protection than other parents (Booth & Booth, 2004; Booth, Booth, & McConnell, 2005; Glaun & Brown, 1999; McConnell & Llewellyn, 2002). It was this disparity that called attention to the fact that parents with intellectual disabilities were experiencing difficulties in their role, forcing researchers and service providers to begin to address the needs of these parents and their children (Tymchuk et al., 2001). This relatively recent concept for social services providers and the lack of specialized services for this population more than forty years after their reintegration into the community is a growing concern, as parents with intellectual disabilities comprise approximately 0.25% of the population (Llewellyn et al., 2008; Mirfin-Veitch, Bray, Williams, Clarkson, & Belton, 1999; Murphy & Feldman, 2002; Tymchuk, 1999; Tymchuk, Llewellyn, & Feldman, 1999).

As it came to be recognized that some parents with intellectual disabilities required support in their role, researchers gradually shifted their focus from parents' capacity to inherently parent to their capacity to learn parenting skills (Llewellyn & McConnell, 2005; Tymchuk & Feldman, 1991). Parents with intellectual disabilities have been shown to acquire and maintain learned parenting skills when instruction uses modeling of skills, verbal instruction, and feedback of parent performance (Feldman et al., 1992). In addition, instruction is aided by visual depictions of each step of a task, the use of multiple exemplars to encourage skill generalization, repetition of material via varying presentation methods, the use of concrete, personalized and in-vivo practice sessions, and



by being delivered in the home or a home-like environment (Feldman, 1994; 2004; Feldman & Case, 1999; Feldman, Case, Rincover, Towns, & Betel, 1989; Llewellyn, McConnell, Russo, Mayes, & Honey, 2002). Llewellyn (1997) also found that parents with intellectual disabilities learn parenting skills via informal means, including family traditions, interactions with others, trial and error, and changing routines. Mildon, Wade, and Matthews (2008) found that when parents with intellectual disabilities were taught parenting skills in a manner that acknowledged their families' contextual fit (i.e., training in keeping with the parents' goals and values), parents reported feeling more satisfied and confident in their parenting roles. Parents have also identified the services that are most useful and important to them as those that are family-centered (i.e., informed family decisionmaking) and provide practical assistance (i.e., provision of resources and supports that enable parents to care for their children) (Booth & Booth, 2005; Wade, Mildon, & Matthews, 2007).

Feldman and Case (1997; 1999) have contributed to the growing body of parent training research through the creation of a self-directed, low-cost learning program. These programs used audiovisual and print materials to teach parents a variety of basic parenting skills for children ages 4 to 51 months, including health and safety and newborn care. Parents quickly learned how to use the materials and most were able to reach the same level of parenting competence as parents without intellectual disabilities and maintained these skills for at least 3.5 years. Although economical, self-directed learning programs such as Feldman and Case's deny parents with intellectual disabilities (who are often socially isolated) the opportunity to meet other parents and expand their social support networks. Furthermore, the home environment itself presents many distractions and disruptions, which may impede parents' ability to learn (Llewellyn, McConnell, Cant, & Westbrook, 1999; Lewellyn et al., 2002; McGaw, Ball, & Clark, 2002).

Teaching parenting skills to parents with intellectual disabilities has also been carried out in a group intervention format, although less frequently so (Heinz & Grant, 2003; Keltner, Finn, & Shearer, 1995; Whitman, Graves, & Accardo, 1989). These groups encouraged socialization among participants and taught parenting skills in a supportive and accepting environment using a variety of teaching methods (i.e., modeling, observation). The skills taught were based on the participants' needs and included toddler safety, basic needs of infants, and hygiene. Researchers also used a group approach to address other needs of parents with intellectual disabilities, such as increasing self-advocacy skills or using social skill training to reduce social isolation (Booth & Booth, 1999; 2003; McGaw et al., 2002). The latter benefits parents with intellectual disabilities in that larger social support networks are associated with increased psychological wellbeing and positive parenting experiences (Kroese, Hussein, Clifford, & Ahmed, 2002). It is also a cost-effective approach, as many parents can receive services simultaneously (Feldman, 1994).

Most of the programs that utilize a group format that have been developed over the years target parents of children of preschool age, or cover specific concrete tasks (Heinz & Grant, 2003; Whitman et al., 1989). Based on our literature search, none of the programs using a group format included a curriculum format that targeted more complex parenting needs of school-aged children, such as the use of discipline techniques. Furthermore, those studies that have used a group intervention format to provide parent training have failed to provide descriptive interventions, thus making it extremely difficult to replicate techniques or incorporate components into new or existing parenting groups (Heinz & Grant, 2003; Keltner et al., 1995; McGaw et al., 2002). Reviews of parent training interventions between 1983 and 1993 and between 1995 and 2003 reveal that the vast majority of research focused on individual intervention using home or home-like instructional settings. Very little research included the use of group intervention as an alternative to individual intervention with parents with intellectual disabilities (Feldman, 1994; Wade et al., 2008). Therefore, an important gap in the literature has emerged, as addressing the needs of these parents through group intervention has not been described nor researched extensively (Feldman, 1994; Hur, 1997; Wade et al., 2008).

Despite the innovative and encouraging research conducted on parent training programs, analyses of these programs revealed that research in this area is still in its infancy. Researchers have also neglected to obtain feedback from parents in relation to their satisfaction with the parenting training they have received, thus making it difficult to determine which aspects of the program they liked and disliked (Feldman, 1994). Eliciting consumer satisfaction has been done in research with parents receiving support with parenting skills on an individual basis, but seldom in relation to group intervention and never on a weekly basis (Booth & Booth, 1999; Heinz & Grant, 2003; Mildon et al., 2008; Young & Hawkins, 2005). Therefore, a second need in the literature on parenting with an intellectual disability has been identified, which is that descriptions of interventions include feedback obtained after each session from the parents participating in a parenting program that uses a group intervention format. This will determine whether the interventions are in keeping with the participants' values and needs.

## **Provincial Situation Around Parenting Services**

Services for persons with intellectual disabilities in Canada are under provincial laws; in the province of Quebec these services are under the ministry of health and social services. Although a reform of services is underway, limited specialization of services related to parenting has been implemented within rehabilitation services. Thus, within the province of Quebec, no specialized programs existed prior to 2005 to support parents with intellectual disabilities in maintaining custody or visitation rights or in regaining custody of their children (Aunos, 2000; Fédération québécoise des centres de réadaptation en déficience intellectuelle et en troubles envahissants du développement, 2008). This has widespread implications, as parents with intellectual disabilities who maintain custody of their children are more likely to be involved in their community, report more satisfaction with the services they receive, and have higher incomes than those who lost custody of their children (Aunos, Goupil, & Feldman, 2004).

As the Montreal Declaration on Intellectual Disability dictates: "States must guarantee the presence, the availability, the access, and the enjoyment of adequate services based on the needs and the free and informed consent of persons with intellectual disabilities" (article 5b; Montreal Declaration on intellectual disabilities; PAHO/WHO, 2004). This issue of gaps in services should be acknowledged, and innovation is needed in addressing the needs of parents with intellectual disabilities in order to create positive change. This paper will describe a pilot project that addresses the psycho-educational and psychosocial needs of parents with intellectual disabilities using group intervention and a specialized parenting curriculum at a rehabilitation centre in Montreal, Quebec. This project was carried out over a three-year period and has led to the development and implementation of the first specialized services for parents with an intellectual disability in Quebec.

## Addressing the Need: Describing a Parenting Pilot Project

### **Objectives of the Article**

The authors will provide a detailed description of the creation and implementation of a group for parents with intellectual disabilities, and will do so according to three objectives. The first is to describe the participants' perception of curriculum, and the second is to describe the participant and staff satisfaction with the program. These two key informants were chosen because this project is aimed at impacting the lives of the participants and their families, and the work of the professionals working with these parents. The third objective is to provide a detailed description of the project that will encourage replication, addressing the paucity of services for parents with intellectual disabilities.

## **Planning Phase**

The parenting pilot project was created to address the identified need for specialized support for parents with intellectual disabilities in the Montreal area. The project's objectives were to identify the specific learning and practical needs of parents with intellectual disabilities through participant assessments and interviews, develop a needs-based parenting curriculum, administer the curriculum via a parenting group that supported participants in their parenting role, and determine the satisfaction of the project's key stakeholders' with the project. The project's main research goals were to determine the curriculum's impact on participant stress, parents' understanding of child development, and parenting abilities. The project was developed within the research department of the West Montreal Readaptation Centre<sup>1</sup> and Centre de Réadaptation Lisette-Dupras, which are public social service establishments that provide habilitation, rehabilitation, and social integration services to individuals with intellectual disabilities and pervasive developmental disorders/autism spectrum disorders. It was supported as part of a general grant offered to a research team, from the Fonds québécois de la recherche sur la société et la culture (FQRSC), which enabled a psychologist and psychoeducator to implement the project. Student interns facilitated each group session and participated in evaluating the project. The project was carried out in three phases: assessment, intervention, and post-intervention assessment; qualitative and quantitative data were collected to monitor and document the process and outcomes.

## **Key Informants**

Participants. Participants in the parenting project were identified through the rehabilitation centre's access department. In order to receive services, clients were required to have an intellectual disability as defined by the American Association on Intellectual and Developmental Disability (AAIDD), (Luckasson et al., 2002). This definition requires one to have an IQ score of at least two standard deviations below the mean and exhibit significant deficits in adaptive behaviours (including communication, social, and conceptual skills), both acquired before the age of 18. Eligibility criteria for participating in the parenting group required that the participants be clients of the rehabilitation centre and that they have at least one child; the participant was not required to have custody of their child during their participation in the project. Twelve parents were initially identified for specialized parenting services, and eight were deemed suitable for group intervention. Two of these parents subsequently refused services, and two others were later deemed ineligible due to personal circumstances that would interfere with their capacity to learn in a group setting. Those parents who did not participate in the parenting group received the curriculum individually. Two parents were referred to the program in its second year and one in its third. Participant characteristics are presented in Table 1.

The participants' consent was obtained using clearly worded forms and a true-false questionnaire to ensure that participants understood the nature of the project, their involvement in the project, and the research implications in terms of publication of data (Munford et al., 2008). The participants' caseworkers also provided consent to participate in the parenting pilot project. Their participation involved reviewing the curriculum individually with their clients each week and their comments regarding its use were then gathered for analysis. Ethics approval for the parenting project was obtained from the Université du Québec à Montréal (UQAM)'s ethical board and by the Comité d'éthique de la Recherche Conjoint (CÉRC-CRDITED). Several meetings were arranged between the intern and the participant, first to build rapport and obtain consent to participate, and then to complete the assessment phase of the project. Following the assessment phase, the intervention phase began when participants attended the parenting group and received the parenting curriculum.

The participants varied in terms of their literacy and social skills and level of participation in the group but came from similar socioeconomic and cultural backgrounds. The ages of the participants' children also varied considerably, from four to twenty years old. In addition, events in the participants' personal lives impacted their participation. For P1, mental health issues made it difficult for her to attend group each week. P4 was unable to travel independently and received assistance with transportation via grant funding during the first year of the project. During the second and third year she attended only when her caseworker arranged to bring her or if P5 arranged to travel with her. In addition, P4 also cared for a sick partner during the third year, which impacted on her attendance; she attended the group more regularly following his death. P5 and P2 found part-time jobs during the third year of the project which sometimes impacted attendance, as did school closures, child or participant illness, and bad weather for all partici-

Editors' Note: Although the Centre de réadaptation de l'Ouest de Montréal translates its name as "West Montreal Readaptation Centre," the term "rehabilitation centre," more common in Ontario, is used in the text when referring to the centre.

							Atter	ndanc	e (%)
Participant	Age	Gender	Marital status	Ages of children	Child disabilities	Parenting situation	Year 1	Year 2	Year 3
P1	46	Female	Divorced	17	Intellectual disability	No custody, weekend visits	50	68	28
				18		No custody, weekend visits	50		
P2	40	Female	Single	6		Custody	100	100	84
P3	42	Female	Separated	10	Intellectual disability	Interfamily adoption, daily contact			
				14		Interfamily adoption, daily contact	87	94	92
				17	Intellectual disability	Interfamily adoption, placement			
P4	52	Female	Divorced	17	Hearing impairment	Custody (daily contact)	100		24
				18	Hearing impairment	Interfamily adoption (little contact)		94	
P5	46	Female	Divorced	9		Custody	N/A		
				18	Intellectual disability	Custody		57	72
P6	50	Female	Widowed	11	Intellectual disability	No custody, weekend visits	N/A	N/A	96
				20		Age of majority			
P7	45	Female	Married	4	Autism	Custody	N/A	N/A	72

pants. Despite these challenges, average attendance rates were generally high, with 84% attendance in the first year of the program and 82% in the second year. Average attendance was 66% in the third year, but when the attendance rates of those who attended irregularly (i.e., P1 and P4) were excluded the average attendance rate increased to 83%.

*Workers and interns.* The workers involved in supporting their clients involved in the parenting project were employed by the rehabilitation centre. They had approximately 16 to 35 years of experience and had been employed at the centre for between 12 and 24 years. The

frequency of meetings with their clients typically ranged from one to four per month, and support included understanding and working with the youth protection system, and accessing community and government resources (i.e., low-income housing, daycare, social assistance). The group was facilitated primarily by social work and psychoeducation interns completing their internships at the rehabilitation centre, as well as professional social workers. They were supervised on a bi-monthly basis by the principal investigator, a psychologist specializing in parenting and intellectual disability who is employed by the centre, who also provided additional support to interns on a needs-basis. The interns also received individual support on a weekly basis from their assigned supervisors, social workers employed by the rehabilitation centre. The interns received 12 hours of training from the principal investigator and/or a social worker involved in the project. Training topics included personal and societal factors impacting the parenting abilities of parents with intellectual disabilities, the unique needs of parents with intellectual disabilities, and how to conduct assessments using the tools chosen for the project. Trainings also included the use of case scenarios to help interns to solve potential problems or ethical dilemmas they may encounter as group facilitators (i.e., maintaining participant focus, addressing the disclosure of child abuse).

### Creating the Curriculum

The parenting curriculum was developed by a psychologist, a psychoeducator, and a social worker over a three-year period. Graduate social work and psychoeducation interns were also involved in developing 18 of the sessions. During the first year of the project, the curriculum consisted of eight sessions. During its second and third year of operation, the parenting project curriculum was comprised of a total of 40 two-hour sessions covering 34 topics (see Tables 2 and 3). The topics and skills included in the curriculum were chosen based on the needs identified by research on parents with intellectual disabilities, as well as the observations and expressed needs of the participants identified in the assessment phase of the project. These include such skills as parent-child interaction, behaviour management, and first aid. Other topics that were developed into curriculums include anger management and coping with grief and loss. These skills are referred to as parallel abilities, as they assist parents in carrying out their parenting duties but are less specific than parenting skills (Aunos & Feldman, 2007). Problems and examples shared by the participants during the assessment phase and within the group were often altered and reintroduced as case scenarios as part of the curriculum.

Curriculum topics were assigned to the interns, who conducted research and developed the curriculum according to a template created by the psychologist and psycho-educator. The template identified the following sections: theme, objectives, materials, review of previous session, introduction, activities (group discussion ques-

tions, case scenarios, handouts, and worksheets), summary, homework, participant feedback, and curriculum summary for workers. The curriculum's delivery was based on the most effective teaching methods for parents with intellectual disabilities as identified by research (i.e., participant handouts with visual depictions of each point, presenting information in multiple ways, using case examples featuring challenges similar to those identified by the participants). The psycho-educator reviewed the curriculums and made recommendations to the interns. Once the curriculum was implemented the interns made changes to it based on both the intern and participant feedback (i.e., length, clarity of content). Each curriculum consisted of three components, one for each stakeholder. The facilitator used the main curriculum, which included detailed content about the topic. The participants received handouts and worksheets corresponding to the topic both during the session and for homework, and the workers received a general summary of the content of each curriculum.

#### Instruments

Evaluation tools were created specifically for the project to gather information from key groups. During the intervention phase, participants completed the Participant Feedback Questionnaire at the end of each session, which included visual aids depicting the session components. Due to varying literacy levels, participants circled one of three faces (satisfied/happy expression, somewhat satisfied/neutral expression, and dissatisfied/unhappy expression) according to their feelings about each of the curriculum's components and their participation in the group session. The interns were available to provide clarification and assist the participants with completing their questionnaire; however, they were instructed to refrain from influencing the participants' responses. The participants were also asked to identify (verbally or in writing) what they liked most and least about each session. Student facilitators completed the *Parenting* Group Summary Form after each session to record group dynamics, session highlights and challenges, and recommendations for curriculum adaptations. These forms were distributed and completed at regular intervals during the project (weekly for participants and facilitators, annually for caseworkers). Finally, at the end of each year caseworkers completed the Parenting Pilot Project Questionnaire for Workers. Workers explained

Parenting skills	Themes
School	Parent and teacher roles and responsibilities, first day of school, establishing routine
Child Development	Areas of development (physical, social, emotional, cognitive), motor skills, language, disabilities, parent roles, developmental stages
Child Sexuality	Privacy, anatomy, puberty, personal safety
My Sexuality	Sexual relations, STIs, contraception, conjugal violence
Child/Adolescent Development	Parent roles, developmental stages and changes, adapting parenting style
Play	Parent roles, age-appropriateness, imaginary friends,
Non-Verbal Communication	Importance of communication, body movements, facia expressions, personal space
Discipline	General discipline strategies, determining age- appropriateness
Verbal Communication and Positive Reinforcement Techniques	Listening, speaking, comprehension, self-expression, positive and negative reinforcement
Consequences and Time-Out	Behaviour, action and reaction, consequences, corpora punishment, time-outs
Review of Child Development and Problem Solving	Review of developmental stages and changes, decision making, problem solving techniques
Child Development: Emotional Development and Attachment I	Influence of childhood attachments on parenting, chil development, influential factors
Child Development: Emotional Development and Attachment II	Secure and insecure attachments, enhancing parent- child attachment
Parent-Child Interaction: Play and Imagination I	Importance of playing with children, game rules and characteristics, economical toys
Parent-Child Interaction: Play and Imagination II	Sportsmanship, social context of play, requirements fo play, encouraging play
Parent-Child Interaction: Play and Imagination III	Integrating play into daily life, videogames and computers, positive game qualities, identifying unsafe games
Review of Parent-Child Interaction: Language and Communication	Non-verbal and verbal communication techniques, assertiveness
Parent-Child Interaction: Language and Communication- Listening, Understanding, and Respecting	Parent-child communication and child development, active listening, understanding, open and closed questions
Parent-Child Interactions: Language and Communication-Increasing Sensitivity Toward Child	Teaching empathy to children, responding to children needs, encouraging empathetic behaviour
Self-Esteem and Assertiveness in Children	Importance of building self-esteem in children, positiv self-concept, teaching assertiveness skills to children

Table 2. Parenting Skill Curriculum Topic

(continued on following page)

Parenting skills	Themes		
Stress Management in Children	Recognizing stressful situations for children, helping children to recognize and express stress, stress management techniques for children		
Behaviour Management: Redirection and Ignoring	Understanding and using redirecting and ignoring techniques, determining proper use of techniques		
Behaviour Management: Correction, Over-Correction, and Repetition	Diminishing negative behaviours, consistency, consequences		
First Aid I	Prevention, emergency situations, first aid kits, recognizing emergencies (e.g., bleeding, fever)		
First Aid II	Reacting to common emergencies (choking, poisoning, seizures), determining consciousness		
Nutrition I	Canada Food Guide, healthy choices and diversity, nutrition for children, food allergies		
Nutrition II	Benefits of healthy eating, serving sizes, techniques for encouraging healthy eating, snacks		

whether their expectations of the project were met, disclosed changes they observed in their client since beginning the project, and indicated the amount of time they dedicated to the project. Student interns were asked to complete a questionnaire about their experiences, impressions of the group, and the amount of time spent working within the parenting project during their internship. During the last group session participants were also asked to verbally describe what they liked and disliked about the group.

### Procedure

In order to describe this parenting pilot project, a content analysis of documents related to the project was performed. The documents included the official proposal for the project prepared by the psychologist involved in the project and annual reports of the project for each year of implementation. Following this step, interviews with key informants, regarding the planning phases of the project, and participants, regarding their perceptions of the project, were carried out. The participant, student facilitator, and caseworker feedback forms regarding satisfaction and recommendations were also examined.

The questionnaires presented in the instrument section were used to gather information in rela-

tion to the participants' satisfaction with the program, its format, and its content. Authors analyzed the content and looked at themes that were discussed and presented in those questionnaires. With this content analysis, authors were able to synthesize general themes and adapt the content and format of the program for future use. The intention of this paper is to describe the creation and implementation of a parenting group; therefore, only the qualitative data will be described. It is beyond the scope of this paper to describe and interpret the quantitative results of the parenting pilot project.

# Implementation of Parenting Curriculum and Group

## **Process of Group**

The group met weekly for two hours during the academic year and was introduced to a new curriculum topic each week. During the program's three years the group met for eight weeks, 20 weeks, and 21 weeks, respectively. Each parent was assigned an intern with whom they completed assessments and from whom they later received psychosocial support as needed.

Table 3. Parallel Skill Curriculum Topics			
Parallel skills	Themes		
Welcoming	Introductions, description of group, establishing rules, ice breaker activities		
Department of Youth Protection (DYP)	DYP roles and process, personal experiences, parent rights and responsibilities, children's rights, neglect and abuse		
DYP: Grief and loss	Loss, experiences of loss, stages of grief, coping strategies		
Stress	Recognizing signs of stress, negative effects of stress, stress management techniques		
Anger management	Emotions, recognizing anger, identifying causes of anger, anger management techniques		
Needs and self-esteem	Needs, support networks, passiveness, aggressiveness, assertiveness, relationships, how to say "no," respect		
Rights and self-assertiveness	Recognizing when to be assertive, self-assertiveness, rights, self-assertiveness in practice		
Support and community resources	Personal values, friendship, social situations, personal interests, locating and accessing community resources		
Dealing with your own disability	Defining disability, identity, emotions, personal experiences, stages of grief		
Dealing with your child's disability	Emotions and experiences of loss, recognizing strengths, limitations, and rights of children with disabilities, locating resources		
DYP and loss	Sharing experiences of having a child placed, grief and loss, coping strategies		
Dealing with death, adoption, and loss	Benefits of sharing experiences, death, reactions to loss, coping strategies		

The curriculum topics focused on teaching parenting skills and parallel skills (i.e., skills used in both parenting and daily life). Participant handouts with pictures and simple text were used frequently in the sessions to increase understanding. Group rules established at the beginning of each year during the "Welcoming" sessions ensured that the participants respected each other and that their information remained confidential. The group was conducted in a manner that was structured, with a pre-determined topic and corresponding curriculum each week (participants were given a calendar each month depicting the group topics). The group was facilitated using a strengths-based perspective, which focused on highlighting the participants' parenting skills, normalizing their experiences and difficulties,

and developing attainable goals. The group was conducted in a manner that was accepting and non-judgmental or shaming, was structured yet al.lowed for flexibility based on participant needs, and considered the participants' individual circumstances (i.e., custody, amount of contact with and accessibility to children, and ages of children).

## **Description of Group Dynamics and Functioning**

In addition to presenting information on parenting and related skills, the curriculum gave participants opportunities to share their experiences related to the session topic. This provided participants with a safe and supportive space to share personal information and encouraged other participants to share their own experiences. This occurred in the session "Dealing with Death or Adoption" during which the participants were asked how they dealt with the death of someone close to them. The facilitator provided general examples, such as sharing their emotions with someone they trust, and the participants then shared their own experiences. In addition, participants had opportunities to share more positive information, such as during the session "Dealing with Your Child's Disability" in which the participants were invited to share their child's interests and accomplishments.

In order to promote generalization of information, the curriculum was designed to present information to participants in several different ways. The session "Self-Esteem and Assertiveness in Children" first defined the two terms, and engaged participants in a selfesteem building exercise. The session also presented problem solving case scenarios in which participants applied what they learned to help the fictional parents boost their child's self-esteem. The "Consequences and Time-out" session employed a role play of two strategies for disciplining a disobedient child, asked participants to identify the techniques used and those they used themselves, and explained how to apply consequences to their child's actions. Time-outs were then discussed and participants determined the appropriate use of this technique using case scenarios and identified the behaviours they felt justified a time-out for their own children.

The sessions often used homework sheets to encourage participants to apply what they learned to their own children. As an example, the homework sheet included in a "Behaviour Management" session required participants to apply the techniques of redirection and ignoring when their child misbehaved. The parents had to further determine its effectiveness by choosing a happy, neutral, or sad face. The participants completed the homework with their caseworker in the home environment. This encouraged participants to try new techniques and develop their skills in a supportive and familiar environment. A homework sheet was also used to help participants to apply what they learned in the "School" session. This sheet helped parents to identify the various teachers and staff involved in their child's education and to recognize who to contact when they have questions or concerns.

### Participant, Facilitator, and Worker Feedback

The tools designed specifically for the parenting pilot project were valuable sources of information in terms of obtaining feedback from participants, student facilitators, and caseworkers. Using the *Participant Feedback* forms, participants repeatedly indicated that they enjoyed the sessions from a moderate to a high degree. None of the participants circled the dissatisfied face for any of the sessions. The participants also wrote or indicated verbally that they enjoyed sharing their experiences, supporting each other, and learning new things. In addition, while participants indicated that they did not enjoy session components involving negative experiences or topics, such as "Department of Youth Protection (DYP) and Loss," they did enjoy having the opportunity to talk about their emotions related to the topic. The participants also stated that they liked the role plays and case scenarios of fictional families used in the curriculum. Further validation of the participants' positive response to the project is the fact that although some participants attended sporadically, all remained involved with the group of their own volition.

Facilitator feedback was a second valuable source of information, as the interns were able to observe the group and its participants over many sessions. They observed that all participants felt more comfortable sharing personal information and participating in the group in general as it progressed. The facilitators also noted, on several occasions, that the participants noticed similarities between the case scenarios and their own experiences with their children, as was intended by the curriculum's creators. In addition, sessions related to parenting younger children (e.g., Play, Child Development) provided opportunities for parents of older children to advise the participants with younger children. The facilitators also noted the participants' recommendations for adapting the curriculum, such as incorporating alternative stages of development in the "Child Development and Problem Solving" session, as several participants' children had developmental disabilities.

Other observations made by the facilitators were that the participants regularly forgot to bring their homework sheets and that sessions with very high participation or a large amount of information were difficult to complete within the allotted time. In addition, the facilitators indicated that those participants who did not have custody of their children found it upsetting to learn about child development, as they had not been actively involved in their children's early years. They also reported that these participants found the "Attachment" sessions difficult because they were unable to spend as much time with their children as they would have liked. While the facilitators helped the participants to identify opportunities in which to apply what they learned and to recognize the valuable role they played in their children's lives within the session, they indicated that these parents' experiences should also be incorporated into the curriculum to a greater degree. Lastly, the facilitators noted that some participants tended to dominate discussions and that the discussion sometimes got off topic if a participant disclosed a crisis they were currently experiencing which the facilitators felt required immediate attention.

The participants' caseworkers were a third valuable source of feedback in the parenting pilot project, as they worked with the participants individually in relation to parenting and other issues. Specific benefits noted by caseworkers included increased positive parent-child interactions, confidence in parenting abilities, competence in setting limits, and decreased social isolation. They also felt that their clients' participation in the program allowed them to reduce the amount of time spent supporting them on a weekly basis and that the group was beneficial to their clients. Early feedback indicated that the caseworkers wanted to be more informed about what their client was learning in the parenting group. However, more recent feedback indicated that they did not have time to regularly review the curriculum summaries (sent weekly by student facilitators) with their clients during home visits. The caseworkers also indicated that they wanted to be invited to some of the sessions and that their clients wanted to return to the group in the future.

## Discussion and Recommendations

The objectives of the parenting project were to determine the learning needs of parents with intellectual disabilities through interviews and assessments, to develop and implement a curriculum based on these needs, and to evaluate the key informants' satisfaction with the project. Within the parenting project, parents were viewed as experts who were capable of caring for their children, developing their children's potential, and having an influence on their development, regardless of the level of involvement in their children's lives. The curriculum itself was developed based on their expressed needs and the research on the needs of parents with intellectual disabilities (Feldman, Case, & Sparks, 1992; Keltner, 1992; Tymchuk, Yokota, & Rahbar, 1990). The awareness of the physical and environmental (contextual) variables impacting on the participants and their parenting abilities was acknowledged in the group, as participants were asked to identify supportive people in their social network and discuss personal struggles and losses in the project's assessment phase. Including the participant examples obtained during this phase in the curriculum increased its relevance and usefulness, as the participants recognized themselves in case scenarios and applied skills learned in that particular session in order to problem solve. Obtaining regular feedback from the participants allowed for adaptations to the curriculums in order to best meet the participants' needs.

According to its key stakeholders, the parenting project was a valuable support for parents with intellectual disabilities, as it provided parents with a weekly opportunity to meet with other parents, learn new things, and share experiences. The high attendance and participation of the participants is also indicative of the participants' satisfaction, and relatively rare for programs with this population (Heinz & Grant, 2003; Ray, Rubenstein, & Russo, 1994). The mechanism of the group itself was useful to the participants, as they had a regular forum to bring their problems and questions, and were able to obtain support and information given in a way that was adapted to their learning needs. As some participants were involved with the project over a three-year period and thus became well acquainted with the project's staff, the staff were better able to

determine how to best respond to these participants' requests for support based on their knowledge of the participants' situations. This type of specialized assistance is invaluable to these parents and their families, as they had few alternative sources of support. A timely example of this need is the H1N1 virus; parents with intellectual disabilities require adapted information about prevention and treatment concerning potential health hazards in order to make informed decisions about protecting the health of their families. Furthermore, although the impact of the social aspect of the group was not measured, other studies have found that parents with intellectual disabilities benefit from attending a group due to improvements in their self-confidence, self-concept, and the size of their social network (Booth & Booth, 1999; Heinz & Grant, 2003; McGaw et al., 2002).

Recommendations for improvement in the parenting pilot project included addressing the fact that the participants regularly forgot to bring their homework sheets to the group for discussion. This may have been because the participants did not perceive it as being important. Some may have viewed the group as an opportunity to have discussions and meet other parents as opposed to being a more formal activity. A review of those homework sheets would be necessary as comprehension levels or their application may also be a factor. A second identified issue was the impact of certain parents monopolizing the group time. Incorporating this issue into the group rules for future reference or providing further information to support the parents on these issues could address this problem. However, if a participant described a current crisis in the group, dealing with that crisis took priority over completing the curriculum, and the crisis was either discussed during the group when relevant, or individually during or after the group with a facilitator. Participant monopolization and crisis management were also issues in the parenting group described by Heinz and Grant (2003), which can be indicative of the limited number of supports these parents have to share their concerns and experiences. Finally, the sessions that the facilitators noted as being too long to complete within the allotted time should be adapted into multiple sessions. These sessions were mostly regarding child development stages and child behavioural management strategies; further discussion of these strategies and their application was deemed necessary to ensure comprehension of all participants.

Although the objectives presented here were achieved, there were limitations to accomplishing more in the parenting project. The lack of funding to continue working with the group, in addition to the fact that caseworkers did not have time to review the curriculum with their clients each week (despite providing positive feedback about the value of the group to their clients), show that well-designed interventions cannot be fully implemented without adequate resources, training, and funding (Clayton et al., 2008). And yet, the results of the project suggest that parents with intellectual disabilities benefit most from more than one type of support (Booth & Booth, 1999; McGaw et al., 2002; Ray et al., 1994). The individual practical support (i.e., housing, youth protection) could not be provided in a group setting, while having a weekly opportunity to share experiences and focus exclusively on parenting and related needs could only be possible through participation in the group.

The small sample size makes it difficult to draw conclusions about the population of parents with intellectual disabilities and additional research is needed to support the positive outcomes of the project reported by the key informants in the group. Validation of the program and its teaching methods with a larger sample size, as well as a review of ways to support front-line workers in the implementation and follow-up of such interventions, would be good starting points. With proven interventions that teach parenting and parallel skills to parents with intellectual disabilities, service providers and researchers may be encouraged to develop their own parenting programs and to examine their current policies and procedures related to supporting parents with intellectual disabilities. Recommendations for future research into parenting and intellectual disability also include studies aimed at outcomes for children, increasing generalization of parenting skills, and identifying factors that promote and inhibit training outcomes (Hur, 1997; Wade, Llewellyn, & Matthews, 2008).

It has been suggested that until parents with intellectual disabilities reach critical mass status, defined as the population size necessary for a group and its needs to be recognized, their needs and those of their families will continue to be unacknowledged (Tymchuk et al., 1999). Without the funding and supports to benefit from the research that has been and continues to be done, parents with intellectual disabilities and their children will continue to be marginalized and prevented from optimizing their learning and maximizing their potential as parents.

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