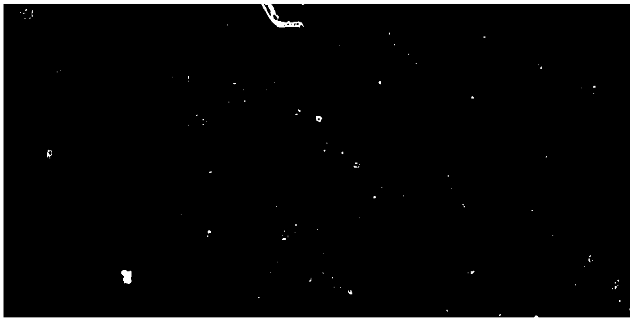

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Two necessary conditions combined to make the completion of this thesis a reality:

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Chapter 1

Introduction

The research literature abounds with studies that deal with the sexual abuse of children. The Seattle Institute for Child Advocacy study conducted in 1985 (cited in Goldman & Gargiulo, 1990) reports that one out of every four girls (25%) and approximately one out of every seven to 10 boys (10%—14%) will experience some type of sexual contact with an adult before age 18. Bass and Davis (cited in Willmuth & Holcomb, 1993) state that one out of every three (33.3%) American females and one out of every seven (14%) American males are at risk of being sexually abused before reaching age 18. A 1988 Saskatchewan Council on Children and Youth conference report on sexual offenses against children states that "at some time during their lives, about one in six (17%) females and one in 12 (8%) males had been victims of one or more direct sexual assaults" (p. 7).

Kempton and Stanfield (cited in Willmuth & Holcomb, 1993) estimate that people with mental retardation are sexually abused four times more often than people without mental retardation. Baladerian (1994) estimates that "children with disabilities are abused at rates at least twice that of the general population and up to approximately 10 times this rate" (p. 93). A national survey conducted in the United States for Westat by Crosse, Kaye and Ratnofsky (1993) reported "the incidence of maltreatment among children with disabilities was 1.7 times higher than the incidence of maltreatment for children without disabilities" (p.vi). Sobsey & Varnhagen (1991) reported the risk for sexual abuse of children with disabilities, or the sexual assault of adults with disabilities is about one and a half times greater than their same-age peers.

The goal of qualitative research is to understand a specific group of individuals and how they interact in their social setting (Berg, 1989). In other words, qualitative studies attempt to describe and explain the life world of a particular group of individuals: "Life worlds include emotions, motivations, symbols and their meanings, empathy, and other subjective aspects associated with naturally evolving lives of individuals and groups" (Berg, 1989, p. 9).

Research Question

Given the overwhelming statistics on incidence rates of sexual abuse, how do parents of adolescents with disabilities cope with their sons' or daughters' vulnerability to sexual exploitation? This study is designed to describe and analyze the life world of parents of adolescents with disabilites in relation to their sons' and daughters' vulnerability to sexual exploitation.

Chapter 2

Literature Review

Although there are books that examine the sexual abuse of children, few of them focus on the sexual abuse of children and adults with disabilities. Sobsey's *Violence and Abuse in the Lives of People with Disabilities: The End of Silent Acceptance?* (1994) is an exception. The first half of Sobsey's book focuses on understanding the abuse experienced by people with disabilities; the second half examines its prevention.

One chapter in Sobsey's book (1994) focuses on the family and individuals who assume the responsibility for caregiving to people with disabilities. This chapter discusses a study (Sobsey & Doe, 1991) that examined the characteristics of offenders who commit offenses of a violent and sexual nature against people with disabilities, and this study found that family members, paid caregivers, and other people with disabilities are responsible for more than half of the abuse experienced by individuals with disabilities.

Research in the general field of child abuse has identified seven factors within families that are associated with increased risk for abuse: isolation, disruptions in attachment among family members, attributes of family members, substance abuse, attitudes toward potential victims of abuse, history of violence, and the perceived stress of caregivers. Sobsey applies these factors to families who have a member with disabilities, in his chapter on families with a member who has a disability. The latter half of this chapter is devoted to ways in which families can be assisted to reduce these factors, thereby reducing the likelihood of abuse. Sobsey suggests that preventive strategies will increase the probability that individuals with disabilities continue to live safely within their natural family homes. If people with disabilities avoid out-of-family placement, they also avoid the increased risk for abuse associated with this type of living arrangement.

Scholars as Parents

An unique situation exists in the field of disabilities research since many scholars are also parents of children with disabilities. By combining personal parental experiences with their professional knowledge and expertise, these scholars bring invaluable insights to the field. Two such scholars are Ann Turnbull and H. Rutherford Turnbull III. In their second edition of *Families, Professionals, and Exceptionality: A Special Partnership* (1990), they present a comprehensive value-based guide on how to "apply the family—systems approach in the context of exceptionality across the life cycle" (p. viii).

The family—system approach is a theoretical framework that explains the family as a system, with components that encompass the demographic and personal characteristics of family members and the interaction patterns within and outside of the family. The goal of the family—systems approach is to explain how these characteristics and patterns are used to meet the needs of family members as they progress through the family life cycle (Turnbull & Turnbull, 1990). Turnbull & Turnbull (1990) feel that the family constantly juggles these components throughout the life cycle in order to achieve a point of balance within the system.

After passing through the first two stages of the life cycle (birth and childhood) the family encounters the transition to adolescence and then to young adulthood. Adolescence is usually signalled by physical and psychological changes: "In a national study, conducted by Olsen, McCubbin, Barnes, Larsen, Muxen, and Wilson in 1983, with over 1000 families in the general population parents reported that the life cycle stages of adolescence and young adulthood were the two stages with the highest amount of stresses and strains" (cited in Turnbull & Turnbull, 1990) . Turnbull and Turnbull (1990) describe four issues encountered by families of adolescents with disabilities: sexuality, growing stigma concerning exceptionality, increased need for physical care, and the development of self-advocacy skills.

Research on Parental Concerns

In a study by Mellon, Wilgosh, McDonald & Baine (1993), parents of adolescents or young adults with severe disabilities were interviewed using in-depth questioning techniques about the types of stresses experienced by their family in the last five years or anticipated in the next five years. The future, the realization that the child has become an adult, and concern with individual vulnerability, defined as incapacity to protect oneself from life's dangers, are three of the six major themes identified in this study. These authors state that parental concern about a "son's or daughter's future was closely linked to individual vulnerability, and physical, financial, sexual, and psychological abuse" (p. 8).

The Brotherson et al (1988) study on parent planning for adult needs of young adults with mental and physical disabilities did not identify affection and sexual expression as important needs. Instead, residential needs, socialization opportunities, and employment needs were considered most important to parents of young adults with disabilities.

Wilgosh (1990a) used an open-ended interview technique to ask parents with offspring who had a wide range of disabilities (e.g , visual and hearing impairments, severe intellectual disabilities, moderate intellectual impairments, learning disabilities) about their parenting experiences. She reports that issues of sexuality education or physical and sexual abuse did not arise, perhaps because the topics were too personal or not part of the family's experience.

In Britain, Hannam (1988) interviewed 29 individuals who had family members with disabilities at three different times over a 13-year span. One interview period focused on adolescence. He provided the following insights: "As we were discussing adolescence and adult life, sexual matters inevitably cropped up but were not discussed in great detail. This is hardly surprising as most of the parents hardly knew me and I did not want to push the interview beyond the limits of their tolerance" (p. 157).

Perhaps other studies have not revealed concerns about vulnerability because of their methodology. Barry's study (1982) examined parental involvement in their child's education and recommended that an in-depth, structured interviewing technique be used, rather than an open-ended interview technique. She states that although the latter technique was conducive to general responses from parents, it revealed little or no information about specific concerns or suggestions.

Thorin and Irvin's (1992) quantitative study contains suggestions for future research. They observe that, "responses from family members regarding stressful concerns in their lives appear to be contingent upon the questions asked" (p. 38). These authors suggest that in order to understand the stress "both, content domains of concerns and type of question must be considered" (p. 38). The most frequently mentioned concerns fell within what Thorin and Irvin (1992) label the Young Adult Daily Life Domain.

Research on Parental Concerns— Sexuality and Abuse

All adolescents strive for independence from parents in the quest to form their own identity, including a sexual identity (Turnbull & Turnbull, 1990). Teenagers with disabilities are no different. They need to develop self-identities separate from their parents and to accept their maleness or femaleness as one aspect of their self-identity. The dependence/independence struggle was cited by about half of the 25 families with offspring with mild disabilities studied by Zetlin and Turner (1985) who used a life history/observation approach. Many of these parents attempted to cope with their anxiety about their sons' or daughters' sexuality by imposing restrictions on their movement within the community. Zetlin and Turner (1985) report that this strategy resulted in one of two outcomes: an inhibition of sexual awareness and development or defiance of the parental restrictions.

Reporting on a panel discussion that involved parents held at the Sexual Assault and Abuse of People with Disabilities International Conference, Wilgosh (1990b) describes two levels of parental concerns: Parents on this panel were concerned about actual abuse and assault cases and prevention of assault and abuse of children and adults with disabilities. These parents asked for education on prevention strategies for the person with disabilities as well as for themselves, but they wondered if this education might lead to the expression of inappropriate sexuality or result in a lack of opportunities to experience life in the community.

Wilgosh (1985) conducted a study that involved parents of adolescents who had been labelled trainable mentally handicapped, and the findings reveal two important parental concerns about their children's life skills development: an overall concern about the future of their adolescent and their children's lack of knowledge about the opposite sex. Concern about the future is summed up by one parent's comment: " She could probably be taken advantage of, if there wasn't someone around..." (p. 226).

Research on Individuals Who have been Abused

A survey of people with disabilities who have been sexually abused conducted by Sobsey and Varnhagen in 1988 revealed that the typical victim is a teenaged (median age of 16) female (84%). Victims are most likely to be abused in their home or place of residence by those individuals who spend a great deal of time with them (p. 207). Individuals with severe or profound retardation are more likely to be living in an out-of-home placement, and this survey reveals that 64% of these people were abused by service providers. Individuals who are mildly mentally disabled were most likely to be abused in their home (80%) by a family member. Within the victim group, 67% of the reported cases were identified as individuals with mental retardation, with others listed as individuals with a hearing impairment or a mobility impairment. Those identified as individuals with mental retardation were further categorized as people with mild disabilities (14%), moderate disabilities (9%), and severe or profound disabilities (14%). There were a large number of individuals (31%) in the survey who were reported as having a mental handicap, but they were not assigned to any of the aforementioned groups.

In addition to reporting the incidence of maltreatment among children with disabilities (1.7 times higher than children without disabilities), the Westat national survey (Crosse, Kaye and Ratnofsky, 1993) identified relationships between child abuse and disability, as well as the incidence of children developing disabilities as a consequence of abuse or neglect. Maltreatment was described as including physical abuse, sexual abuse, emotional abuse, physical neglect, emotional neglect, and educational neglect. Child Protection caseworkers indicated that disability contributed to maltreatment for 67% of abused children who had a serious emotional disturbance, for 76% of abused children who had physical health problems, and for 59% of abused children who exhibited hyperactivity. Data revealed that children with disabilities who experienced abuse were "more likely to be male, White, and from one-child families and over the age of four" (p. 3-5). There was a larger percentage of teens with disabilities, 14 to 17 years old, reported as maltreated (24%) than teens without disabilities (13%).

The research literature provides alarming statistics on the incidence of abuse perpetrated against individuals with disabilities. Qualitative studies have documented disturbing personal accounts of abuse and poignant accounts of the experience of parenting a child with disabilities. It is well-documented that parents of children with disabilities harbor fears about the future of their children (Mellon et al. 1993: Thorin & Irvin, 1992; Wilgosh, 1990b). When asked open-ended questions, some researchers "sensed that some of the parents hesitated to verbalize their fears concerning this topic" (Mellon et al. 1993, p. 8). Given the highly sensitive and personal nature of sexual exploitation, it is not surprising that it did not emerge or only partially emerged in previous studies. This present study frankly examines the fears and concerns of parents of adolescents with disabilities about the real possibility of sexual exploitation, thereby filling a gap in the literature.

Chapter 3

Methodology and Procedures

This study is an exploratory investigation into parental fears and concerns about the possible sexual exploitation of children with disabilities, and it was divided into two phases: The first phase involved interviewing four sets of parents who have adolescents functioning in the moderately mentally handicapped range of ability: and the second phase involved using the themes that emerged from the interview data to design a questionnaire that was sent to a larger sample (125 parents of adolescents with disabilities who were enrolled in both school systems in the city of Edmonton during the 1994-95 school year). The questionnaire responses were analyzed and compared with the data obtained from the interviews.

This study used three data collection strategies: an open-ended conversational interview technique, a closed-and opened-response questionnaire (confirmation survey), and observations of the researcher. This research method is known as triangulation, and Denzin defines triangulation as "the cross validation among data sources, data collection strategies, time periods, and theoretical schemes" (cited in McMillan & Schumacher, 1984, p. 418). A variety of techniques "allow the researchers to share in the understandings and perceptions of others and to explore how people structure and give meaning to their daily lives" (Berg, 1989, p. 6). The use of more than one technique provides more than one line of sight into the parents' life world. Interviews were conducted in Summer, 1994 and the questionnaire data were collected in Spring, 1995.

Qualitative studies have provided invaluable insights into the experiences of parenting a child with disabilities, even if the content was only slightly relevant to this study (Adams, 1987; Fong, 1992). For example, portraits of victims of abuse (Westcott, 1993; Willmuth & Holcomb, 1993) showing these victims' daily suffering have been uncovered using qualitative approaches to data collection. Although the current study focuses on parental perspectives on their children's risk for abuse, the personal accounts of abuse are useful to imagine parental reactions to their own children's abuse.

Phase I

Participants.

The population chosen by purposeful sampling for the qualitative interviews comprised parents of adolescents functioning in the moderately mentally handicapped range of ability and enrolled in programs (Education Experience II) in the Edmonton Catholic School District in the 1993-94 school year. Formal approval to approach the school district was obtained initially through the Field Experiences Office at the University of Alberta and then approval to approach perspective participants was obtained from Dr. Dwight Harley, Administrative Officer of Educational Measurement with the Edmonton Catholic School District.

Three school sites, one senior high school and two junior high schools, were contacted by telephone about the distribution of a letter inviting parent to participate in this study. There were approximately 25 students categorized as moderately or trainable mentally handicapped at these three sites. Teachers at both junior high schools were able to send the letter home with students. Because high school students had already began their summer break, one teacher willingly addressed the envelopes which were then mailed to prospective participants.

One junior high school handed out seven letters, and only one response was received by the researcher. The other junior high school handed out five letters, and no responses were received by the researcher. Of the 13 letters addressed by the high school teacher there were no responses, and two letters were returned because they were incorrectly addressed. In all, only one response was received from the Edmonton Catholic School District.

Then parent organizations were telephoned and asked whether they would be willing to send letters to parents in their organization; two organizations agreed. The Gateway Association for Community Living sent 15 letters to parents of teens with disabilities, and as well, an advertisement was placed in their July newsletter requesting parent participants. Three responses of a positive nature and two responses that indicated that their son or daughter did not fit within the criterion of intellectual functioning were received. The Edmonton Community Living Society sent 10 letters and two positive responses from their membership were received.

The researcher telephoned parents from the response sheet and asked if they were still willing to participate in the study. The need to take notes during the interview or, if they were agreeable, to tape record it was explained to these parents, and the Consent to Participate Form and their choices concerning levels of confidentiality and anonymity were described to them. A date and a time when it was convenient for an interview was requested, along with their street address. Upon completion of the interview, parents received a copy of the *GAPSS DIRECTORY, Giving Attainable Personal Supports and Services to Persons with a Disability Who Have Been Victimized or Are Victims of Crime.* This booklet, compiled by Corrine Gowers and Beth Brooks, lists and briefly describes services and resources within the Edmonton area.

Five parents were interviewed; three parents had male teenagers and two parents had female teenagers. One parent withdrew from the project after the second follow-up request for feedback on the accuracy of the interview summary. This parent cited lack of time to review the taped interview before the researcher's deadline.

One set of parents and three mothers were interviewed about their fears and concerns that their teenage son or daughter with disabilities might be abused. Parent A and Parent B have teenage daughters with disabilities, 15 and 19 years old, respectively. Parents E and Parent F have teenage sons with disabilities, 15 and 17 years old, respectively.

The teens who were 15 years old at the time of the interview are only children in their families. The two other teens with disabilities are members of large families. The 17-year-old male is the oldest of four siblings, and the 19-year-old female is the second oldest of five siblings.

The four parents ranged in age from the mid-30s to the early 40s. All four parents were married. All four stated "Canadian" as their "race or ethnic membership" although two of the mothers gave more specific information: French Canadian and Maritimer. Three of the four parent sets had obtained post-secondary education. One parent left school after grade 8. Two parents listed "homemaker" as their occupation and the other two parents indicated that they were employed outside of the home. One parent was receiving social assistance as a supplement to the family income.

Setting and data.

Interviews were conducted in the parents' homes, presumably a safe and secure setting in which to discuss private, intimate topics. Field notes that described the home setting and the parents were recorded during the interview. Key phrases and major points of the interview were noted. Room sketches were drawn indicating seating arrangements. Nonverbal communication that revealed thoughts and feelings, for example, facial expressions, gestures, tone of voice, eye contact, emphasis of words, and visual displays of emotion, were described. This allowed an interpretation to include the nonverbal as well as the verbal behavior of the participants.

Initially, parents were asked if the interview could be tape recorded and provided with a form entitled Consent to Participate Form (Appendix A). This form allowed them to select a level of confidentiality that ranged from being personally acknowledged, having their tape returned to them or erased, to omitting short phrases from the interviews. In analysis, all the names of the participants were coded to maintain confidentiality. Participants completed an interview facesheet that requested demographic information (Appendix B). Interviews averaged about two hours in length: the shortest one was an hour and 10 minutes and the longest one was two hours and 45 minutes.

The interview began with a statement of the purpose and rationale of the study. This helped to focus responses and to encourage parents to speak frankly. An open-ended, informal conversational questioning technique was used to stimulate parents to discuss this intimate problem of sexual exploitation. To obtain parental responses and to maintain consistency on question topics, an interview guide was designed (Appendix C). The interview guide reflected the researcher's perception of the issues that might concern parents of children with disabilities.

After the first interview, questions and approaches were rethought, and changes were made to maximize the possibility of obtaining frank and open responses from the next participants. Immediately after each interview, the researcher sat down alone without distractions and summarized the interview: a composite of the highlights from memory, observer comments, and field notes (date, number of interview, place and identification code of parents). At that time, any interpretations or ideas to explore in the next interview were described. This strategy was applied after each and every interview.

Field notes were descriptive and factual. The researcher listened and tried to put herself in the role of the parent in order to understand their perceptions. A journal was kept and entries made on reasons for the decisions made about the study, as well as any assumptions or feelings experienced by the researcher throughout the duration of the study. Four of the five interviews were recorded on separate tape cassettes, and all five interviews were summarized. One parent chose not to be tape recorded. Transcripts of the four taped interviews were made for data analysis.

Interview transcripts were summarized in a one and one half page format that captured the essence of the interview. To reduce threats to internal validity, factual descriptions, including direct quotes from the transcripts, were used. Cross validation of the interview summaries was obtained by requesting parents to read the interview summary to correct any misrepresentation of their account. One summary draft required no revisions, but minor revisions were requested by the other four participants. One parent wished to listen to the tape recording, which was returned to her for this purpose. When contacted 10 days later, she stated that she did not have time to review it and did not forsee having time in the near future. In order to meet deadlines, a further delay was not possible, and this participant withdrew from the study. Revised interview summaries were re-submitted to parents for a final check as to their accuracy (Appendix D).

Thorough records were kept and included the transcripts of the interviews, field notes of observations made during the interview, and the interview summary. By creating permanent records of all data, it was possible for other researchers to review the data in order to determine the validity of the conclusions presented in this thesis (Marshall & Rossman, 1989). This record provides evidence for the dependability and confirmability of the study.

Analysis.

Inductive data analysis is a five step process: of " 1) discovery analysis in the field, 2) preliminary analysis of the data, 3) categorization and ordering data to identify emerging patterns and themes, 4) descriptive-analytical synthesis, and 5) possible extension of the analysis to integrate major findings to propose grounded concepts and mini-theories" (McMillan & Schumacher, 1984, p. 415-416).

Discovery analysis strategies in the field involved writing "'many observer comments and elaborations throughout the field notes that identified themes, hunches, interpretations, questions" (McMillan & Schumacher, 1984, p. 416). The researcher continues to read the research literature and think about how it agreed or disagreed with the observations. McMillan and Schumacher (1984) suggest that researchers "play with metaphors and analogies to grasp the essence of what has been observed" (p. 416).

Strategies used in the second step, preliminary data analysis, included organizing all the data by numbering sequentially the field notes, transcripts, and memos. Several copies were made so it was possible to rearrange this data, having preserved the originals. Data were scanned "for possible categories...themes, patterns, ideas" (McMillan & Schumacher, 1984, p. 417). The literature was read "...for useful concepts, models, or theories to help understand the data" (McMillan & Schumacher, 1984, p. 417), and the focus of study was narrowed to match the study's original question.

In the third step of data analysis, interview data were categorized and ordered by the constant comparative method, noting similarities and differences. Data were coded, and each potential category was assigned a tentative name that captured its meaning. Categories were enlarged and combined to create new categories.

The fourth and fifth steps in the process "gauged the trustworthiness of the data using—triangulation, the cross validation" (McMillan & Schumacher, 1984, p. 418) of the patterns and themes from the interview data with the patterns in the questionnaire responses.

Phase II

A questionnaire, **Sexuality And Adolescents With Disabilities Questionnaire: Parental Perspectives** (Appendix E) was designed from the interview summaries, which had been validated by the participants. Items on the questionnaire were examined to ensure they were representative of the themes that emerged from the interviews. The first draft was submitted to an expert in the field, Dr. Dick Sobsey, for confirmation that the questions included on the questionnaire were relevant to the concepts embedded in the issue of sexual abuse of people with disabilities. His suggestions were incorporated into the second and final draft.

The second phase of data collection surveyed parents of adolescents and young adults with disabilities who attended segregated school programs: the Community Life Skills Program in the Edmonton Public Schools system and the Education Experience 2 Program in the Edmonton Catholic School District. Questionnaires were distributed to eight schools: three junior high schools and two senior high schools within Edmonton Public Schools system and two junior high schools and one senior high school within the Edmonton Catholic School District.

The questionnaire package included a covering letter that stated the purpose of the study, an explanation as to why the respondent was included in the study, a request for their cooperation, plus a guarantee that anonymity would be maintained. Respondents were thanked for their cooperation in completing the questionnaire as well as for their interest in the study. A reminder note to return the form was sent out 10 days later.

Analysis.

Initially, questionnaire responses were tallied and examined by sex and age group of the adolescent or young adult. Frequency distributions were studied and sometimes sketched to display patterns embedded in the data. These patterns were compared to the categories and themes that had emerged from the interviews and assessed for similarities and differences. Where appropriate, data were calculated in percentages, cross tabulations were completed and data were displayed in tables.

Chapter 4

Results

Phase I

Interview themes.

Eight major themes emerged from the interview transcripts: fear and concern about sexual exploitation, experiences of teens during puberty (including abusive experiences), ways of coping with concern for teens' personal safety, health issues, encounters with professionals, relationships among family members, plans for the future, and approach to life.

Most parents interviewed expressed fear and concern for their son or daughter concerning sexual exploitation and stated that it is always a concern for them. Parents described their experiences with their teens during puberty and many of them related abusive experiences. One parent related incidents of sexual abuse. Two parents had felt fearful about their sons' approaching puberty. One parent talked about the way in which her son expressed rebellion. Most parents explained that although they had discussed sex education with their children in the past, presently, they did not initiate discussions unless a situation arose.

A third theme centered on ways in which parents cope with their concern for their child's personal safety. Parents stated that their son or daughter is supervised at all times. All parents expressed the word "hectic", when asked about their day-to-day life. Most parents described the personal support provided by family members, and the experience of employing paid relief workers. Two out of the four parents attended parent organizations. One parent spoke of extreme tiredness and stated that she had no time for herself.

Health emerged as a theme for teens and some parents, and most families had experienced chronic health issues. All parents discussed their teens' behavior and two parents described the improvement in their sons' behavior in the last few years.

All parents discussed encounters with professionals: medical, social services, or school. Some parents had had positive experiences but other parents spoke about their concerns regarding the manner in which they were treated and the assumptions made about their sons or daughters by professionals. Two teens were entering high school programs and these parents talked about their expectations of the school over the next few years.

Another theme focused on relationships among family members and explored sibling relations and relations with extended family members. All parents commented on the difficulty their sons or daughters experience in developing friendships.

A theme focused on parents' plans for the future for their teens and included residential plans, vocational plans, and plans for meaningful social relationships. These plans were usually discussed within the context of monetary cutbacks and changes to provincial government funding. The final theme revealed the parents' approach to life and their reflections on their life experiences.

The themes that emerged from the interview data have been integrated into the responses from the questionnaire and are described and elaborated on in other sections of this chapter.

Phase II

Participant descriptions.

Forty-seven people returned the survey entitled, **Sexuality and Adolescents with Disabilities Questionnaire: Parental Perspectives,** a 38% return rate. Almost all respondents were parents or foster parents although two forms indicated the respondents were youth counsellors (4%). Two foster parents completed two forms each because each of them provide care to two teens with disabilities. The majority of the returned questionnaires were completed by females (84%). A few forms were completed by both parents (5%) and a few forms were completed by males only (7%). Half of all parents (53%) reported their age within the 36 - to - 45 - year age range and the majority of parents (73%) indicated their age was between 36 and 50 years of age.

The majority of parents (72%) indicated they were married or living in a common-law relationship. Some parents (16%) indicated they were separated or divorced. Parents who had attended 7 to 11 years of school made up a small part (16%) of this survey group. Some parents (14%) indicated they were high school graduates. Within the parent group, some parents (35%) reported post-secondary education, and some parents (21%) reported they were graduates of a post-secondary institution. In total, over half of the parents (56%) surveyed had obtained post-secondary education.

Most parents (65%) did not respond to the open-ended item on race or ethnic group membership. Some parents (16%) reported Caucasian or white. A few parents (5%) indicated they were Canadian and other parents indicated their membership as Chinese (5%). Parents reported one membership in each of the following groups: Filipino-Asian, Arabic, Sikh, Jewish.

Many parents (28%) did not respond to the open-ended item requesting information on occupation or position. Nursing and "special needs" aide categories were each reported by a few parents (5%), respectively. A group comprising mothers, foster mothers, and homemakers accounted for one quarter of the respondents (26%), and the remainder of the group (37%) represented 16 different positions or occupations.

Descriptions of the adolescents and young adults.

Parental responses that were returned represented 47 adolescents and young adults. There was almost an equal number of males (24) and females (22) in the group, with one unreported.

The 12 to 14 age group represented 12 students, five males and seven females, and comprised one-quarter (26%) of the total number. The 15 to 17 year old group consisted of 17 students, nine males and eight females, and made up more than one-third (36%) of the total number. The age range that included the 18 to 20 year olds consisted of 18 people, 10 males and seven females and one unreported. Young adults, 18 to 20 years old, comprised the majority (38%) of the total number.

Parental reports indicated that 18 (38%) of the 47 people with disabilities were categorized within the moderately or trainable mentally handicapped range of intellectual functioning. Another 14 people (30%) were described as moderately mentally handicapped with an additional disability: moderate and behavior disordered (6), moderate and hearing impaired (3), moderate and physically handicapped (3), moderate and visually impaired (1), moderate and communication disorder (1). Eight of the people (17%) with disabilities were identified as moderate with two additional disabilities, for example, moderate and physically handicapped and visually impaired. A few parents (11%) indicated their teen was mildly mentally handicapped (2) or moderately and mildly mentally handicapped (3). One parent reported a teen as autistic and another parent reported a child as multi-handicapped.

The majority of adolescents and young adults (74%) lived in the family home. Of those who lived outside the family home, most lived in foster homes (19%), although two individuals (4%) lived in a group home. Two-thirds of the teens who lived outside the family home were 15 to 17 years old, the majority of whom were reported to have moderate and behavior disorder disabilities.

People with disabilities in this study lived in families consisting of two children (29%), or three children (24%), or four children (21%), or five children (13%). People with disabilities who were only children comprised a small part (11%) of the total group. Parental responses, when organized by birth order, indicated that people with disabilities in this study were usually in the position of oldest child (39%), or second oldest child (21%) or youngest child (21%).

An Overview

This section integrates thematic data from the parental interviews with the data obtained from the questionnaire on parental concerns about their sons' and daughters' vulnerability to sexual exploitation. Interview transcripts and questionnaire responses revealed that parents of teens with disabilities have many concerns—vulnerability to sexual exploitation being one of them. To understand the context in which these concerns fit, it is important to examine the overall concerns expressed by parents. This section will briefly examine all the concerns reported by the parents in this sample.

Parents Most Important Concerns

Parents indicated their most important concerns: absence of friends in their teen's life (64%), vulnerability to sexual exploitation (57%), and changes in government funding to people with disabilities (57%). The age of the teenager with disabilities was a factor in the parents' selection of most important concerns (See Table 1). Parents whose sons and daughters were in the 12 to 14 years old group indicated their most important concerns, in order, as school placement and behavior, vulnerability to sexual exploitation and absence of friends, and changes to government funding to people with disabilities. Parents whose teens were 15 to 17 years old reported absence of friends, vulnerability to sexual exploitation, behavior, and changes to government funding to people with disabilities as their most important concerns. For young adults who fell within the 18 to 20 year old range, their parents' most important concerns were changes to government funding to people with disabilities, absence of friends, health, and vulnerability to sexual exploitation.

Table 1

Percentage of Parental Concerns by Age Group of Child

Parental concerns	Age Range of Adolescent			
	12 - 14 [a]	15 - 17 [b]	18 - 20 [c]	All Ages
Lack of friends	58 (7)	76 (13)	55 (10)	64 (30)
Changes in government funding	50 (6)	59 (10)	61 (11)	57 (27)
Vulnerability to sexual exploitation	58 (7)	65 (11)	50 (9)	57 (27)
Behavior	67 (8)	59 (10)	44 (8)	55 (26)
Health	42 (5)	29 (5)	55 (10)	43 (20)
School Placement	67 (8)	47 (8)	17 (3)	40 (19)

[a] 12 teens, five male and seven female. [b] 17 teens, nine male and eight female. [c] 18 adults, 10 male and seven female and one unreported.

Absence of friends.

The absence of friends in the lives of teenagers with disabilities was the most important concern of the parents in this study. This concern peaked at 76% among parents of teens in the 15 to 17 year old range. Parent F stated, "...that whole friendship issue that is the biggest problem. [They] just can't give back in the same way, and that needs to be recognized." This parent has tried to foster her son's friendships with his classmates by phoning other parents and trying to arrange times when these teens can visit each other. Presently, it seems that this teenager might be forming a friendship with a boy whose birthday party he attended over the summer.

Parent A said her daughter had friends at school and described her as an open person who likes everybody. She has observed that a lot of kids will play with her, but she also stated that her daughter does not telephone classmates, and does not have friends her own age with whom she spends time.

"Friends are just not happening!" said Parent B. She has observed how easily her daughter confuses social roles and friendship: "She thinks the sales clerk in the clothing store, who is nice, is her friend." She thinks it is important for her daughter to have male and female friends. She has found friends for her daughter through the parent support group. One of her male friends lives in a group home, and this mother has "...tried to get him to come over [to the house] but they [group home staff] say he's busy. They won't make it a priority." She thinks that some of the expectations social service professionals have regarding friendship are unrealistic. For example, her daughter with disabilities is expected to have a circle of friends, but another younger daughter without disabilities has only one friend and a group of acquaintances, a situation she considers realistic and normal.

When asked, "Do you see friends developing in his life?" Mother E responded,

> No, I don't. It's his lack of ability to participate in what's necessary to form and maintain a friendship. It's their lack of interest and limited patience because you need a lot of that to interact with him, and partly it's our distrust.

Father E described his son as "...really limited as far as being able to carry on a conversation. And there is so much language involved in developing a friendship that he's really limited that way."

Mother E has observed that her son "really doesn't feel jilted or unhappy" when workers hired for the summer fade out of his day-to-day life: "There's no feelings of rejection or hurt." She elaborated on the relationship: "He's enjoying the time he's spending, it's again, it's not a friendship, it really can't be a friendship because you know, he's just limited in what he can give to any relationship." Neither parent has any expectation that these relationships with summer workers will continue after the summer job ends.

Changes to government funding.

Two concerns—changes in government funding to people with disabilities and vulnerability to sexual exploitation—were rated by over half of all parents (57%) as most important. Parental concern with changes to government funding increased as teens grew older. Only 50% of parents of 12 to 14 year old children were concerned with changes to government funding compared to 59% of parents of teens in the 15 to 17 year old range. By the time teens were young adults, 18 to 20 years of age, 61% of parents indicated that this was their most important concern.

Parent F spoke at length about government funding. She thinks the present government's focus is on monetary cutbacks, and its planning does not reflect the present and future needs of people with disabilities. Parent F said,

> my biggest fear is that the money has stopped.... There's a certain amount of money, and it's within that amount of money everybody has to be funded.... Either some of those people that now are being funded have to be reassessed and have less funding. You know, I don't know how it's going to work.

One parent wrote the following comment on the questionnaire form:

> I have found that...government agencies/assistance are starting to close the door!...Parents with younger children are assumed to require more assistance, relief and funding....On the contrary, as with other adolescents, children with disabilities become more irritable, are under more pressure, and face as much, if not more, danger of exploitation than younger children.

When her daughter became an adult. Parent B found the change to be a difficult one: "I'm treated like a nobody, and social workers make you feel that you can't make decisions for her." Parent B said she is annoyed by professionals' constant questions about her status as her daughter's legal guardian.

Parent B has submitted an IF (Individualized Funding) proposal covering her daughter's move from high school to the world of post-secondary training and work. The process of obtaining IF dollars to meet her daughter's needs as a young adult was difficult for Parent B. She said, "It was one of the hardest things to go through." However, it is an absolute necessity if parents want to keep and obtain needed services for their children with disabilities. She takes pride in the fact that she was the first member of the public to demand and receive clearance to attend the final IF funding approval meeting for her daughter. She thinks the way in which policy is implemented actually promotes the breakup of families instead of helping them meet their needs.

Behavior.

Behavior was a concern for 55% of all the parents in this study, but it declined in importance as the teen got older. A higher percentage of parents of teens in the 12 to 14 year old range (67%) were concerned about behavior compared to parents of teens in the 15 to 17 age old range (59%) and parents of young adults in the 18 to 20 year old range (44%). A number of teens were identified as "behavior disordered" in the 15 to 17 year old group.

All four families interviewed commented on behavior. Parent A said that some of her daughter's behavior is the result of the medication prescribed for epilepsy: " She is very, very stubborn.

She's got an attitude that everybody is wrong and she's right. " Parent B described how her daughter had hit another student at school, a third time occurrence, and received an out-of-school suspension. She thought her daughter was experiencing a lot of stress as the result of her father's failing health. Parents E mentioned that their son had "gone through major behavioral changes, tons of them; stopped eating for a long time, lost a whole bunch of weight". They described him at two and a half years old as being out of control, unable to sit, unable to focus, but "the older he is, like these days, he's really quite wonderful to be with." Parent F stated that life had been difficult when her son was younger and struggling to control his behavior; however, the "last few years he's been very much in control and quite a wonderful person to be around."

Health.

Health was more of a concern for parents of young adults than the other two parent groups. Even so, most of the families interviewed were concerned about the health of their sons and daughters with disabilities. Parent A's daughter experiences seizures that are partially controlled by medication. Last year, her doctor prescribed an experimental drug, but it triggered such severe seizure activity that she required hospitalization. The medication that she is on presently carries a warning about avoiding exposure to the sun. At the time of the interview, her daughter's name was on a waiting list for brain surgery to remove a cyst. Parent B's daughter has always had poor health and been on medication. Parents E's son takes medication on a daily basis.

School placement.

As a parental concern, school placement declined in importance as the teen aged. Among parents of teens 12 to 14 years old, 67% expressed concern about school placement; among parents of teens 15 to 17 years old, 47% expressed concern; and among parents of young adults, 17% expressed concern about school placement.

The daughter (age 15) of Parent A will attend a high school program in the Fall. She expressed dissatisfaction with the current school: "They didn't want her on the transit bus because they were scared that she was going to take a seizure." Parent A hopes the high school staff will teach her daughter how to manage her money and how to spend it wisely: "Next year...she 's going into high school, and they are going to start teaching them about going out into the world. I'm...hoping they're going to teach them about how to get a job and work".

Mother E thinks her son's school has a "really, really good program. Her son (age 15) has been integrated, to a degree, ever since Kindergarten.

> The [grade nine class] will have him to a sock-hop at the school, and they all know him really well, and they all know he loves music, and they all choose to talk to him about the different groups.

This parent feels problems can always be worked out:

> Relations with school staff haven't always been wonderful. There have been a lot of problems at the school and with the program over the years and things that I have not particularly felt comfortable about. And there have been people that I didn't want him working with and he didn't work with them. But I've always felt that it's my right to see that they change and that's always worked out.

Parents E are really happy that the school program their son is enrolled in will continue to operate at the same site and that he may attend until he is 21 years old.

Parent F talked about the varied school placements her son (age 17) has had within segregated and integrated settings. He once enjoyed a successful integrated placement for a year. He also had a very negative experience in which his needs were not met by the classroom teacher. She expressed concern about his high school placement, but she is hopeful that this year will bring some changes in the way in which students with disabilities are viewed by other students. She thinks it is the responsibility of people who work with children and adults with disabilities to present them in a positive light and to "sell them" and create good publicity for them.

Adult placement.

Some parents of young adults in the 18 to 20 year old group (22%) expressed concern about "adult placement" and the "limited scope of purposeful activities" available for young adults after school graduation. Parent F spoke about employment plans for her son: "I would also like him to find a job. He needs to work. He's very unusual that way, he works very hard and diligently....He feels very good, successful about himself."

Parent F has discussed employment with other parents and discovered that policy regulations discourage people with disabilities from pursuing full-time employment. They are permitted to earn only a small amount of money, and anything above that amount is deducted from their government funding. Earning money in excess of this amount could put them in a position where pre-paid health care benefits are in jeopardy: "It's a real disadvantage for those adults who could actually help pay through positions, through part-time positions, within companies." Parent F thinks that if corporations who employ people with disabilities were given a tax break it would enhance the status of people with disabilities as well as the status of the corporation.

In order to receive sufficient funds to meet her son's need for 24-hour supervision, Parent F had to emphasize his negative attributes rather than present a balanced picture:

> I feel troubled because it means that...there are aspects of [my son] that I'm going to have to exaggerate and...I feel that I'm forced into a position which I just hate, that I don't feel comfortable with the rest of my conscience.

When commenting on the kind of documentation required, Parent B spoke about the frustration of continually setting goals for her daughter's continued improvement.

Future residential plans.

Some parents (4%) were concerned about their teens' quality of life after their death, specifically, who would look after their child. Three out of four parents interviewed talked about the plans they had made for their teenager concerning residential options and the hopes they have for their child's future.

Parent F thinks that, as an adult, her son should not live in the family home but with others in a living arrangement that she monitors closely:

> [I] would like to find...people of like mind who could, together with me, create some kind of residential situation that would really complement everything that I've done all my life, that I've worked really hard for. I want him to have the same kind of quality that he's had here.

Although Parent F prefers a co-ed housing arrangement, she knows parents of girls with disabilities who express a real opposition to this idea. If he lived in the family home, Parent F does not think that she would be able to treat him as an adult and allow him all the choices that he should experience as an adult. She is aware that she treats him differently than his younger teenaged sister. She has also observed the experience of her brother-in-law who has disabilities and lives with his mother.

Parent A would like her daughter to "live in a home where there were five or six people and counsellors with them day and night. She would have her own chequing account, go to work everyday, buy her own groceries and be on her own." Parent B sees her daughter living near the family home. She presently lives on the other side of the family's duplex.

Relationships.

Parent B thinks it is important for her daughter to have male and female friends: "We were at a dance, and she was dancing with a male friend and having a wonderful time. I felt good just watching them together." She thinks her daughter should have a special relationship with a male:

> Maybe she will marry. I want her to have a normal relationship because she has feelings even if it is holding hands. She should have the freedom to develop a relationship. I want for her what I want for all my kids—having a special person in her life.

Parent F recalled that some girls had pursued her son in the past, but it was not initiated by him. He tolerated it, but he did not seem that interested. It makes her sad to think that he may never meet a girl with whom he might form a relationship that could lead to sexual fulfillment. As Parent F said, "It's sad that as they get older they get lonelier and no one hugs them anymore and they don't experience any physical expression of affection." Parent E mother reflected:

> you really don't know what the future is in terms of that, but I just can't see, just because of the limitations he has in communication and his inability to get close to people on any level, that a [sexual relationship] would ever become an issue.

Two parents on the questionnaire volunteered the following information: concern about paid caregivers and strangers and concern about suicide threats and attempted suicides by her teen with disabilities. A foster parent worried that the teenager in her care would be placed with his mother..

It is clear from these reports that parents live with many concerns, and sexual exploitation is but one of them, although an extremely important one.

Vulnerability to Sexual Exploitation

Vulnerability to sexual exploitation was the second most important concern expressed by parents. Fifty-seven percent of all parents surveyed were concerned about their sons' and daughters' vulnerability to sexual exploitation. When asked to indicate the type of concern they had, 81% of them indicated that they were concerned that their teen would be sexually exploited by others.

Two of the four sets of parents interviewed expressed deep concern and fear about their teens' vulnerability to exploitation by others. Parents E described their son (age 15) as "totally vulnerable." They thought their son was more susceptible to sexual abuse at 11 or 12 years of age because he was more interested in sexual matters at that time; however, somewhat paradoxically, they still think he is " as vulnerable as he's ever been." Parent A revealed that her daughter (age 15) had been abused at least twice when they resided in another province. Some parents (17%) were concerned their teen would sexually exploit others, and some parents (15%) harbored both concerns. Parent F stated that her son behaves in socially appropriate ways and was able to handle "skinny dipping" by relatives at the lake. She feels that "he is totally safe, and nobody would ever need to concern themselves" about him expressing his sexuality in an inappropriate way.

The time parents worried most

Parents were asked, "During which childhood years did you worry most about the sexual exploitation of your child with disabilities?" Table 2 indicates the childhood years when parents worried most about exploitation. Questionnaire responses indicated that for half of the parents (49%) there has been no change in the amount they worry. When interviewed, Parent A stated that she was just as fearful now as when her daughter was younger. Mother E said:

> It's been something I've always, always been concerned about since he was little. I've never thought this couldn't ever happen. When he was two or three or four (years old), I had the major fear of him being kidnapped and hauled off and molested. Now...I don't fear that so much as that devious kind of infiltration ...that through very insidious ways abuse would occur with him. When he's actually working with somebody, and he's trusting that person that they could so easily lead him into a really horrifying situation with him completely unaware that anything bad is actually taking place.

Table 2

The Time Parents Worried Most About Sexual Exploitation, in Percentages, by Current Age Group of Child

Time	Current Age Group			
	12 to 14 [a]	15 to 17 [b]	18 to 20 [c]	All Ages
Child 4 years or younger	8 (1)	0	0	2 (1)
Child 5 to 9 years old	0	0	0	0
Child 10 to 17 years old	33 (4)	35 (6)	39 (7)	36 (17)
Child 10 years old to current age	0	0	6 (1)	2 (1)
No change, worry is constant	50 (6)	53 (9)	44 (8)	49 (23)
No response	8 (1)	12 (2)	11 (2)	11 (5)

[a] 12 teens, five male and seven female. [b] 17 teens, nine male and eight female. [c] 18 adults, 10 male and seven female and one unreported.

Some parents (17%) indicated that they had worried more when their child was younger. Parent F stated she was somewhat concerned when her son was little that he would be abused, but presently, she is "not overly concerned." Some parents (36%) reported the childhood years from 10 to 17 as the time they worried most. Many of these responses (21%) were from parents whose teens are currently in this age group. Perhaps this is an indication that the time they worry most is the present. A few parents (11%) did not respond to this item.

Feelings of concern at puberty

Parents were asked if their feelings of concern increased as their child began to develop sexually. The majority of responses (68%) indicated that feelings of concern had increased, although some parents reported no increase (23%). A few parents (9%) did not respond to this item. When her son was 10 years of age, a psychiatrist told Parent F that her son probably would behave in a very sexually inappropriate manner and suggested he would need medication if he was out in public. She described how fearful she felt about her son's approaching adolescence. Parents E described the experience of coping with their autistic son's emerging adolescence as "unnerving."

Concern compared to their children without disabilities

When comparing their concern about their teen's sexual development with their concern about their other children, 36% reported the same amount of concern. Some parents (26%) expressed more concern, and many parents (30%) reported this item was not applicable to them. A few parents (4%) expressed less concern, and a few parents (4%) did not respond to this question.

Factors Affecting Parental Concern

Many factors contributed to the concern parents had about their sons' and daughters' vulnerability to sexual exploitation: public sources of information, experiences of teens with disabilities, comments from other parents of teens with disabilities, and comments from professionals.

Public sources of information.

Half of all parents (49%) identified public sources of information, such as literature, television, film, or lectures, as a major contributing factor to their fears. Mother E stated, "I was really frightened about the onset of puberty in an autistic male because of some of the literature I'd seen."

Teen experiences.

Many parents (34%) indicated that their teens' experiences had contributed to feelings of worry and concern. The 15-year-old daughter of Parent A had been abused on two occasions. As many as 68% of teens with disabilities in this study were reported as having had abusive experiences, ranging from being taken advantage of socially to experiencing multiple and repeated forms of physical and sexual abuse. Father E thinks his son might enjoy more independence but "...he doesn't get a whole bunch of that because of the way that we are." Mother explained,

> I have a really, really hard time letting him risk. And I understand the value of allowing people to risk without putting them at risk. I understand that. But I can honestly say that I have a hell of a hard time with both. It's difficult.

This mother went on to describe that she was not sure she would change:

> I don't know how quickly that's going to dissipate. I don't know really how it can because I don't feel I'm getting feedback from him that's showing me that he's capable of handling any of the situations that terrify me.

Some parents (28%) said that comments from other parents of teenagers with disabilities added to their concern.

Comments from professionals.

One-quarter of parental responses (26%) indicated that comments from school personnel added to their concern. Some parents (17%) indicated that comments from medical personnel gave them cause for concern. Because of a prediction a psychiatrist made, Parent F had the following experience: "With horror, I waited for this sexual inappropriate awakening which fortunately never came. He [the psychiatrist] made it seem like my son would be almost predatory in his sexual behavior."

A few parents (15%) were concerned by comments made by social service personnel. Other factors that added to parents' feelings of worry and concern were memories from their own experiences, personal observations of their teen, their child's trusting nature, their experiences as a volunteer at the Sexual Assault Center, and comments from friends.

Experiences of Teens

Adolescence is viewed as a tumultuous time for all parents, however, parents of teens with disabilities have unique experiences. Parents were asked to indicate which of eight different experiences were most typically experienced by their teenager with disabilities during puberty: teen talked about sexual body parts using slang or socially appropriate terms, teen experienced a change in mood with more episodes of emotional upset, teen touched his or her own sexual body parts while in a public place, teen touched the sexual body parts of others, teen resisted assistance and wanted to do things by himself or herself, teen had difficulty completing hygiene routines, female teen showed upset with the appearance of blood during monthly menstrual periods, female teen required assistance to complete menstrual tasks each month. Table 3 indicates the typical experiences of teens during puberty.

Typical Experiences During Puberty

Change in mood.

Half of all parents (51%) indicated that the most typical experience was a change in moods displayed by their adolescents. A change in mood was defined as wider mood swings, with more episodes of emotional upset. The percentage of parents reporting "a change in mood" experience at the rate of one to five times daily was almost constant across the three age groups. More girls (62%) than boys (38%) experienced this change in mood. One parent indicated that her daughter had experienced changes in mood more than 10

times a day. Parents E described their son's change in mood as similar to those of other teenagers, although he picked his own form of expression: "He would just act bratty, like a young, young kid."

Table 3

Typical Experiences during Puberty, in Percentages, by Age Group and Sex of Child

Typical Experiences	Age Group of Adolescent						
	12 to 14 [a]		15 to 17 [b]		18 to 20 [c]		All Ages
	M	F	M	F	M	F	
Change in mood	40 (2)	50 (3)	43 (3)	71 (5)	38 (3)	71 (5)	51 (21)
Difficulty with Hygiene	40 (2)	67 (4)	43 (3)	43 (3)	38 (3)	57 (4)	49 (20)
Talked of Body Parts	40 (2)	50 (3)	71 (5)	57 (4)	25 (2)	57 (4)	49 (20)
Resisted Assistance	40 (2)	67 (4)	0	57 (4)	50 (4)	57 (4)	44 (18)
Touched Own Body Parts	40 (2)	67 (4)	29 (2)	57 (4)	25 (2)	43 (3)	41 (17)
Touched Body Parts of Others	40 (2)	0	57 (4)	43 (3)	38 (3)	14 (1)	32 (13)
Assisted with Menstrual Tasks	0	67 (4)	0	14 (1)	0	86 (6)	55 (11)
Upset by Appearance of Blood	0	50 (3)	0	14 (1)	0	43 (3)	35 (7)

[a] 11 teens, five male and six female. [b] 14 teens, seven male and seven female. [c] 16 teens, eight male and seven female and one unreported.

Difficulty with hygiene routines.

Parental reports on adolescents experiencing difficulty completing hygiene routines, for example, using deodorant and bathing, indicated that this was more of a concern for some parents (for example, parents with younger teens (55%) and young adult's (50%) than for other parents . More than half of the parents who reported difficulty with hygiene routines indicated that this was a frequent experience, occurring more than 10 times. More girls (55%) than boys (40%) experienced this difficulty. Parent A described the difficult time she has in getting her daughter to wash every day.

For parents of females with disabilities, 55% of them reported that their daughters required assistance to complete menstrual tasks each month. Parents whose daughters were 12 to 14 years old (67%) indicated this was a more typical experience, than did parents of daughters 15 to 17 years old (14%). For parents of daughters who were young adults. 86% indicated this was a typical experience. One or more parents of daughters within all three age groups indicated that their daughter had experienced difficulty with menstrual grooming on more than 10 occasions. One mother wrote this comment on the questionnaire: "The hardest time was puberty. She started developing breasts at eight years [of age] and periods at 10 years [of age]."

Parent B said that, in a way, her 19 - year - old daughter is still going through adolescence. She recounted her daughter's inability to cope with menstrual grooming, and after about four years, this family chose a surgical solution.

One third of the parents (35%) reported that their daughters were upset with the appearance of blood during monthly menstrual periods. Although three out of seven reports were from parents of 12 to 14 year olds, parents of one girl in the 15 to 17 year old group and one parent in the 18 to 20 year old group reported having this experience more than 10 times.

Talk of sexual body parts.

Forty-nine percent of all parents reported that "talk about sexual body parts, using slang or socially appropriate terms" was a typical experience during puberty. Most parents reported that it occurred one to five times daily, although two out of 20 parents indicated that it happened one to five times weekly, and another parent indicated that it had occurred six to 10 times daily. This experience was common to both parents of girls (55%) and parents of boys (45%). This experience was reported more often by parents of teens in the 15 to 17 year old group. Parent F described her 17-year-old son as a sexual being, curious about bodies, and she said he has always known the correct names for body parts. He realizes that sexuality is a topic for private conversation. Parents E recalled that their 15 - year - old son had talked a lot about sexual body parts and bodily functions.

Resisting assistance.

The adolescent behavior of "wanting to do things by myself" and showing more resistance to assistance was reported by 44% of all parents. The largest number of reports were from the parents who had teens in the 12 to 14 year old group (55%). Twice as many parents of girls (67%) as parents of boys (33%) reported these experiences occurring one to five times daily. One parent indicated that she had this experience with her daughter, 12 to 14 years of age, more than 10 times a day. Mother E talked about her 15-year-old son's resistance as a normal adolescent behavior:

> He'll just act bratty, like a young, young kid. But it's just the same. It's just the rebelling...trying to disassociate from the parents. But the only way he knows how, which is not staying out late or storming out, but acting up, like making faces at us. He's doing the same stuff, but just at his own level.

Touched his or her own sexual body parts.

When asked if their adolescent had touched his or her own sexual body parts while in public, 41% of all parents indicated that it had occurred. This experience was reported more by parents of teens 12 to 14 years old (55%) than by parents of teens 15 to 17 years old (43%) and parents of young adults 18 to 20 years old (31%). Parents E began the interview by relating that their son experienced puberty when he was 11 or 12 years old: "[They] were the worst years, both for himself, the changes he was going through and the maturing and the sexual stuff, and the peer kids...those were...the really nasty years."

Among the parents who reported adolescents touching their own sexual body parts, there were more reports of girls (65%) than boys (35%) engaging in this behavior. Although most parental reports (65%) indicated that this had occurred one to 5 times, some parents (18%) reported that it had occurred six to 10 times, and a few parents (18%) indicated that it had occurred more than 10 times.

Touched the sexual body parts of others.

One third of all parents (32%) indicated that their adolescent had "touched the sexual body parts of others." Teens in the 15 to 17 year old group accounted for more than half of this number (54%). Among all parents who reported this problem, there were more reports of boys (70%) than girls (30%) touching the sexual body parts of others. The majority of parental reports on this behavior indicated that it occurred one to five times, although two reports indicated that it had occurred six to 10 times. Parents E revealed that their son (age 15) had been very curious and interested in touching.

Experiences with Abuse

Parents were asked to indicate which of six types of abusive situations their teenagers with disabilities had experienced: Of the 46 parents who responded to this item on this survey, 30% reported no abusive experiences. Thirty-two parents (70%) reported some type of abusive experience (See Table 4).

Psychological abuse.

The most common form of abuse reported by the parents in this study (50%) was emotional or psychological abuse, defined as repeated name calling or disrespectful treatment because of a disability. This rate of abuse was constant across all three age groups. Of the 23 reports from parents, 12 of them indicated that this had occurred more than five times.

Table 4

Experiences with Abuse in Percentages by Age Group of Child

Experience with Abuse	Age Group of Adolescent			
	12 - 14 [a]	15 - 17 [b]	18 - 20 [c]	All Ages
Psychological abuse	50 (6)	47 (8)	53 (9)	50 (23)
Physical abuse	25 (3)	47 (8)	35 (6)	37 (17)
Rude treatment by sales people	42 (5)	35 (6)	35 (6)	37 (17)
Taken advantage of socially	25 (3)	41 (7)	35 (6)	35 (16)
No abusive experiences	25 (3)	29 (5)	35 (6)	30 (14)
Sexual abuse	17 (2)	41 (7)	24 (4)	28 (13)
Financial abuse	0	24 (4)	24 (4)	17 (8)

[a] 12 teens, five male and seven female. [b] 17 teens, nine male and eight female. [c] 17 teens, nine male and seven female and one unreported.

Physical abuse.

There was a tie between physical abuse and rude treatment by service people for the second most common type of abuse. Physical abuse was defined as being slapped, hit, punched, kicked, cut, pushed, burned, or confined because of a disability. This was reported by 37% of all parents, and parents of teens 15 to 17 years old reported the highest percent of occurrence (47%). Seventeen parents indicated that their teens had been physically abused, and seven of them indicated it had occurred more than five times.

Rude treatment by service people.

Treated rudely or indifferently by service people because of a disability was reported by 37% of all parents. This was the experience of Parent F's son. Because he does not appear handicapped on first meeting some people do not make this judgment about him. When they realize that he has disabilities, they sometimes reject him, sometimes subtly, sometimes not. Among the 17 reports on rude or indifferent treatment by service people, five of them indicated that this had occurred more than five times. Parent F thinks that her son (age 17) has to cope with social rejection from other members of society, at least once a day.

Abuse within a social situation.

Being taken advantage of in social situations because of a disability, defined as being told to do something socially inappropriate, was reported by 35% of all parents and by more parents of teens in the 15 to 17 year old group. Parents E described how outraged they were to discover that students at school had taken advantage of their son's compliant nature. While in the bathroom, they told Parent E's son to do things that were inappropriate as well as unsanitary. They related another incident that occurred about five years earlier with a young cousin who learned that their son would do exactly as he was told. The young cousin had him standing up and sitting down repeatedly until Parent E arrived. Of the 16 parental reports indicating social situations abuse, nine indicated that this abuse had occurred more than five times.

Sexual abuse.

Sexual abuse, defined as any sexual touching, sexual intercourse, or sexual exploitation by another child or adult, was reported by 28% of all parents. Again, there were more reports from parents of teens in the 15-to 17-year-old group (41%). Among all parents who reported that their adolescents had been sexually abused, there were far more reports of girls (77%) than boys (23%). Of the 13 reports, all of them indicated that it had occurred one to five times. Parent A's daughter (age 15) has been sexually abused at least two times; the first time, her two-year-old daughter was abused by a male friend of a babysitter.

The data revealed that many adolescents had experienced repeated abuse (See Table 5).

Table 5

Number of Abusive Experiences by Type of Abuse and Sex of Child

Type of Abusive Experience	Number of times					
	1 to 5		6 to 10		10 +	
	M	F	M	F	M	F
Psychological abuse [a]	6	5	0	3	5	4
Physical abuse [b]	3	7	2	1	2	2
Rude treatment [c]	4	8	1	2	2	0
Taken advantage of socially [d]	[illegible]	3	2	2	2	3
Sexual abuse [e]	3	10	0	0	0	0
Financial abuse [f]	1	5	1	0	1	0

[a] 23 reports. [b] 17 reports. [c] 17 reports [d] 16 reports. [e] 13 reports. [f] eight reports.

Financial abuse.

Being taken advantage of financially by others because of a disability was reported only by parents of teens 15 years of age or older. Eight parents reported financial abuse, and two of them indicated it had occurred more than 5 times.

Teens Who Had Been Abused

Although a few parents (28%) indicated that their adolescents had experienced a single form of abuse, the majority (72%) reported that their teens had experienced multiple abuse (See Table 6). Some parents (13%) reported that their teens had experienced all six types of abuse defined by the questionnaire. Thirty-two (out of 46) or 70% of all parents of people with disabilities reported abusive experiences. Two thirds of the teens who had experienced abuse currently live in their family home; the other one-third do not.

The 12 teens who lived outside the family home consist of seven males and five females. Two thirds of them were 15 to 17 years old. Although five parents reported their teens as moderately or mildly mentally handicapped, the majority of the other seven individuals were categorized as moderate and behavior disordered. All but one of this group of 12 teens (92%) had experienced abuse, and 75% of the parents reported sexual abuse, physical abuse, or both.

A large number of adolescents who were abused were only children or from two-children families. All four only children in this study had been abused and nine out of 11 two-children families reported abusive experiences. Adolescents with disabilities who were the oldest child in the family (11 out of 15 families) were reported to have had abusive experiences.

Table 6

Multiple Abusive Experiences in Percentages by Age Group and Sex of Child

Number of Types of Abuse	Age Group			Sex	
	12 to 14 [a]	15 to 17 [b]	18 to 20 [c]	M	F
One type of abuse	33 (3)	25 (3)	27 (3)	36 (5)	18 (3)
Two types of abuse	33 (3)	17 (2)	9 (1)	14 (2)	24 (4)
Three types of abuse	22 (2)	8 (1)	27 (3)	21 (3)	18 (3)
Four types of abuse	11 (1)	17 (2)	9 (1)	14 (2)	12 (2)
Five types of abuse	0	17 (2)	9 (1)	0	18 (3)
Six types of abuse	0	17 (2)	18 (2)	14 (2)	12 (2)

[a] nine teens, four male and five female. [b] 12 teens, six male and six female. [c] 11 teens, four male and six female and one unreported.

The surveys were grouped into parents reporting abuse and those reporting no abuse. Table 7 shows the percentage of occurrences of the typical experiences during puberty for both groups. Parents of teens who were abused reported more incidences of "talk about sexual body parts," touching sexual body parts of others, and resisting assistance. There was little difference in incidence rates among the other experiences of change in mood, touching his or her own sexual body parts, and difficulty completing hygiene routines. The experiences exclusive to female teens, menstruation, (teen showed upset with the appearance of blood during monthly menstrual periods, teen required assistance to complete menstrual tasks each month), were unable to be compared because of the small sample size.

Parental reports revealed the types of pubertal experiences that occur on a daily basis. These reports indicated that two thirds of teens had abusive experiences, and for many of them, this abuse took the form of multiple and repeated abuse. Teens who were reported as abused displayed more incidences of problematic behavior during puberty than teens reported as not abused.

Table 7

Typical Experiences during Puberty of Abused and Non-abused Adolescents,by Percentage of Total Cases

Typical Experiences	Adolescents with disabilities	
	Abused [a]	Non-abused [b]
Change in mood	53	45
Talk about body parts	53	36
Difficulty with hygiene	50	45
Resist assistance	53	18
Touch own body parts	43	36
Touch body parts of others	37	18

[a] 30 teens [b] 11 teens.

Parental Views on Life and Family

Views on Life

Parenting their teens with disabilities is only one part of the life experiences that parents integrate into an overall perspective. Comments by parents revealed a stoic resignation in their approach to life. Parent A, whose daughter had been sexually abused, stated, "[you] have got to face life, life is what it is...[You] have got to deal with the problem, and learn to understand it." When school staff advised her to keep her daughter at home because of a cold. Parent A disagreed: "Later on in life if she has a job they're going to say, ' Well, hey, just because you had a cold you can't stay home.' We have to learn to cope with it."

Parent B, whose husband had a fourth stroke, thinks families are constantly changing. She personally welcomes change and would like to be a part of making the changes necessary within the present (social service) system: "Things can change drastically in one day. Things constantly change with my daughter, and I can't be afraid of change. That's just the way it is."

Parents have survived many traumatic experiences within their families and have developed a way of perceiving them one at a time. Periods of time are pared down into manageable blocks that these parents can envision. When discussing her daughter's move to a high school in the Fall, Parent A said, "We'll take one step at a time." Parents E were really happy that the school program their son (age 15) had been attending would accept him until his 21st year and would continue to operate at the same site. When asked about their son's future, Father E said, "beyond that, well, we just don't know."

Parent F revealed her view of education for all when she discussed children in the community elementary school who did not have money to attend field trips. She said, "No child should pay...for the sins of their parents...and that's what it's coming down to. We have to believe in their education as being just as valuable as everyone else's."

Lifestyle.

All of the parents interviewed commented on their lifestyle. Parent A frequently yawned and spoke of tiredness as she described her busy daily routine. When asked if it had been more hectic when her daughter was in the hospital last Spring, she responded, " Oh, yeah but it's...always like that". She described her own health concerns and said, "I m just too tired. I'm even too tired to go outdoors and that's awful to say that, but I am....I just don't feel like going out."

Two parents had experienced medical crises with their spouses. Parent A discussed how her husband had been critically ill. Parent B told of her husband's fourth stroke and how she meets all his health needs within the family home. She has five children and stated, "We have a hectic lifestyle."

She commented: "It's not easy being a parent, but it's a very important job. You've got to show them love and respect." She feels large families are always on display because everyone takes notice of them. She said there is no difference between her daughter with disabilities and her other children." I want her to fit right in, and she has chores like everyone else." Parent A explained that she does not have the energy to work with her daughter on household chores because she is so tired from work.

Two parents of male teens recalled that life had been more hectic in the past. Parent F explained that life had been especially difficult when her son was younger and struggling to control his behavior. Parents E stated, "It's a lot different than when he was little and really rambunctious and on the go a lot more."

Relationships among family members.

When talking about the relationship between her husband and her daughter, Parent A said, "They're constantly arguing, so I'm caught in the middle...I'm tired, and I don't feel like doing anything with her or my husband because I'm so tired." She felt her husband has a harder time with the abusive experiences than her daughter and "probably needs the counseling more than she does." She has observed that "sometimes...he pushes her away...he's scared that people will think that he's abusing her, you know."

Parent B said,

> having a daughter with a disability has helped to keep the family together. Her siblings have learned that no one is perfect. Having her for my daughter has taught me coping skills, necessary to handle my husband's fourth stroke. She looks after him and it's made me so thankful that I've got her to coach me.

Parent F said she sometimes finds it difficult to observe her other children try to reconcile their brother's disability within themselves:

> They feel...a lot of love and responsibility for him, and I think they see that as something that will continue throughout their lives. They're very...strong in that. Yet I certainly have seen, too, that [in] their social situations, they're very uncomfortable being connected to this person who makes everyone stop, turn around, look, and listen. I think that it's harder for them than anyone else. I mean I think they just hate themselves for feeling that way....[I] try to let them know they don't need to be a buffer. That what he's saying and what he's doing is just fine and that it's the other person's problem. They have to learn to deal with it....The best thing they can do is [to be a] model themselves.

Her daughter and son attend the same high school. Parent F elaborated,

> Within that environment, within that high school, these kids are mostly considered just weird....There isn't a really good sense of who they are, until recently. I don't feel very good about his position within...that population at all.

Parent F felt that if her daughter had been apart of her brother's integrated school placement where he was respected and well-liked by classmates, it would have been a positive experience for her as well: "now she feels that she's taking the weight of her brother on her shoulders."

Parent F described how her two sons stay home together and "that (it's) worked out quite well." The youngest son considers it " baby-sitting," but he is afraid to be alone, and if her oldest son with disabilities is not at home, the younger son is not at home.

When Parent A was asked if she had family living here, she said, "No, they all live in another province, and I like it better that way." She explained that it was good to be away from her husband's family, who had been physically and verbally abusive to her husband as a child. Parent A telephones her mother once a month and has offered to pay her air flight for a visit.

Coping Strategies

The questionnaire asked parents, "How do you cope with your worries and concerns for your teenager's vulnerability to sexual exploitation?" The majority of parents (78%), indicated that they provide their teens with constant supervision.

Constant supervision.

When Parent A, whose daughter had been abused, was asked about her daughter's movement in the community, she replied, "...basically, she's home all the time....I know where she is at all times....She doesn't go on the street or go to parties." Parent A supervises her at all times to prevent any further opportunities for abuse. Although Parent B also supervises her daughter constantly or delegates supervision to a trusted individual, she said that she is more worried about the vulnerability of her three other daughters: "I guess I'm over-protective with all my kids." Parents E are very protective of their son and restrict his movements. Mother E finds it difficult to permit him to be in the backyard where she is unable to spot him from inside the house. Father E stated,

> Well, we're very protective, you know. We don't allow him to do a lot of things. ...We kick ourselves for [it] at times because, in a sense, we're...depriving him of opportunities and experiences that maybe he should be entitled to. But in order for us to live with ourselves, we are very protective.

Mother E elaborated on their position:

> I would rather schedule my life, my career, my social outings, all of that around him....I've always taken him to school and picked him up after school and I mean, I've always been really involved in programs he's in at school. I've always been more afraid that he's more likely to be a victim than anyone else based on all the different factors. So it's easier, I think, to be a lot more cautious and perhaps overprotective,

> and I'd much rather be accused of being that than having him come home and something really horrible has happened.

Parent F tries to balance her son's movements so as to prevent an opportunity for abuse from occurring while providing him with enough freedom to live and enjoy life:

> I feel like there's a lot of risks out there and that's just one of them that he's going to take. It would just be so confining. His life would be very dull if he wasn't able to really go out and check out the neighborhood and the new construction sites.

She elaborated, " I always know where he is....I actually never leave him unsupervised....Yeah, it is a bit of a dilemma, I find, because he is quite independent and yet I do feel that there always has to be somebody here for him."

<u>Supervision by family or friends</u>.

Most parents (63%) reported that they provide constant supervision with the help of family members and friends. Parents E explained that they have arrangements in place for them to enjoy time off: "Both of us have family close by, and they have been an excellent source of relief. He's got aunts and uncles that are really good and take him for sleepovers and do things with him."

Parent A indicated that occasionally a baby-sitter in her building unit supervises her daughter, but even then, precautions are in place:

> We just don't leave her with anybody. D. has been around for two years since we've been here. We know what he's like, and he's pretty good with the kids.... Basically we're not very far if we leave her here because she didn't want to go out. We're right here so we can hear....So if she screams, we could tell.

Some parents (17%) indicated they use family, friends, and paid agency workers to supervise their adolescents with disabilities. Parent B stated her daughter requires constant supervision, but she has had assistance from HCS (Handicapped Children's Services) since she was eight years old. For this mother, the "thrill of having a worker was that it gave me choices, for example, if I wanted to pop out I could."

Parent F had also had the assistance of HCS and had employed someone in a relief position for quite a long time. In the last year, she had employed her daughter in this position:

> It was really, really...a wonderful experience for all of us. She was very, very, good at it, and it was curious because there was nothing that made my son happier....Of course, she was a lot better at it than all those other people.

Parent F described how this arrangement with her daughter allowed her to have some flexibility: "She was a bit on call....It means that if something comes up, you know, I have to go out that evening, I want [her] available."

The summer of 1994 was the first time Parents E employed a male to work with their son. The aide was a relative, someone their son has known for a long time, and "someone they trust[ed] and have extreme confidence in."

Supervision by paid agency workers.

Parent B thoroughly screens potential workers and has hired both male and female staff who were same-age peers. She views this position as that of a companion to her daughter. She spoke about the differences in obtaining relief since her daughter has become an adult. She can no longer hire her children but must employ someone outside of the family. In her experience, trained workers may or may not show any initiative in their interactions with her daughter. Her other children always initiate interactions and activities. Parent F responded with the word "disappointed" when she realized that once her son becomes an adult relief funding cannot be used to employ siblings.

A few parents (11%) indicated that they use only paid agency workers. This was the experience of two teens who lived in group homes. Parent A did not find the arrangement with an in-home worker, who came to their apartment a few hours on Sundays, all that helpful. Parent A found the constant problem of what the worker and the daughter would do together a burden she said this form of relief was a personal inconvenience. Often, she just wanted to stay home and relax, but she felt she had to leave if a worker was there. Any activity that the pair of them participated in cost money; as well, money was needed for bus transportation. She stated that certain leisure activities were not possible because of the daughter's propensity to seizures. She stated, "Maybe I'm over protective, too." When a suggestion was made about free activities, Parent A responded, "I don't have time. By the time I get home, I don't think of them. I just don't feel like doing it, and that's a sin."

Very few parents (11%) indicated that they used a formal network for relief. Parent A did not perceive CBS (Community Behavioral Services) as helpful to her or her daughter. Although Parents E have used formal relief services, both of them reiterated strongly that they would not hire a male worker for their son. Mother E expressed discomfort with some of the relief services available: "I've never felt confident enough to use the host families because I don't believe there are enough checks and balances in place. I don't feel comfortable using that program." She justified their position:

> I think when it comes to baby-sitting, be your children abled or disabled, I think a lot of moms don't feel comfortable with male baby-sitters for the exact reason that there are far fewer advances with women and girls.

One questionnaire respondent jotted the phrase "no trust" beside this item.

Personal support network.

Parents reported the use of a personal support network as the second most frequent coping strategy (51%). One questionnaire response revealed that when one mother wanted a night out she hired a baby-sitter who had been recommended by family or friends. When this mother's daughter was younger, the daughter had spent time away from home at camp. Parent E commented, "I'm connected with my family and friends." She described an experience at the lake when a group of cousins hauled her son off to play volleyball. Initially, she thought he could not play or would not play, and that he would drift back in a few minutes. She found him enjoying it, and later, his cousins took him for a seado ride on the lake.

One parent's comment revealed the lack of a personal support network. Parent A said she does not get much of a chance to talk to anyone. She can afford a long distance telephone call about once a month to her mother or a friend.

Leisure time.

About one third of all parents (32%) reported they took some leisure time for themselves. Parents E explained that they had more time to themselves now that their son was older: "He's independent in that, typically, if we want to be upstairs watching TV or entertaining he chooses to be downstairs watching the other TV. "

When asked what she did to relieve stress, Parent A replied, "Nothing." She elaborated, "It's always been like this. I'm used to it. The doctor said I should go for walks. I'm too tired when I get home from work....I told him, 'You're not in my shoes, doctor.'" Parent A's comments revealed that she had little time for herself:

> My boss told me, 'You look awful.' I said, 'Well I'm tired.' And she said, 'If you need a week off let me know.' But there is no sense taking a week off while she's here because I'm not going to get any rest, so when she goes back to school in September I'll take a week or two off. Just to be by myself!...My husband will be gone in the daytime....Then I will have time to myself. I won't be going anywheres, but the point is I'll be by myself until she gets back home from school.

When asked what she did for herself, Parent A responded, "I like BINGO. That's what I'm going to do! I'm going to BINGO tonight, even if I'm tired."

Parenting information.

One third of all parents (32%) indicated they obtained information on parenting skills to help them cope with their concerns. Parent B stated that she reads to inform herself about everything (in the area), for example, on agencies and the Premier's Council on Family. On the questionnaire, one parent stated she had attended an university workshop on the topic of counseling sexually abused children.

Twenty-eight percent of all parents reported that they attend parent organizations or conferences. Parent F was contacted through a parent organization, in which she is an active member. Parent B rejoined a parent organization in the last year, and she has started her own parent support group, which has about ten members. They talk about "what we as parents go through. There's so many changes that people are afraid," although she, herself, welcomes change.

Mother E mother remembered attending a parent support group when her son was very young, but presently, she chooses not to belong. She believes they are helpful for other families, but she said, "I'm connected with my family and with friends." When asked if she belonged to any organizations, Parent A stated, "I just don't have the time." Parent B thinks some parents purposely isolate themselves from other parents of children with disabilities because they worry that their child will pick up bad habits from the other children. She explained that she felt badly about this and mentioned that "we could have learned from each other."

Solace in religious beliefs.

Almost one quarter of all parents (23%) indicated that they took solace in religious beliefs and/or church affiliations. The following comments about abuse were made by two mothers, both of whom described their sons as autistic. Parent E said,

> I pray a lot about it. I pray a lot for protection [that it never happens]. I pray a lot to be able to handle it [if it should happen] in a good way and that it won't be so detrimental that it would wreck his life. I feel that's the only thing that I can do.

A questionnaire had this comment:

> Just pray nothing happens to my child and if it happens, how will I be able to know? because my child is incapable of telling me what has happened to him, except he cries if something goes wrong.

Parents expressed resignation about life's experiences and relied almost exclusively on family and friends to assist them to cope with the needs of their teens.

Prevention and Education

One parent stated in her response to the question on coping strategies, "[I] talk to [my] teen and try to instill values."

Who Has Taught the Adolescents With Disabilities?

Parents.

Parents were asked, "Who has provided education and training in abuse prevention to your teenager with disabilities?" About three quarters of all parents (78%) reported that their teens had been taught within the family. Parents of older teens and young adults, reported more teaching within the family, than parents of younger teens. Among parents of teens in the 12 to 14 year old group, 70% taught abuse prevention; 79% of parents of teens in the 15 to 17 year old group taught abuse prevention; and among parents of young adults in the 18 to 20 year old range, 81% reported abuse prevention training within the family.

Parents of sons with disabilities stated they stressed the concept of appropriate and inappropriate behaviors, and one family identified private places in their home where it was appropriate for their son to engage in sexual behaviors. Parents E and Parent F discovered that a frank, straight forward approach was most effective. Parent A reported that her daughter talked about wanting a baby. She responded by focusing on the many responsibilities of motherhood, and her daughter has not talked about having a baby.

Three out of four parents interviewed stated that, presently, they do not initiate discussions about human sexuality with their teens with disabilities. They preferred to discuss it only when the teen raised the topic. Parent F explained that she has observed her son learns best when something is relevant to him; therefore, she handles all situations as they arise: "I don't feel that I am going to really address it unless something comes up." A questionnaire response indicated a similar approach with the statement, "Supplemental when potential situation could arise."

Schools.

School-taught classes on sexuality and abuse prevention were indicated by 70% of all parents. One questionnaire response indicated that school "personnel had talked a little bit about sexuality and abuse prevention." When examined by age range of teen, 80% of parents with 12 to 14 year old children indicated that their teens had been taught at school. Of parents of students in the 15 to 17 year old group, 64% indicated that their teens had participated in school classes. For young adults in the 18 to 20 year old group, 69% reported school classes.

Looking at the group of students attending Edmonton Public Schools, which represented 40 of the 47 questionnaire responses, 67% of their parents reported that the school taught classes in the area of sexuality and abuse prevention. Of the seven responses from parents of students attending Edmonton Catholic Schools, 71% indicated that the school taught classes in the area of sexuality and abuse prevention.

Agencies.

Some parents (15%) indicated that their teens had participated in a course taught by a social service agency. Parent F enrolled her son in a three-month course on human sexuality offered by an agency in the city, but the instructor did not share much of the information with parents. She stated that professionals need "to realize that they are only temporarily involved in the lives of people with disabilities; whereas, parents will always be involved." Her son was overheard giving two younger cousins an informal "in service on the birds and the bees."

Counselors.

A few parents (9%) rep [illegible] had participated in personal counseling sessions. One questionnaire response reported th [illegible] school brought in a counselor after an abusive incident had occurred at school. Although [illegible] was told a number of times that counseling would be available for her daughter, she stated that her daughter "hasn't really seen anybody, like, as far as it goes, like counseling or anything like that." Parent A said that "I've just let it go. As long as there's no, like she doesn't say anything or bring it up."

Teens unable to be taught.

Three parents (6% [illegible] o responded to the questionnaire indicated that their teens had not received any training in abuse prevention because, as one parent phrased it, "my child doesn't understand much." Given the nature of their son's disabilities, parents E perceive him as incapable of learning personal preventative strategies. They are not sure their son would tell them if somebody did something to him, although mother E thought she would know by a change in behavior. Parent F voiced the same thought. Mother E elaborated:

> The only ways that I know are protection rather than trying prevention through teaching because he's incapable of knowing a good touch from a bad touch..."

She added,

> I do believe if somebody physically, like really quite overtly tried to hurt him, I really do think he may lash out and make them stop.

Mother E explained their family's dilemma:

> That's the only thing [protection] I know how to do, that I know works because you spend all this time early on with a person with autism who was completely out of control at two and a half, couldn't sit, couldn't focus. We spend all this time teaching the child that they need to look at people and they need to listen and they need to react to what they're being told to do. And then somehow now change all the rules around adolescence saying, 'If somebody tells you, pull down your pants, you don't.'

Some parents did not respond (15%) to this item on the questionnaire.

What Has Been taught?

The need for a curriculum designed to prevent the exploitation of people with disabilities has been validated by experts in the field (Sobsey, Mansell, & Wells, 1991). Missall (1991) surveyed experts on the prevention of abuse of people with disabilities, and eight major areas of prevention were identified from the data. Missall (1991) focuses on direct prevention methods, which include training for families, clients, service providers, and members of the general public. According to Missall (1991) family training should focus on teaching parents to recognize signs of abuse in their sons and daughters: for example, sexually inappropriate behavior, unexplained withdrawal, and fearfulness. Client training can be further delineated into seven skill and/or curricular content components: assertive training, sex education, individual rights, personal safety, social skills, choice making, and communication.

On the questionnaire, parents were asked to indicate "the skill areas in which your teenager with disabilities has received some training." Table 8 indicates the skill areas and the percentage of instruction adolescents with disabilities have received.

Table 8

Percentage of Adolescents Receiving Abuse Prevention Training by Age Group

Abuse Prevention Areas	Age Group of Adolescent			
	12 to 14 [a]	15 to 17 [b]	18 to 20 [c]	All Ages
Assertive Training	70 (7)	81 (13)	87 (13)	80 (33)
Personal Safety Training	50 (5)	56 (9)	80 (12)	63 (26)
Communication	40 (4)	69 (11)	67 (10)	61 (25)
Social Skills	30 (3)	50 (8)	67 (10)	51 (21)
Individual Rights	20 (2)	63 (10)	47 (7)	46 (19)
Sex Education	20 (2)	50 (8)	53 (8)	44 (18)
Choice-making	40 (4)	44 (7)	47 (7)	44 (18)

a 10 teens, four male and six female. b 16 teens, nine male and seven female. c 15 teens, nine male and six female.

Assertive training.

The majority (80%) of parents of students with disabilities indicated that their teens had received instruction in assertive training (saying "no," asking for help, physical self-defense). Parent A stated that her daughter was very assertive and would speak up and let others know if someone had behaved abusively toward her, and indeed she had done so the last time she was abused. Parent B thinks the school encourages students to apologize for their behavior rather than encouraging them to develop assertive skills.

Personal safety training.

A majority of parents (63%) indicated that their teens experienced training in personal safety (good touch/bad touch, situations to avoid, risks, when to say "no," seeking help persistently, seeking advise, disclosure). As the teen grew older, there was an increase in the percentage of parents reporting personal safety training Parents E thought their son "might not realize there is something to tell." Parent B revealed that her daughter will not permit anyone to touch her body, and medical appointments are difficult to manage.

Communication training.

More than one half of all parents (61%) reported that their teenagers had received communication training (expressing feelings, describing experiences, initiating communication). Parents of the middle teen group, 15 to 17 years old, reported the highest percentage of communication training (69%) of any age group.

Social skills.

Half of all parents (51%) reported that their teens had obtained training in the area of social skills (friendship, family, dating, client-service provider, stress management). As the teen grew older, there was an increase in the percentage of parents reporting social skills training. A mother's comment on the questionnaire form offered the following suggestion:

TMH children do not "pick up" on social clues and hints that would help them understand the reactions of other people. Direct, hands-on training is needed to impart social/sexually appropriate skills. Rol playing is one technique that might be helpful.

Individual rights.

In the curricular area of individual rights, 46% of all parents indicated that their teens had received training. This skill area includes values, self-concept, basic human rights, and private behavior. Parents of the middle teen group, 15 to 17 years old, reported the highest percentage of individual rights training (63%), of any age group.

Sex education.

Training in sex education and choice-making were the two areas least reported by parents. The proportion of teens who had received sex education training (love and sex, body parts, puberty, physical affection, sex vocabulary, hygiene, lifestyle choices) was calculated at 44%. Parent F described her son, 17 years old, as sexually curious and well-informed about the correct terms for body parts. A mother's advise from the questionnaire suggested that,

> extensive time and patience is a must. Explaining periods was great, but when it came to feelings of sexuality, that was very difficult....She liked boys and hormones would override the right decision. It took a lot of help and explaining and reading books with pictures, and finally, at the age of 16 or 17 years old...she knows that "say[ing] no and tell" is [acceptable].

Choice-making.

Parental reports of teens who had received training in choice-making (problem solving, exploring alternatives, decision making) was calculated at 44%. Parents E described the difficulty their family was experiencing in teaching their son choice-making: "He can't seem to comprehend that he is allowed to make choices." Both parents have observed that he looks to them for a clue, almost as if to say, "Which one am I suppose to want?"

It is apparent that parents perceive that teens are not receiving the type nor the amount of instruction, at home or at school, required to help them understand experiences of puberty or learn preventative strategies that might help them to avoid abusive situations.

Chapter 5

Discussion, Implications, Conclusions

Discussion of the Current Study

The goal of this study is to identify, describe, and analyze the thoughts and feelings parents po[illegible]on the vulnerability of their adolescen[illegible]d daughters with disabilities to sexual abuse. The research procedures chosen helped to achieve this goal. Different styles among interviewers have been discussed as a possible explanation for varying results in qualitative studies on parental concerns about the vulnerability of teens with disabilities. Some parents find the topic too sensitive and distressing to discuss with a stranger. A telephone call from one mother confirmed this situation. In a voice close to tears, she stated that she felt unable to complete the questionnaire because her child's abuse had just recently been uncovered. A casual conversational style, with an interview guide, proved to be very effective in creating an atmosphere where parents felt comfortable enough to discuss the intimate and sensitive issues inherent in this study.

The questionnaire encouraged parents to add their own responses. There were eight different items with a choice entitled "other." Almost half of all respondents (45%) used one of these for a reply, many added two or three personalized responses. Three parents took advantage of the request to use the back page to write further comments, two of which were a page in length.

This study reveals that parents have many worries about their children with disabilities, a finding that is consistent with other life experience studies of similar families (Fong, 1992; Mehon et al., 1993; Wilgosh, 1990a). In the present study, the most common concern of all parents was the absence of friends in their children's lives. Although parents promote friendships, development is slow and almost nonexistent. Because they see their teen as unable to communicate in a fully appropriate way, some parents think he or she is incapable of obtaining a friend. Making friends and getting along with others was one part of the Young Adult Daily Life Domain in Thorin and Irvin's (1992) study of parental concerns. Thorin and Irvin (1992) state that the most frequently mentioned concerns of parents in their study were within this domain.

The next most common concerns, reported with almost equal frequency, center on changes to government funding and vulnerability to sexual exploitation. Changes to government funding could involve many different scenarios, all of which are big concerns for parents. Families fear that options and services that they have been receiving may cease to be available or services that parents have been planning to use in their teens' future may be withdrawn. A change might mean that the process or criteria for obtaining services would change, making it necessary for parents to negotiate yet another minefield of government forms and government offices.

Parents of teens in the 12 to 14 year old age group indicate that behavior and school placement are their two most important concerns. Two of the parents in this group (out of a total of 12) identify themselves as parents of sons with autism, 12 to 14 years old. The concerns expressed by these two parents agree with the findings of Fong (1992) whose parents of teens with autism (predominantly male, 13 to 15 years of age) are primarily concerned with behavioral and social skills.

In the present study, half of all parents report that there has been no change in the amount they worry, yet two thirds of them also report heightened concern as their teens begin to mature sexually. The majority of parents indicate that public sources of information and the experiences of their teen are two factors that contribute most to their concern.

Parents state that many things about their life with their child with disabilities do not change. Turnbull and Turnbull (1990) argue that teens with disabilities do not seem to pass through the normal transition from childhood to adolescence to adulthood. Parents realize that their teens are not going to develop independence, but rather, they will require constant supervision. When asked about their son's future, Father E responded, "We'll have very difficult things down the road, I'm sure."

Because parents report serious and on-going health and behavioral needs of their children, they have frequent and continual contact with professionals. "Professionals can be sources of strength and practical assistance as well as sources of stress" (Huang & Heifetz, 1984, p. 289.) About one quarter of parents report that comments from professionals (school, medical, social service) contribute to their feelings of worry and concern.

The type and frequency of experiences teens have during puberty are important contributing factors to parental concern. Parents in this study described frequent mood changes, continual need for assistance with hygiene routines, and frequent resistance to help from others as "typical" experiences for their adolescents. Zetlin and Turner (1985) cite that the dependence/independence struggle occurred in about half of the 25 families that they studied.

In spite of their desire for independence, many teens with disabilities continue to require a great deal of help with most daily routines, while other teens begin to develop some independence at performing basic living tasks. In this study, parents of female teens report the continual need to assist with menstrual grooming. Many report that their daughters are repeatedly upset by the appearance of blood, even though they have experienced it month after month.

Turnbull and Turnbull (1990, p.121) describe sexuality as one of four issues encountered by families of adolescents with disabilities. In Fong's study (1992), the issue of sexuality arose in the second round of interviews when she specifically asked parents, "What do you think are the most important issues for adolescents with autism?" Parents stated that there was a lack of information on the sexual development of children with autism. They expressed concern about behaviors that indicated a lack of social skills and a lack of understanding of the concepts of private and public behavior. In this study, Parents E described similar experiences, and their solution was to teach their son that private behavior can occur only in private places in the home.

Many parents report on talk about sexual body parts, touching one's own sexual body parts in public, and touching the sexual body part of others. Forty-nine percent of all parents report "talk about sexual body parts" by both male and female teens. Forty-one percent of the parents report that adolescents touch their own sexual body parts while in public, with more reports of girls than boys, and more reports by parents of young teens (12 to 14 years old). The findings of this study show a decrease in the frequency of this behavior as teens age. Because families and schools provide some instruction in the area of sex education and socially appropriate behavior, perhaps the older teens and young adults learn to apply these concepts to their own behavior.

One quarter of the reports indicate that those adolescents who "touch the sexual body parts of others" fall within the 15 to 17 year old group and are male rather than female. The small group of teens who exhibit these behaviors were also reported as abused and as behavior disordered. It is impossible to know how these experiences occurred. Perhaps these children were abused, and as a consequence of the abuse, they developed problem behavior, or perhaps they presented challenging behaviors that make them more likely victims for abuse. Research indicates that these experiences are closely linked in the lives of abused individuals with disabilities. About 30% of abused people in the University of Alberta Abuse & Disability Project "exhibited noncompliance, aggression, or sexually inappropriate behavior." (Sobsey, 1994, p. 84). Although all teens demonstrate problematic behavior, those who are abused present greater and more frequent problems.

About two thirds (70%) of the parents in this study report that their teens had experienced abuse. The majority of those reports indicate multiple abuse, some reporting all six types of abuse indicated on the questionnaire. The data reveal that many adolescents also have experienced repeated abuse of the same type. One half of all parents indicate that emotional or psychological abuse is a constant occurrence across all three age groups. One third of all parents report physical abuse of their teen, usually in combination with another form of abuse. Numerous studies report physical violence as a part of the overall abuse experience (Westcott, 1993). Rude treatment by service people and the experience of being taken advantage of in a social situation was reported by one third of parents. Sexual abuse was indicated in about one quarter of all reports. Many more girls (10) were abused than boys (3). This finding agrees with that of the University of Alberta Abuse & Disability Project study (Sobsey, 1994) in which female victims comprised approximately 79% and males 21% of the total group of victims.

Parental responses from only children families revealed that all four of them had experienced multiple abuse. Physical abuse was indicated on all reports and sexual abuse indicated on two of the reports. This finding is in agreement with those of the Westat national survey (Crosse, Kaye and Ratnofsky, 1993) which reported that "maltreated children with disabilities were more likely to come from one-child families than from families with multiple children..." (p.3-5).

Three quarters of the teens in this study live in their family homes. Most of those who reside outside the family live in foster homes; two live in group homes. Senn (cited in Sobsey, 1994, p. 68) lists placement outside the home as one of eight factors that are not only associated with disability, but also increase the risk of abuse. Of the 12 teens living outside the home, 75% had experienced physical abuse, sexual abuse, or both. Westcott (1993) states that the behavior exhibited by individuals who have been abused reflects the type of abuse and the severity of abuse they experienced. People with disabilities who exhibit extreme behaviors have often been placed outside the family home.

The parents in this study reported that their teens had experienced repeated incidents of various types of abuse. Those experiences contribute to parental concern, and parents have a realistic fear of future exploitation. The parents provide constant supervision for their teens in order to prevent abuse or further abuse.

The research literature on child abuse identifies social isolation as a factor associated with family violence and abuse (Finklehor, 1979). Singer and Irvin (cited in Sobsey, 1994) identify four factors that contribute to family isolation: fatigue, limited leisure time, stigma attached to a family who has a member with a disability, and absence of social networks. Half of all the parents in this study rely on a personal support network to cope with their day-to-day routine and about one third of the parents indicate that they take some leisure time for themselves. These two strategies assist the parents in this study to minimize the effect of two of the factors that contribute to family isolation.

Parent A talks about being tired, absence of someone with whom to talk, and the shortage of time for herself for leisure activities. Kathryn Morton (cited in Turnbull & Turnbull, 1978) discussed two enemies she has encountered, fatigue and loneliness. She states,

> There is an expectation by others that we should live "normalcy" as if in fact, there were nothing unnormal about our lives. Who—besides another parent of a handicapped child—understands the extraordinary effort it takes to hang onto friends, respond to family, attend back-to-school nights, take children to dentists, entertain for husbands, shop for groceries, do the housework, take the car to be fixed, drop one

> child off to play with a friend, pick up another after a piano lesson, or heaven forbid, hold down a job while attending to the needs of a child who is disabled and needs extraordinary care? (p. 143)

However, the majority of the parents in this study report that they rely on family members and friends in their personal support network to help them cope. One third of all parents report taking personal leisure time or taking advantage of information on parenting skills. About one quarter of the parents belong to organizations that provide support, or they find solace in their religious beliefs.

Many studies have selected subjects or co-researchers from parent organizations, perhaps because of ease of accessibility. In this study, parents who belong to parent organizations represent only one quarter of the sample of parents. If researchers continue to sample parents from such organizations, they need to be aware that these parents represent a small portion of the total population of parents who have children functioning in the moderately mentally handicapped range of intellectual ability.

Kathyrn Morton (cited in Turnbull & Turnbull, 1978) presents a different view of parent organizations:

> Perhaps special classes, special schools, special buses, and even our special parent organizations are ultimately doing as much to segregate and isolate parents from the mainstream of adult life as they isolate children from the mainstream of child life. (p. 147)

In this study, Parents E chose not to belong to a parent group, while Parent A said that a lack of leisure time prevented her from attending organizational meetings.

Parents in this study were distrustful of formal networks for relief and relied on informal networks of family and friends almost exclusively. Parent A did not perceive the relief arrangement to be helpful to her, and at times, she thought it was a personal inconvenience. Singer and Irvin (cited in

Meyer, Peck, & Brown, 1992) emphasize "the need for a match between the perceived need for support, the kind of support desired, and the source of support in order for a parent to feel satisfied with a social tie". (p.288).

Implications of the Current Study

Wilgosh (1990b) reports that parents at the Sexual Assault and Abuse of People with Disabilities International Conference expressed concern about issues surrounding actual abuse and requested education on prevention strategies for the person with disabilities, as well as for themselves. About three quarters (78%) of the parents in this study report that they teach abuse prevention skills to their teens within the family, and slightly fewer parents (70%) indicated that their teens receive instruction on sexuality and abuse prevention at school. The 15-to 17-year-old teens, the group reported to have the highest rates of physical abuse (47%) and sexual abuse (41%) and the most challenging behavior during puberty, receive less instruction in abuse prevention than students in the young adult age group.

The implications of the findings of this study are numerous. High abuse rates indicate that two thirds of teens with disabilities are victims of abuse, usually multiple and repeated abuse. They require assistance and treatment, to cope with the abusive experiences, from parents and school personnel to enable them to recover and heal. In addition, teens need comprehensive instruction in abuse prevention skills to stop the pattern of repeated abuse. Social service professionals need to provide parents with information on services and resources on counseling and treating individuals with disabilities who have been abused.

Instruction in specific curricular areas that correspond to the areas of difficulties experienced by teens could help to reduce the frequency of occurrence of problematic behavior and thereby reduce parental concern. The findings of this study reveal that a sizable minority of teens (22%) receive no prevention instruction from either families or school, indicating a need for increased prevention.

Experts in the field of disabilities have validated seven skill areas that address sexuality and abuse prevention: assertive training, sex education, individual rights, personal safety, social skills, choice making, and communication. The social skills area should receive priority from schools because it addresses the most important concern of parents, the absence of friends.

If teens are taught to express their feelings appropriately, perhaps they would experience fewer mood swings. The communication area includes the skills of initiating communication, describing experiences and expressing emotions. If teens are taught to recognize the physical signals within their bodies that precede feelings of anger, they could learn ways of dissipating these feelings thereby gaining control of their feelings and their behavior.

Six of the eight "typical experiences during puberty" reported by parents are imbedded in the curricular area of sex education. Talk about sexual body parts and the touching of one's own sexual body parts while in a public place could be addressed by sex education and individual rights education. The problem of touching others' sexual body parts could be resolved by training teens to use personal safety skills. Choice-making skills and communication skills training could provide teens with some control over aspects of their lives, thereby promoting independence.

Information of a specific nature—on content and instructional strategies to teach the content needs to be distributed to parents through parenting forums and workshops. Schools need to examine the curricula they are presently teaching and compare it to the curricular areas validated by experts. Administrators and consultants need to assume a leadership role and ensure that all students receive training in the areas that address abuse prevention and recovery. Teachers need to demonstrate a commitment to assist teens and their families to reduce the negative consequences of abuse as well as to reduce the students' continuing vulnerability to abuse. Teachers require workshops to develop a comfort level with the content of the curricula as well as practice in using specific instructional strategies. Appropriate resource materials for parents, teachers, and students must be identified and made available.

Limitations of the Current Study

The sample in this study is a very specific group of parents, those who have an adolescent son or daughter with disabilities who attends a segregated school program in the Edmonton Public Schools system or the Edmonton Catholic School District and is described as functioning in the moderately mentally handicapped range of intellectual ability. The findings of this study are generalizable to similar groups of parents.

Charles Hannam (1988) made this statement about economic changes in Britain:

> There have been so many calls for economy in the Health Service, stringent cuts and reduction of what had been generous plans, that many parents must be fearful of new developments.

In an effort to eliminate the provincial debt, the government of Alberta over the last two years has made significant budgetary cuts to education, health, and to some extent, to the social services. Employees in the public sector have absorbed salary rollbacks of five percent and many public services have been reduced. Some health programs have been transferred to sites away from hospitals or substantially reduced or completely eliminated and everyone speculates about where and when the next round of cuts will occur. All Albertans have been greatly affected by these changes including the parents in the current study. Their concern is reflected in the high percentage (57%) of them indicating this as one of the most important concerns they have for their son or daughter. A different monetary climate, perhaps, would reveal a different percentage of parental concern on changes to government funding.

Conclusion

This study identifies, describes, and analyzes the thoughts and feelings parents express on the vulnerability of their adolescent sons and daughters with disabilities to sexual abuse. They have many concerns about their children; sexual exploitation is but one of them, yet it is a source of constant worry. Public sources of information and the experiences of their teens are the two factors that contribute most to their concern. Given the experiences of teens during puberty, including the fact that two thirds of the teens discussed in this study have experienced abuse, parents are justified and realistic in their concern. Abuse usually takes on multiple forms and is repeated. Parents cope with their concerns by providing their teens with constant supervision and by relying on a personal support network of family members and friends. Two thirds of the parents and more than half of the school programs represented teach abuse prevention skills. The parents and school program most often teach assertive training, personal safety training, and communication skills. Areas of the curriculum (sex education, social skills, individual rights) that could assist families to cope with experiences of puberty and also focus on abuse prevention, are least taught; less than one half of parental reports indicate instruction in these areas.

Clearly, parents who have adolescents with disabilities need help. Too often they are overlooked by researchers, professionals, and teachers alike—all of whom focus their attention on the child. In the end, however, it is the parents who are left with most of the responsibility and all of the worry for their child's vulnerability to sexual exploitation. Their voices need to be heard. This study has taken a small exploratory step in that direction.

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Appendix A

CONSENT TO PARTICIPATE FORM

I agree to be interviewed as a participant in the research study conducted by Donna Voisey, a graduate student in Educational Psychology at the University of Alberta, about my experience as a parent of an adolescent with disabilities concerning the area of sexuality and the prevention of sexual abuse.

My participation involves two contact sessions with the interviewer, an initial interview of approximately an hour and a follow-up session. I agree to be recorded on a tape cassette which will be transcribed for analysis. Later, I will be presented with a summary of the contents of the interview in order to confirm or correct any of the statements. I may terminate my involvement at any time if I decide I no longer wish to participate.

I am aware that the interviewer is legally obligated to report to Family and Social Services any incident of abuse that is discussed that has not previously been reported.

If I consent to the quotation of short phrases from my interview, my name and names of family members will be changed to ensure anonymity when interview data is reported. If I have any questions or concerns about how the research is being conducted I can contact Dr Dick Sobsey at the Department of Educational Psychology at 492-3755. I will be given a photocopy of this form indicating the type of consent I have agreed to provide to the interviewer.

__________ (date)

____________________ (name of parent printed clearly)

____________________ (signature of parent)

INDICATE YOUR PREFERENCE BY INITIALIZING ON THE LINE UNDER YOUR RESPONSE

	YES	NO
I would like to be acknowledgeded as a participant.	____	____
I permit short quotes to be used from my interview.	____	____
I would like a copy of the completed study.	____	____
I would like my interview tape reurned to me.	____	____
I would like my interview tape to be erased.	____	____

Appendix B

Sexuality and Adolescents with Disabilities: Parental Experiences

Interview of Parents who have an Adolescent with a Disability

Parent Participant Information Sheet

Number of Interview:

Name or Code Number:

Date of Interview:

Gender of Parent(s):

Age(s):

Marital Status:

Adolescent's Gender:

Adolescent's Age:

Adolescent's Birth Order.

Race or Ethnic Membership:

Occupation or Position:

Education Level:

Adapted from Lofland & Lofland (1984, p. 57).

Appendix C

Interview Guide

-"Tell me about your experiences with your son or daughter concerning sexuality?"

_"Describe how your concern for his/her vulnerability affects the day-to-day routine of your household and the different members of your family?"

-"How have your concerns affected his/her opportunities to meet and make friends?"

-"How have your concerns changed as the result of him/her moving from childhood to adolescence?"

-"How do you feel about your son or daughter wanting to do more things on his or her own, without your supervision?"

-"How do you feel about your son or daughter developing a boyfriend or girlfriend relationship?"

-"How has your son or daughter handled situations in the past that put him or her at personal risk?"

-"How do you alleviate your feelings of worry and concern for your son's/daughter's safety?"

-"Please describe how frequently you experience these concerns and how stressful or anxiety producing they are for you?"

-"What do you know about programs available on the prevention of abuse of people with disabilities?"

-"What do you believe the schools' role should be in your son's or daughter's sexuality training?"

Appendix D

INTERVIEW SUMMARY A070794F15

Parent A is a married woman, 40 years old, whose only child is a 15-year-old daughter with disabilities. The family was living in New Brunswick until about two years ago when they moved to Edmonton. Parent A has a Grade 8 education, works part time as a nurse's aide with Comcare, and receives Social Assistance.

Daughter has been sexually abused three times, the first time as a 2 year old by a male friend of a babysitter. The last time she was abused Social Services advised Parent A not to talk with her about it. Daughter has not received any counselling to help her deal with previous abusive experiences.

Parent A thinks her husband has a harder time dealing with the abuse than the daughter. She notices that he "shies away" from showing affection to the daughter, and she thinks he is afraid that the daughter might say he has abused her, or other people will think he is abusing the daughter, or that the daughter thinks that he will abuse her. The family decided to "let it go" because the daughter does not

n the incidents. Parent A said if the daughter ever mentions the incidents she would talk to her

ut them.

Parent A said a lot of her daughter's behaviors have to do with the medication she is on to control seizure activity. Last Spring her doctor decided to try an experimental drug, but she began to have so many seizures that she was hospitalized. She is waiting for surgery to remove a cyst by the temple in her brain.

Daughter is supervised at all times. She does not telephone classmates from school nor have friends her own age with whom she spends time.

A social worker has explained resources available to the family. They will be moving into low rental housing on the ground floor with a backyard sometime this month. Parent A views many of the suggestions as not being really helpful to her or finds it difficult to find the time to contact resource people. She has had unpleasant experiences with people from Social Services in the past, when the daughter was in foster care.

Parent A spoke of being very tired as well as having inflammation in her knee joints and back. She said she was used to the stress and that "it's always there." She has not noticed any change from when her daughter was a child: "I'm tired but I just cope with it." She does not really do anything for herself to get rid of stress. Possibly she will take some time off in Sept. when daughter is back in school and mother can have some time to herself. She said she loves Bingo and talked about going that night. She displayed a sense of humor about daily events in her life. She talked about furniture she had bought for the house that would soon be paid off. She said she plans for some things, but other things she "plays by ear."

Parent A did not think the school was teaching the daughter very much. She felt it was unfair of the school to ask her daughter to stay at home when they had outings because they were scared that the daughter would have a seizure while on the transit. She is glad the daughter is going to high school and going to learn money management and how to get a job and work. She wants her to learn to be on her own, i.e., perhaps live with other people and have assistance from counsellors.

She mentioned that husband and daughter argue a lot, and she ends up in the middle. Parent A wishes husband would find a job so she could quit hers and stay at home. Her husband is unable to read or write, which makes it hard for him to find a job. He has had a nervous breakdown in the past, and his doctor has given him a report stating that he is unable to work for the rest of his life.

Parent A is hopeful that things will be better once they are living in the Edmonton housing unit—perhaps she will not feel so tired if she does not have four flights of stairs to climb.

Summarized on Aug 2/94

INTERVIEW SUMMARY B040894F19

Parent B is a married woman in her forties who is a high school graduate with some post-secondary training, i.e., secretarial courses. She works at home and is the mother of five children. Her second oldest, a daughter 19 years old, has disabilities. She is very proud of her family and feels that "I've done a good job with my kids."

Parent B mentioned that her daughter had difficulty coping with her menstrual grooming and after four years they decided to go with a surgical solution. She needs constant supervision, and the family has received assistance from Social Services, in the form of money to hire a worker, since she was school aged. Having a worker for her daughter allowed Parent B a choice, "If I wanted to pop out I could."

Experiencing the process of obtaining IF (Independent Funding) dollars to meet her daughter's needs as a young adult created different emotional stages in Parent B: "It was one of the hardest things to go through." She thinks the way in which policy is implemented actually promotes the breakup of families rather than assistance to meet the needs of one of its members. Parent B said, "They are destroying parents by taking their right to parent disabled children They treat you like a number. They treat you like a nobody."

Daughter has always had chores and responsibilities while growing up, just like other family members. Parent B has attempted to treat her like her siblings. The three other teenaged daughters are also given close parental supervision and not permitted to go places that might put their personal safety at risk. Parent B sees them as being more at risk than their "big sister" because she is supervised closely or Parent B knows who is accompanying her. Daughter's presence in the family has helped to keep the family together and taught her siblings that no one is perfect.

Parent B thinks agency workers are establishing unrealistic routines with people with disabilities i.e. no one goes out every evening of the week and participates in recreation/leisure programs: "We stay home and enjoy doing things together with other family members." Agencies also promote a one-on-one relationship, which results in the person with disabilities being very isolated from peers. She has observed workers with people with disabilities in public and been very concerned with the lack of dignity and respect shown them within the interaction. She sees the group home residents on such tight schedules that they appear like "robots." Professionals expect her daughter with disabilities to have a circle of friends, but one of her other daughters has one friend and a group of acquaintances in her life. She said, " I'm tired of the mold placed on disabled people."

Parent B has started a parent support group She personally welcomes change and would like to be a part of making the changes necessary within the present system. Families are constantly changing and she is not afraid of change. She thinks that parents have purposely isolated themselves from each other and "it really hurts! We could have learned from each other."

Daughter has had both male and female workers, a requirement being they are her peer in age. School friendships have not continued outside of school, so Parent B decided to foster friendship through the parent support group. She wants her daughter to have both male and female friends: "I want for her what I want for all my kids." She would like her to have the freedom to develop a special relationship with a man with whom she could express affection. She might marry.

Parent B thinks the school tends to teach people with disabilities to apologize for their behavior. Schools do not seem to teach them to be assertive and to say "no;" rather, they teach them to state, "I'm sorry." Daughter was taught that no one should touch her body and will not allow anyone to do so. This makes visits to the doctor quite stressful for her and Parent B.

Her husband has has another stroke and is unable to work outside the home. Because she learned coping skills from parenting her daughter with disabilities, she is better able to handle her husband's loss of capabilities. Daughter's health as a[illegible] poor this last year, although for the first time ever she is off medication. Parent B made comments about doctors being "out for the money to be made. They treat you as a machine not a person." She feels they tend to dismiss her observations about her husband i.e., "I'm the one that notices changes in him but I can't do anything, only the Doctor can."

Summarized on Aug 18/94

INTERVIEW SUMMARY E170894M15

Parents E are a married couple in their mid-thirties with a 15 1/2-year-old son, who they described has having autism. Both parents have post-secondary education. Father is a graduate of Northern Alberta Institute of Technology and is employed as a shop superintendent Mother has completed course work at the university level and is employed with a social service agency.

Father described his son as "totally vulnerable." Mother said he was perhaps more susceptible at age 11 or 12 because he was interested in sexual matters: whereas, he does not seem to be presently. They handled his sexual curiosity in a very straight forward manner and taught him the rooms in the house in which it was appropriate for him to engage in private sexual behavior.

Their fears concerning his vulnerability to exploitation by others have not changed over the years. Mother used to fear he would be kidnapped and molested but now she fears that "when he's actually working with somebody and he's trusting that person, they could so easily lead him into a really horrifying situation, with him completely unaware that anything bad is actually taking place." Father explained that they are very protective of their son and restrict his activities, but they feel this approach is necessary. Mother said she would "much rather be accused of being overprotective than have him come home and something horrible has happened." They choose to schedule their lives, careers, and social outings around him.

Their son has been in situations where other children have taken advantage of him, telling him, for example, to do things that were inappropriate. He did not protest this treatment nor did he appear upset by the experience. The parents provide him with constant supervision to prevent any opportunities for abuse from occurring. Father thinks their son might enjoy a little more independence around the backyard, but mother is not sure the son wants more independence.

Both parents perceive their son as being incapable of learning preventative strategies, such as distinguishing a "good touch" from a "bad touch," or protesting behavior. Mother described the early years and how they focused on teaching him to listen and to do as asked. The idea of teaching him to protest seems to be contradictory to these earlier teachings.

Parents E do not think their son will form relationships, in the sense of a friendship. The onus would be entirely on the other person to initiate and maintain the relationship because of the nature of his disability (inability to carry on a conversation, lack of understanding of feelings, limited ability in choice making).

When asked what they do to cope with their concerns, mother stated, "It's something that's always there, and I don't obsess about it all the time, but it's always, always there."

Both parents have very supportive family members who take their son for sleepovers and weekends from time to time. They also have used female inhome workers from the "Y." Although he presented many challenges at a younger age, presently, their son is "quite wonderful to be with." They do not feel the need for lots of relief. Mother stated that " I pray a lot about it. I pray a lot for protection [that it never happens]. I pray a lot to be able to handle it [if it should happen] in a good way and that it won't be so detrimental that it would wreck his life. I feel that's the only thing I can do."

Although mother attended a parent support group when her son was very young she stated, "I'm connected with my family and with friends. I think support groups are wonderful but I choose not to be a part of them."

Summarized November 6/94

INTERVIEW SUMMARY F230894M17

Parent F is a married woman in her late thirties who has post-secondary education. She is a homemaker and mother of four children, two girls and two boys. The oldest boy is 17 and has disabilities.

Parent F is " not overly concerned with abuse" in regards to her son with disabilities. She was somewhat concerned when he was little that he would be abused. However, she decided that she was not going to restrict his movements because he loves to ramble about the community and explore the neighborhood. She knows where he is at all times, and there is always someone at home. She tries to balance restricting his movements so as to prevent an opportunity for abuse from occurring, while providing him with enough freedom to live and enjoy life.

Her son has had a variety of school placements and once enjoyed a successful integrated placement. He also had a very negative experience in which his needs were not met by the classroom teacher. She expresses concerns about his high school placement but is hopeful that this year will bring some changes in the way in which students with disabilities are viewed by the other students.

She thinks that it is the responsibility of people who work with children and adults with disabilities to present then in a positive light and to "sell them" and create good publicity for them.

At times it has been very tough on his siblings who love him very much but are acutely aware of the way in which others view him in social situations. She thinks that at least once a day he has to cope with social rejection from other members of society. Because he does not appear handicapped on first meeting, some people do not make this judgment about him. When they realize that he has disabilities, they sometimes reject him, sometimes subtly, sometimes not. Parent F thinks we need to change society's view of people with disabilities and it is the job of educators in the school system to teach children when they are young and so accepting of others.

It has been difficult at times, especially when he was younger and struggling to control his behavior. "Last few years he's been very much in control and quite a beautiful person to be around, so I think now he could live with me for another 5 to 7 years before moving." She wants him to have a job because he feels good about himself when he works. She thinks that, as an adult, her son should not live in the family home but with others in a living arrangement that she monitors closely. Although Parent F prefers a co-ed housing arrangement, parents of girls with disabilities she knows express a real opposition to co-ed housing If he lived in the family home, Parent F does not think that she would be able to treat him as an adult and allow him all the choices that he should experience as an adult. She is aware that she treats him differently than his younger teenage sister. Parent F has observed the experience of her brother-in-law who has disabilities and lives with his mother.

She sees her son as a sexual being who is curious about bodies. On one occasion at their private lake front, he went skinny dipping, something other family members do quite frequently. He has a sexual vocabulary and has attended a 3-month course about human sexuality given by an agency. Neither her son nor the professional shared much of the information with her. Parent F wants professionals to realize that they are only temporarily involved in the lives of people with disabilities: whereas, parents will always be involved.

At 10 years of age, a psychiatrist told them their son could become sexually deviant when he underwent puberty. Parent F was extremely fearful of his approaching adolescence. Only on one occasion did he engage in inappropriate touching, and a frank discussion was all that he required to understand that it was not acceptable. If such a situation arises again, she'll talk about it with him, but she is not going to schedule discussions. It makes her sad to think that he may never meet a girl with whom he might form a relationship that could lead to sexual fulfillment. As Parent F said, "It's sad that as they get older they get lonelier, and no one hugs them anymore, and they don't experience any physical expression of affection."

She has tried to foster friendships among his classmates by phoning parents and arranging times to visit each other. Presently, it seems that he might be forming a friendship with a boy whose birthday party he attended over the summer.

She has had good working relationships with Handicapped Children Services, but the regulations for adults really worry her. In order to receive sufficient funds to meet her son's need for 24 hour supervision, she must er [illegible] only his negative attributes rather than presenting a balanced picture of him. Parent F thinks the present government's focus is on monetary cutbacks, and the planning does not reflect the present and future needs of people with disabilities. If corporations who employ people with disabilities were given a tax break it would enhance the status of people with disabilities as well as the status of the corporation.

Summarized on Feb. 20/95

Appendix E

Sexuality And Adolescents With Disabilities Questionnaire: Parental Perspectives

Adolescent Information:

Sex of adolescent: ___ male ___ female

Age of adolescent: ___ 12 to 14 ___ 15 to 17 ___ 18 to 20

Number of children in family: ____

Birth order of adolescent: ___ only child ___ oldest ___ second oldest

___ third oldest ___ fourth oldest ___ youngest

other ______________________________

Disability of adolescent: **Check all that apply**

____ moderate or trainable mentally handicapped

____ physically handicapped

____ mild or educable mentally handicapped

____ multi-handicapped

____ autistic

____ behavior disorder

____ visually impaired

____ hearing impaired

other ____

Where does your teenager with disabilities currently live?

___ family home ___ group home ___ foster home other ______________

What are your **most important** concerns for your teenager with disabilities? Check all that apply.

___ health concerns

___ vulnerability to sexual exploitation

___ concern about school placement

___ behavioral concerns

___ changes to government funding to people with disabilities

___ absence of friends in life of teenager with disabilities

other ____

Check the concerns you have for your teenager with disabilities concerning sexual exploitation.

___ teen will sexually exploit others.   ___ teen will be sexually exploited **by** others.

What type of abusive situations has your teenager with disabilities experienced? **Check all that apply, then, indicate the number of times it has occurred.**

___ none.

___ been taken advantage of in social situations, because of a disability: eg. told to do something socially inappropriate.

___ 1 to 5 times ___ 6 to 10 times ___ more than 10 times

___ been taken advantage of financially by others, because of a disability.

___ 1 to 5 times ___ 6 to 10 times ___ more than 10 times

___ been treated rudely or indifferently by service people (sales people, cashier), because of a disability.

___ 1 to 5 times ___ 6 to 10 times ___ more than 10 times

___ been physically abused because of a disability, eg. slapped, hit, punched, kicked, cut, pushed, burned, confined.

___ 1 to 5 times ___ 6 to 10 times ___ more than 10 times

___ been sexually abused: eg. any sexual touching, sexual intercourse or sexual exploitation by another child or adult.

___ 1 to 5 times ___ 6 to 10 times ___ more than 10 times

___ been emotionally or psychologically abused because of a disability: eg. repeated name calling, treated disrespectfully.

___ 1 to 5 times ___ 6 to 10 times ___ more than 10 times

other ___ ____

During which childhood years did you worry **most** about the sexual exploitation of your child with disabilities?

___ when child was 4 years old or younger.

___ when child was 5 to 9 years old.

___ when child was 10 to 17 years old.

___ there has been no change in the amount I worry.

Did your feelings of concern increase, as your child began to develop sexually?

___ no ___ yes

Were you more concerned when your teenager with disabilities began to develop sexually, than when your other children experienced puberty?

___ more concerned ___ less concerned ___ the same amount of concern

___ not applicable

Which of the following factors contributed to your feelings of worry and concern? **Check all that apply.**

___ comments from medical personnel

___ memories of your own experiences

___ comments from social service personnel

___ experiences of your teenager with disabilities.

___ comments from school personnel

___ public sources: eg. literature, television, film, lectures.

___ comments from other parents of teenagers with disabilities.

other____

How do **you** cope with your worries and concerns for your teenager with disabilities' vulnerability to sexual exploitation?

___ provide teen with constant supervision with the help of...

___ family members and friends ___ paid agency workers

___ take some leisure time for yourself: eg. physical exercise, social outing

___ use personal support network: eg. family members, friends

___ obtain information on parenting skills: eg. behavior management, natural consequences

___ use formal network for relief: eg. hire agency staff, agency consultants

___ attend organizations or conferences designed for parents with children with disabilities: eg. parent groups

___ take solace in religious beliefs and/or church affiliation

other ___________________________

Which of the following experiences are **most typical** of those you shared with your teenager with disabilities during puberty? **Check the number of times it has occurred**.

___ talked about sexual body parts, using slang or socially appropriate terms.

___ 1 to 5 times daily ___ 6 to 10 times daily ___ more than 10 times a day

___ experienced a change in moods, eg. wider swings, more episodes of emotional upset

___ 1 to 5 times daily ___ 6 to 10 times daily ___ more than 10 times a day

___ touched his/her own sexual body parts while in a public place.

___ 1 to 5 times ___ 6 to 10 times ___ more than 10 times

___ touched the sexual body parts of others.

___ 1 to 5 times ___ 6 to 10 times ___ more than 10 times

___ showed upset with the appearance of blood during monthly menstrual periods.

___ 1 to 5 times ___ 6 to 10 times ___ more than 10 times

___ required assistance to complete menstrual tasks each month, eg. changing pads.

___ 1 to 5 times ___ 6 to 10 times ___ more than 10 times

___ had difficulty completing hygiene routines, eg. deodorant use, bathing more often.

___ 1 to 5 times ___ 6 to 10 times ___ more than 10 times

___ wanted "to do things by myself" and showed more resistance to assistance.

___ 1 to 5 times daily ___ 6 to 10 times daily ___ more than 10 times a day

other____

Who has provided education and training in abuse prevention to your teenager with disabilities? **Check all that apply.**

___ I have taught her/him within the family.

___ The school taught classes on sexuality and abuse prevention.

___ S/He participated in a course taught by a social service agency.

___ S/He participated in personal counselling sessions.

other___________________________________

Following is a list of skills that can reduce vulnerability to sexual exploitation. **Check** off the skill areas in which your teenager with disabilities has received some training.

___ assertive training: eg. saying "no", asking for help, physical self defense

___ sex education: eg. love and sex, body parts, puberty, physical affection, sex vocabulary, hygiene, lifestyle choices

___ individual rights: eg. values, self concept, basic human rights, private behavior

___ personal safety: eg. good touch/bad touch, situations to avoid, risks, when to say 'no', how to say 'no', seeking help persistently, seeking advise, disclosure

___ social skills: eg. friendship, family, dating, client-service provider, stress management

___ choice making: eg. problem solving, exploring alternatives, decision making

___ communication: eg. expressing feelings, describing experiences, initiating communication

Parent Information:

Sex of parent(s) who completed this form: ___ male ___ female

Age of parent(s): ___ 30 or under ___ 31 to 35 ___ 36 to 40

___ 41 to 45 ___ 46 to 50 ___ 51 to 55

___ 56 to 60 ___ 61 to 65 ___ 65 or over

Occupation or position: ______________________________

Educational level: ___ completed 7 to 11 years of schooling

___ high school graduate

___ some post secondary education

___ graduate of post secondary institution

Race or ethnic group membership: ______________________________

Marital status: ___ single ___ widowed ___ separated or divorced

___ married or common-law relationship

Thank you for your cooperation in completing this questionnaire!

If you have additional comments about your teenager with disabilities and their experiences during puberty, please use the back of this page.