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ABSTRACT

This study (stage two of a proposed four-part study) employed qualitative methods and descriptive statistics to examine child mental retardation from the perspective of the family. Ninety-five mothers of children with mental retardation were surveyed using an 80-item questionnaire and 3 open-ended questions which provided mothers an opportunity to articulate their own experiences in their own words. Data were analyzed to determine children's and mothers' needs and experiences, including educational needs and experiences, and to compare experiences with those of three case study families from stage one of the study. Recommendations are offered in terms of attitude change, policy change, and suggestions for service providers. Recommendations support current levels of understanding in the field of "best practices" for service delivery to families of children with disabilities. A bibliography of approximately 65 items is provided. Appendices offer a copy of the survey form, statistical data from the survey, and responses to the open-ended questions. (Contains 11 references, 22 tables, and 6 figures.) (JDD)

PARENT SURVEY:

THE EXPERIENCE OF PARENTING A CHILD WITH DISABILITIES

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ACKNOWLEDGEMENTS

It is always very difficult to write the acknowledgements for a piece of research like this one. This is very 'low-budget" research. Very few of the participants received any direct pay for their efforts. All the parents were volunteers and all of the children were "examples" without any direct opportunity to articulate their points of view. Yet it was the lives of these parents and children that were studied. Without them there would have been no "data" and no study. It is to these parents and children that I offer my primary acknowledgements.

Five agencies providing services to persons with developmental delay and mental retardation gave me access to their clients an act of faith not to be discounted. Each agency provided whatever help was possible within the confines of their very tight budgets. I was astonished and gratified at the levels of support. One agency (a school system) provided their early intervention workers' time and energy for distributing, monitoring, and collecting questionnaires. Two agencies (advocacy groups for persons with intellectual disabilities) publicised the call for participation in the study and helped with the collection of completed questionnaires. A university child study clinic contacted possible participants, informing them of the study and encouraging them to take part in this research opportunity. A final agency (one providing services for adults with mental retardation) contacted clients, distributed questionnaires, collected completed questionnaires, word processed each of the three open-ended questions and sent all of the gathered information to me.

Due to the research commitment to keep confidential the identity of the study parents and their children, none of these contributors can be identified by name. All should be acknowledged, however. Each person or agency contributed as much as was possible, without knowing me or knowing much about my work. I want to pay special tribute to all of these many people and to the confidence that they placed in me and to the directors of each agency and contact persons with whom a working relationship was so easy to establish and maintain.

Lastly, I want to acknowledge the contribution of two long-time colleagues. Ordinarily, persons who receive "pay" for their contributions to research reports are not acknowledged in other ways. I suppose their wages theoretically limit the necessity for proper acknowledgement. Because this is likely my last large research report, however, I want to acknowledge, Ann Romano-Crichlow, word processing magician, and Sheila Flory, computer programmer extraordinary, for their excellent work on this project and all the projects we have done together. Both of these women have helped me enormously, contributing to all my research projects and most of my papers over the quarter of a century that I have been employed at the University of Saskatchewan. I have relied on them without limit and they have never let me down. I acknowledge their long-time support and assistance as well as their particular assistance for this project. They made my work easier and my finished "products" better than I could have accomplished alone.

Barbara Bloom

Barbara Bloom PhD
Professor
University of Saskatchewan
January, 1996

DEDICATION

This study is dedicated to the children,
parents, brothers and sisters
from whose lives
came the information without which
this study would never have been possible.

ABSTRACT

PARENT SURVEY: THE EXPERIENCE OF PARENTING A CHILD WITH DISABILITIES

Over the past several decades, early Intervention (EI) for children with disabilities has become common practice in North America. In response to research findings, services to young children have moved increasingly from child-centred, to family-centred interventions. This changing focus of service delivery to young children has been a wedge of change for service delivery to people with disabilities at all age levels. As a result, many professionals are attempting to understand child disability from the broader perspective of the meaning of disability to the family.

This study is Stage Two of a proposed four stage study. Like Stage One, it employs qualitative methods and descriptive statistics. The purpose of the total study is to examine child disability from the perspective of the family. Each stage builds upon previous stages. The disability area under study is mental retardation, principally at the moderate, severe and profound levels.

Stage One of the study asked the question: What does it MEAN to a family to have a child with disabilities? Three families, each with a child with disabilities took part. Mothers (regarded as "co-researchers") and, to a lesser extent, fathers and siblings, were interviewed and observed. Mother interviews, parent questionnaires and summaries of family discussions and planning sessions were the primary sources of study data. Qualitative methods,

procedures and analyses were employed throughout. Transcripts of interviews and all written analyses and discussions were examined by the co-researchers for confidentiality, clarity and interpretation verification.

Stage Two of the study asks the question: To what extent do other mothers agree with the findings of Stage One? In Stage Two, ninety-five mothers of children with disabilities were surveyed using an eighty item questionnaire developed from direct quotations of the mothers of Stage One. In addition, three open-ended questions were asked of the mothers. Responding to these questions provided the Stage Two mothers an opportunity to articulate their own experiences as parents of children with disabilities. Qualitative methods, procedures and analyses were employed throughout. All proper names of people and places presented in the narratives of each stage were changed to protect participant anonymity.

Results of Stage One indicate that families of children with disabilities do all the things that families ordinarily do to help their children grow and develop; but they do these things more intensely and for a longer period of time. Of particular note for these families, was the intensity of the illnesses of their children and the level and intensity of family interactions with health care professionals. Each family had many interactions with other service delivery agencies, notably education. While many professionals provided positive, appropriate, and responsive service, many professionals did not. Particularly striking are three findings: the amount of time and energy parents are compelled to direct toward obtaining and maintaining services for their children; the level and quality of family adaptations and coping strategies; and the level of respect and love the families generate, maintain, and continue to express to each other.

While it was not possible to know the ninety-five families of Stage Two as intimately as the three families of Stage One, verification of the attitudes, both positive and negative; the quality of services provided; and the kind and quality of demands placed on parents of children with disabilities is provided by the Stage Two data. Recommendations resulting from the two completed stages of this study support current levels of understanding in the field of "best practices" for service delivery to families of children with disabilities.

BACKGROUND MATERIAL

The broader family-systems approach to intervention focuses on the exchange between the child; the setting (various environments); and the significant individuals in the child's life, with growing interest in fathers and siblings (Marsh, 1992). The family is becoming the unit of intervention, rather than the child Fewell and Vadasy, 1986; Turnbull, 1986). It is, therefore, important that service delivery professionals have an understanding of child disability from the perspective of the family. This study is stage two of what will be a three or possibly four stage endeavour.

The Initial Study (Stage One)

In the fall of 1991, I began examining the "meaning" of child disability for families, by studying three two-parent families, each with a child with disabilities. These families are all from the middle-class and have benefitted from opportunities for good educations. Their children with disabilities were, at the time of the study, 5, 9, and 18 years of age. In this initial study (Bloom, 1993a) the mothers of the three study families are regarded as "co-researchers" and most information was gathered through individual interviews with them. In addition to recording family histories, the purpose of the first interview can best be stated as, "Tell me what I need to know". Each subsequent interview elaborated on and examined more closely, material articulated in the first interview and also encouraged each mother to examine the personal meaning of her child's disability. About five hours of interview information were recorded and transcribed for each mother.

"Meaning" was addressed through each mother's response to systematic open-ended questions in the interviews. These planned questions were used only as devices to start the discussions. The interviewer, while attempting to keep the material focused, encouraged digression and elaboration. Both were completely under the control of each mother. Written transcriptions of the interview information were analyzed for emerging themes of meaning. All Transcripts of interviews and all written analyses and discussions were examined by the co-researchers for respect for anonymity, clarity of meaning, and verification of interpretation.

Additionally, mothers and fathers independently completed questionnaires (Dunst, Trivette & Deal, 1988) concerning various aspects of family life and the effects of child disability on each parent and each family constellation. Responses to questionnaire items, and the discussion of these with each parent pair, provided additional information and provided fathers with an opportunity to contribute their views and some of their experiences to the study.

Finally, a family discussion using MAPS (Forest and Lusthaus, 1989; 1990) a planning tool which focuses on the individual child with special needs within the context of the family environment and other environments, provided further information valuable to answering the study questions (see below). Where appropriate, siblings attended the MAPS planning session. Where there were no siblings, or where the siblings were too young, some additional person was invited to the session to help in the planning and to give additional information about each child's and each family's situation. Invited participants, in each case, were people involved in the education of the children. The initial study (Stage One) of this series asked the following questions:

> What does it mean to a family to have a disabled child?
>
> What are the special needs of these children?
>
> What roles do family members take on?
>
> What supports (formal and informal) exist for each family?
>
> What coping skills and strategies have the families developed?
>
> What are each family's (current and future) concerns?

Learning from Parents

Results indicate that the Stage One study families do all the things that families ordinarily do to help their children grow and develop; but they do these things more intensely and for a longer period of time. Child disability meant considerable change in each family's situation. Child rearing and family responsibilities became more intense. Adjustments had to be made by all family members to recognize and adapt to the special needs which each child presented. Family members took on many helping and educational roles with reference to the child with disabilities and many educational roles and advocacy roles with reference to individuals and groups outside of the immediate family circle.

In this study, while some specific service providers were mentioned as excellent supports and excellent resources, most of the emotional and intellectual support for family members (particularly the mothers) came from within the immediate family circles, themselves, or from support services for which the families paid a fee. Child disability in each of these families forced the parents, particularly the mothers, to acquire coping skills that they likely would not have needed without the presence of disability in the family and which definitely forced them to adopt strategies and learn skills that would not have been necessary had they not been the parent of a child with disabilities.

Family concerns surrounding each study child varied according to the child's needs. For the younger two children, community-based schooling was a major concern. For the family with the oldest child, feeling somewhat rejected by the schools, concerns were more focused on adult living, work possibilities, and social/recreational opportunities. All three families were concerned about and worked very hard to find age-appropriate companions and activities for their children in school and outside of school. Two of the families continued to have very real and very serious concerns about their children's health. Of particular note, with regards to these families, was the intensity of the illness(es) of all three children and the level and intensity of family interactions with health care professionals.

These continue for two of the three families, and will continue throughout the lifetimes of their children.

As a result of doing the study, I was particularly struck by three things: the amount of time and energy study parents were compelled to direct toward obtaining services for their children; the level and quality of family adaptations and coping strategies; and the level of respect and love these families generate, maintain, and continue to express to each other. At the completion of the study, however, I could not help but ask this question: If these articulate, well-educated, main-stream culture mothers, supported financially and emotionally by loving husbands, are facing so many problems and are dealing with so many stressors in the process of rearing their children with disabilities, what is happening to poor mothers? to culturally different mothers? to racially or ethnically different mothers? to single-parent mothers? to mothers who support their children on some kind of social assistance?

As well, as an educator, of particular interest to me was the experience that each family had had with education personnel. Some experiences with educators were very distressing, yet, some experiences were excellent, for both children and parents. This same situation was true with regard to every agency or system of service providers. Observers of this could choose to focus on how terrible the experience of these parents has been (and continues to be) or we could focus on the many good experiences that these families have had (and continue to have) with service providers.

It is my hope that this series of studies will help us to understand the experience of families and parents with a child with disabilities from **their** perspective. From this understanding and by being introduced to the specifics of their experiences, service providers can focus on what has been good and right for parents and families with a child with disabilities and avoid what has been bad or wrong. With improved knowledge, a more mature perspective, and a positive focus, we can develop the skills and provide the services that will truly support parents and families in their work of helping **all** their children develop to their most optimum level.

The complete report of this first stage study (Bloom, 1993a) or its summary (Bloom, 1993b) can be obtained through the Educational Resource Information Center (ERIC) Clearinghouse for Disabilities and Gifted Children, Council for Exceptional Children (CEC). A briefer summary can be found in the current research literature (Bloom, 1993c).

The Present Study (Stage Two)

Stage two of the study is a survey of 95 North American mothers (from five different sites) using a survey instrument consisting of eighty statements plus three open-ended statement requests. The eighty statements are direct quotes from the three mothers of the stage one study. The survey mothers examined each of the

80 statements and then indicated how similar (on a five point scale) their experience is or has been to the statement from the mother of the original study. The open-ended requests provide the survey mothers with an opportunity to describe their own experience in their own words. All data were analyzed using descriptive statistics and qualitative methods.

Recognizing the limitations of survey inquiries and the very limited opportunity for the survey mothers to articulate their own experience, this research asks the questions:

1. How similar is the experience of the survey mothers to that of the mothers in the original study of three families?
2. What themes of experience will emerge from the written comments of the survey mothers?

METHODS AND PROCEDURES

Sample

Mothers from five different geographical locations in North America were invited to take part in this study. Four of the five sites, in addition to their convenience, were chosen for size of city, urban/rural population blends and farm economies, all of which are similar to that of the home site of the three families in stage one of the study. The remaining site is the same home site as the original study. "Recruitment" was undertaken by local personnel. Families were given information about the project and encouraged to take part. Some mothers enroled immediately, writing for the appropriate forms with little more than a brief notice in a newsletter. Other mothers required assistance and encouragement. Local agencies were free to define their level of involvement in this study. Personnel from one site wrote to their list of clinical registrants to inform parents of the study and to encourage participation. Personnel at another site contacted their clients, provided all appropriate forms, collected the completed questionnaires and forms and entered the responses to the open-ended questions into a computer for our later use.

There was no attempt to select mothers by using any specific sampling procedures. The mothers are all self-selected. All submissions were included in the study, except for one which failed to provide adequate information. For several complex reasons, two fathers completed cover sheets and questionnaires. I elected to include their submissions with all the others. As a result, our category of "mothers" includes two fathers. I will discuss this more completely, later in the study.

Data Collection Instruments

Cover Sheet

The cover sheet of the questionnaire (see Appendix A) provides space for mothers to indicate many items of information about their families, their children and themselves. This sheet also provides opportunities for the mothers to give information about their needs and their children's needs, both "basic" needs associated with care and daily living and social/recreational needs associated with the quality of their lives.

Questionnaire

The questionnaire (see Appendix B) consists of eighty statements articulated by the three mothers in the stage one study. Each survey mother was instructed to read each statement and then decide to what extent she would share the ideas and feelings expressed in the statement. She was then asked to indicate in the space provided to the right of each statement, which option best communicates the degree of similarity of her experience with that of the mothers of stage one. Six response options were available: "Not Applicable", "Almost Never", "Seldom", "Sometimes", "Often", "Almost Always". In addition, three open-ended statements with space for written responses were provided the mothers: "Briefly tell me one positive experience you have had with reference to your child with disabilities"; "Briefly tell me one negative experience you have had with reference to your child with disabilities"; "Do you have anything more that you want to say?".

Time Line

Searching and finding appropriate sites for subjects began in the spring of 1993. Because I am interested, primarily, in families of children with mental retardation, I asked for and received considerable help from local advocacy groups particularly concerned with children and adults with this disability. In addition, one school system was very helpful, as were one vocational centre for adults with mental retardation and one university. These latter two polled lists of participants in their program or clinical activities. Personnel from each site accepted varying amounts of responsibility within the process of connecting researcher and "subjects". Materials were created by me. They were sometimes sent out from my office and sometimes sent out by personnel at each local site. Each participating mother completed the cover sheet and the questionnaire and returned them either to the personnel at their site or sent them to me, directly. Level of responsibility was decided at each site, and often depended on budgets and number of persons available for this kind of work. Because the researcher resides in Canada and some of the research sites are in the United States, the possible psychological effects on the mothers of having to mail their materials across a border was taken into consideration. All responses originating in the United States were gathered together there and sent or given to me by the personnel at each site.

As site volunteers became involved in the study, the process of data gathering began. We did not wait for all five sites to state their levels of commitment. As a result, almost all the data from the first site was gathered by the time the process was initiated at the fifth site. Each stage of data gathering continued, site by site, until material from all five sites were in hand. In general, the sequence of activity was the same for each site:

1. select site
2. obtain volunteers
3. send out materials
4. gather responses
5. assign "subject" numbers
6. code cover sheets
7. code responses to statements 1-80
8. word process responses to the three open-ended statement opportunities (81, 82, 83) in preparation for content analysis.

All data were in appropriate forms by December of 1994 and analysis was begun.

Treatment of Data

Considerable data were generated in this study. These had to be "reduced" and "grouped" in order to make them understandable (Bogdan and Biklen, 1982;

Guba & Lincoln, 1982). A major effort was directed toward maintaining access to information by site and by significant variables as well as by the total group. Most data are presented in the various appendices of this study and are identified by individual sites as well as by totals.

Information from the cover sheets and responses to statements 1-80 were subjected to SPSS analysis using descriptive statistics. Responses to items 81, 82, and 83 were word processed by sites, thus allowing inspection of the group as a whole and by sites. These responses were then grouped by items (i.e. 81, 82, 83) for easy comparison and analysis of the survey mothers' emerging themes of experience. All appendices are listed in the Table of Contents.

FINDINGS

Ninety-five mothers completed cover sheets and questionnaires to provide the data of this study. Two of the mothers have three children with disabilities and three of the mothers have two children with disabilities. This means the N of the study will be either 95 and 102, depending on whether the question being examined at the time concerns mothers or children. As well, mothers were not expected to respond to every item of the questionnaire or cover sheet; therefore, item n's will vary according to the level of response to the item being examined.

In early drafts of these findings, these various N's and n's were systematically reported; but the tables proved too cumbersome to convey good information. As a result, this practice was abandoned and the tables now simply state the general N of 95 for mothers and 102 for children. These are reported appropriately in the tables.

Because of mothers' illnesses, two cover sheets and two questionnaire responses were completed and returned by fathers. I elected to include their data in the analyses because the information about the children and the family would not detract from the study questions. While one of the fathers stated, "I am sure my wife would have answered some of these questions differently", I reasoned that it was better to obtain the data from two fathers than to fail to obtain the information at all.

Who Is Taking Part in This Research?

Tables 1-5 and figures 1-6 provide the Information for the narrative of this section. In general, narratives in this report will focus on the total group, not on individual sites. For information concerning specific sites, the reader is referred to the tables themselves.

Mothers and Children

Ages

Data concerning mothers' ages are grouped into five ranges of age: 20-29; 30-39; 40-49; 50-59; and 60 and older (Table 1). The median age range for mothers is 40-49 years (Table 3); but the two middle ranges (30-39 years and 40-49 years) constitute 65% of the mothers in the total group. There are very few young mothers in this study (3%) but older mothers (age 60 or more) represent 14% of the total group.

Data concerning children's ages are grouped into six ranges of age: infant and toddler, 0-3 years; preschool, 4-5 years; elementary school age, 6-12 years; secondary school age, 13-18 years; young adult, 19-24 years; and adult children, older than 24 years (Table 2). The median age of the children is in the secondary school age range (Table 4); but this can be explained by the large group of adult children (23%) in the total sample, which pulls the median toward the older groups. Secondary school-aged children represent only 13% of the total group and young adult children represent only 16% of the total group. Collapsing the two youngest age categories to make one category of approximately the same range of years as the other age range categories (5-6 years) gives it 25% of all the children, matched by elementary school-aged children also at 25%.

There is a reasonably good spread of "subject" ages (Tables 3 and 4) especially of the children. Ages of both mothers and children, however, vary considerably between the five research sites. Site 1 is made up of clients from an agency which primarily serves young families. Clients from another agency (in a different state) which primarily serves adults and their families, constitutes Site 2. Sites 3 and 4 are represented by clients from two provincial agencies and Site 5 is made up of clients from a university clinical roster. As we might expect, the youngest median ages of mothers and children come from Site 1. The oldest median ages come from Site 2. The middle ranges of median ages and the biggest "spreads" of ages can be found in the data from Sites 3, 4, and 5.

Children's Levels of Disability

Mothers were asked first to state the level of disability as provided them by professionals. Then they were asked to describe their children's level of disability as they see it. Using their reporting of the professional "diagnoses" and their descriptions of the children's levels of disability; professional "diagnoses" and family "diagnoses were categorized into the traditional levels of "mild", "moderate", "severe", and "profound" (Table 5). There is considerable agreement between the professional "diagnoses" as reported by the mothers and the mothers' own "diagnoses", for the total group (see Figure 1). There is greater variation between these two perspectives for the sites (see Figures 2-6). Because of this agreement for the total group, I have chosen to focus on the level of disability as described by the mothers and will use these levels to describe the children's disabilities, throughout the study.

"Diagnoses" become more stable as children get older, so we would expect more agreement between professionals and families with older children as compared to younger children. We can see this in Figures 2 and 3. There is considerable agreement between professionals and families about the level of disability of the study children in Site 2 (Figure 3) which has the oldest children; but less agreement at Site 1 (Figure 2) which has the youngest children. No doubt, as well, the large n at Site 2 had an important influence on the amount of agreement on "diagnoses" between professionals and families for the total group.

Additional Disabilities

Thirty-five of the children in this study (34%) have no additional disabilities, other than mental retardation (Table 2). Thirty children (29%) are described as having physical disabilities, while thirteen (13%) have sensory disabilities in addition to mental retardation. Twenty-one children (21%) have both physical and sensory disabilities and mental retardation. Three children (3%) are described as having disabilities, but no mental retardation. One child (Table 5) is regarded by his family to be age-appropriate in development and to have no disabilities.

Gender of Children

There is information from the lives of 53 male children (52%) and 49 female children (48%) in this study (Table 2). This represents slightly more female children than one might expect, in a study about children with disabilities, especially where mental retardation is of primary interest. This is a curious phenomenon; but I have no information that would shed light on the "missing" males. One guess is that they are no longer living at home, and hence local personnel would have no contact with them and would, logically, exclude them from the study. Some could have died.

School or Work

Most of the study children (53%) are in school or preschool programs (Table 2) and thirty children (29%) take part in at least part-time work. The remainder of the children (18%) are not designated to be either in school or working. These children are likely all under the age of six. Questionnaire information both structured and unstructured, indicate that all of the older children, young adults and adults are in day programs of some kind.

Domiciles

Most of the families in this study (62%) live in urban areas and most, whether urban or rural, live in or near a population centre of 30,000 or less (Table 1). Only eleven families (12%) live in cities of 100,000 or more. The remaining families live in cities with populations of 31,000-60,000 (17%) or 61,000-100,000 (6%). Of the 33 rural families who indicated "distance", 29 (88%) reside within 50 kilometres/30 miles of their home cities. Because an attempt was made to survey families in circumstances similar to those of the original Stage One families of this study, these findings are not remarkable.

Descriptions of Families

Marital Status and Income

Eighty-one percent of the families in this study represent two parent households (Table 1) and nineteen percent are headed by divorced or widowed mothers (16%) or mothers separated from their husbands (3%). The median income is $24,000-48,000 Canadian funds or $20,000-$40,000 US funds (Table 1). Most of the families (60%) have incomes in the middle two ranges of income and many (24%) have incomes in the highest income category of this study (more than $72,000, Canadian funds, and more than $60,000, US funds.) On indicators of income, most families of this study are well into the middle-class, as were the original Stage One families.

Number of Children

Two to three children is the median number of children (Table 1) for study families. Fifty-seven percent of the families can be found within this category. Twenty-six percent of the families have four to six children and three percent of the families have more than six children. Thirteen study children with disabilities (14%) are "only children".

Parental Levels of Education

Study parents are well educated with sixty-three percent of the mothers and forty-five percent of the fathers having completed high school or some post secondary education (Table 1). Twelve of the mothers (13%) and nine of the fathers (9%) have university degrees. Eighteen of the mothers (19%) and nineteen of the fathers (20%) have graduate degrees. The median education for both mothers and fathers is within the post secondary range of education. This is similar to the parental levels of education for the Stage One families.

Parental Employment

None of the fathers and only one of the mothers (1%) identified herself as unemployed at the time of this study (Table 1). Eighty-seven percent of the mothers are employed in skilled jobs (including full-time homemaking) or professional work, while seventy-one percent of the fathers are employed in skilled jobs or professional work. Four of the mothers (4%) and four of the fathers (4%) are in unskilled jobs. One mother (1%) and two fathers (2%) are students. Seven mothers (7%) and ten fathers (11%) are retired while two fathers (2%) are deceased. Stage One families are similar to the median here, as well.

What Are Their Needs?

This section is concerned with the expressed needs of the children and mothers indicated by mothers' responses to items on the cover sheet of the questionnaire. These responses are summarized in Tables 6, 7, and 8 and needs are ranked in

Tables 9, 10, and 11. Table 12 provides a summary of the top six items for each of the categories: Children's (basic) Needs; Mothers' Needs; and Children's Social/Recreational Needs.

Children's (Basic) Needs

The first group of options for mothers to mark to indicate needs, refers to basic physiological and developmental needs like "eating" and "toileting", "playing" and "language". From Table 6 we can see that the children in this study, as a total group, are quite in need of help with many everyday physiological and developmental requirements of life. Almost half of them, for example, need help with toileting (47%); virtually two-thirds of them need help with personal hygiene (67%) and help with creating their own language (66%). Slight variations can be observed between the several sites. The rank ordering of these basic children's needs for the total group is presented in Table 9.

Mothers' Needs

From Table 7 we can see a listing of the expressed needs of the mothers. Some variation, depending on site, can be observed. For example, "time to myself" was a high need for the mothers in Sites 3, 4, and 5. Site 2 mothers, on the other hand, indicate relatively low mother needs for every option except for "someone to help me plan for the future". Site 1 mothers indicate a relatively high need for "time for other family members". These differences can probably be explained by the ages of the children at each site, and the likely ages of their siblings. Mother needs are rank ordered, for the group as a whole, in Table 10. Here we can see relatively high needs for "Someone to help me plan for the future" (53%) and "Time for myself" (51%). While the expressed needs of the mothers appear relatively low, it should be remembered that these are mothers of families who are already known to service providers and who are already receiving services. An expression of 25-30% of the total group or even 25% indicates that 25%-30% of these mothers, despite attention by service providers, still need some “hands-on” help each day. It is disturbing that a third of these mothers, for example, are still indicating a need for occasional respite care.

Children's Social and Recreational Needs

Needs in this category represent those things that can improve the quality of life of any individual. It is interesting to see in Table 8, that the high needs (greater than 50%) are social or interactional in nature. These are listed by rank in Tables 11 and 12. Though some of the "access needs" are still too high, the really high expressions of needs are all social and could be labelled as "opportunities for fun and for caring human relationships", something all human beings need and from which we can thrive. This finding takes on more meaning when we remember, in addition to human caring and nurturing, success in the work-force for all individuals and especially for those with mental retardation, is highly related to the individual's social competence and ability to get along with fellow workers.

Needs And Other Variables of Interest

Needs, Location and Income

Tables 13, 14, and 15 display information about expressed needs and whether of not the family lives in an urban centre or a rural area; the size of the urban centre or closest "business city" for rural dwellers; and the family income. Numbers in parentheses within each cell of the table indicate percentage of total response for that item with regard to the variable being examined. These variables, "Urban/Rural", "Size of City", "Income" are indicated at the top of each table. Double vertical lines indicate the boundaries on the table of each of these comparison variables. This same procedure is followed on all subsequent tables that compare and contrast demographic characteristics (variables) with indicators of needs (items from the cover sheet of the questionnaire).

Not every mother responded to cover sheet items concerning these variables, and it was not expected that mothers would "tic" every listed need. As a result, some of the n's will sum to less than 95. Occasionally the n's will sum to 96 because one mother with two children with disabilities filled out two cover sheets. (The other mothers with more than one child with disabilities, incorporated the needs of their multiple children onto one cover sheet.) What is important here, and on many of the tables to follow, is to compare each item percentage in the columns to the percentage for that characteristic in the total Population Sample. Population Sample characteristics, taken from Tables 1 and 2, are listed at the top of each comparison table. For example, we can see that the proportion of children from rural homes is 38% of the whole sample, yet there are a number of indicated basic needs (Table 13) in the "Rural" column that are in excess of 38%. The Population Sample for urban dwellers of this study is 62%, yet we can see several mothers' needs (Table 14) in the "Urban" column which are in excess of this. The items of interest, therefore, are those items sorted by urban/rural, size of city, or family income that are remarkably in excess of the proportion (%) found in the Population Sample for any demographic variable.

All numbers in parentheses indicate percent from that population variable who responded to that item. As a general "rule" for this study, proportions toward the middle of the range (40% - 60%) which show a 7% or more excess as compared to the Population Sample are of interest. Proportions showing a 3% or more increase towards the outer limits of the range, are of interest.

The Urban/Rural variable can provide a good example for reading these tables because every family responded to the urban/rural category item. Of these respondents, for example, only thirty-three mothers indicated their children needed help with eating/feeding (Table 13) and of these thirty-three, 20 (61%) are urban dwellers and 13 (39%) are living in rural areas. These proportions of 61% and 39% are not very different from the Population Sample where 62% are urban dwellers and 38% are living in rural areas. This is not a very interesting finding. We would not expect, anyway, that where a family is living would have any relationship to whether or not a child needed help with eating.

When we look at access to community-based dental services, however, we see a big difference between the proportion of mothers who indicate their children's need for this service (Table 13). Many more mothers living in urban areas (80%) indicate this need than we might expect from the population sample, because only 62% of the Population Sample comes from urban centres. Moreover, this is exactly in the opposite direction of what we might expect, should a difference occur. We would expect that rural mothers would be more likely to indicate this need than urban mothers. This is a very interesting finding. If we examine the size of city, we can see that most of the Population Sample (61%) live in or near cities of 30,000 or less, and 13 (87%) of the 15 mothers who indicate that their children need community-based dental services live in or near these small towns. The larger-sized urban centers show a lower proportion of mothers responding to this item than we would expect from the population sample. The problem, if there is a problem (only 15 of 95 mothers indicate community-based dental services is a need of their children) seems to lie in the small urban centres, not the larger ones. As well, income is likely a factor, for 42% of those mothers indicating need for community-based dental services for their children are from income level 1, a proportion far in excess of the income level 1 Population Sample of 15%.

In this manner, readers interested in any specific needs of children or mothers can compare the specific need of a sample with the reported Population Sample variable(s).

Needs, Site, Level of Disability and Marital Status

Table 16 displays information about expressed needs and site, level of disability, and marital status of the parents. Using a "rule" of looking for items with a percentage of response 3-5 percentage points above the population sample for that variable, Sites 3, 4, and 5 seem to indicate higher levels of unmet needs than do Sites 1 and 2. This could be explained by the ages of the children, rather than by any real differences in services at these sites. Not surprisingly, the more severe levels of disability show higher levels of unmet needs. Single parent mothers indicate slightly higher levels of need for their children but not for themselves. The only high level of maternal need indicated by the single mothers is "planning for child's future". To my surprise, single mothers indicate less need than married mothers for a "parent support group" and "someone to talk to". Perhaps they are so busy that they don't have time for either a support group or a confidant.

Needs, Gender, Age and Number of Children in the Family

Table 17 displays information about expressed needs and child's gender, age, and number of children in the family. There are few gender differences reflected in these data; but the ones that appear are very interesting. Mothers of female children indicate more need of help for their children in creating language and in finding leisure activities that are community-based than do mothers of male children. I cannot explain the first finding. Perhaps the second is explained by a general gender bias of fewer recreation activities for females. Mothers of younger children indicate more need of help to meet their children's basic needs than do other mothers. This is not surprising. Mothers of only children indicate more need of help for their children's basic needs and slightly more need of help for themselves. In this latter instance, the mothers of only children indicate need of time for themselves. Interestingly, both groups of mothers of more than one child showed a lower proportion of selection of this item than is indicated by the Population Sample. While multiple children is in many ways more work, older siblings likely take on some of the work and near-age siblings likely provide amusement and play for each other, thus affording their mothers some measure of time for themselves. These possibilities are not available to mothers of only children.

Needs, Mothers' Education and the Presence of Additional Disabilities

Table 18 displays information about needs and mother's level of education and the presence (or absence) of physical and/or sensory disabilities, in addition to mental retardation. Interestingly, the mothers with the highest level of education indicate the highest level of need for their children. Perhaps more of these mothers are in full-time employment and the daily basic needs and social needs of their children would loom large in the managing of their families' routines. These same mothers (category 6) along with their post secondary education counterparts (category 4) indicate high levels of personal need as compared to the mothers from the three other educational categories. Mothers with university degrees (category 5) indicate a very low level of personal need, and those with a grade 12 diploma or less (categories 1 and 2) indicate high need for only one item each, "planning for child's future" and "parent support group", respectively. I cannot explain these differences.

Children with sensory and sensory and physical disabilities along with mental retardation (categories 2 and 3) show the highest levels of social and recreational needs. Both groups indicate very high levels of need in the social/recreational area. In contrast, children with mental retardation alone and those with mental retardation and physical disabilities appear to be finding ways to meet their social and recreational needs. The critical variable here seems to be sensory disability along with mental retardation.

What is Their Experience?

This section is concerned with the experiences of survey mothers as communicated by their responses to questionnaire items. Because of the quantity of questionnaire data generated in this study, most data are presented in individual appendices found at the end of this report. Appendix C provides a listing of all responses to all items for the total group. Appendix D presents an analysis of all items for total group and for each site. In Appendix D, "High Extreme" items (those attracting 50% or more responses of "often" or "almost always") and "Low Extreme" items(those attracting 50% or more responses of "seldom" or "almost never") are indicated by asterisks. "High Extreme" and "Low Extreme" items can be examined more closely in Tables 19 and 20, respectively. Appendix E lists each "High Extreme" item in statement form for the total group and for each site. Appendix F provides that same information for "Low Extreme" items. Appendix G gives a list of "Item Groups" (groups of items or single items which point to a specific theme of experience such as "isolation" or "acceptance") which are important to this research. Table 21 summarizes the response data concerning the "Item Groups" for the 95 mothers as a total group and for each site. Appendix H provides information about means and standard deviations for the "Item Groups" analysis for the total group and for each site. Lastly, responses of the 95 survey mothers to the open-ended portions of the questionnaire (items 81, 82, 83) are found in Appendices I, J, and K. Responses are sorted by sites (Appendix I) and by items (Appendix J). Themes of experience which emerge from these responses can be found in Appendix K.

Questionnaire Items 1-80

Individual Items

The focus of this section is on Tables 19 and 20. These Tables tell us which questionnaire items survey mothers marked to indicate agreement with their experience ("High Extreme") (Table 19) or lack of agreement with their experience ("Low Extreme") (Table 20).

Table 19 rank orders items of agreement for the total group and for sites. From this we can see that for the group as a whole, 22 items (28%) attracted high agreement of experience. Of these, the greatest number of items (6) are those which indicate the mother or the siblings or the family is functioning well or doing well despite the circumstances (items 1, 5, 6, 15, 31, 39); five reflect the demands on parents/families (items 7, 42, 55, 67, 78); five are statements about support (items 10, 49, 53, 54, 61); three statements focus on professionals (items 16, 24, 29); two statements describe a strategy (items 26, 30) and one articulates parental sadness (item 51).

It is nice to see agreement with those statements which portray positive coping of parents and families and to see a valuing of and agreement with experiences of support. Agreement with statements concerning the demands on parents, strategies and parental sadness highlight the real situations that these mothers and their families face. Seeing agreement with these particular statements concerning negative professional practices should give us pause, however.

Specific information concerning the amount of agreement of mothers from the different sites can be gleaned from Table 19, itself. It is interesting to note that some sites are in more agreement than others with the statements of the questionnaire. Site 5 agreed with a surprising 42 statements (53%) and Site 1 agreed with 28 statements (35%). Site 2 agreed with 19 items (24%); Site 4 agreed with 17 statements (21%); and Site 3 agreed with 15 of the statements (19%).

Table 20 tells us about lack of agreement with specific questionnaire items for the group as a whole and for each site. For the total group, only one statement (item 76) elicits 50% or more responses of "seldom" or "almost never" from the survey mothers. This represents a lack of agreement of one percent of the total statements of the questionnaire. Site 1 shows the greatest lack of agreement by indicating seven statements (items 13, 14, 43, 45, 62, 69, 76) to which 50% or more mothers marked "seldom" or "almost never". This is 9% of the total number of statements of the questionnaire. This unique level of lack of agreement might be explained by the young ages of the children at Site 1. Likely they are receiving adequate services in early intervention. Perhaps, however, there will be more parental agreement with the sentiments of more questionnaire statements as the children get older. Parents would have, by then, more years of experience trying to meet the needs of their children and trying to obtain services for older children. Site 2 indicates lack of agreement for two statements (items 18, 76) as did site 4 (items 43, 76). These represent about three percent of the total statements of the questionnaire for each of these sites. Site 5 indicates lack of agreement with only one questionnaire statement (item 76), similar to that of the total group, and representing only one percent of the total questionnaire statements.

Grouped Items

The focus of this section is Table 21. From this table we can see mean scores of responses to grouped items of the questionnaire for the group as a whole and for each site. (Appendix G provides the grouped statements and Appendix H provides means and standard deviations for the responses to "Item Groups" for the total group and for each site.) Responses of 5.0 indicate agreement "almost always" and responses of 4.0 indicate agreement "often". Because these are means it would be quite unusual to observe a response mean of 5.0. Nevertheless, using the very stringent criterion of a mean of 4.0 or above as indicative of "agreement", we can see that for the group as a whole, there are three grouped items which meet criterion: "parents have enough to do"; "positive self-statements"; and "family survival".

The first tells us there is agreement from the total group that demands on parents are high; the second tells us that despite the circumstances, the survey mothers feel good about themselves; the third tells us that these families are surviving, despite the demands of having a child with disabilities in the family.

Individual site levels of agreement can be discerned from Table 21, as well. Using the same stringent criterion of 4.0, we can see that there are slight differences in agreement by site. Site 5 is outstanding in that mothers at that site respond with a mean at 4.0 or above to seven out of 26 possible groupings of items. This represents about 27% of the item groups.

Sites 2, 3, and 4 responded to only three groupings (12%) in this manner, and Site 1 to only two of twenty-five possible groupings, an agreement response level of only 8%. Site 5 is the only site to really distinguish itself in terms of level of agreement. It should be noted, not surprisingly, that these levels of agreement are similar to those already reported in the above analysis of individual statements.

Because these are means, using the less stringent criterion of 3.5 is likely a more reasonable indicator of agreement. Examining these same data with this criterion indicates that the total group agreed with 11 of the 26 item groupings (42%). Site 5 agreed with 14 of the 26 item groupings (54%); Sites 3 and 4 agreed with 11 items (42%); Site 1 agreed with 10 of 25 item groupings and Site 2 agreed with 10 of 26 item groupings for 40% and 38% agreement, respectively. As we can see, more information about the specific sentiments to which the mothers agreed can be discerned; but rankings of levels of agreement show slight changes.

It is nice to see that survey mothers show only a very moderate level of agreement concerning negative experiences with professionals. Nevertheless, they are agreeing that **sometimes** experiences with professionals are negative. As well, while agreement concerning positive experiences with professionals is also only moderate, according to survey mothers, positive experiences occur slightly more often that negative experiences. In other words, survey mothers are saying that experiences with professionals are only sometimes positive, but these sometimes positive experiences are at least slightly more frequent than the sometimes negative experiences. Unfortunately, this must mean that most of the time their experiences with professionals are neither positive nor negative.

Questionnaire Items 81, 82, 83

Questionnaire items 81 and 82 are open-ended requests provided for survey mothers to describe experiences each has had with or because of her child with disabilities. Mothers were asked to describe one positive experience (item 81) and one negative experience (item 82). Item 83 is an open-ended request asking each mother if there is anything more that she wants to say. Almost all survey mothers took advantage of all three of these opportunities to offer written descriptions of experience and other important information.

A level of structure was imposed by the two items asking mothers to focus on either positive or negative experience. All responses to items 81, 82, and 83 were pooled, however, and then analyzed according to themes of experiences. Responses sorted according to group (total group and by each site) can be found in Appendix I. Responses sorted by each item (81, 82, or 83) can be found in Appendix J. Responses sorted by themes of experience can be found in Appendix K.

The primary research question for Stage Two (To what extent is the experience of the survey mothers similar to that of the mothers of the original study?) shaped the handling of all study data, especially those recovered from the responses to questionnaire items 81, 82, and 83. The five major emerged themes of the Stage One study ("Children", "Stress/Anxiety", "Services", "Personal", and "Survival") served as general categories for the Stage Two data. Responses of survey mothers to items 81, 82, and 83 were first placed into these five major categories, then the themes of Stage Two were discerned. Table 22 lists the major themes of Stage One and the emerged themes of Stage Two. The focus of this section is Appendix K and Table 22.

High frequencies of the major categories and of any of their subcategories are of particular interest. Except for the category of "Personal", survey mothers made good quantities of comments for each major category. Forty-eight comments describe the children in some specific way. Of these, comments about the parents' positive feelings toward their children are frequent (19) as are statements about how the children have grown; how they learn; or what they know (15). Sixty-three comments reflect stress or anxiety. Of these, twenty-seven statements of lack of support and subsequent stress are recorded. Services are commented upon in ninety-nine of the mothers' statements. Of these, twenty-three are general positive statements about services; but thirty-eight statements describe varying degrees of parent or family struggles with service provisions and/or service providers. Ninety statements indicate observations of positive survival of parents, families, or siblings. Sixteen of these describe positive experiences of their children in the community; eighteen describe positive survival despite negative experiences of their children in the community; and twenty-eight give descriptions of mothers' personal growth as a result of parenting a child with disabilities.

Similarity of Experience: Stage One and Stage Two

Summary of Findings: Stage One

Results of the Stage One study (Bloom, 1993a) helps us to see child disability from the perspective of the study parents, especially the mothers. Their stories indicate that study parents did all the things that parents ordinarily do to help their children grow and develop, but they did these things more intensely and for longer periods of time. In addition, study parents spent a great deal of time getting and maintaining services for their children.

Parental pairs in each study family supported each other and spelled each other in accomplishing the child care and domestic tasks necessary for daily living. Each family obtained some degree of support from outside the immediate family, but most of it was paid support, and much of it was not very helpful. Study parents, especially the mothers, indicated that they have many needs: respite care; others with whom to talk about their struggles and their successes; time for themselves; relief from isolation; freedom from exploitation; and freedom from having to advocate so much for services which rightfully should be a part of the everyday experiences of their children.

While each acknowledged the demands on their lives which result from the disabilities of their children with special needs; each also acknowledged positive life experiences, opportunities for growth, and many satisfactions associated with having a child with disabilities within their family circles.

Several recommendations from Stage One of this study were developed (Bloom, 1993a) and are presented here under three category headings: recommended attitude changes; recommended policy changes; and specific suggestions for service providers.

Attitude Change

1. Societal
   a. Disability is part of human existence. Some of us are born with disabilities; some of us become the parents of disabled children; some of us become disabled. It is a normal risk of life. People with disabilities and other children or adults, are a part of us. We must be prepared to help people with disabilities to live and work among us.
   b. The parent who is the principal household organizer and caregiver is as valuable in contribution and expertise as is the parent who is the principal provider of economic resources for the household.
2. Professionals
   a. People with disabilities are a part of the normal spectrum of humanity. Professionals are paid to help people because we

have knowledge and skills that are of value for the optimum development and the quality of life of the clients who come to us. People with disabilities are our responsibility as much as any other clients.

b. Parents of disabled children are a rich resource of information and experience concerning their children. We will be most effective, as professionals, if we learn to work with parents and learn to include them into the planning, goal-setting, and decision-making about their children.

c. Even though it is imperative that we work **with** parents, the responsibility for the development and monitoring of programs and services is ours. We know who the clients are and through planning with parents, what services they need now, and will need in the future. It is our responsibility to see that appropriate services are available without having to be "pressured" by parents. Parents have enough to do.

d. Our response to the parent who is the primary household organizer and caregiver should be as respectful and responsible as it is to the parent who is the principal provider of economic resources to the family. Similarly, we should be respectful and responsive to the parent who is the sole parent in any household. In all cases, we need to be mindful of the time and energy demands which parents face.

Policy Change

a. Because of the benefits to both those with disabilities and those free from disabilities, life in the mainstream is the option of choice, as much as possible, for all human activities.

b. A system of financial equity must be created in order to minimize the differences between natural and adoptive parents' financial risks when parenting a child with disabilities as compared to foster parents' risks. This is especially important with reference to natural and adoptive parents who care for an adult child.

c. Provisions for more respite care, especially in the client's home; more direct support in meeting the daily needs of clients; and more specific support in meeting the social and recreational needs of children and adults with disabilities are desperately needed.

d. Provisions for adequate, affordable, and reliable child care as an option for families, is basic to any kind of equity in quality of life for all parents. Having reliable childcare is especially important for parents of children with disabilities, some of whom require specific kinds of child care for much longer periods of time, sometimes for a lifetime, as compared to children without disabilities.

Service Providers

a. Work **with** parents, valuing them and their contributions and ideas; acknowledge their expertise.

b. Start with the positive. Celebrate the child and her competence. Only then, move into the child's areas of need and how parents and service providers can help the child.

c. Don't overwhelm parents; don't dishearten parents. They are aware of the child's limitations. Provide information and ask parents about what they know; what they think. Focus on two or three achievable goals. Support parents. Try to see the situation from the point of view of the family. Look at the whole child and look at him within the context of his family. See the child first and then look at the disability.

d. Try to appreciate what it means to be responsible for the child's care 24 hours a day, seven days a week. Contemplate alternatives. Would the child REALLY be better off? All indications assure us that children grow and develop best at home. Give parents a hand.

e. When parents are asked to work on skill development, select skills that are truly appropriate and useful and which make sense to the child. Ask the parents, "Would it be possible to work on this? Do you have the time? Will it work into your family's schedule? Would acquiring the skill be helpful and useful?" Ask parents to provide feedback on the process. Don't be afraid to admit error. Do be willing to rewrite the plan. If the plan fails, ask, "Could there be reasons for failure other than simply parental disinterest, incompetence, or neglect?"

f. When planning programming and making professional suggestions ask, "How can we use this family's strengths? How can we avoid making any family members feel left our? What information and supports have to be in place in order to avoid failure, and especially, in order to avoid disaster?"

g. Be prepared to change "the system", or the school, or the classroom, or whatever, to meet the child's needs; do not expect the child to make adaptions to fit into what "the system", or the school, or the classroom, currently has to offer.

Summary of Findings: Stage Two

This section will examine findings of Stage Two, bringing into focus any items of reporting relevant to understanding similarities and/or differences of findings between Stage One and Stage Two of the study. Categories of recommendations from Stage One will provide structure for this comparison.

Attitude Change

The focus of this section is Appendix K and Tables 19, 21 and 22. An examination of the mothers' comments categorized by themes of experience (Appendix K) gives us some insights into the attitudes of others toward the survey families and toward the children of these families with disabilities. At first reading, it would seem that about equal numbers of positive and negative attitudes are reported by these mothers. Because the questionnaire items asked specifically for descriptions of positive experiences (item 81) and negative experiences (item 82) we would expect that these would be reported in about equal numbers. In addition, however, twenty-seven mothers' comments indicate "lack of support" (under "Stress/Anxiety") and thirty-eight comments describe personal or family "struggles" (under "Services"). These descriptions of "lack of support" and family "struggles" show negative attitudes on the parts of others and support the Stage One finding that families of children with disabilities face many negative attitudes from both service providers and the general public. On the other hand, Table 21 indicates that the mothers provide an experiential level of agreement with the (positive) acceptance of their children somewhere between "sometimes" and "often" as indicated by their mean score of 3.66 for the "Others' Acceptance" item. It appears that negative attitudes do exist; but mothers and families and children with disabilities are experiencing, as well, positive and receptive attitudes that are helping them to live and grow within their communities.

It can be seen that there is some variation, by site, concerning the acceptance of study children by others. Site 1, with the youngest children, has the highest level of agreement (mean = 3.93) with the grouped acceptance items. This is probably to be expected; but the oldest (adult) children (Site 2), contrary to what we might expect, do **not** indicate the lowest level of agreement. That place falls to Site 4, which has a full age range of children. No doubt there are many different and complex variables that might explain the site differences in perceived acceptance of the study children, including the possibility that there is a very positive social environment at Site 2 and a less positive social environment at Site 4.

The Stage One finding of a perceived difference in service provision, depending on whether or not the service provider is interacting with the mother ("principal household organizer and caregiver") or father ("principal provider of economic resources") was not supported. The mean score for this grouped item (Table 21) for the 95 mothers is 2.66 (about halfway between "seldom" and "sometimes"). Site 5 indicated the highest level of agreement with this item with a mean score of 3.00 ("sometimes"). Site 2, on the other hand, tied this item for first place in their rank order of items with which they **disagreed** (Table 20).

The attitudes of professionals elicited a variety of comments from the 95 mothers. A reading of items categorized under "Services" (see Appendix K) will help readers see the various colors and shades of experience these mothers and their families have faced while obtaining or attempting to obtain services for their children. We can be heartened by the positive reports; but the negative reports are very discouraging. Table 19 shows us that three questionnaire items (29, 24, 16) concerned with professionals were high on the rank ordering of items to which more than 50% of the 95 mothers responded with a high level of agreement ("often" or "almost always"). This indicates that some, perhaps many, interactions with professionals are not satisfactory from the parents' point of view. These items are high for many of the sites, as well. While analysis of grouped items (Table 21) shows a slightly higher score for "positive experience" with professionals (3.32) as compared to "negative experience" (2.98) for the group as a whole, these scores are saying only that sometimes negative things happen and sometimes positive things happen when we interact with professionals. As well, the grouped items of "advice to professionals" received a mean score of 3.71 indicating high agreement (approaching "often") and Site 5 (4.27) followed closely by Site 4 (3.91) indicate mean levels of agreement with the advice at or very close to "often". Attitudes of professionals and service providers and the manner in which we carry out work with parents appear to be seriously questioned by these mothers. Yes, they have had some "good" experiences; but far too many of their experiences have been "bad".

An open-minded reading of the mothers' accounts of their negative experiences is very sobering.

Certainly the demands on parents are clearly indicated by this survey. Table 19 lists five items (55, 7, 78, 67, 42) which describe demands on parents and to which 50% or more of the survey mothers indicate a high level of agreement. As well, the mean score of the 95 mothers on the grouped items ("parents have enough to do") is 4.00 showing that the mothers agreed with these items "often". Site 4 is unusually high (4.42) for these items and Site 3 provides the lowest mean (3.70). This is an important group of items for these mothers.

In summary, it seems that these mothers are saying:

> Sometimes the attitudes of society and service providers toward our children is "good" and sometimes it is "bad". Sometimes we get good support from service providers and sometimes we get no support or even bad treatment and have a negative experience. Mostly, we see no differences in professionals' treatment of us whether mother or father is seeking help; but the interactions of service providers' with us could be better. Service providers need to truly listen to us and to include us into the making of decisions and special programming for our children and they need to remember that parents of kids with disabilities already have "enough" to do.

Policy Change

Parents of children living at home, or adult children who lived at home and are now living in group homes are the participants in this study. Therefore it is not unusual to find so many examples (both positive and negative) of these children's interacting with their communities. An examination of positive and negative experiences of integration ("interface with the community") under the "Survival" category of Appendix K provides an understanding of these experiences. Several mothers point out that most good things happen for their children in integrated settings by involvement with the non-disabled world. True, some people, members of society and professionals alike, have responded to these children in negative ways; but none of the mothers indicates that she is giving up on integration. Many point out the benefits to society as a whole, and to individual people, both with and without disabilities. As previously reported, Table 21 shows, as well, a high level of agreement (mean = 3.66) with the grouped items of "acceptance" (approaching "often").

Survey mothers did not support the finding from Stage One that a system of financial equity for natural and adoptive parents as compared to foster parents needs to be created to minimize the differences in financial risks in parenting a child with disabilities. They did not disagree but indicated that their level of agreement with that statement (# 80) (see Appendix G) ranged from 2.08 ("seldom") for Site 2 to 3.17 ("sometimes") for Site 3 with a total mean of 2.70 (between "seldom" and "sometimes"). More importantly, an informal comment of a foster mother indicates that foster parents are always in the red. Perhaps the original statement, along with at least part of the conflict between foster and other mothers concerning "costs", lacks full understanding of the foster parent's position. We need more information on this topic.

Despite the many positive experiences and the developmental reasons for rearing children at home, in their own communities, parents sometimes feel isolated, tied down, and overwhelmed, and sometimes find their total responsibilities to be very great (Table 21). Certainly feeling "tied down" is something all the survey mothers experience at least some of the time (mean = 3.51). At the same time, the 95 mothers agree "sometimes" with the positive experiences associated with respite and other support (mean = 3.14) but they approach "often' in their agreement with negative experiences associated with respite and other support (mean = 3.61).

In summary, it seems these mothers are saying:

> We want to rear our children at home and in our own communities. While we have experienced some rejection of our children in the community, we have experienced much acceptance, too. Keeping our children at home, however, means there is a lot for us to do, and sometimes we have very practical needs. Child care and respite are two good examples of the kind of "hands-on" help we can use. We

need this kind of help; but our experience in getting these has been good only some of the time. We feel tied down and somewhat isolated.

Service Providers

Research findings from Stage One listed seven recommendations for service providers when working with parents and children with special needs. (See "Summary of Findings: Stage One" of this document, page 35). The tenor of the findings of Stage Two support these practical recommendations for service providers, as well. In particular, the section on "Services" (Appendix K) is useful for gaining insight into survey mothers' ideas of how to provide useful and supportive services (and how not to); and the "Survival" section (especially "Personal Growth", "Strategies" and "Advice to Professionals") gives information from the 95 mothers of what has been helpful and supportive for them.

Other Findings

The focus of this section is Appendix G and Table 21. It can be seen from Table 21 that there is high agreement from the 95 mothers with the articulated strategies of the Stage One mothers (mean = 3.80). Four of the Sites (1, 2, 3, 4) indicate means from 3.71 to 3.76 (agreement close to "often". Site 5 mothers indicate a very high degree of agreement with these strategies by their mean of 4.04 ("often").

The 95 mothers agree, as well, that the experience of having a sibling with disabilities is more positive (mean = 3.46) than negative (mean = 2.42) for their children without disabilities. Mothers from Sites 2 and 5 clearly indicate the overall positive experience of siblings by their mean scores above 4.0 for "positive reality overall". This pulls the group mean to 3.99, a very small distance away from "often" for the whole group. The lowest mean for this item is 3.58 (between "sometimes" and "often") from Site 3. Clearly, the feeling of the survey mothers, as a total group, is that having a sibling with disabilities, while having some negative aspects, is a positive experience overall for their children without disabilities.

While the total group of 80 mothers (Site 1 had no older children in its sample) agree with grouped items concerning adult children only "sometimes" (mean = 3.21). Mothers of the children of Site 5 clearly indicate that they "often" agree with these statements (mean = 4.29). The median age of the children of Site 5 is within the age range of 13-18 (with five young adult children in the age range of 19-24). This might explain their higher level of agreement concerning the statements about adult children. Site 2, on the other hand, is constituted almost entirely by adult children with a median age over 24 years. The level of agreement for Site 2 is only 2.48. In fact, the mothers of Site 2, with the oldest (adult) children provide the lowest level of agreement for this item group. Clearly something other than simply having the experience of trying to obtain services for adult children is operating here. Perhaps the experience is more positive at Site 2 than at any other site.

At the same time, the item group which contrasts junior high school services as better than high school services ("older child") is agreed to "sometimes" (mean = 3.14) by the total group (excluding Site 1, made up of very young children). For this item Sites 3 and 5, with means of 4.00 and 3.80, respectively, indicate high agreement with the item. The median age for the children of Site 3 is within the age range 6-12, with five children within the high school age range. The median age, as stated before, for Site 5 children is within the high school range. I am not sure how the mothers of Site 3 could express a mean score of 4.00 from their experience, except if all five mothers of high school age children responded with the highest scores possible ("almost always"). Nevertheless, between Stage One and Stage Two mothers of this study, there are 36 responses that indicate a better quality of service for junior high school students with disabilities as compared to services for senior high school students with disabilities. Practitioners often hear this comparison being made; but more information concerning this possible phenomenon is needed.

A small but interesting finding of Stage One was the desire of the mothers to be at least part-time employed in the paid work force. This interest and need was supported by the 95 survey mothers who indicate a high level of agreement (mean = 3.75) with the item group that expressed this need. Sites 3, 4 and 5 scored means of 3.57, 4.57 and 4.07, respectively. The median level of education for mothers at Site 3 is grade 12; but mothers at both Sites 4 and 5 are more highly educated (Table 1) and give maternal ages within the working age range. Site 1 and 2 mothers responded with means of 3.40 and 3.47, respectively. These are the lowest means of agreement for the whole group. Site 1 mothers have very young children and are younger, themselves, and less highly educated, to date, than mothers of Sites 4 and 5. Many Site 2 mothers are highly educated; but they are older. Many are within an age range for retirement. As well, they are in an age group socialized to work at home. I think it is fair to say, however, that despite these differences in ages, levels of education, and possibly socialization; the mothers of Stage Two agree with the Stage One mothers that opportunities to be in the paid work force should be an option for them.

Stage One mothers were described (Bloom, 1993a) as articulate, self-confident and feeling positive about themselves. They indicated that they see themselves as survivors and good problem-solvers who feel good about themselves. They make an effort to look after their own needs as well as their families' needs and the needs of their children with disabilities.

From Table 21, we can see that while the Stage Two mothers agree only at a rather low level (mean = 2.90) with the Stage One mothers' statements for ambivalent feelings about their roles; they agree more highly (mean = 3.65) about taking care of themselves and agree at a very high level (mean = 4.22) with the positive statements the Stage One mothers about themselves. As well, personal growth statements categorized under "Survival" (see Appendix G) support this indication of maternal strength. It is nice to see the 95 survey mothers agreeing so strongly with these positive, winning statements about self. One must be cautious, however, in interpreting these findings because in a survey like this, people who feel more positively about their situation are more likely to respond to requests that they take part than are those who are depressed or who feel defeated.

In Summary, it seems these mothers are saying:

> We employ many positive strategies in our efforts to obtain services for our children and we have many survival strategies for ourselves and for our families. Overall, we feel the experience of having a sibling with disabilities has been positive for our children without disabilities. As well, we feel we and our families have grown and have risen to the demands of our situation. We may see more problems in obtaining services as our children get older. Like our counterparts who do not have child disability within their family circles, we want to have the option of being in the paid work force, perhaps when our children are school-aged or older. We are problem-solvers and we are optimistic. We are not defeated. Despite everything, we feel good about ourselves and about our abilities to meet the demands of our lives.

CONCLUSIONS

Stage One and Stage Two: Sample

Similarities

This study gives 95 mothers of children with disabilities a unique opportunity to compare their experiences of parenting a child with disabilities with that of three mothers studied in greater depth four years earlier. The purpose of both studies (Stage One: Three Families and Stage Two: Ninety-five Families) is to better understand the meaning of child disability from the point of view of families, particularly mothers of families. There was a selection bias in place to enroll parents into Stage Two of the study with traits similar to those of the parents of Stage One and results should be interpreted with this bias in mind. All interested parents were enrolled, however, giving us information, though somewhat limited, about families with traits dissimilar to those of the Stage One families.

Stage One children were aged 5, 9 and 18 years of age at the time of the study. Stage Two children range in age from infants to middle-aged adults. Most are of school age. Not surprisingly, most Stage Two mothers are between ages thirty to fifty. Stage One mothers were between ages 31 and 38 at the time of the study. Very few young mothers took part in Stage Two and because of the relatively large group of adult children in the study, about 60% of the mothers are older than 40 years of age. While there is a wide range of disabilities among the Stage Two children, most are moderately disabled, with mental retardation a primary factor. About 63% of the children have physical and/or sensory disabilities in addition to mental retardation. These characteristics are similar to those of the Stage One children. Just under three percent of the children of Stage Two, however, have disabilities but no mental retardation.

Stage One families were lower-middle to middle income two-parent families with parental education levels primarily in the post secondary education levels. These three families had one, two, and three children. The 95 families of Stage Two are primarily lower-middle to middle income earners in two-parent families with two to three children. Similar to the Stage One families, most Stage Two families live in small towns or in rural areas. Most Stage Two mothers and fathers have completed grade 12 or post-secondary education, not necessarily university. It should be noted, however, that many parents of families studied in Stage Two have university degrees and some have graduate degrees.

Differences

Stage Two mothers appear to be "better" employed than their spouses, a trait like only one of the Stage One families. Questions concerning these data should be raised, however, because of the difficulty of assigning "levels" to occupations, especially with the limited data about occupation available from Stage Two Families. As well, Stage Two parents as a whole might be at slightly lower occupational and income levels than Stage One parents.

Stage One and Stage Two: Findings

Stage One parents did all the things that parents ordinarily do to help children to live their daily lives and to grow and develop to an optimum level. For their children with disabilities they did all these things more intensely and for a longer period of time than parents of normally developing children. In addition, they spent an inordinate amount of time getting and monitoring services for their children with special needs, services that theoretically are "available" for children with disabilities. While doing these things, the Stage One parents maintained loving and caring households and support for each other.

While it was not possible to know the 95 families of Stage Two as intimately as those of Stage One, these same factors seem to be a definitional part of the family lives of the Stage Two families. There is some individual variation, here, as well as some variation by site. These conclusions are discerned from the indications of need from responses to the cover sheet items; the level of responses to the statements of the Stage One mothers (questionnaire responses); and the quality of responses to the open-ended questionnaire items (81, 82, 83).

Child Needs

Like one mother of Stage One, many Stage Two mothers indicate that their children have basic needs which someone, other than the child, must meet every day. Most notable among these are help with toileting, personal hygiene, dressing, and social interaction. All of the Stage One children needed help with communication. This was also true for many Stage Two children, especially help with understanding others' language; help with the formulation of their own verbal communications; and community-based speech therapy. In addition, like Stage One mothers, Stage Two mothers indicate their children have many social and recreational needs, particularly a need for age-mate friends; social and recreational activities with age-mates; having someone "special" in their lives; and perhaps better access to community-based sports and recreation. Single mothers, in particular, show more need in finding help for their children's social interactions and finding access to community-based leisure activities than do their married counterparts. I suspect that reduced amounts of spare time and money are important factors in this finding.

These indications of need show that there is room for some kind of daily practical assistance and perhaps periodic respite care for most of these families. One Stage Two mother volunteers, however, that it is not help with childcare that she needs (she wants to do that); her major need is for help with the demands of housekeeping. She finds that the childcare demands, under the circumstances of child disability, **in addition to** the housework, is what she sometimes finds overwhelming. She has articulated an important point, which I think few funding agency and service providers have seriously considered. Perhaps service providers and funding bodies need to be more creative in the way we define how the special needs of children with disabilities are to be met.

There seems to be room, as well, for better inclusion of these children into programs to help them with language and speech (or alternative forms of communication), sports and recreation and other "special" and community-based opportunities for social interaction, and growth in social relationships. Many of the children's special social and recreational needs seem to be related to family income for a disproportionate number of expressed needs in this area come from mothers whose family incomes are in the two lowest categories.

As we would expect, the Stage Two data indicate the younger and/or the more severely disabled a child is the greater are his/her needs. Contrary to what we might expect, however, "only children" in the Stage Two families need more help with basic needs than do children with brothers and sisters. As well, Stage Two mothers with graduate degrees expressed more child needs than did mothers in any other category of level of education. The first of these might be explained by either the additional help that siblings provide, or the higher expectation for independence of mothers with more than one child. The latter might be explained by greater awareness of needs and rights to service on the part of mothers with graduate degrees. An interesting question might be: How many of these graduate degrees are in the area of child exceptionality (earned after becoming a parent of a child with disabilities)?

Coming from a rural area seems to put children at risk for not gaining access to community-based scouts/guides and perhaps for not having someone "special" in their lives; while coming from an urban area seems to put children at risk for not gaining access to community-based summer camp and supported living opportunities. The former of each of these might "make sense", but neither of the latter do. Being female seems to put children at risk for not gaining access to community-based recreation activities. In any case, all of the above risks could be overcome in our delivery of services to families of children with special needs. Working with families and respecting each of their special features and possible risks could go a long way in improving the quality of services provided and the quality of life for our clients.

Mother Needs

Both Stage One mothers and Stage Two mothers have been less outspoken about their own needs than about the needs of their children. Nevertheless, Both groups of mothers indicate a need of time for themselves. This was true of all of the Stage One mothers and by half of the mothers of Stage Two. In addition, they indicate a need for more time for family members other than the child with disabilities; someone to help them plan for the future; someone with whom to talk about their children with disabilities; and perhaps the need of some form of respite care. Mothers of only children and single mothers expressed a serious need for help in planning for their children's futures; and mothers of only children indicate a serious need for time for themselves.

The first of these maternal needs could be met with a broadened view by service providers concerning how to meet the needs of children. Help with the demands of housework, stated above, would free mothers not only for a more relaxed attending to their children but for a bit of time for maternal re-creation in the form of time for themselves, as well. The other needs could be met by a broadened view on the part of service providers and advocacy groups of the demands on parents and a recognition of the special needs of the mothers of only children and of single mothers. This broadened view could lead advocacy groups and service providers to provide regular opportunities for emotional support, practical planning sessions, and the dissemination of information as well as opportunities for parent advocacy. Advocacy groups and service providers already do some of this; but it appears that more could be done to meet the human quality of life needs of family members for comfort, support, practical help and information.

Questionnaire Items

Items 1-80

There is a high degree of similarity of experience between Stage One and Stage Two mothers as indicated by the levels of agreement of the 95 mothers with the eighty questionnaire statements. Most notably, Stage Two mothers indicate that there are many demands on their lives. While they feel supported in many ways, and find others' attitudes toward their children to be mostly positive; they also feel tied down, isolated, and sometimes overwhelmed. They agree with the strategies articulated by Stage One mothers and the advice given by them to professionals, and offer some advice of their own. Their experiences with professionals is only slightly more positive than negative. Lastly, they agree that paid work in the work force should be an option for mothers of children with disabilities.

Like Stage One mothers, Stage Two mothers feel good about themselves and about their families' abilities not only to survive but to thrive and grow from the experience of having child disability within their family circles. They take care of their families but do not neglect their own needs. They feel the experience of having a sibling with disabilities, while sometimes difficult, is overall a positive reality for their children without disabilities. Stage Two mothers from three of the four sites with older children agree with Stage One mothers that it is more difficult to obtain appropriate services for older children and for adult children than it is for younger children. Site 2, constituted almost entirely by adult children, does not agree with this point, however.

Stage Two mothers indicate only mild similarity of experience with Stage One mothers' statements reflecting differential treatment of mothers as compared to fathers when seeking services for their children; differential financial support for foster mothers as compared to natural or adoptive mothers; and statements of negative effects on siblings of children with disabilities. Lastly, as a group, they seem to have experienced less serious and less ongoing illnesses in their children with disabilities than Stage One mothers.

Items 81, 82, and 83

Stage Two mothers write descriptions of the same kinds of experiences that Stage One mothers spoke about in their interviews. They give many positive statements: their feelings of love and respect toward their children; their children's growth and development; services for their children and service providers; and experiences as members of their communities. They describe quite well the demands they face; the strategies they have developed; the stresses and anxieties in their lives, related to their children with disabilities; and the many instances of positive personal growth. They also describe the dark sides of their lives as parents of children with disabilities: the many frustrations with service providers as well as with their children; the many instances of lack of support, from people paid to provide a service and from others; the instances of rejection and pain as members of their communities; and the many, many, struggles.

DISCUSSION

This two-staged qualitative study of the experience of mothers of children with disabilities shows considerable agreement of experience between the 95 mothers of Stage Two with the three mothers and their families studied in greater depth four years previously. While there was no attempt to compare results across the five sites, differences between sites is apparent for some items or groups of items and for some themes of experience. These differences can most likely be explained by different ages of children, and/or different ages of mothers; and/or different levels of disability. Mothers at Site 2, however, indicate that they are receiving good service for their adult children and mothers at Site 1 indicate that they are receiving good service for their very young children through their early intervention service providers. Sites 3, 4, and 5 are each mixtures of ages of children and mothers and depict a mixture of responses to study demands.

More important than possible site differences, however, is the overall statement of these mothers concerning their experiences in parenting a child with disabilities. While both Stage One and Stage Two mothers articulate many positive features involved in parenting a child with disabilities and in keeping that child at home and in the community; they indicate, as well, far too many instances of lack of support from community people and from service providers. These parents are spending an inordinate amount of time getting and monitoring services for their children.

This study is an exploratory one, designed to increase our understanding of child disability from the point of view of mothers and families. From the study we can see that we continue to have a long way to go in North America to develop positive attitudes toward people with disabilities; to provide services that will be truly helpful and truly supportive; and to ease the demands on parents to meet the daily needs and developmental needs, both "basic" and social/recreational, of children and adults with disabilities.

The mothers' comments speak for themselves. If anyone doubts the struggles of these parents and families, or doubts the meaning of the descriptive statistics presented here, read the statements of the mothers themselves. These statements do not reflect communities and service providers who have no room to grow to do a better job in welcoming people with disabilities into their communities and in providing the necessary support services for them, so that they can live in families and in communities with some ease. This is especially apparent for Sites 3, 4, and 5.

Parents of children with disabilities cannot be expected to endlessly apply pressure to service providers **and funding agencies** to provide appropriate services. Parents have enough to do. Time and energy expended on us, to cajole us into doing what we are paid to do, is time and energy taken away from the demands of their children and from their families. It is our responsibility, **in collaboration with families**, to anticipate the demands and see that appropriate and helpful services are in place when they are needed. Any model of service delivery which does not include a real collaboration with the parents and families of children with disabilities is out of date and, in the long run, may be destructive to the families and to the children, themselves.

Limitations of the Study

This study is descriptive in nature and uses qualitative methods and procedures. It provides insights into the experiences of 95 mothers in comparison to three mothers and their families studied four years earlier. This Stage Two study "verifies" the findings of the original in depth qualitative study. In addition it provides a window into the lives of the 95 mothers that can help us to understand something of their experience. Results cannot be generalized to other mothers of children with disabilities. Instead, results can give us ideas about how to examine our own models of service delivery and our own services to see if what we are doing is truly any service or funding agency to better understand the experiences of their specific clientele.

Implications for Research

This study raises many questions amenable to future quantitative and qualitative research. In particular, questions of differences on several variables such as gender (child and parent accessing a service), age (child, parent), family income, domicile location (urban/rural), are of interest. More importantly, because the families in both Stage One and Stage Two of this study are primarily "mainstream" families, questions surrounding the delivery of services to non-mainstream families need to be raised. What is happening to the children with disabilities of poor, or culturally and/or ethnically different families? What is happening to the children with disabilities of single parent families? The nagging questions of whether or not services decline as children get older; as well as the complexities of financial support for foster mothers of children with disabilities, as compared to natural or adoptive mothers, also need to be studied. Information concerning these research questions vary from location to location and need to be studied on the basis of single jurisdictions (or perhaps several sub-jurisdictions). Lastly, the experience of fathers is only beginning to be studied either in depth and by examining the experience of groups of fathers. Much more needs to be done to help us to understand child disability from the point of view of fathers and of other family members.

Implications for Service Providers

This study, particularly the mothers' written comments provides much thought provoking information for service providers. In addition to the suggestion that service agencies design their own studies to try to see child disability from the perspective of their own clients and their families, several general recommendations, resulting from this study are given below.

Recommendations

Recommendations are a compilation of findings from Stage One and Stage Two of this research. They are presented under three major headings or categories: recommended attitude changes; recommended policy changes; and specific suggestions for service providers.

Attitude Change

Societal Level

People with disabilities are a normal part of the spectrum of humanity. In neither Canada not the United States can people with disabilities be excluded legally from life opportunities, solely because of their disabilities. Despite this, the mothers taking part in this study clearly indicate that all of their children and they themselves, as parents of children with disabilities, have experienced varying degrees of exclusion. As a society we must increase our efforts to acknowledge and support the rightful presence of persons with disabilities into every aspect of our community lives; including, where necessary, specific adaptations in the "normal" structure of an activity, in order to render inclusion possible.

Inclusion provides powerful learning experiences for both persons with disabilities and those without. For the former, inclusion enhances self-concept and with successful practice in mainstream experiences, enhances the development of self-confidence. For the latter, inclusion of persons with disabilities protects us from a far too sheltered life experience, thus helping us to develop proactive behaviours and expanded notions of the family of humanity. Our children, with or without disabilities, have a right to experience these learning opportunities.

Professional Level

We are paid to help people because we have knowledge and skills that are of value for the optimum development and quality of life of the clients who come to us. We are responsible to all people who come to us. We cannot reject or select clients on the basis of the presence or absence of disabilities. Moreover, we are responsible for openess to our clients; and when working with clients who are children, openess to their parents, in order to capitalize on the wealth of information and expereince available to us from these sources.

While responsible for working **with** clients and their parents, it remains our duty to develop and monitor programs and services. We know who the clients are, and through planning with the parents, we know what programs and services they need now and will need in the future. Parents should not be expected to pressure or cajole us into doing what we are getting paid to do. Parents have enough to do.

Policy Change

Respite and Childcare

Parents of children with disabilities experience considerable stress and demands, over and above the usual stress and demands of child-rearing. Parents of children with disabilities need affordable and reliable respite care, preferably in their own homes. They also need the possiblity of periodic affordable, relaible childcare, just as parents of typical children make use of childcare. Lastly, parents of children with disabilities need the option of daycare, should both parents want or need to work in the paid labour force. All these services need to be available in the home perhaps with typical siblings as well as in other possible locations; and they are sometimes needed for children beyond the usual chronological ages requiring childcare. These options are necessary so that parents of children with disabilities have all the choices that other parents have. Without childcare options, the parents of children with disabilities, themselves, are excluded from the usual opportunities of adult life.

School and Work

People with disabilities need to go to school and to work right in the mainstream of life. It must become a matter of public policy for these choices to be available to persons with disabilities. While considerable effort in this area has been rewarded with a notion of inclusion and a vocabulary of inclusion both at school and at work, having appropriate supports and resources in place for the success of inclusion remains problematic. Policies **and funds** must be directed toward truly accomplishing the inclusion of persons with disabilities into these critical areas of life in the community. Appropriate programs at all levels of elementary education are not yet available; nor are there adequate programs in place for appropriate transitions from school to the world of work; nor are adults with disabilities (particularly mental retardation) finding work in the mainstream.

Parents wonder what is the point of inclusion in the early grades of school if, as the children mature and as they become adults, there is nothing for them except a workshop or daytime TV and occasional outings with their immediate family?

Service Providers

1. Work with parents, valuing them, their contributions and ideas; acknowledge their expertise.
2. Start with the positive. Celebrate the child and her competence. Only then, move into the child's areas of need and how parents and service providers can help the child.
3. Don't overwhelm parents; don't dishearten parents. They are aware of the child's limitations. Provide information and ask parents about what they know; what they think. Focus on two or three achievable goals. Support parents. Try to see the situation from the point of view of the family. Look at the whole child and look at him within the context of his family. See the child first and then look at the disability.
4. Try to appreciate what it means to be responsible for the child's care 24 hours a day, seven days a week. Contemplate alternatives. Would the child really be better off? All indications assure us that children grow and develop best at home. Give parents a hand.

5. When parents are asked to work on skill development, select skills that are truly appropriate and useful and which make sense to the child. Ask the parents, "Would it be possible to work on this? Do you have the time? Will it work into your family's schedule? Would acquiring the skill be helpful and useful?" Ask parents to provide feedback on the process. Don't be afraid to admit error. Do be willing to rewrite the plan. If the plan fails, ask, "Could there be reasons for failure other than simply parental disinterest, incompetence, or neglect?"

6. When planning programming and making professional suggestions ask, "How can we use this family's strengths? How can we avoid making any family members feel left out? What information and supports have to be in place in order to avoid failure, and especially, in order to avoid disaster?"

7. Be prepared to change "the system", or the school, or the classroom, or whatever, to meet the child's needs; do not expect the child to make adaptations to fit into what "the system", or the school, or the classroom, currently has to offer.

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FIGURES

Figure 1

Levels of Disability: A Comparison of "Diagnoses" by Professionals and Families

Total Group
(N = 102)

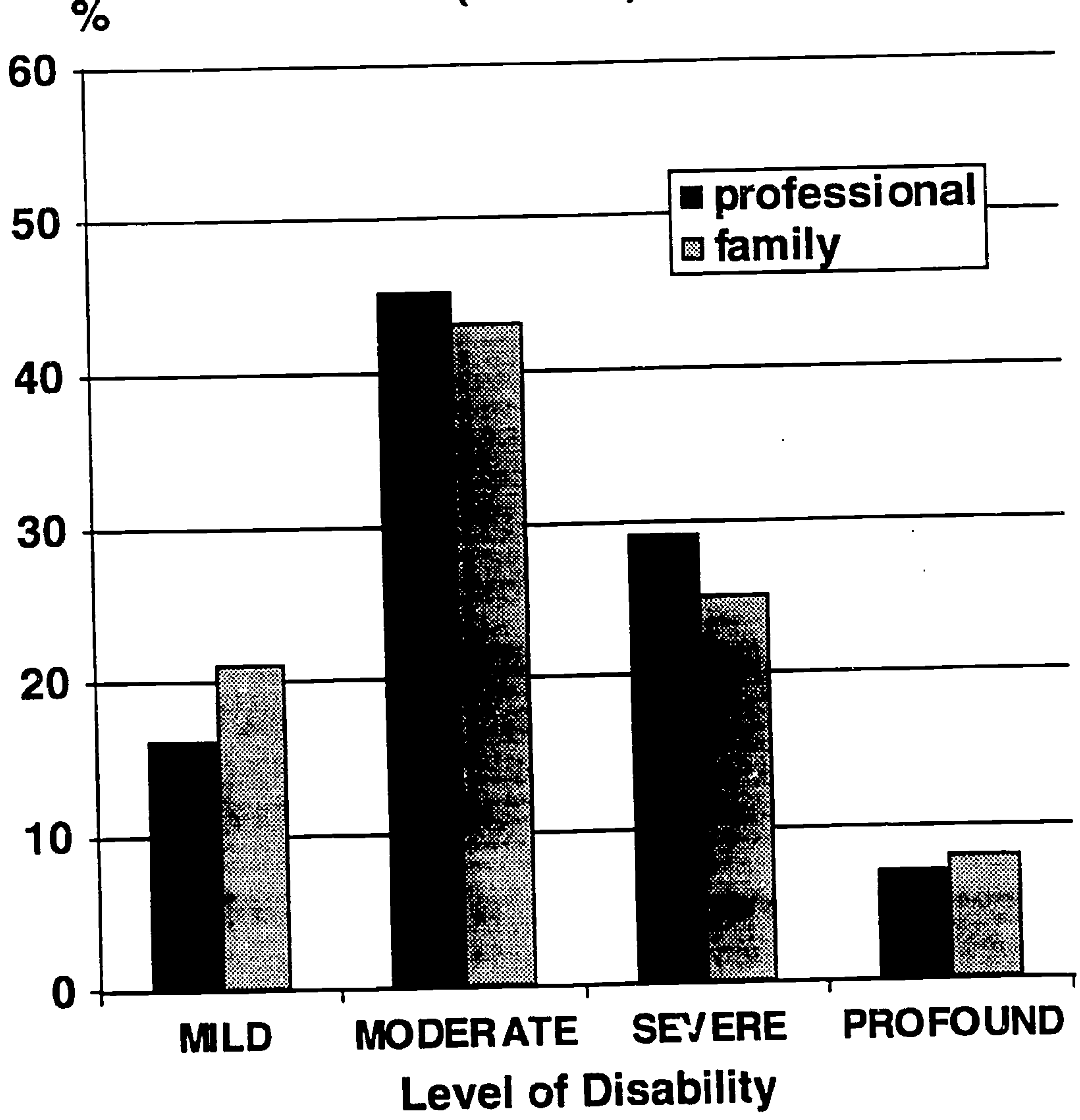


Figure 2

Levels of Disability: A Comparison of "Diagnoses" by Professionals and Families

Site 1

(n = 15)

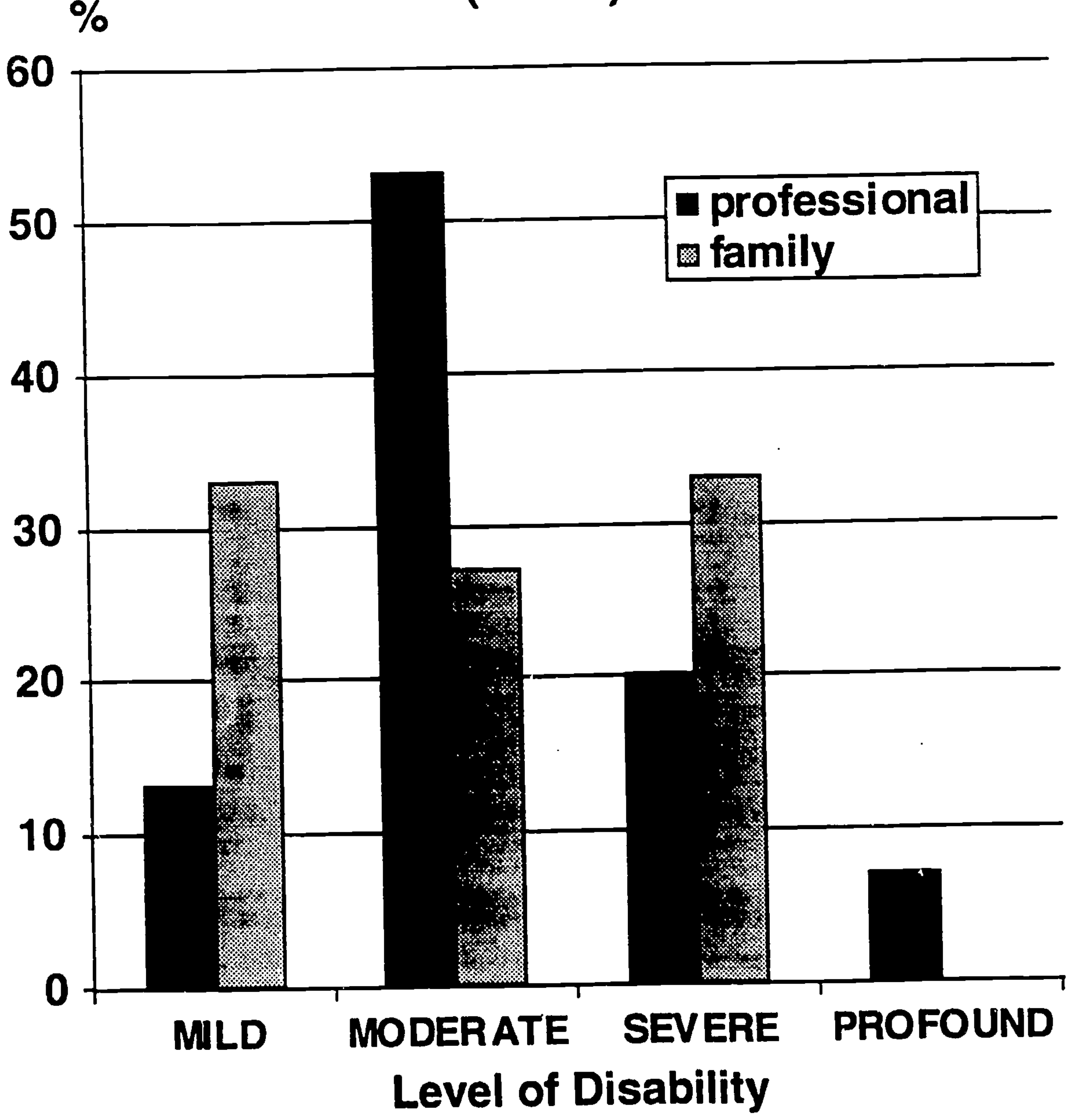


Figure 3

Levels of Disability: A Comparison of "Diagnoses" by Professionals and Families

Site 2
(n = 29)

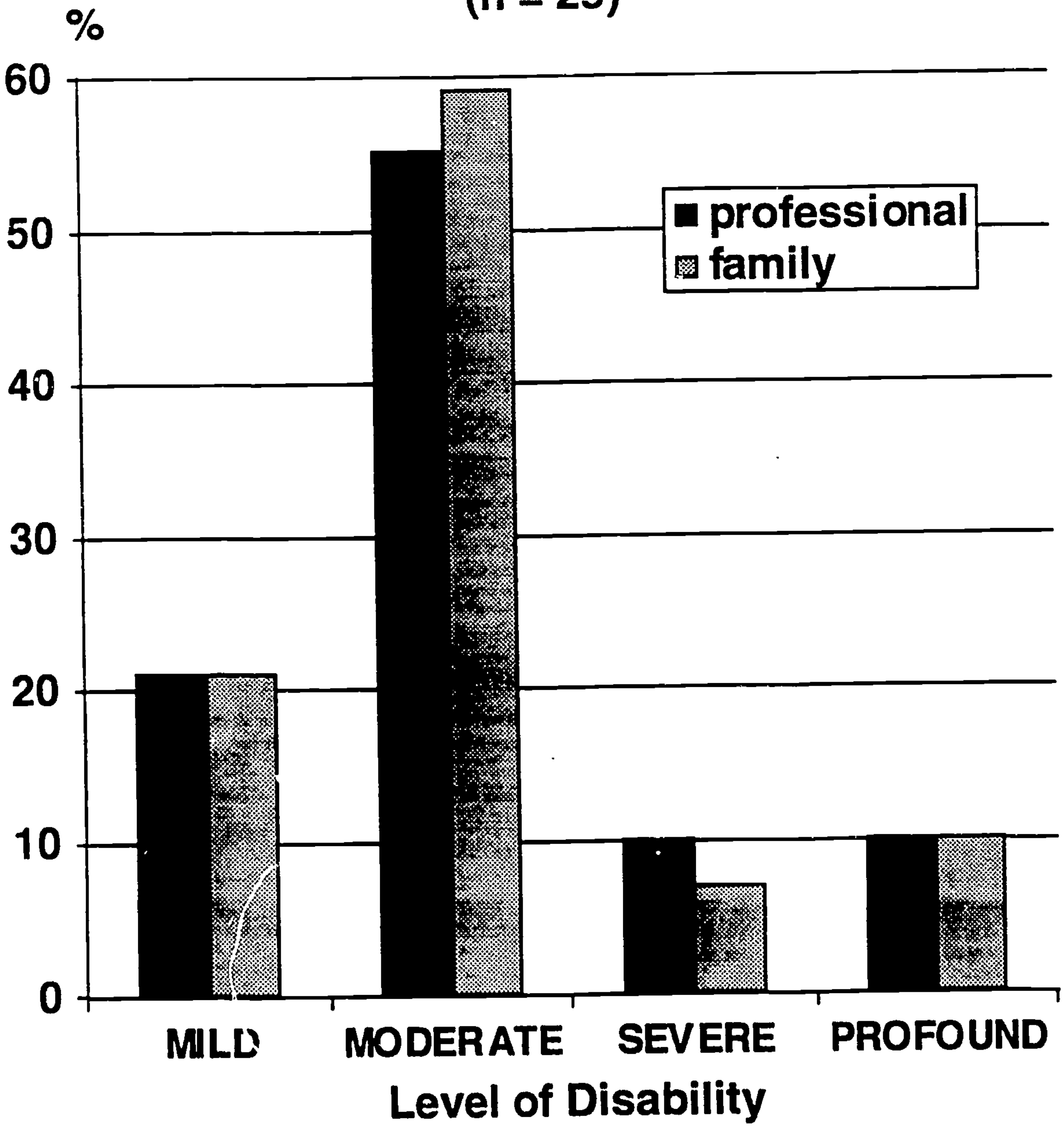


Figure 4

Levels of Disability: A Comparison of "Diagnoses" by Professionals and Families

Site 3

(n = 21)

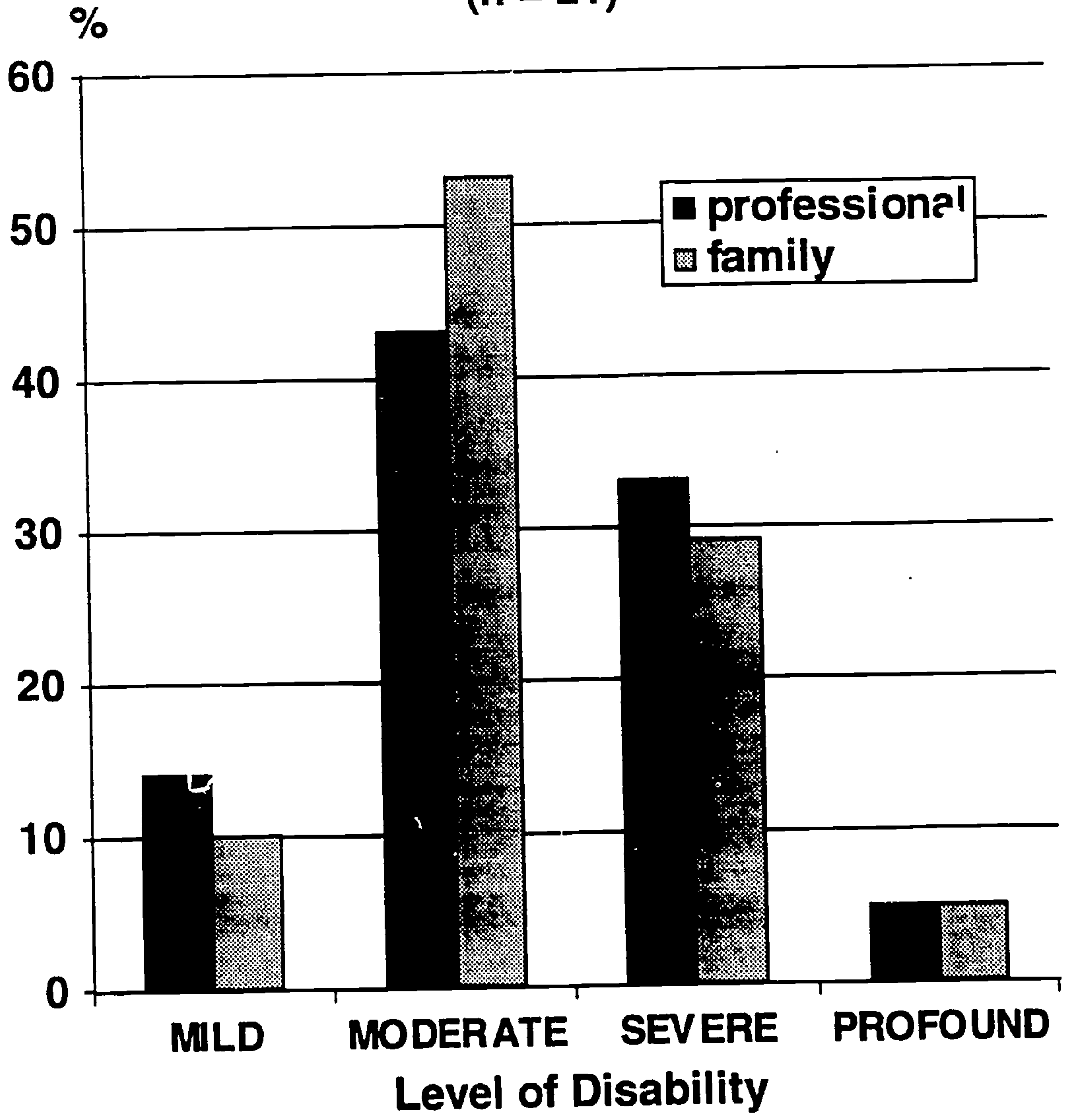


Figure 5

Levels of Disability: A Comparison of "Diagnoses" by Professionals and Families

Site 4

(n = 18)

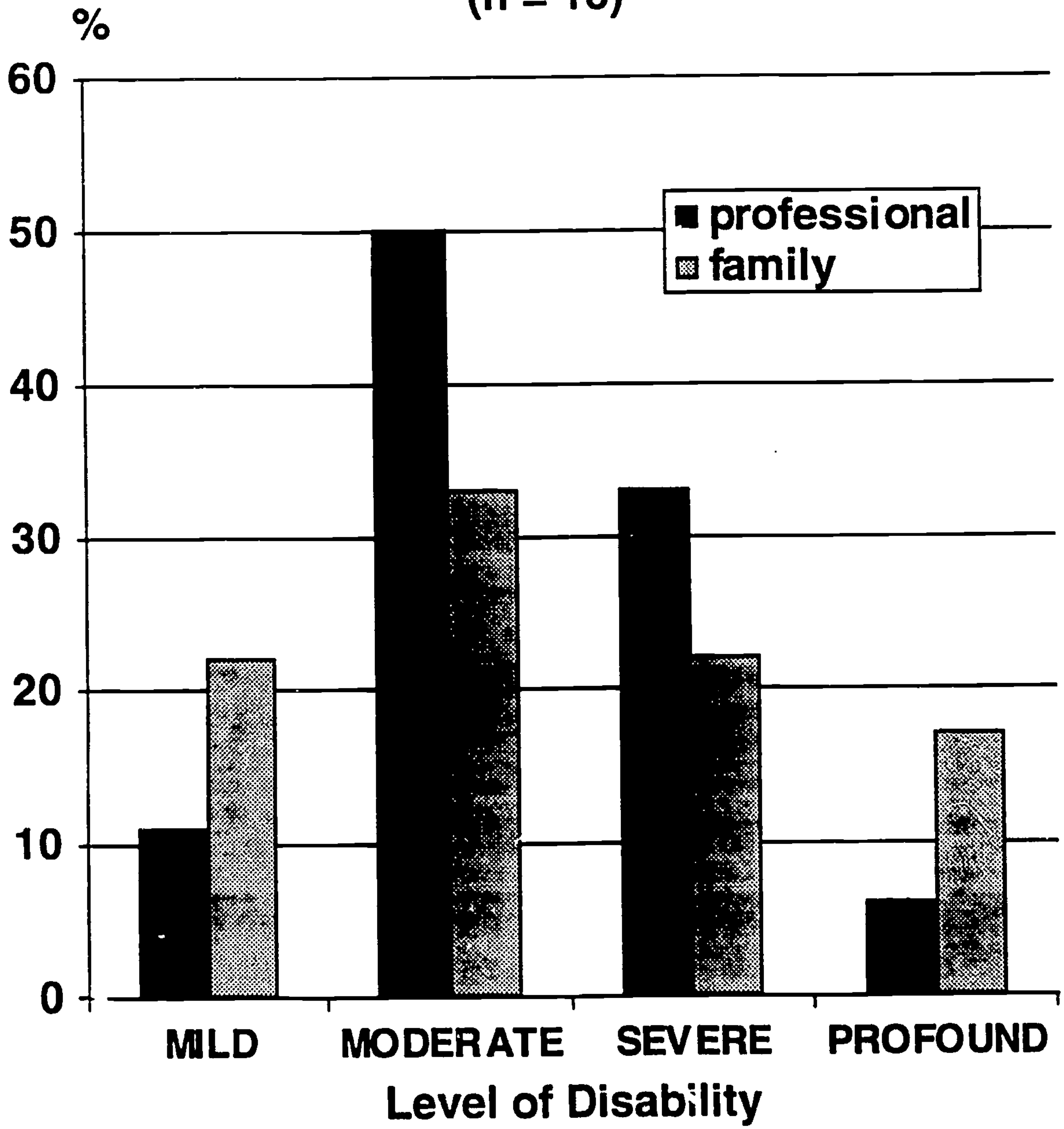
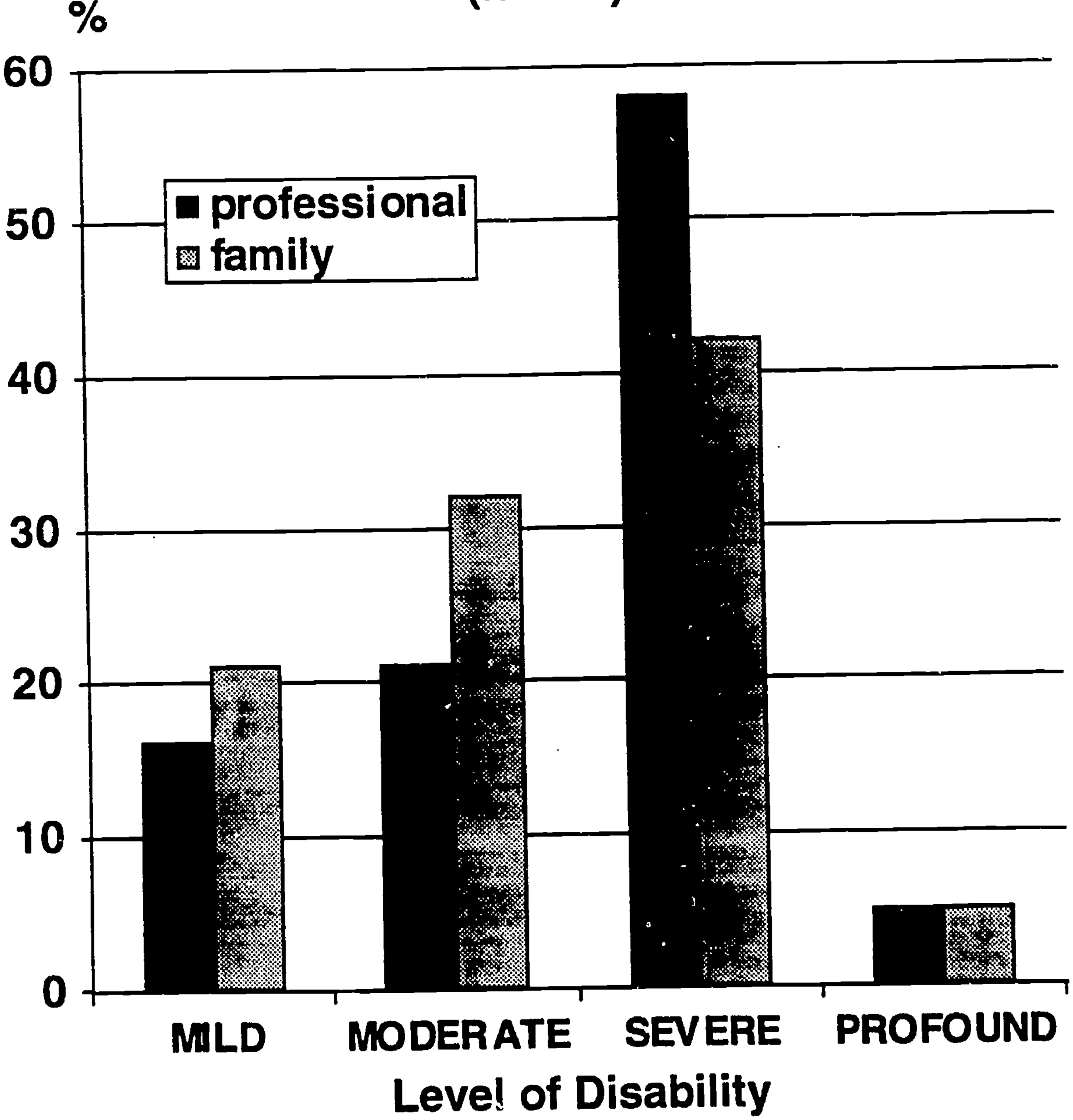


Figure 6

Levels of Disability: A Comparison of "Diagnoses" by Professionals and Families

Site 5
(n = 19)



TABLES

TABLE 1
Summary Table : Descriptions of the Families

Sites

	1 (n=15)	2 (n=29)	3 (n=17)	4 (n=16)	5 (n=18)	Totals (N =95)	Totals %
Mothers' ages							
20-29	3	-	-	-	-	3	3
30-39	11	-	7	8	8	34	36
40-49	1	7	6	6	8	28	29
50-59	-	9	1	2		14	15
60 or more	-	11	2	-	-	13	14
Urban	9	19	7	12	12	59	62
Rural	6	10	10	4	6	36	38
Pop. of city/closest city							
30,000 or less	13	18	16	2	9	58	61
31,000-60,000	1	6	1	7	1	16	17
61,000-100,000	1	2	-	0	3	6	6
more than 100,000	-	1	-	7	3	11	12
Distance to city (for rural)							
15k/10mi or less	4	3	6	-	2	15	16
16-50k or 11-30mi	1	6	4	1	2	14	15
51-80k or 31-50mi	-	-	-	1	-	1	1
more than 80k or 50mi	1	-	-	2	-	3	3
Marital status							
married	12	22	15	12	16	77	81
single/divorced/widowed	2	7	2	3	1	15	16
separated	1	-	-	1	1	3	3
Total number of children							
only child	4	1	2	4	2	13	14
2-3 children	8	15	11	8	12	54	57
4-6 children	2	8	7	5	3	25	26
more than 6	-	1	1	1	-	3	3

Table 1 Cont'd

	1 (n=15)	2 (n=29)	3 (n=17)	4 (n=16)	5 (n=18)	Totals (N=95)	Totals %
Occupation self							
unemployed	-	-	1	-	-	1	1
unskilled	1	2	1	-	-	4	4
skilled (incl.homemaker)	12	13	14	7	7	53	56
professional	2	6	3	8	10	29	31
student	-	-	1	-	-	1	1
retired	-	7	-	-	-	7	7
Occupation spouse							
unemployed	-	-	-	-	-	-	-
unskilled	1	1	2	-	-	4	4
skilled	8	6	14	5	8	41	43
professional	3	7	-	9	8	27	28
student	1	-	1	-	-	2	2
retired	-	8	2	-	-	10	11
deceased	-	2	-	-	-	2	2
Education self							
grade 8 or less	-	-	-	-	-	-	-
some high school	-	1	3	-	1	5	5
high school completed	3	14	4	4	3	28	29
post secondary	7	4	14	2	5	32	34
university degree	3	-	-	6	3	12	13
graduate degree	-	7	-	5	6	18	19
Education spouse							
grade 8 or less	-	1	1	1	1	4	4
some high school	-	2	7	1	-	10	11
high school completed	5	6	2	2	6	21	22
post secondary	4	4	8	4	2	22	23
university degree	2	2	1	2	2	9	9
graduate degree	1	7	1	5	5	19	20
Income (total family)							
< $24,000(CDN) or $20,000(US)	2	6	4	2	-	14	15
$24-48,000(CDN) or $20-40,000(US)	10	5	8	8	10	41	43
$49-72,000(CDN) or $41-60,000(US)	3	5	3	1	4	16	17
> $72,000 (CDN) or$60,000(US)	-	8	5	5	5	23	24

TABLE 2
Summary Table : Descriptions of the Children
Sites

Child's age (yrs)	1 (n=15)	2 (n=29)	3 (n=21)	4 (n=18)	5 (n=19)	Totals (N=102)	Totals %
0-3	5	-	1	1	1	8	8
4-5	6	-	1	5	5	17	17
6-12	4	1	12	6	2	25	25
13-18	-	1	5	1	6	13	13
19-24	-	8	-	3	5	16	16
older than 24 yrs	-	19	2	2	-	23	23
Child's gender							
male	4	15	13	7	14	53	52
female	11	15	7	11	5	49	48
In school	11	2	17	13	11	54	53
Working	-	22	2	2	4	30	29
Diagnosis -"professionals"							
age appropriate	-	-	-	-	-	-	-
mild	2	6	3	2	3	16	16
moderate	8	16	9	9	4	46	45
severe	3	3	7	6	11	30	29
profound	1	3	1	1	1	7	7
Diagnosis - family							
age appropriate	1	-	-	-	-	1	1
mild	5	6	2	4	4	21	21
moderate	4	17	11	6	6	44	43
severe	5	2	6	4	8	25	25
profound	-	3	1	3	1	8	8
Physical and/or sensory disabilities							
physical	5	9	5	7	4	30	29
sensory	3	1	2	5	2	13	13
both	3	3	6	4	5	21	21
none	4	15	6	2	8	35	34
disabled but no mental retardation	-	1	2	-	-	3	3

TABLE 3
Chronological Ages of Mothers

	Sites 1 (n=15)	2 (n=29)	3 (n=17)	4 (n=16)	5 (n=18)	Total N=(95)
Chronological age						
20-29	3(20)	-	-	-	-	3(3)
30-39	11(73)*	-	7(41)	8(50)*	8(44)	34(36)
40-49	1(7)	7(24)	6(35)*	6(38)	8(44)*	28(29)*
50-59	-	9(31)*	1(6)	2(13)	2(11)	14(15)
60 or older	-	11(38)	2(12)	-	-	13(14)

* Median age for each group
Numbers in parentheses are percent.
Not all mothers responded.

TABLE 4
Chronological Ages of Children

	Sites					
	1 (n=15)	2 (n=29)	3 (n=21)	4 (n=18)	5 (n=19)	Total N=(102)
Chronological age						
0-3	5(33)	-	1(5)	1(6)	1(5)	8(8)
4-5	6(40)*	-	1(5)	5(28)	5(26)	17(17)
6-12	4(27)	1(3)	12(57)*	6(33)*	2(11)	25(25)
13-18	-	1(3)	5(24)	1(6)	6(32)*	13(13)*
19-24	-	8(28)	-	3(17)	5(26)	16(16)
older than 24	-	19(66)*	2(10)	2(11)	-	23(23)

* median age for each group
numbers in parentheses are percent.

TABLE 5
Levels of Disability: A Comparison of "Diagnoses" by Professionals and Families

	1 (n=15)		2 (n=29)		3 (n=21)		4 (n=18)		5 (n=19)		Total N=(102)	
Level	P	F	P	F	P	F	P	F	P	F	P	F
(none)	-	1	-	-	-	-	-	-	-	-	-	1
		(7)										(1)
mild	2	5	6	6	3	2	2	4	3	4	16	21
	(13)	(33)	(21)	(21)	(14)	(10)	(11)	(22)	(16)	(21)	(16)	(21)
moderate	8	4	16	17	9	11	9	6	4	6	46	44
	(53)	(27)	(55)	(59)	(43)	(53)	(50)	(33)	(21)	(32)	(45)	(43)
severe	3	5	3	2	7	6	6	4	11	8	30	25
	(60)	(33)	(10)	(7)	(33)	(29)	(33)	(22)	(58)	(42)	(29)	(25)
profound	1	-	3	3	1	1	1	3	1	1	7	8
	(7)		(10)	(10)	(5)	(5)	(6)	(17)	(5)	(5)	(7)	(8)

P = professionals
F = family
Numbers in parentheses are percent.

TABLE 6
Summary Table : Expressed (Basic) Needs of the Children

Sites

	1 (n=15)	2 (n=29)	3 (n=21)	4 (n=18)	5 (n=19)	Totals (N=102)	Totals %
Help with eating	8(53)	3(10)	4(19)	10(56)	8(42)	33	32
...drinking	7(47)	1(3)	4(19)	5(28)	3(16)	20	20
...toileting	12(80)	3(10)	9(43)	10(56)	14(74)	48	47
...personal hygiene	12(80)	12(41)	15(71)	14(78)	15(79)	68	67
...mobility	7(47)	3(10)	9(43)	5(28)	5(26)	29	28
...dressing	10(67)	6(21)	11(52)	12(67)	15(79)	54	53
...use of hands	4(27)	2(7)	6(29)	5(28)	8(42)	25	25
...playing	5(33)	2(7)	7(33)	8(44)	7(37)	29	28
...social interaction	9(60)	13(45)	14(67)	7(39)	14(74)	57	56
...understanding others'language	9(60)	13(45)	9(43)	9(50)	9(47)	49	48
...creating own language	14(93)	15(52)	13(62)	12(67)	13(68)	67	66

Mothers could select any number of items.
Numbers in parentheses are percent.

TABLE 7
Summary Table : Expressed Needs of the Mothers

	Sites						
	1 (n=15)	2 (n=29)	3 (n=17)	4 (n=16)	5 (n=18)	Totals (N=95)	Totals %
Regular child care	3(20)	-	2(12)	5(31)	6(33)	16	17
Regular respite care	4(27)	2(7)	10(59)	7(44)	8(44)	31	33
Time to myself	7(47)	4(14)	16(94)	10(63)	11(61)	48	51
"Hands on" help each day	3(20)	3(10)	6(35)	6(38)	8(44)	26	27
Occasional child care	4(27)	3(10)	6(35)	5(31)	5(28)	23	24
Occasional respite care	4(27)	6(21)	10(59)	7(44)	6(33)	33	35
Someone to talk to about my child	5(33)	6(21)	13(76)	4(25)	7(39)	35	37
A support group with other parents	5(33)	7(24)	11(65)	3(19)	11(61)	37	39
Mediator between my child & school	1(7)	4(14)	7(41)	5(31)	9(50)	26	27
Someone to help me plan for the future	6(40)	13(45)	10(59)	10(63)	11(61)	50	53
Time for other family members	8(53)	7(24)	7(41)	8(50)	8(44)	38	40

Mothers could select any number of items.
Numbers in parentheses are percent.

TABLE 8
Summary Table : Expressed Social & Recreational Needs of the Children

Sites	1 (n=15)	2 (n=29)	3 (n=21)	4 (n=18)	5 (n=19)	Totals (N=102)	Totals %
Age-mate friends	12(80)	18(62)	15(71)	14(78)	15(79)	74	73
Peer Tutor(s)	3(20)	9(31)	10(48)	9(50)	10(53)	41	40
Social activities with age-mates	11(73)	18(62)	16(76)	15(83)	17(90)	77	76
Recreational activities with age-mates	11(73)	18(62)	14(67)	15(83)	17(90)	75	74
Easier access to community-based							
...school	5(33)	1(3)	5(24)	6(33)	6(32)	23	23
...job	-	5(17)	1(5)	3(17)	7(37)	16	16
Vocational training	-	7(24)	3(14)	4(22)	5(26)	19	19
...religious instruction	2(13)	3(10)	4(19)	2(11)	1(5)	12	12
...scouts/guides	2(13)	1(3)	2(10)	4(22)	2(11)	11	11
...sports & recreation	4(27)	11(38)	7(33)	9(50)	9(47)	40	39
...summer camp	4(27)	5(17)	4(19)	6(33)	2(11)	21	21
...medical services	3(20)	6(21)	2(10)	4(22)	3(16)	18	18
...dental services	2(13)	7(24)	3(14)	1(6)	2(11)	15	15
...speech therapy	2(13)	5(17)	7(33)	5(28)	12(63)	31	30
...physical therapy	2(13)	3(10)	3(14)	3(17)	7(37)	18	18
...occupational therapy	1(7)	4(14)	4(19)	4(22)	8(42)	21	21
"supported living"	-	8(28)	3(14)	10(56)	6(32)	27	27
Someone"special" in child's life (e.g. Big Brother or Big Sister)	8(53)	21(72)	11(52)	12(67)	13(68)	65	64

Mothers could select any number of items.
Numbers in parentheses are percent

TABLE 9

Rank Order of Responses: Children's (Basic) Needs
Total Group
(N=102)

Rank		Percent
1	Help with personal hygiene	67
2	... creating own language	66
3	... social interaction	56
4	... dressing	53
5	... understanding others' language	48
6	... toileting	47
7	... eating	32
8	... mobility	28
8	... playing	28
10	... use of hands	25
11	... drinking	20

TABLE 10

Rank Order of Responses: Mother's Needs
Total Group
(N=95)

Rank		Percent
1	Someone to help me plan for the future	53
2	Time for myself	51
3	Time to be with other family members	40
4	A support group with other parents	39
5	Someone to talk to about my child	37
6	Occasional respite care	35
7	Regular respite care	33
8	"Hands on" help each day	27
8	A mediator between my child and the school	27
10	Occasional child care	24
11	Regular child care	17

TABLE 11

Rank Order of Responses:
Children's Social and Recretional Needs
Total Group
(N=102)

Rank		Percent
1	Social activities with age-mates	76
2	Recreational activities with age-mates	74
3	Age-mate friends	73
4	Someone "special" in child's life	64
5	Peer tutor	40
Easier access to community-based		
6	... sports and recreation	39
7	... speech therapy	30
8	... "supported living"	27
9	... school	23
10	... summer camp	21
10	... occupational therapy	21
12	... vocational training	19
13	... medical services	18
13	... physical therapy	18
15	... job	16
16	... dental services	15
17	... religious instruction	12
18	... scouts/guides	11

TABLE 12

Items Most Often Chosen:
Mother's Needs, Children's (Basic) Needs
and Children's Social/Recreational Needs
Total Group
(Parent's N=95) (Children's N=102)

Items	Percent
Children's Basic Needs	
1 personal hygiene	67
2 creating language	66
3 help with social interactions	56
4 ... dressing	53
5 ... understanding others' language	48
6 ... toileting	47
Mother's Needs	
1 planning for child's future	53
2 time for myself	51
3 time for other family members	40
4 parent support group	39
5 someone to talk to about my child	37
6 occasional respite care	35
Children's Social/Recreational Needs	
1 social activities with age-mates	76
2 recreational activities with age-mates	74
3 age-mate friends	73
4 someone special in their lives	64
5 peer tutors	40
6 community-based sports, rec., leisure	39

TABLE 13
Summary: Children's (Basic) Needs
Total Group
(N=95)

			SIZE OF CITY				INCOME			
Population Sample (Table 1) →	Urban n=59 (62)	Rural n=36 (38)	1 n=58 (61)	2 n=16 (17)	3 n=6 (6)	4 n=11 (12)	1 n=14 (15)	2 n=41 (43)	3 n=16 (17)	4 n=23 (24)
CHILDREN'S (BASIC) NEEDS										
Eating/feeding	20 (61)	13 (39)	22 (73)	2 (7)	1 (3)	5 (17)	3 (9)	15 (47)	7 (22)	7 (22)
Drinking	11 (55)	9 (45)	14 (74)	1 (6)	1 (6)	2 (11)	1 (5)	12 (63)	5 (26)	1 (5)
Toileting	27 (56)	21 (44)	30 (69)	4 (9)	3 (7)	7 (16)	3 (7)	25 (54)	11 (24)	7 (15)
Personal hygiene	38 (56)	30 (44)	42 (68)	7 (11)	4 (7)	9 (15)	11 (17)	29 (45)	12 (19)	13 (20)
Mobility/walking	19 (66)	10 (35)	19 (70)	3 (11)	1 (4)	4 (15)	3 (11)	15 (56)	8 (30)	1 (4)
Dressing	33 (61)	21 (39)	33 (67)	6 (12)	3 (6)	7 (14)	8 (15)	25 (48)	10 (19)	9 (17)
Using hands	15 (60)	10 (40)	17 (74)	2 (9)	1 (4)	3 (13)	3 (13)	11 (46)	7 (29)	3 (13)
Playing	16 (55)	13 (44)	18 (67)	4 (15)	1 (4)	4 (15)	3 (11)	13 (48)	6 (22)	5 (19)
Social interaction	32 (56)	25 (44)	38 (75)	5 (9)	3 (6)	5 (10)	7 (13)	25 (46)	10 (19)	12 (22)
Understanding other's language	29 (59)	20 (41)	33 (73)	5 (11)	3 (7)	4 (9)	6 (14)	19 (44)	10 (23)	6 (19)
Creating language	43 (64)	24 (36)	43 (72)	6 (10)	4 (7)	7 (12)	8 (13)	30 (48)	14 (22)	11 (18)

Parentheses indicate (rounded) percent of total responses for each item.

Size of City
1 = 30,000 or less
2 = 31,000 - 60,000
3 = 61,000 - 100,000
4 = larger than 100,000

Income
1 = less than $24,000 (CDN) or 20,000 (US) per year
2 = $24,000 - $48,000 (CDN) or $20,000 - $40,000 (US) per year
3 = $49,000 - $72,000 (CDN) or $41,000 - $60,000 (US) per year
4 = more than $72,000 (CDN) or $60,000 (US) per year

Table 13 Cont'd
Summary: Children's (Basic) Needs
Total Group
(N=95)

	SIZE OF CITY						INCOME			
Population Sample (Table 1) →	Urban n=59 (62)	Rural n=36 (38)	1 n=58 (61)	2 n=16 (17)	3 n=6 (6)	4 n=11 (12)	1 n=14 (15)	2 n=41 (43)	3 n=16 (17)	4 n=23 (24)
Access: community-based school	16 (70)	7 (30)	12 (55)	3 (14)	3 (14)	4 (18)	3 (14)	11 (52)	4 (19)	3 (14)
job	12 (75)	4 (25)	9 (56)	3 (19)	3 (19)	1 (6)	1 (7)	5 (33)	2 (13)	7 (47)
vocational training	13 (68)	6 (32)	9 (50)	4 (22)	2 (11)	3 (17)	1 (7)	4 (27)	2 (13)	8 (53)
medical services	14 (78)	4 (22)	11 (73)	1 (7)	2 (13)	1 (7)	3 (21)	9 (64)	1 (7)	1 (7)
dental services	12 (80)	3 (20)	13 (87)	1 (7)	- (-)	1 (7)	5 (42)	5 (42)	1 (8)	1 (8)
speech therapy	20 (65)	11 (36)	17 (63)	4 (15)	3 (11)	3 (11)	3 (10)	15 (52)	3 (10)	8 (28)
physical therapy	14 (78)	4 (22)	9 (50)	5 (28)	2 (11)	2 (11)	2 (14)	7 (50)	2 (14)	3 (21)
occupational therapy	13 (62)	8 (38)	12 (60)	3 (15)	3 (15)	2 (10)	3 (18)	9 (53)	2 (12)	3 (18)
religious instruction	6 (50)	6 (50)	8 (73)	1 (9)	1 (9)	1 (9)	2 (20)	3 (30)	3 (30)	2 (20)

TABLE 14
Summary: Mother's Needs
Total Group
(N=95)

	SIZE OF CITY						INCOME			
Population Sample (Table 1) →	Urban n=59 (62)	Rural n=36 (38)	1 n=58 (61)	2 n=16 (17)	3 n=6 (6)	4 n=11 (12)	1 n=14 (15)	2 n=41 (43)	3 n=16 (17)	4 n=23 (24)
MOTHER'S NEEDS										
Regular Child Care	12 (75)	4 (25)	9 (69)	2 (15)	2 (15)	0 (-)	1 (7)	11 (73)	1 (7)	2 (13)
Regular Respite Care	17 (55)	14 (45)	19 (70)	4 (15)	1 (4)	3 (11)	2 (7)	17 (59)	6 (21)	4 (14)
Time for Myself	29 (60)	19 (40)	30 (68)	5 (11)	3 (7)	6 (14)	2 (5)	23 (52)	6 (14)	13 (30)
Hands-on Help	14 (54)	12 (46)	19 (79)	2 (8)	1 (4)	2 (8)	2 (8)	15 (60)	5 (20)	3 (12)
Occasional Child Care	14 (61)	9 (39)	17 (81)	3 (14)	0 (-)	1 (5)	4 (18)	10 (46)	7 (32)	1 (5)
Occasional Respite Care	22 (67)	11 (33)	22 (73)	5 (17)	2 (7)	1 (3)	2 (7)	17 (57)	4 (13)	7 (23)
Someone to Talk To ...	21 (60)	14 (40)	24 (73)	1 (3)	5 (15)	3 (9)	2 (6)	16 (49)	7 (21)	8 (24)
Parent Support Group	23 (62)	14 (38)	26 (74)	2 (6)	4 (11)	3 (9)	2 (6)	19 (58)	6 (18)	6 (18)
Mediator (Home & School)	15 (58)	11 (42)	18 (72)	4 (16)	1 (4)	2 (8)	3 (13)	12 (50)	3 (13)	6 (25)
Planning for Child's Future	33 (66)	17 (34)	28 (62)	6 (13)	6 (13)	5 (11)	7 (15)	22 (46)	8 (17)	11 (23)
Time for Other Family Members	23 (61)	15 (40)	25 (71)	4 (11)	3 (9)	2 (9)	2 (6)	21 (58)	7 (19)	6 (17)

Parentheses indicate (rounded) percent of total responses for each item.

Size of City
1 = 30,000 or less
2 = 31,000 - 60,000
3 = 61,000 - 100,000
4 = larger than 100,000

Income
1 = less than $24,000 (CDN) or 20,000 (US) per year
2 = $24,000 - $48,000 (CDN) or $20,000 - $40,000 (US) per year
3 = $49,000 - $72,000 (CDN) or $41,000 - $60,000 (US) per year
4 = more than $72,000 (CDN) or $60,000 (US) per year

Table 15
Summary: Children's Social/Recreational Needs
Total Group
(N=95)

	SIZE OF CITY						INCOME			
Population sample (Table 1) →	Urban n=59 (62)	Rural n=36 (38)	1 n=58 (61)	2 n=16 (17)	3 n=6 (6)	4 n=11 (12)	1 n=14 (15)	2 n=41 (43)	3 n=16 (17)	4 n=23 (24)
Children's Social/ Recreational Needs										
Age-mate friends	46 (62)	28 (38)	47 (68)	7 (10)	6 (9)	9 (13)	8 (12)	29 (43)	12 (18)	19 (28)
Peer tutors	28 (63)	15 (37)	19 (53)	6 (17)	5 (14)	6 (17)	3 (8)	18 (49)	6 (16)	10 (27)
Social activities with age-mates	48 (62)	29 (38)	46 (65)	9 (13)	6 (9)	10 (14)	8 (11)	33 (46)	12 (17)	19 (26)
Recreational activities with age-mates	48 (64)	27 (36)	45 (65)	9 (13)	6 (9)	9 (13)	7 (10)	33 (49)	11 (16)	17 (25)
Access to community-based scouts/guides	6 (55)	5 (46)	7 (64)	2 (18)	- (-)	2 (18)	1 (11)	4 (44)	3 (33)	1 (11)
sports, recreation, leisure	25 (63)	15 (38)	23 (64)	6 (17)	2 (6)	5 (14)	4 (11)	21 (60)	3 (9)	7 (20)
summer camp	16 (76)	5 (24)	11 (58)	5 (26)	- (-)	3 (18)	3 (20)	8 (53)	2 (13)	2 (13)
supported living	21 (78)	6 (22)	13 (57)	5 (22)	2 (9)	3 (13)	3 (13)	12 (52)	1 (4)	7 (30)
Someone "special" in child's life	39 (60)	26 (40)	36 (62)	9 (16)	5 (9)	8 (14)	8 (14)	28 (48)	13 (22)	10 (17)

Parentheses indicate (rounded) percent of total responses for each item.

Size of City
1 = 30,000 or less
2 = 31,000 - 60,000
3 = 61,000 - 100,000
4 = larger than 100,000

Income
1 = less than $24,000 (CDN) or 20,000 (US) per year
2 = $24,000 - $48,000 (CDN) or $20,000 - $40,000 (US) per year
3 = $49,000 - $72,000 (CDN) or $41,000 - $60,000 (US) per year
4 = more than $72,000 (CDN) or $60,000 (US) per year

TABLE 16
Items Most Often Chosen and Site, Level of Disability and Marital Status
Total Group (N=95)

	SITES					LEVEL OF DISABILITY				MARITAL	
Population sample → (Tables 1 & 2)	1 n=15 (15)	2 n=29 (28)	3 n=21 (21)	4 n=18 (18)	5 n=19 (19)	1 n=21 (21)	2 n=44 (43)	3 n=25 (25)	4 n=8 (8)	1 n=77 (81)	2&3 n=18 (19)
Children's (Basic) Needs											
1. Personal hygiene	12 (18)	12 (18)	15 (22)	14 (21)	15 (22)	12 (19)	22 (34)	23 (35)	7 (11)	57 (84)	11 (16)
2. Creating language	14 (21)	15 (22)	13 (19)	12 (18)	13 (19)	10 (15)	25 (39)	23 (35)	7 (11)	55 (83)	11 (17)
3. Help with social interaction	9 (16)	13 (23)	14 (25)	7 (12)	14 (25)	7 (13)	23 (42)	19 (35)	5 (9)	42 (75)	14 (25)
4. " " dressing	10 (19)	6 (11)	11 (20)	12 (22)	15 (28)	10 (19)	14 (26)	22 (42)	7 (14)	46 (85)	8 (15)
5. " " understanding language	9 (18)	13 (27)	9 (18)	9 (18)	9 (18)	9 (19)	19 (40)	13 (28)	6 (13)	39 (81)	9 (19)
6. " " toileting	12 (25)	3 (6)	9 (19)	10 (21)	14 (29)	9 (20)	12 (26)	19 (41)	6 (13)	41 (85)	7 (15)
Children's Soc/Rec Needs											
1. Social activities with age-mates	11 (14)	18 (23)	16 (21)	15 (19)	17 (22)	13 (17)	34 (45)	23 (31)	5 (6)	61 (80)	15 (20)
2. Recreational activities with age-mates	11 (15)	18 (24)	14 (19)	15 (20)	17 (23)	13 (18)	32 (44)	22 (30)	5 (7)	59 (80)	15 (20)
3. Age-mate friends	12 (16)	18 (24)	15 (20)	14 (19)	15 (20)	14 (20)	31 (44)	22 (31)	3 (4)	59 (81)	14 (19)
4. Someone special	8 (12)	21 (32)	11 (17)	12 (19)	13 (20)	12 (19)	28 (45)	19 (31)	3 (5)	50 (78)	14 (22)
5 Peer tutors	3 (7)	3 (22)	10 (24)	9 (22)	10 (24)	8 (21)	16 (41)	11 (28)	4 (10)	31 (76)	9 (23)
6. Community-based leisure activities	4 (10)	11 (28)	7 (18)	9 (23)	9 (23)	4 (11)	18 (50)	13 (36)	1 (3)	28 (70)	12 (30)

One child diagnosed as "age appropriate" is omitted
Level of disability (using family's "diagnosis")
1 = mild
2 = moderate
3 = severe
4 = profound
Parentheses indicate (rounded) percent of total responses for each item

Marital
1 = married
2 = divorced
3 = separated

TABLE 16 continued
Items Most Often Chosen and Site, Level of Disability and Marital Status
Total Group (N=95)

	SITES					LEVEL OF DISABILITY				MARITAL	
Population sample (Tables 1 & 2)	1 n=15 (15)	2 n=29 (28)	3 n=21 (21)	4 n=18 (18)	5 n=19 (19)	1 n=21 (21)	2 n=44 (43)	3 n=25 (25)	4 n=8 (8)	1 n=77 (81)	2&3 n=18 (19)
Mothers' Needs											
1. Planning for child's future	6 (12)	13 (26)	10 (20)	10 (20)	11 (22)	12 (25)	18 (37)	15 (31)	4 (8)	37 (74)	13 (26)
2. Time for myself	7 (15)	4 (8)	16 (33)	10 (21)	11 (23)	10 (22)	18 (40)	14 (31)	2 (4)	37 (79)	10 (21)
3. Time for other family members	8 (21)	7 (18)	7 (18)	8 (21)	8 (21)	10 (26)	11 (29)	11 (29)	5 (13)	30 (81)	7 (19)
4. Parent support group	5 (14)	7 (19)	11 (30)	3 (8)	11 (30)	8 (22)	15 (42)	9 (25)	4 (11)	34 (94)	2 (8)
5. Someone to talk to	5 (14)	6 (17)	13 (37)	4 (11)	7 (20)	9 (27)	9 (27)	12 (36)	3 (9)	32 (94)	2 (6)
6. Occasional respite	4 (12)	6 (18)	10 (30)	7 (21)	6 (18)	13 (41)	13 (41)	11 (34)	4 (13)	27 (84)	5 (16)

' Level of Disability (using family's "diagnosis)
1 = mild
2 = moderate
3 = severe
4 = profound
Parentheses indicate (rounded) percent of total for each item

Marital:
1 = married
2 = divorced
3 = separated

TABLE 17
Items Most Often Chosen and Child's Gender, Age and Number of Children in Child's Family
Total Group (N=95)

	CHILD'S GENDER		CHILD'S AGE					NUMBER OF CHILDREN		
Population sample ➜ (Tables 1 & 2)	1 n=53 (52)	2 n=49 (48)	1&2 n=25 (25)	3 n=25 (25)	4 n=13 (13)	5 n=16 (16)	4 n=23 (23)	1 n=13 (14)	2 n=54 (57)	3 n=28 (29)
Children's (Basic) Needs										
1. Personal hygiene	34 (50)	33 (49)	21 (31)	18 (27)	11 (16)	8 (12)	10 (15)	11 (17)	38 (59)	15 (23)
2. Creating language	31 (46)	36 (54)	24 (36)	18 (27)	7 (10)	9 (13)	9 (13)	12 (19)	34 (55)	16 (26)
3. Help with social interaction	31 (55)	25 (45)	17 (30)	15 (26)	8 (14)	11 (19)	6 (11)	8 (15)	32 (60)	13 (25)
4. " " dressing	27 (50)	27 (50)	19 (35)	15 (28)	9 (17)	7 (13)	4 (7)	10 (20)	30 (60)	10 (20)
5. " " understanding language	24 (50)	24 (50)	13 (27)	14 (29)	6 (12)	7 (14)	9 (18)	6 (13)	24 (53)	15 (33)
6. " " toileting	25 (52)	23 (48)	20 (42)	16 (33)	7 (15)	5 (10)	-	9 (20)	27 (60)	9 (20)
Children's Soc/Rec Needs										
1. Social activities with age-mates	40 (52)	37 (48)	18 (24)	20 (26)	12 (16)	15 (20)	12 (16)	11 (15)	42 (58)	19 (26)
2. Recreational activities with age-mates	40 (53)	35 (47)	19 (25)	19 (25)	11 (15)	15 (20)	11 (15)	11 (16)	40 (57)	19 (27)
3. Age-mate friends	36 (49)	37 (51)	18 (24)	19 (26)	11 (15)	15 (20)	11 (15)	11 (16)	39 (57)	19 (28)
4. Someone special	32 (51)	31 (49)	13 (20)	14 (22)	9 (14)	13 (20)	16 (25)	9 (16)	34 (59)	15 (26)
5 Peer tutors	22 (55)	18 (45)	7 (17)	15 (37)	11 (27)	4 (10)	4 (10)	3 (8)	24 (65)	10 (27)
6. Community-based leisure activities	17 (44)	22 (56)	8 (20)	8 (20)	6 (15)	10 (25)	8 (20)	6 (16)	19 (50)	13 (34)

Gender: 1 = male
2 = female

Ages: 1+2 = 0-5 years
3 = 6-12 years
4 = 13-18 years
5 = 19-24 years
6 = older than 24 years

Number of children: 1 = only child
2 = 2-3 children
3+4 = 4 or more children

Parentheses indicate (rounded) percent of total responses for each item

TABLE 17 continued
Items Most Often Chosen and Child's Gender, Age and Number of Children in Child's Family
Total Group (N=95)

	CHILD'S GENDER		CHILD'S AGE					NUMBER OF CHILDREN		
Population sample (Tables 1&2)	1 n=53 (52)	2 n=49 (48)	1+2 n=25 (25)	3 n=25 (25)	4 n=13 (13)	5 n=16 (16)	6 n=23 (23)	1 n=13 (14)	2 n=54 (57)	3+4 n=28 (29)
Mothers' Needs										
1. Planning for child's future	26 (53)	23 (47)	11 (22)	13 (26)	9 (18)	10 (20)	7 (14)	11 (23)	27 (56)	10 (21)
2. Time for myself	30 (64)	17 (36)	14 (29)	18 (38)	7 (15)	6 (13)	3 (6)	9 (19)	26 (55)	12 (25)
3. Time for other family members	19 (50)	19 (50)	12 (32)	12 (32)	2 (5)	8 (21)	4 (11)	5 (14)	20 (57)	7 (19)
4. Parent support group	21 (57)	16 (43)	10 (27)	9 (24)	6 (16)	6 (16)	6 (16)	5 (14)	20 (57)	10 (29)
5. Someone to talk to	21 (62)	13 (38)	9 (26)	12 (34)	6 (17)	4 (11)	4 (11)	6 (18)	20 (61)	7 (21)
6. Occasional respite	20 (61)	13 (39)	4 (12)	11 (33)	7 (21)	8 (24)	3 (9)	3 (10)	20 (65)	8 (26)

Gender: 1 = male
2 = female

Ages: 1+2 = 0-5 years
3 = 6-12 years
4 = 13-18 years
5 = 19-24 years
6 = older than 24 years

Number of children: 1 = only child
2 = 2-3 children
3+4 = 4 or more children

Parentheses indicate (rounded) percent of total responses for each item.

TABLE 18
Items Most Often Chosen and Mother's Education and Presence of Physical &/or Sensory Disability Total Group (N=95)

	MOTHER'S EDUCATION					PHYSICAL &/OR SENSORY DISABILITY			
Population sample → (Tables 1 & 2)	1+2 n=5 (5)	3 n=28 (29)	4 n=32 (34)	5 n=12 (13)	6 n=18 (19)	1 n=29 (30)	2 n=13 (13)	3 n=21 (21)	4 n=35 (34)
Children's (Basic) Needs									
1. Personal hygiene	4 (6)	16 (25)	23 (35)	8 (12)	14 (22)	23 (35)	7 (11)	17 (26)	19 (29)
2. Creating language	4 (6)	17 (27)	21 (33)	8 (13)	13 (21)	18 (28)	11 (17)	17 (26)	19 (29)
3. Help with social interaction	3 (6)	13 (25)	20 (38)	4 (8)	12 (23)	15 (28)	6 (11)	14 (26)	19 (35)
4. " " dressing	4 (8)	11 (22)	17 (33)	7 (14)	12 (24)	18 (35)	6 (12)	16 (31)	12 (23)
5. " " understanding language	2 (5)	14 (23)	13 (30)	3 (7)	12 (27)	12 (26)	6 (13)	14 (30)	15 (32)
6. " " toileting	2 (4)	9 (20)	17 (38)	6 (13)	11 (24)	15 (32)	7 (15)	16 (34)	9 (19)
Children's Soc/Rec Needs									
1. Social activities with age-mates	5 (7)	19 (27)	24 (34)	6 (9)	17 (24)	13 (17)	34 (45)	23 (31)	5 (6)
2. Recreational activities with age-mates	4 (6)	19 (28)	23 (33)	7 (10)	16 (23)	13 (18)	32 (44)	22 (30)	5 (7)
3. Age-mate friends	4 (6)	18 (26)	23 (34)	6 (9)	17 (25)	14 (20)	31 (44)	22 (31)	3 (4)
4. Someone special	3 (5)	19 (33)	19 (33)	6 (10)	11 (19)	12 (19)	28 (45)	19 (31)	3 (5)
5. Peer tutors	3 (8)	11 (30)	13 (35)	3 (8)	7 (19)	8 (21)	16 (41)	11 (28)	4 (10)
6. Community-based leisure activities	1 (3)	11 (30)	12 (32)	6 (16)	7 (19)	4 (11)	18 (50)	13 (36)	1 (3)

Mother's education:
(1+2 = less than grade 12; 3 = grade 12 completed; 4 = post secondary; 5 = university degree; 6 = graduate degree
Physical/sensory/disabilities.
(1 = physical, 2 = sensory; 3 = both; 4 = neither) (Note: only children with MR are included)

TABLE 18 continued
Items Most Often Chosen and Mother's Education and Presence of Physical &/or Sensory Disability Total Group (N=95)

	MOTHER'S EDUCATION					PHYSICAL &/OR SENSORY DISABILITY			
Population sample ➔ (Tables 1 & 2)	1+2 n=5 (5)	3 n=28 (29)	4 n=32 (34)	5 n=12 (13)	6 n=18 (19)	1 n=29 (30)	2 n=13 (13)	3 n=21 (21)	4 n=35 (34)
Mothers' Needs									
1. Planning for child's future	4 (9)	9 (20)	15 (33)	4 (9)	13 (29)	14 (29)	6 (13)	8 (17)	20 (42)
2. Time for myself	2 (4)	8 (19)	20 (47)	3 (7)	10 (23)	12 (26)	8 (17)	14 (30)	12 (26)
3. Time for other family members	2 (6)	8 (24)	13 (38)	2 (6)	9 (26)	12 (33)	7 (19)	9 (24)	9 (24)
4. Parent support group	2 (6)	12 (35)	13 (38)	1 (3)	6 (17)	10 (27)	5 (14)	10 (27)	10 (32)
5. Someone to talk to	1 (3)	9 (28)	13 (41)	2 (6)	7 (22)	7 (21)	5 (15)	9 (26)	13 (38)
6. Occasional respite	2 (7)	5 (17)	12 (40)	2 (7)	9 (30)	7 (23)	5 (16)	7 (23)	12 (39)

Mother's education:
(1+2 = less than grade 12; 3 = grade 12 completed; 4 = post secondary; 5 = university degree; 6 = graduate degree)
Physical/sensory/disabilities:
(1 = physical; 2 = sensory; 3 = both; 4 = neither) (note: only children with MR are included)

TABLE 19
Rank Order of Questionnaire Items Receiving 50% or More Responses: "Often" and "Almost Always" (High Extreme)

		SITES				
Item	Total group Rank %	1 Rank %	2 Rank %	3 Rank %	4 Rank %	5 Rank %
5. I have the confidence that I am doing the best I can in this situation.	1(76.5)	2(80.0)	1(93.1)	1(71.4)	12(55.6)	9(73.7)
55. I'm busy keeping her busy. I can't just send her down to the rink or to swimming. I have to go too.	2(75.5)	1(86.7)	9(65.5)	1(71.4)	1(83.3)	6(78.9)
6. Most of the parents are trying their best to do a good job; otherwise they never would have shown up for the appointment.	3(71.6)	2(80.0)	2(75.9)	4(61.9)	8(61.1)	6(78.9)
7. Education, as far as day to day living goes, is a joint effort from the whole family.	3(71.6)	2(80.0)	2(75.9)	7(57.1)	2(72.2)	9(73.7)
54. Our ability to support one another builds our inner strength.	5(70.6)	2(80.0)	5(72.4)	12(52.4)	5(66.7)	4(84.2)
78. If she's going to benefit from it, it's because of our efforts to make sure she gets there and does it.	6(67.6)	19(60.0)	8(69.0)	7(57.1)	2(72.2)	6(78.9)
1. I'd say our ability to deal with Marianne's disabilities as a family is pretty good. So far, nothing has destroyed us.	7(63.7)	2(80.0)	9(65.5)	12(52.4)	5(66.7)	23(57.9)
39. Generally, I'm satisfied with my life.	7(63.6)	13(66.7)	5(72.4)	7(57.1)	8(61.1)	23(57.9)
61. You can talk to your friends but they wouldn't understand the way another parent of a child with disabilities would understand.	9(62.7)	9(73.3)	9(65.5)	-	2(72.2)	23(57.9)

Table 19 continued

Item	Total group Rank %	SITES 1 Rank %	 2 Rank %	 3 Rank %	 4 Rank %	 5 Rank %
29. Professionals have to realize that they have to work with parents. If they work against us, nothing will work out.	10(61.8)	24(53.3)	12(62.1)	-	8(61.1)	1(89.5)
10. I really think that there should be two parts to our parent's group: an advocacy part and a part that is purely support for us parents.	11(58.8)	19(60.0)	17(51.7)	-	8(61.1)	1(89.5)
31. I am optimistic. I know things will work out. I have to be patient.	11(58.8)	9(73.3)	5(72.4)	4(61.9)	-	-
24. Don't provide parents with a list of "do's and dont's". Ask them. "Do you think this is possible? Would you have time to do that?"	13(56.9)	13(66.7)	-	-	5(66.7)	9(73.7)
49. I have a friend that I can share confidences with.	13(56.9)	13(66.7)	14(58.6)	-	12(55.6)	1(89.5)
16. I think there is a difference between listening to somebody and hearing somebody. Most professionals listen; but only some of them hear what we are saying.	15(54.9)	-	-	3(66.7)	-	14(68.4)
30. We're trying very hard this year to get off to a good start with the school. We are trying to keep things positive.	15(54.9)	2(80.0)	-	4(61.9)	-	4(84.2)
15. It's been hard on her brothers; but overall I'd say they gained more than they lost.	17(53.9)	-	2(75.9)	-	-	23(57.9)
51. When she was diagnosed, there were a lot of "nevers" going through my mind. You know, there would never be school.. birthday parties... brownies...	17(53.9)	19(60.0)	12(62.1)	-	14(50.0)	34(52.6)

Table 19 Cont'd

		SITES				
Item	Total group Rank %	1 Rank %	2 Rank %	3 Rank %	4 Rank %	5 Rank %
67. I feel like I'm trying to spread myself around to everyone. There is not enough time. There's not enough time for me.	17(53.9)	13(66.7)	-	12(52.4)	-	18(63.2)
26. I don't do a lot of work one-on-one with Shane at home. I want him to know there is a place to work and a place to relax. Here at home he can just be plain old Shane. He can have his own space.	20(52.9)	24(53.3)	14(58.6)	-	14(50.0)	34(52.6)
42. We don't get a whole lot of support unless we're willing to go out there and fight for it.	21(51.0)	-	17(51.7)	7(57.1)	-	9(73.7)
53. I think it would be good if we just started a group (of parents of children with disabilities) and said, "This is a place you can share your struggles and celebrate your successes."	21(51.0)	13(66.7)	-	-	14(50.0)	14(68.4)
23. The services she has received were excellent. They accomodated her and helped me to feel good about myself, too.	-	2(80.0)	14(58.6)	-	-	
56. Shane's early intervention experience was very helpful and optimistic.	-	2(80.0)	-	-	-	23(57.9)
52. I'm seeing things happen more and more. Shane was crying and my brother comforted him. It was nice to know that there were other people who could comfort my child.	-	9(73.3)	-	-	-	34(52.6)
77. One thing that really struck me was the way she interacted with Bruce. She could really "read" him. There was a lot of warmth. She took delight in his small accomplishments.	-	9(73.3)	-	-	-	-

Table 19 Cont'd

Item	Total group Rank %	SITES 1 Rank %	 2 Rank %	 3 Rank %	 4 Rank %	 5 Rank %
35. The kids will talk to him even though he doesn't speak back to them.	-	13(66.7)	-	-	-	34(52.6)
9. They didn't try to take her and stick her into their system. They made their system work around her.	-	19(60.0)	-	-	-	-
58. I am finding the school very supportive.	-	19(60.0)	-	7(57.1)	-	
11. She had a good year at school. There was a very understanding set of parents and she was well received.	-	24(53.3)	-	-	-	9(73.7)
27. Don't send me a few dollars trying to keep me happy. That's not what I'm looking for. I need someone to come in here for a few hours to give me a break. It's no good sending me the money if I don't have the person.	-	-	-	-	-	-
37. I try to find time for myself each day. I go for a walk, or I listen to music. I do something that nourishes me.	-	24(53.3)	-	-	-	34(52.6)
41. His brother has started to see Bruce differently. He is starting to notice that Bruce is really doing great.	-	-	17(51.7)	-	-	-
50. There are times that I wish I had more freedom of movement. I always feel that I have to be available to whomever has Marianne, at any given moment.	-	-	-	12(52.4)	14(50.0)	34(52.6)
21. I am just one person. There are a lot of other people involved with this child. Show them. Show the whole family.	-	-	-	-	-	14(68.4)
17. If you are dealing with a bunch of professionals, you do feel that they are on one side and you are on the other.	-	-	-	-	-	18(63.2)
39. The pressure is on us, the parents, to always see that he sees his friends after school, evenings, that sort of thing.	-	-	-	-	-	18(63.2)

Table 19 continued

Item	Total group	SITES				
		1	2	3	4	5
	Rank %	Rank %	Rank %	Rank %	Rank %	Rank %
59. I think the social services system abuses parents of disabled adults. We are treated like "slave labor".	-	-	-	-	-	18(63.2)
63. I went back to work part-time. I had to, I had to get back in contact with the adult world.	-	-	-	-	-	18(63.2)
12. One professional is not supportive. I work around him.	-	-	-	-	-	23(57.9)
13. The only hands on support we ever had is what we bought and paid for.	-	-	-	-	-	23(57.9)
22. I spent nine months trying to get that service for Shane, and in the end the answer was so simple. Give me a break! So simple... and yet they made it so complicated for me.	-	-	-	-	-	23(57.9)
43. Sometimes i'ts like we are against everyone, that there is just our family against the world.	-	-	-	-	-	23(57.9)
69. I can't do one thing over the phone for Marianne. It's a meeting, then there would be another meeting and then they take it to someone else for another meeting.	-	-	-	-	-	23(57.9)
72. I feel that time is running out and things aren't getting done. He has rights that are not being awarded him.	-	-	-	-	-	23(57.9)
20. We have had struggles at school for a couple of years now.	-	-	-	-	-	34(52.6)
25. Babysitting for us; well, is it ever going to end?	-	-	-	-	-	34(52.6)
46. A lot of the professionals you deal with, you come home feeling disheartened.	-	-	-	-	-	34(52.6)
62. We never go alone to a meeting concerning Bruce. We always go as a couple.	-	-	-	-	-	34(52.6)

TABLE 20
Rank Order of Questionnaire Items
Receiving 50% or More Responses:
"Seldom" and "Almost Never"
(Low Extreme)

			SITES				
	Item	Total group Rank %	1 Rank %	2 Rank %	3 Rank %	4 Rank %	5 Rank %
76.	I always felt there was something holding me back from totally loving Shane the way he should be loved. I think it was the fear that he was going to die. I didn't know what to do.	1(51.0)	3(73.3)	1(51.7)	-	1(55.6)	1(57.9)
43.	Sometimes its like we are against everyone, that there is just our family against the world.	-	1(80.0)	-	-	1(55.6)	-
13.	The only hands-on support we ever had is what we bought and paid for.	-	2(76.3)	-	-	-	-
69.	I can't do one thing over the phone for Marianne. It's a meeting, then there would be another meeting and then they take it to somebody else for another meeting.	-	4(66.7)	-	-	-	-
14.	No one was paying attention. I felt frustrated that no one was listening to my concerns about Shane.	-	4(66.7)	-	-	-	-
62.	We never go alone to a meeting concerning Bruce. We always go as a couple.	-	6(60.0)	-	-	-	-
45.	I remember a six page report from a professional. Of six type-written pages there was not one positive thing about Marianne in it.	-	7(53.3)	-	-	-	-
18.	Sometimes it just takes a couple of words from the man (husband/father) to get them to do something that I had been talking about to them for months.	-	-	1(51.7)	-	-	-

TABLE 21
Summary: Responses to Item Groups
(Means Only)

Item Groups	Site 1 (n=15)	Site 2 (n=29)	Site 3 (n=17)	Site 4 (n=16)	Site 5 (n=18)	Total Group (N=95)
Total Parental Responsibility	2.81	3.04	3.09	3.07	3.11	3.03
- isolation	2.77	3.15	2.97	2.63	3.34	3.01
- feeling overwhelmed	2.84	3.10	3.36	3.35	3.42	3.21
- sickness of child	2.38	2.20	2.55	3.04	2.41	2.47
- negative feelings	2.83	2.81	2.73	2.87	2.84	2.82
- feeling tied-down	3.20	3.65	3.73	3.57	3.37	3.51
Respite Care. Support. Friends						
- negative experiences	2.50	3.11	3.44	2.92	3.59	3.14
- positive experiences	3.83	3.67	3.01	3.57	3.92	3.61
Parents have enough to do	3.82	3.94	3.70	4.42	4.18	4.00
Mother						
- ambivalence	3.23	2.81	2.88	2.77	2.89	2.90
- positive self statements	4.23	4.43	4.26	3.94	4.07	4.22
- care of self	3.80	3.71	3.53	3.63	3.58	3.65
Others' Acceptance	3.93	3.77	3.60	3.46	3.52	3.66
Siblings' Experience						
- negative	2.64	2.52	2.13	2.75	1.92	2.42
- positive	2.70	4.00	3.25	3.18	3.58	3.46
- positive reality overall	3.62	4.35	3.58	3.92	4.07	3.99
Experience with Professionals						
- negative	2.63	2.81	3.24	2.75	3.45	2.98
- positive	3.71	3.39	3.26	3.28	3.01	3.32
- advice to professionals	3.53	3.41	3.51	3.91	4.27	3.71
Strategies	3.71	3.73	3.74	3.76	4.04	3.80
Other						
- adult children	- *	2.48	2.86	3.69	4.29	3.21**
- advice to professionals	3.53	3.41	3.51	3.91	4.27	3.71
- getting services (man/woman)	2.60	2.33	2.64	2.92	3.00	2.66
- older child	- *	2.30	4.00	3.00	3.80	3.14**
- mother and paid work	3.40	3.47	3.57	4.57	4.07	3.75
- foster mother/regular mother	2.13	2.08	3.17	3.00	3.08	2.70
- family survival	4.36	3.78	4.19	4.43	3.78	4.04

1 = almost never
2 = seldom
3 = sometimes
4 = often
5 = almost always
* There are no "older children" at this site (1994).
** N = 80. in this instance

Table 22
Responses to Items 81. 82. and 83:
Major Themes from Stage One
and
Emerging Themes from Stage Two

Major Themes (Stage One)	Emerging Themes (Stage Two)	Quantity
Children		
	1. Positive Parental Feelings	19
	2. Growth. Learning. Knowing	15
	3. Learning/Knowing (Negative)	6
	4. Communication	5
	5. Other Descriptions	3
		(total 48)
Stress/Anxiety		
	1. General	13
	2. Lack of Support	27
	3. Demands on Parents	17
	4. Illness and Stress	4
	5. Lack of Friendship	1
	6. Miscellaneous Parental Emotions	1
		(total 63)
Services		
	1. Positive Experiences (General)	23
	2. Negative Experiences (General)	14
	3. Positive Experiences (Schooling)	7
	4. Negative Experiences (Schooling)	10
	5. Struggles	38
	6. Positive Support	2
	7. Positive and Negative Support	1
	8. "The System"	2
		(total 99)
Personal	(three comments. all from one mother)	
		(total 3)
Survival		
	1. Interface. . Community (Positive)	16
	2. Interface. . Community (Negative)	18
	3. Personal Growth	28
	4. Personal Growth (Siblings	1
	5. Positive Support	2
	6. Strategies	8
	7. Changes That Give Hope	3
	8. Characteristics of Family Members	2
	9. Advice to Professionals	12
		(total 90)

APPENDIX A

Parent Questionnaire (CDN form)

Research number or name ______________________ age _____ prov. __________

urban ________ size of your city (population) ______________________

rural ________ size of closest "business city" (population) __________ distance __________

married _____ single _____ total number of children ________

occupation: self ______________________ (spouse) ______________________

education (last grade/certificate/degree completed): self __________ (spouse) __________

annual family income (before taxes) from all sources:

less than $24,000 ______ $48,000 - $72,000 _______

$24,000 - $48,000 ______ more than $72,000 _______

first name of "focus child" ______________________

age ________ gender ________ still in school? ________ working? ________

your relationship to "focus child": mother ________ father ________

---

1. What term best describes how professionals (psychologists, teachers, doctors, therapists) designate your child's level of development?
   - mild disability ______
   - moderate disability ______
   - severe disability ______
   - profound disability ______
2. Using your own words, describe your child's level of development.
3. Does your child have physical and sensory disabilities which require special assistance?
   yes _____ no _____
   If so, describe these. ______________________
4. Check all items wherein <u>your child</u> needs daily help:
   - eating/feeding _____
   - drinking _____
   - toileting _____
   - personal hygiene _____
   - mobility/walking _____
   - dressing _____
   - using hands _____
   - playing _____
   - social interaction _____
   - spoken language:
     - understanding others' _____
     - creating own lanugage _____
5. Check all items wherein <u>you</u> could use some help:
   - hands-on help with some daily child-care tasks _____
   - regular child care _____ - occasional child care _____
   - regular respite child care _____ - occasional respite child care _____
   - someone to talk to about my child and his/her disabilities _____
   - a support group of parents of children with special needs _____
   - someone to mediate between my child and the school _____
   - someone to help me plan for my child's future _____
   - time for myself _____ - time to be with other family members _____
6. Check all items you'd like to see available for your child:
   - age-mate friend(s) _____ - social activities with age-mates _____
   - peer tutor(s) _____ - recreational activities with age-mates _____
   - easier access to "<u>community-based</u>" services or groups:
     - school _____
     - vocational training _____
     - religious instruction _____
     - guides/scouts _____
     - sports & recreation/leisure _____
     - summer camp _____
     - job _____
     - medical _____
     - dental _____
     - speech therapy _____
     - physical therapy _____
     - occupational therapy _____
     - "supported living" _____
     - other _____
7. Would you like your child to have someone "special" in his/her life for social and recreational activities. (Someone like a "Big Brother" or "Big Sister")? Yes _____ No _____

Parent Questionnaire (U.S. form)

Research number or name ____ age ____ state ____
urban ____ size of your city (population) ____
rural ____ size of closest "business city" (population) ____ distance ____
married ____ single ____ total number of children ____
occupation: self ____ (spouse) ____
education (last grade/certificate/degree completed): self ____ (spouse) ____
annual family income (before taxes) from all sources:
less than $20,000 ____
$20,000 - $40,000 ____
$40,000 - $60,000 ____
more than $60,000 ____
first name of "focus child" ____
age ____ gender ____ still in school? ____ working? ____
your relationship to "focus child": mother ____ father ____
____ ____

1. What term best describes how professionals (psychologists, teachers, doctors, therapists) designate your child's level of development?
   mild disability ____
   moderate disability ____
   severe disability ____
   profound disability ____
2. Using your own words, describe your child's level of development.
   ____
   ____
   ____
3. Does your child have physical and sensory disabilities which require special assistance?
   yes ____ no ____
   If so, describe these. ____
   ____
   ____
4. Check all items wherein <u>your child</u> needs daily help:
   - eating/feeding ____
   - drinking ____
   - toileting ____
   - personal hygiene ____
   - mobility/walking ____
   - dressing ____
   - using hands ____
   - playing ____
   - social interaction ____
   - spoken language:
     - understanding others' ____
     - creating own lanugage ____
5. Check all items wherein <u>you</u> could use some help:
   - hands-on help with some daily child-care tasks ____
   - regular child care ____
   - occasional child care ____
   - regular respite child care ____
   - occasional respite child care ____
   - someone to talk to about my child and his/her disabilities ____
   - a support group of parents of children with special needs ____
   - someone to mediate between my child and the school ____
   - someone to help me plan for my child's future ____
   - time for myself ____
   - time to be with other family members ____
6. Check all items you'd like to see available for your child:
   - age-mate friend(s) ____
   - social activities with age-mates ____
   - peer tutor(s) ____
   - recreational activities with age-mates ____
   - easier access to "<u>community-based</u>" services or groups:
     school ____
     vocational training ____
     religious instruction ____
     scouts ____
     sports & recreation/leisure ____
     summer camp ____
     job ____
     medical ____
     dental ____
     speech therapy ____
     physical therapy ____
     occupational therapy ____
     "supported living" ____
     other ____
7. Would you like your child to have someone "special" in his/her life for social and recreational activities. (Someone like a "Big Brother" or "Big Sister")? Yes ____ No ____

APPENDIX B

CHILD DISABILITY: THE PARENTAL EXPERIENCE

Barbara Bloom

Research number or name ______________________ Date ______________________

This scale asks you to indicate what your experience of parenting a child with disabilities means to you. Please CIRCLE the response that best indicates how much you can identify with each of the following statements.

To what extent do you share the ideas and feelings of the following parental statements?	Not Applicable	Almost Never	Seldom	Sometimes	Often	Almost Always
1. I'd say our ability to deal with Marianne's disabilities as a family is pretty good. So far, nothing has destroyed us.	NA	1	2	3	4	5
2. We struggle the most in trying to get the school to see they have a role to play to help Bruce have friends.	NA	1	2	3	4	5
3. We decided to have Marianne repeat that year in school because she had such a terrific teacher.	NA	1	2	3	4	5
4. The whole system just changes when your child reaches adulthood. You are treated differently. It is much more impersonal and you get the feeling they think you are trying to "rip off" the system.	NA	1	2	3	4	5
5. I have the confidence that I am doing the best I can in this situation.	NA	1	2	3	4	5
6. Most of the parents are trying their best to do a good job; otherwise they never would have shown up for the appointment.	NA	1	2	3	4	5
7. Education, as far as day to day living goes, is a joint effort from the whole family.	NA	1	2	3	4	5
8. We go to visit relatives; but one of us has to constantly sit with him. Nobody will say, "Well let me sit with him a while." It's easier to care for Bruce here at home.	NA	1	2	3	4	5
9. They didn't try to take her and stick her into their system. They made their system work around her.	NA	1	2	3	4	5
10. I really think that there should be two parts to our parent's group: an advocacy part and a part that is purely SUPPORT for us parents.	NA	1	2	3	4	5
11. She had a good year at school. There was a very understanding set of parents and she was well received.	NA	1	2	3	4	5
12. One professional is not supportive. I work around him.	NA	1	2	3	4	5
13. The only hands-on support we ever had is what we bought and paid for.	NA	1	2	3	4	5
14. No one was paying attention. I felt frustrated that no one was listening to my concerns about Shane.	NA	1	2	3	4	5
15. It's been hard on her brothers; but overall I'd say they gained more than they lost.	NA	1	2	3	4	5
16. I think there is a difference between listening to somebody and hearing somebody. Most professionals listen; but only some of them hear what we are saying.	NA	1	2	3	4	5

1/94

To what extent do you share the ideas and feelings of the following parental statements?	Not Applicable	Almost Never	Seldom	Sometimes	Often	Almost Always
17. If you are dealing with a bunch of professionals, you do feel that they are on one side and you are on the other.	NA	1	2	3	4	5
18. Sometimes it just takes a couple of words from the man (husband/father) to get them to do something that I had been talking about to them for months.	NA	1	2	3	4	5
19. I'm no hero. There are plenty of days I said, "I'm not fighting any more. I'll keep her home." That only lasted a little while. Then you start again.	NA	1	2	3	4	5
20. We have had struggles at school for a couple of years now.	NA	1	2	3	4	5
21. I am just one person. There are a lot of other people involved with this child. Show them. Show the whole family.	NA	1	2	3	4	5
22. I spent nine months trying to get that service for Shane, and in the end the answer was so simple. Give me a break! So simple... and yet they made it so complicated for me.	NA	1	2	3	4	5
23. The services she has received were excellent. They accommodated her and helped me to feel good about myself, too.	NA	1	2	3	4	5
24. Don't provide parents with a list of "do's and dont's". Ask them, "Do you think this is possible? Would you have time to do that?"	NA	1	2	3	4	5
25. Babysitting for us; well, is it ever going to end?	NA	1	2	3	4	5
26. I don't do a lot of work one-on-one with Shane at home. I want him to know there is a place to work and a place to relax. Here at home he can just be plain old Shane. He can have his own space.	NA	1	2	3	4	5
27. Don't send me a few dollars trying to keep me happy. That's not what I'm looking for. I need someone to come in here for a few hours to give me a break. It's no good sending me the money if I don't have the person.	NA	1	2	3	4	5
28. For a long time his sister was jealous of him.	NA	1	2	3	4	5
29. Professionals have to realize that they have to work with parents. If they work against us, nothing will work out.	NA	1	2	3	4	5
30. We're trying very hard this year to get off to a good start with the school. We are trying to keep things positive.	NA	1	2	3	4	5
31. I am optimistic. I know things will work out. I have to be patient.	NA	1	2	3	4	5
32. She gave me that book and said, "Here, do this." I didn't know where to begin. I just put that book on the dresser. Everytime I went by it, I felt guilty.	NA	1	2	3	4	5
33. It's lonely. If you had another family with a child trying to be integrated...it would be better.	NA	1	2	3	4	5

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To what extent do you share the ideas and feelings of the following parental statements?	Not Applicable	Almost Never	Seldom	Sometimes	Often	Almost Always
34. I did not want his sister to feel left out, because he was getting so much attention.	NA	1	2	3	4	5
35. The kids will talk to him even though he doesn't speak back to them.	NA	1	2	3	4	5
36. Things went well in junior high; but at senior high it's been just one roadblock after another.	NA	1	2	3	4	5
37. I try to find time for myself each day. I go for a walk, or I listen to music. I do something that nourishes me.	NA	1	2	3	4	5
38. The pressure is on us, the parents, to always see that he sees his friends after school, evenings, that sort of thing.	NA	1	2	3	4	5
39. Generally, I'm satisfied with my life.	NA	1	2	3	4	5
40. Most of the time I'm patient; but some days I let her stubbornness get the best of me.	NA	1	2	3	4	5
41. His brother has started to see Bruce differently. He is starting to notice that Bruce is really doing great.	NA	1	2	3	4	5
42. We don't get a whole lot of support unless we're willing to go out there and fight for it.	NA	1	2	3	4	5
43. Sometimes it's like we are against everyone, that there is just our family against the world.	NA	1	2	3	4	5
44. I had no problem trying to get her into that program. And even though they are very competitive, they went out of their way to help Marianne.	NA	1	2	3	4	5
45. I remember a six page report from a professional. Of six type-written pages there was not one positive thing about Marianne in it.	NA	1	2	3	4	5
46. A lot of the professionals you deal with, you come home feeling disheartened.	NA	1	2	3	4	5
47. One of my friends has been a lot of support. It's not possible to cry on her shoulder for very long. Soon you come away with positive things to do to help change the situation.	NA	1	2	3	4	5
48. By the time you fight the issue, the semester's over and the kids have gone on to something else.	NA	1	2	3	4	5
49. I have a friend that I can share confidences with.	NA	1	2	3	4	5
50. There are times that I wish I had more freedom of movement. I always feel that I have to be available to whomever has Marianne, at any given moment.	NA	1	2	3	4	5
51. When she was diagnosed, there were a lot of "nevers" going through my mind. You know, there would never be school... birthday parties... brownies...	NA	1	2	3	4	5
52. I'm seeing things happen more and more. Shane was crying and my brother comforted him. It was nice to know that there were other people who could comfort my child.	NA	1	2	3	4	5

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To what extent do you share the ideas and feelings of the following parental statements?	Not Applicable	Almost Never	Seldom	Sometimes	Often	Almost Always
53. I think it would be good if we just started a group (of parents of children with disabilities) and said, "This is a place you can share your struggles and celebrate your successes."	NA	1	2	3	4	5
54. Our ability to support one another builds our inner strength.	NA	1	2	3	4	5
55. I'm busy keeping her busy. I can't just send her down to the rink or to swimming. I have to go too.	NA	1	2	3	4	5
56. Shane's early intervention experience was very helpful and optimistic.	NA	1	2	3	4	5
57. I spent a lot of time last year, being on the receiving end of phone calls from the school ... come and get him; take him home; he shouldn't be here, all that kind of stuff.	NA	1	2	3	4	5
58. I am finding the school very supportive.	NA	1	2	3	4	5
59. I think the social services system abuses parents of disabled adults. We are treated like "slave labor".	NA	1	2	3	4	5
60. The teacher was astounded that Marianne could do that. From that day forth, whatever tasks the other children were getting in the classroom, Marianne got too.	NA	1	2	3	4	5
61. You can talk to your friends but they wouldn't understand the way another parent of a child with disabilities would understand.	NA	1	2	3	4	5
62. We never go alone to a meeting concerning Bruce. We always go as a couple.	NA	1	2	3	4	5
63. I went back to work part-time. I had to, I had to get back in contact with the adult world.	NA	1	2	3	4	5
64. Sometimes I've felt that he has been used as a guinea pig, to try out medications.	NA	1	2	3	4	5
65. One of the instructors from the college is volunteering to take the load off of us. He's meeting with the school and will mediate this issue between us and the school.	NA	1	2	3	4	5
66. He was very sick. I had to give him his shots. We missed a lot of work. He cried all the time. It was a nightmare.	NA	1	2	3	4	5
67. I feel like I'm trying to spread myself around to everyone. There is not enough time. There's not enough time for me.	NA	1	2	3	4	5
68. It hasn't been a stressful situation with one professional. It's his attitude. He tries to understand and he is willing to learn things from me.	NA	1	2	3	4	5
69. I can't do one thing over the phone for Marianne. It's a meeting, then there would be another meeting and then they take it to somebody else for another meeting.	NA	1	2	3	4	5

To what extent do you share the ideas and feelings of the following parental statements?	Not Applicable	Almost Never	Seldom	Sometimes	Often	Almost Always
70. I worry that something will get in the way of my being able to keep it all together.	NA	1	2	3	4	5
71. I have one professional who starts with the positive and then works her way around to telling you the things that are not so positive.	NA	1	2	3	4	5
72. I feel that time is running out and things aren't getting done. He has rights that are not being awarded him.	NA	1	2	3	4	5
73. That professional made that book on language come alive to me. She showed me how to do those things with Shane in my daily work around the house.	NA	1	2	3	4	5
74. You're frustrated with the school board and you feel you'd like to punch the principal in the mouth! A lot of parents feel guilty about that...about feeling so angry.	NA	1	2	3	4	5
75. I have excellent support from my family support worker. She keeps me informed; but also tries not to let me get overwhelmed by too much information.	NA	1	2	3	4	5
76. I always felt there was something holding me back from totally loving Shane the way he should be loved. I think it was the fear that he was going to die. I didn't know what to do.	NA	1	2	3	4	5
77. One thing that really struck me was the way she interacted with Bruce. She could really "read" him. There was a lot of warmth. She took delight in his small accomplishments.	NA	1	2	3	4	5
78. If she's going to benefit from it, it's because of our efforts to make sure she gets there and does it.	NA	1	2	3	4	5
79. I wish that I had started right from the first in including my husband in all the meetings with professionals; but it wasn't always possible.	NA	1	2	3	4	5
80. If I were a foster parent, I wouldn't have to worry about going out working to make some money.	NA	1	2	3	4	5

81. Briefly tell me one positive experience you have had with reference to your child with disabilities.

82. Briefly tell me one negative experience you have had with reference to your child with disabilities.

83. Do you have anything more that you want to say?

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APPENDIX C

APPENDIX C
Summary of Questionnaire Responses

		Questions									
Site	Label	1	2	3	4	5	6	7	8	9	10
1	almost never	1	6	2	-	-	-	1	3	-	1
	seldom	-	1	-	-	-	-	-	2	4	-
	sometimes	1	3	2	-	3	-	2	3	1	2
	often	3	1	-	-	4	5	5	3	5	2
	almost always	9	1	-	-	5	7	7	2	4	7
	not applicable	1	3	11	15	-	3	-	2	1	3
2	almost never	6	1	5	7	-	1	1	6	3	-
	seldom	1	1	-	4	-	-	-	4	3	1
	sometimes	1	1	1	3	1	2	3	2	5	4
	often	4	3	-	3	5	8	3	2	5	5
	almost always	15	2	-	2	22	14	19	3	3	10
	not applicable	2	21	23	10	1	3	3	11	10	7
3	almost never	-	3	4	3	-	-	-	2	2	-
	seldom	-	4	-	-	-	-	-	-	-	1
	sometimes	5	2	3	1	1	2	4	5	5	3
	often	3	1	-	-	6	5	3	2	6	1
	almost always	8	3	-	2	9	8	9	2	2	7
	not applicable	1	4	10	11	1	2	1	6	2	4
4	almost never	-	3	1	-	1	-	-	4	3	2
	seldom	1	1	-	-	-	-	-	1	1	-
	sometimes	1	3	1	2	5	1	3	2	5	1
	often	3	2	-	2	5	7	5	5	-	7
	almost always	9	-	1	1	5	4	8	1	3	4
	not applicable	1	6	12	11	-	3	-	2	2	2
5	almost never	1	2	6	1	-	-	-	5	3	-
	seldom	1	2	-	2	1	-	-	2	6	-
	sometimes	5	5	-	-	4	1	4	2	5	1
	often	6	3	-	-	6	8	5	6	2	5
	almost always	1	3	-	5	8	7	9	2	1	12
	not applicable	-	4	13	11	-	3	1	2	2	1

"Null rasponses" are not reported

APPENDIX C
Summary of Questionnaire Responses

Questions Cont'd

Site	Label	11	12	13	14	15	16	17	18	19	20
1	almost never	-	4	9	7	-	-	2	2	4	6
	seldom	-	1	2	3	1	1	3	3	1	-
	sometimes	-	3	-	4	6	7	8	[illegible]	1	1
	often	4	3	1	1	3	5	2	1	5	1
	almost always	4	4	-	-	3	2	-	1	1	-
	not applicable	7	1	3	-	2	-	-	4	3	7
2	almost never	2	3	4	7	-	4	6	10	4	2
	seldom	4	2	6	4	1	1	7	5	4	1
	sometimes	2	7	6	7	3	7	4	4	5	3
	often	3	5	2	5	8	7	4	1	2	1
	almost always	3	1	4	-	14	7	6	4	4	3
	not applicable	5	11	7	6	3	2	2	5	9	19
3	almost never	-	1	1	1	2	1	2	3	2	4
	seldom	1	-	3	3	-	-	1	2	3	1
	sometimes	3	6	4	6	2	2	7	6	3	3
	often	4	3	3	3	5	9	4	3	4	3
	almost always	6	3	3	2	3	5	2	-	-	2
	not applicable	3	4	3	2	5	-	1	3	5	4
4	almost never	-	2	4	2	-	2	3	3	1	3
	seldom	-	3	4	3	2	-	1	-	3	1
	sometimes	2	5	4	5	3	5	6	4	4	1
	often	4	1	-	1	2	3	4	5	3	2
	almost always	2	1	2	4	6	5	2	-	-	1
	not applicable	7	2	1	-	3	-	-	3	4	7
5	almost never	1	1	3	2	-	1	-	2	2	1
	seldom	2	-	4	2	1	-	2	3	4	1
	sometimes	2	5	1	6	3	5	5	5	5	2
	often	2	5	3	6	5	4	6	5	3	8
	almost always	2	6	8	3	6	9	6	1	2	2
	not applicable	8	2	-	-	4	-	-	3	3	5

APPENDIX C
Summary of Questionnaire Respons

Questions Cont'd

Site	Label	21	22	23	24	25	26	27	28	29	30
1	almost never	1	2	-	1	2	3	2	2	2	-
	seldom	-	4	1	1	-	2	2	3	-	-
	sometimes	5	2	2	2	5	2	3	3	4	1
	often	6	3	4	1	4	5	2	3	2	8
	almost always	-	2	8	9	8	3	3	-	6	4
	not applicable	2	2	-	1	1	-	3	4	1	2
2	almost never	6	6	-	3	2	3	3	9	3	-
	seldom	3	-	2	4	1	3	1	2	3	1
	sometimes	5	5	5	2	2	1	5	3	2	1
	often	3	6	8	2	5	8	5	4	4	1
	almost always	3	4	9	11	7	9	4	3	14	8
	not applicable	8	8	5	6	12	4	10	8	3	17
3	almost never	2	-	1	1	1	1	1	4	2	-
	seldom	3	2	2	-	1	-	1	1	-	1
	sometimes	4	3	7	5	5	6	1	2	3	-
	often	4	5	4	7	3	4	4	-	1	5
	almost always	1	3	2	2	3	6	5	1	8	8
	not applicable	2	4	1	2	4	-	5	9	3	3
4	almost never	2	-	1	1	2	2	1	3	-	-
	seldom	-	-	1	-	-	1	-	1	2	-
	sometimes	6	6	7	2	3	4	2	5	2	3
	often	2	3	2	3	4	3	4	2	2	3
	almost always	1	3	4	9	4	6	4	1	9	3
	not applicable	4	3	1	-	2	-	4	3	-	6
5	almost never	-	-	1	1	4	-	1	7	-	-
	seldom	-	-	7	1	1	1	1	-	2	-
	sometimes	2	8	6	2	2	7	-	4	-	-
	often	9	4	4	3	4	7	6	1	3	5
	almost always	4	7	1	11	6	3	8	-	14	11
	not applicable	2	-	-	-	2	1	2	7	-	3

APPENDIX C
Summary of Questionnaire Responses

Questions Cont'd

Site	Label	31	32	33	34	35	36	37	38	39	40
1	almost never	-	2	1	-	-	-	3	2	1	-
	seldom	-	4	1	-	-	-	1	1	1	2
	sometimes	4	4	7	7	2	-	3	2	3	6
	often	5	1	2	4	6	-	2	5	4	6
	almost always	6	-	2	2	4	-	6	-	6	1
	not applicable	-	4	2	2	3	15	-	9	-	-
2	almost never	-	4	1	2	1	3	4	3	1	6
	seldom	1	1	3	2	1	3	5	4	1	5
	sometimes	6	5	4	6	5	2	7	2	6	12
	often	10	1	5	2	5	2	1	4	5	3
	almost always	11	1	3	9	7	-	8	6	16	3
	not applicable	1	17	12	8	10	19	4	10	-	-
3	almost never	-	2	3	2	-	-	3	3	1	1
	seldom	-	2	3	1	-	-	4	-	-	4
	sometimes	4	2	3	4	2	1	4	2	4	8
	often	7	3	2	-	1	-	3	2	6	3
	almost always	6	2	3	5	6	1	3	7	6	1
	not applicable	-	6	3	5	8	15	-	3	-	-
4	almost never	-	3	4	2	1	1	1	-	-	2
	seldom	2	2	-	1	1	-	-	-	1	1
	sometimes	7	3	3	3	4	1	5	2	2	9
	often	1	-	2	4	3	-	3	3	9	2
	almost always	5	2	3	2	2	1	4	5	2	-
	not applicable	-	5	3	3	4	12	2	5	1	-
5	almost never	1	3	3	2	-	-	1	-	-	1
	seldom	2	4	1	1	-	-	1	-	1	4
	sometimes	7	4	2	1	6	1	7	1	7	6
	often	7	2	6	2	4	4	2	4	7	5
	almost always	2	1	3	7	6	-	8	8	4	1
	not applicable	-	5	4	6	3	14	-	6	-	2

APPENDIX C
Summary of Questionnaire Responses

Questions Cont'd

Site	Label	41	42	43	44	45	46	47	48	49	50
1	almost never	-	2	3	1	5	-	1	4	-	2
	seldom	3	2	9	2	3	5	1	-	1	3
	sometimes	7 -	6	-	3	3	5	7	1	4	3
	often	-	2	2	4	1	2	3	1	2	4
	almost always	5	2	1	3	1	2	3	-	8	2
	not applicable		1	-	3	2	1	-	9	-	1
2	almost never	-	3	5	1	9	5	5	3	4	2
	seldom	1	2	1	1	4	5	3	-	-	1
	sometimes	6	4	8	6	6	5	4	3	6	5
	often	7	7	5	6	1	9	4	3	2	6
	almost always	8	8	4	7	1	3	4	3	15	8
	not applicable	7	5	5	8	8	2	8	17	2	6
3	almost never	1	1	2	1	2	1	2	2	3	-
	seldom	1	-	3	2	2	3	5	3	1	2
	sometimes	5	3	5	4	4	6	4	8	9	2
	often	4	5	2	5	1	3	1	1	1	5
	almost always	1	7	3	2	4	3	1	1	3	6
	not applicable	5	1	2	3	4	1	4	2	-	2
4	almost never	-	2	5	2	5	2	3	-	2	2
	seldom	2	2	5	2	2	2	3	1	2	1
	sometimes	6	4	2	3	1	5	2	3	1	3
	often	2	4	2	-	3	4	4	4	3	5
	almost always	1	3	1	-	-	2	2	-	7	4
	not applicable	4	-	-	8	4	-	1	7	-	-
5	almost never	-	-	5	3	2	2	-	1	-	3
	seldom	-	-	-	1	4	3	2	-	1	-
	sometimes	5	5	3	5	4	4	7	4	1	6
	often	7	4	4	3	5	7	3	4	7	7
	almost always	-	10	7	-	-	3	6	5	10	3
	not applicable	7	-	-	6	4	-	1	5	-	-

APPENDIX C
Summary of Questionnaire Responses

Questions Cont'd

Site	Label	51	52	53	54	55	56	57	58	59	60
1	almost never	3	-	1	1	-	-	5	1	1	-
	seldom	1	2	1	-	-	-	-	-	-	-
	sometimes	2	2	3	2	2	2	2	2	3	2
	often	3	3	3	3	2	4	-	2	1	-
	almost always	6	8	7	9	11	8	-	7	-	6
	not applicable	-	-	-	-	-	1	8	3	10	7
2	almost never	2	-	4	1	2	3	4	1	6	-
	seldom	2	4	3	2	1	-	1	2	3	-
	sometimes	3	8	4	4	1	6	4	5	6	5
	often	10	7	3	4	5	3	2	1	3	5
	almost always	8	7	11	17	14	6	1	4	4	3
	not applicable	3	2	4	1	6	11	17	16	7	16
3	almost never	2	1	1	1	-	1	5	1	1	-
	seldom	1	3	-	-	-	1	1	1	3	2
	sometimes	3	8	8	5	1	6	3	1	1	4
	often	7	2	-	6	5	1	2	7	-	3
	almost always	2	2	6	5	10	4	1	5	4	5
	not applicable	2	1	1	-	1	3	5	2	8	3
4	almost never	4	1	2	-	-	2	3	1	-	1
	seldom	-	-	-	-	-	2	2	-	1	1
	sometimes	2	6	2	2	-	2	1	3	2	2
	often	5	5	2	5	4	3	1	3	1	2
	almost always	4	3	7	7	11	5	-	4	1	1
	not applicable	-	-	1	-	-	1	8	4	9	8
5	almost never	3	-	1	-	-	-	1	1	-	1
	seldom	3	1	-	-	-	2	5	1	-	1
	sometimes	2	8	3	3	4	3	4	6	-	6
	often	6	5	3	5	7	4	2	4	4	2
	almost always	4	5	10	11	8	7	1	2	8	1
	not applicable	1	-	2	-	-	3	6	[illegible]	6	8

APPENDIX C
Summary of Questionnaire Responses

Questions Cont'd

Site	Label	61	62	63	64	65	66	67	68	69	70
1	almost never	-	7	1	2	2	6	2	-	6	3
	seldom	-	2	1	3	-	-	-	-	4	2
	sometimes	4	2	3	2	1	1	3	7	2	4
	often	4	-	3	-	-	2	4	3	2	3
	almost always	7	3	2	1	-	2	6	2	-	3
	not applicable	-	-	5	7	12	4	-	3	1	-
2	almost never	1	10	3	6	6	6	4	1	6	4
	seldom	4	4	1	2	-	3	2	1	1	3
	sometimes	5	3	2	7	-	2	4	10	7	4
	often	10	3	4	-	2	3	5	2	5	7
	almost always	9	3	5	2	-	-	9	8	2	5
	not applicable	-	6	11	12	21	14	5	6	8	5
3	almost never	1	4	3	3	4	1	-	1	1	3
	seldom	-	5	-	-	1	1	-	1	2	-
	sometimes	6	3	1	4	-	3	4	8	6	8
	often	4	2	5	-	-	-	3	2	2	4
	almost always	6	1	4	1	-	2	8	2	2	1
	not applicable	-	2	4	9	12	10	2	3	4	1
4	almost never	-	2	-	2	1	1	-	-	3	1
	seldom	1	-	-	2	-	-	-	1	-	1
	sometimes	-	4	1	1	1	4	7	6	7	5
	often	6	5	1	3	-	2	1	3	3	6
	almost always	7	3	5	-	-	2	7	3	1	2
	not applicable	1	2	8	7	13	6	-	2	1	-
5	almost never	-	3	1	7	8	4	1	1	2	3
	seldom	1	6	-	1	-	2	2	3	3	2
	sometimes	7	-	2	2	-	-	4	8	3	6
	often	4	4	6	1	-	1	6	4	7	7
	almost always	7	6	6	2	-	4	6	2	4	1
	not applicable	-	-	4	6	11	8	-	1	-	-

APPENDIX C
Summary of Questionnaire Responses

		Questions									
Site	Label	71	72	73	74	75	76	77	78	79	80
1	almost never	4	3	-	4	4	11	-	-	-	4
	seldom	3	4	4	2	1	-	-	-	1	1
	sometimes	4	4	4	1	1	-	2	5	4	2
	often	1	2	2	1	2	-	7	6	3	-
	almost always	-	-	1	1	4	1	4	3	3	1
	not applicable	3	2	4	6	3	3	1	1	2	4
2	almost never	3	7	6	5	1	15	2	1	6	8
	seldom	7	4	-	1	2	-	1	1	4	-
	sometimes	7	5	4	5	4	2	7	3	1	2
	often	2	3	2	2	3	1	6	9	2	2
	almost always	1	3	1	2	3	-	2	11	3	1
	not applicable	9	6	16	14	16	11	11	3	11	11
3	almost never	2	-	2	6	4	5	1	1	1	2
	seldom	2	4	4	-	-	-	1	-	3	3
	sometimes	4	7	4	5	5	3	8	2	6	1
	often	3	3	1	1	3	2	2	3	2	3
	almost always	2	2	-	1	1	-	2	9	2	3
	not applicable	4	1	6	4	4	7	3	2	3	5
4	almost never	2	4	3	1	2	10	-	-	2	3
	seldom	4	1	2	1	2	-	2	-	1	-
	sometimes	6	3	6	1	-	1	7	1	-	1
	often	2	5	-	3	1	-	3	5	3	2
	almost always	-	2	1	2	1	1	1	8	3	2
	not applicable	1	-	3	7	9	3	2	1	6	7
5	almost never	4	7	2	-	3	9	1	-	4	4
	seldom	1	1	4	2	1	2	1	-	1	1
	sometimes	7	4	4	6	3	1	8	3	5	2
	often	3	7	2	2	2	3	8	6	3	2
	almost always	2	4	1	3	1	-	1	9	1	4
	not applicable	2	1	6	6	9	4	-	1	5	6

APPENDIX D

Appendix D
Summary: High and Low
Responses to Questionnaire Items

			SITES				
Item	Extreme	Total Group	1	2	3	4	5
1	low	11(10.8)	1(6.7)	7(24.1)	-	1(5.6)	2(10.5)
	high	65(63.7)*	2(80.0)*	19(65.5)*	11(52.4)*	12(66.7)*	11(57.9)*
2	low	24(23.5)	7(46.7)	2(6.9)	7(33.3)	4(22.2)	4(21.1)
	high	19(18.6)	2(13.3)	5(17.2)	4(19.0)	2(11.1)	6(31.6)
3	low	18(17.6)	2(13.3)	5(17.2)	4(19.0)	1(5.6)	6(31.6)
	high	1(1.0)	-	-	-	1(5.6)	-
4	low	16(15.7)	-	11(37.9)	3(14.3)	-	2(10.5)
	high	16(15.7)	-	5(17.2)	2(9.5)	3(16.7)	6(31.6)
5	low	2(2.0)	-	-	-	1(5.6)	1(5.3)
	high	78(76.5)*	12(80.0)*	27(93.1)*	15(71.4)*	10(55.6)*	14(73.7)*
6	low	1(1.0)	-	1(3.4)	-	-	-
	high	73(71.6)*	12(80.0)*	22(75.9)*	13(61.9)*	11(61.1)*	15(78.9)*
7	low	2(2.0)	1(6.7)	1(3.4)	-	-	-
	high	73(71.6)*	12(80.0)*	22(75.9)*	12(57.1)*	13(72.2)*	14(73.7)*
8	low	29(28.4)	5(33.3)	10(34.5)	2(9.5)	5(27.8)	7(36.8)
	high	28(27.5)	5(33.3)	5(17.2)	4(19.0)	6(33.3)	8(42.1)
9	low	25(24.5)	4(26.7)	6(20.7)	2(9.5)	4(22.2)	9(47.4)
	high	31(30.4)	9(60.0)*	8(27.6)	8(38.1)	3(16.7)	3(15.8)
10	low	5(4.9)	1(6.7)	1(3.4)	1(4.8)	2(11.1)	-
	high	60(58.8)*	9(60.0)*	15(51.7)*	8(38.1)	11(61.1)*	17(89.5)*
11	low	10(9.8)	-	6(20.7)	1(4.8)	-	3(15.8)
	high	34(33.3)	8(53.3)*	6(20.7)	10(47.6)	6(33.3)	4(21.1)
12	low	16(15.7)	4(26.7)	5(17.2)	1(4.8)	5(27.8)	1(5.3)
	high	32(31.4)	7(46.7)	6(20.7)	6(28.6)	2(11.1)	11(57.9)*
13	low	40(39.2)	11(76.3)*	10(34.5)	4(19.0)	8(44.4)	7(36.8)
	high	26(25.5)	1(6.7)	6(20.7)	6(28.6)	2(11.1)	11(57.9)*
14	low	34(33.3)	10(66.7)*	11(37.9)	4(19.0)	5(27.8)	4(21.1)
	high	25(24.5)	1(6.7)	5(17.2)	5(23.8)	5(27.8)	9(47.4)
15	low	7(6.9)	1(6.7)	1(3.4)	2(9.5)	2(11.1)	1(5.3)
	high	55(53.9)*	6(40.0)	22(75.9)*	8(38.1)	8(44.4)	11(57.9)*
16	low	10(9.8)	1(6.7)	5(17.2)	1(4.8)	2(11.1)	1(5.3)
	high	56(54.9)*	7(46.7)	14(48.3)	14(66.7)*	8(44.4)	13(68.4)*
17	low	27(26.5)	5(33.3)	13(44.8)	3(14.3)	4(22.2)	2(10.5)
	high	36(35.3)	2(13.3)	10(34.5)	6(28.6)	6(33.3)	12(63.2)*

* Items greater than 50%

Appendix D Cont'd
Summary: High and Low
Responses to Questionnaire Items

					SITES		
Item	Extreme	Total Group	1	2	3	4	5
18	low	33(32.4)	5(33.3)	15(51.7)*	5(23.8)	3(16.7)	5(26.3)
	high	21(20.6)	2(13.3)	5(17.2)	3(14.3)	5(27.8)	6(31.6)
19	low	28(27.5)	5(33.3)	8(27.6)	5(23.8)	4(22.2)	6(31.6)
	high	24(23.5)	6(40.0)	6(20.7)	4(19.0)	3(16.7)	5(26.3)
20	low	20(19.6)	6(40.0)	3(10.3)	5(23.8)	4(22.2)	2(10.5)
	high	23(22.5)	1(6.7)	4(13.8)	5(23.8)	3(16.7)	10(52.6)*
21	low	17(16.7)	1(6.7)	9(31.0)	5(23.8)	2(11.1)	-
	high	33(32.4)	6(40.0)	6(20.7)	5(23.8)	3(16.7)	13(68.4)*
22	low	14(13.7)	5(40.0)	6(20.7)	2(9.5)	-	-
	high	40(39.2)	6(33.3)	10(34.5)	8(38.1)	6(33.3)	11(57.9)*
23	low	16(15.7)	1(6.7)	2(6.9)	3(14.3)	2(11.1)	8(42.1)
	high	14(45.1)	12(80.0)*	17(58.6)*	6(28.6)	6(33.3)	5(26.3)
24	low	13(12.1)	2(13.3)	7(24.1)	1(4.8)	1(5.6)	2(10.5)
	high	58(56.9)*	10(66.7)*	13(44.8)	9(42.9)	12(66.7)*	14(73.7)*
25	low	14(13.7)	2(13.3)	2(10.3)	2(9.5)	2(11.1)	5(26.3)
	high	43(42.2)	7(46.7)	12(41.4)	6(28.6)	8(44.4)	10(52.6)*
26	low	16(15.7)	5(33.3)	6(20.7)	1(4.8)	3(16.7)	1(5.3)
	high	54(52.9)*	8(53.3)*	17(58.6)*	10(47.6)	9(50.0)*	10(52.6)*
27	low	13(12.7)	4(26.7)	4(13.8)	2(9.5)	1(5.6)	2(10.5)
	high	45(44.1)	5(33.3)	9(31.0)	9(42.9)	8(44.4)	14(73.7)*
28	low	32(31.4)	5(33.3)	11(37.9)	5(23.8)	4(22.2)	7(36.8)
	high	15(14.7)	3(20.0)	7(24.1)	1(4.8)	3(16.7)	1(5.3)
29	low	14(13.7)	2(13.3)	6(20.7)	2(9.5)	2(11.1)	2(10.5)
	high	63(61.8)*	8(53.3)*	18(62.1)*	9(42.9)	11(61.1)*	17(89.5)*
30	low	2(2.0)	-	1(3.4)	1(4.8)	-	-
	high	56(54.9)*	12(80.0)*	9(31.0)	13(61.9)*	6(33.3)	16(84.2)*
31	low	6(5.9)	-	1(3.4)	-	2(11.1)	3(15.8)
	high	60(58.8)*	11(73.3)*	21(72.4)*	13(61.9)*	6(33.3)	9(47.4)
32	low	27(26.5)	6(40.0)	5(17.2)	4(19.0)	5(27.8)	7(36.8)
	high	13(12.7)	1(6.7)	2(6.9)	5(23.8)	2(11.1)	3(15.8)
33	low	20(19.6)	2(13.3)	4(13.8)	6(28.6)	4(22.2)	4(21.1)
	high	31(30.4)	4(26.7)	8(27.6)	5(23.8)	5(27.8)	9(47.4)
34	low	13(12.7)	-	4(13.8)	3(14.3)	3(16.7)	3(15.8)
	high	37(36.3)	6(40.0)	11(37.9)	5(23.8)	6(33.3)	9(47.4)

Appendix D Cont'd
Summary: High and Low
Responses to Questionnaire Items

			SITES				
		Total Group	1	2	3	4	5
Item	Extreme						
35	low	4(3.9)	.	2(6.9)	.	2(11.1)	.
	high	44(43.1)	10(66.7)*	12(41.4)	7(33.3)	5(27.8)	10(52.6)*
36	low	7(6.9)	.	6(20.7)	.	1(5.6)	.
	high	8(7.8)	.	2(6.9)	1(4.8)	1(5.6)	4(21.1)
37	low	23(22.5)	4(26.7)	9(31.0)	7(33.3)	1(5.6)	2(10.5)
	high	40(39.2)	8(53.3)*	9(31.0)	6(28.6)	7(38.9)	10(52.6)*
38	low	13(12.7)	3(20.0)	7(24.1)	3(14.3)	.	.
	high	44(43.1)	5(33.3)	10(34.5)	9(42.9)	8(44.4)	12(63.2)*
39	low	7(6.9)	2(13.3)	2(6.9)	1(4.8)	1(5.6)	1(5.3)
	high	65(63.7)*	10(66.7)*	21(72.4)*	12(57.1)*	11(61.1)*	11(57.9)*
40	low	26(25.5)	2(13.3)	11(37.9)	5(23.8)	3(16.7)	5(26.3)
	high	25(24.5)	7(46.7)	6(20.7)	4(19.0)	2(11.1)	6(31.6)
41	low	8(7.8)	3(20.0)	1(3.4)	2(9.5)	2(11.1)	.
	high	30(29.4)	.	15(51.7)*	5(23.8)	3(16.7)	7(36.8)
42	low	14(13.7)	4(26.7)	5(17.2)	1(4.8)	4(22.2)	.
	high	52(51.0)*	4(26.7)	15(51.7)*	12(57.1)*	7(38.9)	14(73.7)*
43	low	38(37.3)	12(80.0)*	6(20.7)	5(23.8)	10(55.6)*	5(26.3)
	high	31(30.4)	3(20.0)	9(31.0)	5(23.8)	3(16.7)	11(57.9)*
44	low	16(15.7)	3(20.0)	2(6.9)	3(14.3)	4(22.2)	4(21.1)
	high	29(28.4)	6(40.0)	13(44.8)	7(33.3)	.	3(15.8)
45	low	38(37.3)	8(53.3)*	13(44.8)	4(19.0)	7(38.9)	6(31.6)
	high	17(16.7)	2(13.3)	2(6.9)	5(23.8)	3(16.7)	5(26.3)
46	low	28(27.5)	5(33.3)	10(34.5)	4(19.0)	4(22.2)	5(26.3)
	high	38(37.3)	4(26.7)	12(41.4)	6(28.6)	6(33.3)	10(52.6)*
47	low	25(24.5)	2(13.3)	8(27.6)	7(33.3)	6(33.3)	2(10.5)
	high	31(30.4)	6(40.0)	8(37.6)	2(9.5)	6(33.3)	9(47.4)
48	low	14(13.7)	4(26.7)	3(10.3)	5(23.8)	1(5.6)	1(5.3)
	high	22(21.6)	1(6.7)	6(20.7)	2(9.5)	4(22.2)	9(47.4)
49	low	14(13.7)	1(6.7)	4(13.8)	4(19.0)	4(22.2)	1(5.3)
	high	58(56.9)*	10(66.7)*	17(58.6)*	4(19.0)	10(55.6)*	17(89.5)*
50	low	16(15.7)	5(33.3)	3(10.3)	2(9.5)	3(16.7)	3(15.8)
	high	50(49.0)	6(40.0)	14(48.3)	11(52.4)*	9(50.0)*	10(52.6)*
51	low	21(20.6)	4(26.7)	4(13.8)	3(14.3)	4(22.2)	6(31.6)
	high	55(53.9)*	9(60.0)*	18(62.1)*	9(42.9)*	9(50.0)*	10(52.6)*
52	low	12(11.8)	2(13.3)	4(13.8)	4(19.0)	1(5.6)	1(5.3)
	high	47(46.1)	11(73.3)*	14(48.3)	4(19.0)	8(44.4)	10(52.6)*

Appendix D Cont'd
Summary: High and Low
Responses to Questionnaire Items

			SITES				
Item	Extreme	Total Group	1	2	3	4	5
53	low	13(12.7)	2(13.3)	7(24.1)	1(4.8)	2(11.1)	1(5.3)
	high	52(51.0)*	10(66.7)*	14(48.3)	6(28.6)	9(50.0)*	13(68.4)*
54	low	5(4.9)	1(6.7)	3(10.3)	1(4.8)	-	-
	high	72(70.6)*	12(80.0)*	21(72.4)*	11(52.4)*	12(66.7)*	16(84.2)*
55	low	3(2.9)	-	3(10.3)	-	-	-
	high	77(75.5)*	13(86.7)*	19(65.5)*	15(71.4)*	15(83.3)*	15(78.9)*
56	low	11(10.8)	-	3(10.3)	2(9.5)	4(22.2)	2(10.5)
	high	45(44.1)	12(80.0)*	9(31.0)	5(23.8)	8(44.4)	11(57.9)*
57	low	27(26.5)	5(33.3)	5(17.2)	6(28.6)	5(27.8)	6(31.6)
	high	10(9.8)	-	3(10.3)	3(14.3)	1(5.6)	3(15.8)
58	low	9(8.8)	1(6.7)	3(10.3)	2(9.5)	1(5.6)	2(10.5)
	high	39(38.2)	9(60.0)*	5(17.2)	12(57.1)*	7(38.9)	6(31.6)
59	low	15(14.7)	1(6.7)	9(31.0)	4(19.0)	1(5.6)	-
	high	26(25.5)	1(6.7)	7(24.1)	4(19.0)	2(11.1)	12(63.2)*
60	low	6(5.9)	-	-	2(9.5)	2(11.1)	2(10.5)
	high	28(27.5)	6(40.0)	8(27.6)	8(38.1)	3(16.7)	3(15.8)
61	low	8(7.8)	-	5(17.2)	1(4.8)	1(5.6)	1(5.3)
	high	64(62.7)*	11(73.3)*	19(65.5)*	10(47.6)	13(72.2)*	11(57.9)*
62	low	45(44.1)	9(60.0)*	14(48.3)	9(42.9)	4(22.2)	9(47.4)
	high	30(29.4)	3(20.0)	6(20.7)	3(14.3)	8(44.4)	10(52.6)*
63	low	10(9.8)	2(13.3)	4(13.8)	3(14.3)	6(33.3)	1(5.3)
	high	41(40.2)	5(33.3)	9(31.0)	9(42.9)	1(5.6)	12(63.2)*
64	low	28(27.5)	5(33.3)	8(27.6)	3(14.3)	4(22.2)	8(42.1)
	high	10(9.8)	1(6.7)	2(6.9)	1(4.8)	3(16.7)	3(15.8)
65	low	22(21.6)	2(13.3)	6(20.7)	5(23.8)	1(5.6)	8(42.1)
	high	2(2.0)	-	2(6.9)	4(19.0)	-	-
66	low	24(23.5)	6(40.0)	9(31.0)	2(9.5)	1(5.6)	6(31.6)
	high	18(17.6)	4(26.7)	3(10.3)	2(9.5)	4(22.2)	5(26.3)
67	low	11(10.8)	2(13.3)	6(20.7)	-	-	3(15.8)
	high	55(53.9)*	10(66.7)*	14(48.3)	11(52.4)*	8(44.4)	12(63.2)*
68	low	9(8.8)	-	2(6.9)	2(9.5)	1(5.6)	4(21.1)
	high	31(30.4)	5(33.3)	10(34.5)	4(19.0)	6(33.3)	6(31.6)
69	low	28(27.5)	10(66.7)*	7(24.1)	3(14.3)	3(16.7)	5(26.3)
	high	28(27.5)	2(13.3)	7(24.1)	4(19.0)	4(22.2)	11(57.9)*

Appendix D Cont'd
Summary: High and Low
Responses to Questionnaire Items

			SITES				
Item	Extreme	Total Group	1	2	3	4	5
70	low	22(21.6)	5(33.3)	7(24.1)	3(14.3)	2(11.1)	5(26.3)
	high	39(38.2)	6(40.0)	12(41.4)	5(23.8)	8(44.4)	8(42.1)
71	low	32(31.4)	7(46.7)	10(34.5)	4(19.0)	6(33.3)	5(26.3)
	high	16(15.7)	1(6.7)	3(10.3)	5(23.8)	2(11.1)	5(26.3)
72	low	30(29.4)	7(46.7)	11(37.9)	4(19.0)	5(27.8)	3(15.8)
	high	31(30.4)	2(13.3)	6(20.7)	5(23.8)	7(38.9)	11(57.9)*
73	low	27(26.5)	4(26.7)	6(20.7)	6(28.6)	5(27.8)	6(31.6)
	high	11(10.8)	3(20.0)	3(10.3)	1(4.8)	1(5.6)	3(15.8)
74	low	22(21.6)	6(40.0)	6(20.7)	6(28.6)	2(11.1)	2(10.5)
	high	18(17.6)	2(13.3)	4(13.8)	2(9.5)	5(27.8)	5(26.3)
75	low	20(19.6)	5(33.3)	3(10.3)	4(19.0)	4(22.2)	4(21.1)
	high	21(20.6)	6(40.0)	6(20.7)	4(19.0)	2(11.1)	3(15.8)
76	low	52(51.0)*	11(73.3)*	15(51.7)*	5(23.8)	10(55.6)*	11(57.9)*
	high	8(7.8)	1(6.7)	1(3.4)	2(9.5)	1(5.6)	13(15.8)
77	low	9(8.8)	-	3(10.3)	2(9.5)	2(11.1)	2(10.5)
	high	36(35.3)	11(73.3)*	8(27.6)	4(19.0)	4(22.2)	9(47.4)
78	low	3(2.9)	-	2(6.9)	1(4.8)	-	-
	high	69(67.6)*	9(60.0)*	20(69.0)*	12(57.1)*	13(72.2)*	15(78.9)*
79	low	23(22.5)	1(6.7)	10(34.5)	4(19.0)	3(16.7)	5(26.3)
	high	25(24.5)	6(40.0)	5(17.2)	4(19.0)	6(33.3)	4(21.1)
80	low	26(25.5)	5(33.3)	8(27.6)	5(23.8)	3(16.7)	5(26.3)
	high	20(19.6)	1(6.7)	3(10.3)	6(28.6)	4(22.2)	6(31.6)

APPENDIX E

Appendix E
Rank Order of Questionnaire Items
High Extreme: 50% or More
TOTAL GROUP

5. I have the confidence that I am doing the best I can in this situation.

55. I'm busy keeping her busy. I can't just send her down to the rink or to swimming. I have to go too.

6. Most of the parents are trying their best to do a good job; otherwise they never would have shown up for the appointment.

7. Education, as far as day to day living goes, is a joint effort from the whole family.

54. Our ability to support one another builds our inner strength.

78. If she's going to benefit from it, its because of our efforts to make sure she gets there and does it.

1. I'd say our ability to deal with Marianne's disabilities as a family is pretty good. So far, nothing has destroyed us.

39. Generally, I'm satisfied with my life.

61. You can talk to your friends but they wouldn't understand the way another parent of a child with disabilities would understand.

29. Professionals have to realize that they have to work with parents. If they work against us, nothing will work out.

10. I really think that there should be two parts to our parent's group: an advocacy part and a part that is purely support for us parents.

31. I am optimistic. I know things will work out. I have to be patient.

24. Don't provide parents with a list of "do's and dont's". Ask them, "Do you think this is possible? Would you have time to do that?"

49. I have a friend that I can share confidences with.

16. Most professionals listen; but only some of them hear what we are saying.

30. We're trying very hard this year to get off to a good start with the school. We are trying to keep things positive.

15. Its heen hard on her brothers; but overall I'd say they gained more than they lost.

51. When she was diagnosed, there were a lot of "nevers" going through my mind. You know, there would never be school ...birthday parties ... brownies ...

67. I feel like I'm trying to spread myself around to everyone. There is not enough time. There's not enough time for me.

26. I don't do a lot of work one-on-one with Shane at home. I want him to know there is a place to work and a place to relax. Here at home he can just be plain old Shane. He can have his own space.

42. We don't get a whole lot of support unless we're willing to go out there and fight for it.

53. I think it would be good if we just started a group (of parents of children with disabilities) and said, "This is a place you can share your struggles and celebrate your successes."

76. I always felt there was something holding me back from totally loving Shane the way he should be loved. I think it was the fear that he was going to die. I didn't know what to do.

SITE 1

55. I'm busy keeping her busy. I can't just send her down to the rink or to swimming. I have to go too.

1. I'd say our ability to deal with Marianne's disabilities as a family is pretty good. So far, nothing has destroyed us.

5. I have the confidence that I am doing the best I can in this situation.

6. Most of the parents are trying their best to do a good job; otherwise they never would have shown up for the appointment.

7. Education, as far as day to day living goes, is a joint effort from the whole family.

23. The services she has received were excellent. They accomodated her and helped me to feel good about myself, too.

30. We're trying very hard this year to get off to a good start with the school. We are trying to keep things positive.

54. Our ability to support one another builds our inner strength.

56. Shane's early intervention experience was very helpful and optimistic.

31. I am optimistic. I know things will work out. I have to be patient.

52. I'm seeing things happen more and more. Shane was crying and my brother comforted him. It was nice to know that there were other people who could comfort my child.

61. You can talk to your friends but they wouldn't understand the way another parent of a child with disabilities would understand.

77. One thing that really struck me was the way she interacted with Bruce. She could really "read" him. There was a lot of warmth. She took delight in his small accomplishments.

24. Don't provide parents with a list of "do's and dont's". Ask them, "Do you think this is possible? Would you have time to do that?"

35. The kids will talk to him even though he doesn't speak back to them.

39. Generally, I'm satisfied with my life.

49. I have a friend that I can share confidences with.

53. I think it would be good if we just started a group (of parents of children with disabilities) and said, "This is a place you can share your struggles and celebrate your successes."

67. I feel like I'm trying to spread myself around to everyone. There is not enough time. There's not enough time for me.

9. They didn't try to take her and stick her into their system. They made their system work around her.

10. I really think that there should be two parts to our parent's group: an advocacy part and a part that is purely support for us parents.

51. When she was diagnosed, there were a lot of "nevers" going through my mind. You know, there would never be school ...birthday parties ... brownies

58. I am finding the school very supportive.

78. If she's going to benefit from it, it's because of our efforts to make sure she gets there and does it.

11. She had a good year at school. There was a very understanding set of parents and she was well received.

26. I don't do a lot of work one-on-one with Shane at home. I want him to know there is a place to work and a place to relax. Here at home he can just be plain old Shane. He can have his own space.

29. Professionals have to realize that they have to work with parents. If they work against us, nothing will work out.

37. I try to find time for myself each day. I go for a walk, or I listen to music. I do something that nourishes me.

SITE 2

5. I have the confidence that I am doing the best I can in this situation.

6. Most of the parents are trying their best to do a good job; otherwise they never would have shown up for the appointment.

7. Education, as far as day to day living goes, is a joint effort from the whole family.

15. Its heen hard on her brothers; but overall I'd say they gained more than they lost.

31. I am optimistic. I know things will work out. I have to be patient.

39. Generally, I'm satisfied with my life.

54. Our ability to support one another builds our inner strength.

78. If she's going to benefit from it, its because of our efforts to make sure she gets there and does it.

1. I'd say our ability to deal with Marianne's disabilities as a family is pretty good. So far, nothing has destroyed us.

55. I'm busy keeping her busy. I can't just send her down to the rink or to swimming. I have to go too.

61. You can talk to your friends but they wouldn't understand the way another parent of a child with disabilities would understand.

29. Professionals have to realize that they have to work with parents. If they work against us, nothing will work out.

51. When she was diagnosed, there were a lot of "nevers" going through my mind. You know, there would never be school ... birthday parties ... brownies ...

23. The services she has received were excellent. They accomodated her and helped me to feel good about myself, too.

26. I don't do a lot of work one-on-one with Shane at home. I want him to know there is a place to work and a place to relax. Here at home he can just be plain old Shane. He can have his own space.

49. I have a friend that I can share confidences with.

10. I really think that there should be two parts to our parent's group: an advocacy part and a part that is purely support for us parents.

41. His brother has started to see Bruce differently. He is starting to notice that Bruce is really doing great.

42. We don't get a whole lot of support unless we're willing to go out there and fight for it.

SITE 3

5. I have the confidence that I am doing the best I can in this situation.

55. I'm busy keeping her busy. I can't just send her down to the rink or to swimming. I have to go too.

16. I think there is a difference between listening to somebody and hearing somebody. Most professionals listen; but only some of them hear what we are saying.

6. Most of the parents are trying their best to do a good job; otherwise they never would have shown up for the appointment.

30. We're trying very hard this year to get off to a good start with the school. We are trying to keep things positive.

31. I am optimistic. I know things will work out. I have to be patient.

7. Education, as far as day to day living goes, is a joint effort from the whole family.

39. Generally, I'm satisfied with my life.

42. We don't get a whole lot of support unless we're willing to go out there and fight for it.

58. I am finding the school very supportive.

78. If she's going to benefit from it, it's because of our efforts to make sure she gets there and does it.

1. I'd say our ability to deal with Marianne's disabilities as a family is pretty good. So far, nothing has destroyed us.

50. There are times that I wish I had more freedom of movement. I always feel that I have to be available to whomever has Marianne, at any given moment.

54. Our ability to support one another builds our inner strength.

67. I feel like I'm trying to spread myself around to everyone. There is not enough time. There's not enough time for me.

SITE 4

55. I'm busy keeping her busy. I can't just send her down to the rink or to swimming. I have to go too.

7. Education, as far as day to day living goes, is a joint effort from the whole family.

61. You can talk to your friends but they wouldn't understand the way another parent of a child with disabilities would understand.

78. If she's going to benefit from it, it's because of our efforts to make sure she gets there and does it.

1. I'd say our ability to deal with Marianne's disabilities as a family is pretty good. So far, nothing has destroyed us.

24. Don't provide parents with a list of "do's and dont's". Ask them, "Do you think this is possible? Would you have time to implement that?"

54. Our ability to support one another builds our inner strength.

6. Most of the parents are trying their best to do a good job; otherwise they never would have shown up for the appointment.

10. I really think that there should be two parts to our parent's group: an advocacy part and a part that is purely support for us parents.

29. Professionals have to realize that they have to work with parents. If they work against us, nothing will work out.

39. Generally, I'm satisfied with my life.

5. I have the confidence that I am doing the best I can in this situation.

49. I have a friend that I can share confidences with.

26. I don't do a lot of work one-on-one with Shane at home. I want him to know there is a place to work and a place to relax. Here at home he can just be plain old Shane. He can have his own space.

50. There are times that I wish I had more freedom of movement. I always feel that I have to be available to whomever has Marianne, at any given moment.

51. When she was diagnosed, there were a lot of "nevers" going through my mind. You know, there would never be school ... birthday parties ... brownies

53. I think it would be good if we just started a group (of parents of children with disabilities) and said, "This is a place you can share your struggles and celebrate your successes."

SITE 5

10. I really think that there should be two parts to our parent's group: an advocacy part and a part that is purely support for us parents.

29. Professionals have to realize that they have to work **with** parents. If they work against us, nothing will work out.

49. I have a friend that I can share confidences with.

30. We're trying very hard this year to get off to a good start with the school. We are trying to keep things positive.

54. Our ability to support one another builds our inner strength.

6. Most of the parents are trying their best to do a good job; otherwise they never would have shown up for the appointment.

55. I'm busy keeping her busy. I can't just send her down to the rink or to swimming. I have to go too.

78. If she's going to benefit from it, it's because of our efforts to make sure she gets there and does it.

5. I have the confidence that I am doing the best I can in this situation.

7. Education, as far as day to day living goes, is a joint effort from the whole family.

24. Don't provide parents with a list of "do's and dont's". Ask them, "Do you think this is possible? Would you have time to do that?"

27. Don't send me a few dollars trying to keep me happy. That's not what I'm looking for. I need someone to come in here for a few hours to give me a break. It's no good sending me the money if I don't have the person.

42. We don't get a whole lot of support unless we're willing to go out there and fight for it.

16. I think there is a difference between listening to somebody and hearing somebody. Most professionals listen; but only some of them hear what we are saying.

21. I am just one person. There are a lot of other people involved with this child. Show them. Show the whole family.

53. I think it would be good if we just started a group (of parents of children with disabilities) and said, "This is a place you can share your struggles and celebrate your successes."

17. If you are dealing with a bunch of professionals, you do feel that they are on one side and you are on the other.

38. The pressure is on us, the parents, to always see that he sees his friends after school, evenings, that sort of thing.

59. I think the social services system abuses parents of disabled adults. We are treated like "slave labor".

63. I went back to work part-time. I had to, I had to get back in contact with the adult world.

67. I feel like I'm trying to spread myself around to everyone. There is not enough time. There's not enough time for me.

1. I'd say our ability to deal with Marianne's disabilities as a family is pretty good. So far, nothing has destroyed us.

12. One professional is not supportive. I work around him.

13. The only hands-on support we ever had is what we bought and paid for.

15. Its heen hard on her brothers; but overall I'd say they gained more than they lost.

22. I spent nine months trying to get that service for Shane, and in the end the answer was so simple. Give me a break! So simple... and yet they made it so complicated for me.

39. Generally, I'm satisfied with my life.

43. Sometimes its like we are against everyone, that there is just our family against the world.

56. Shane's early intervention experience was very helpful and optimistic.

61. You can talk to your friends but they wouldn't understand the way another parent of a child with disabilities would understand.

69. I can't do one thing over the phone for Marianne. Its a meeting, then there would be another meeting and then they take it to somebody else for another meeting72. I feel that time is running out and things aren't getting done: he has rights that are not being awarded him.

20. We have had struggles at school for a couple of years now.

25. Babysitting for us; well, is it ever going to end?

26. I don't do a lot of work one-on-one with Shane at home. I want him to know there is a place to work and a place to relax. Here at home he can just be plain old Shane. He can have his own space.

35. The kids will talk to him even though he doesn't speak back to them.

37. I try to find time for myself each day. I go for a walk, or I listen to music. I do something that nourishes me.

46. A lot of the professionals you deal with, you come home feeling disheartened.

50. There are times that I wish I had more freedom of movement. I always feel that I have to be available to whomever has Marianne, at any given moment.

51. When she was diagnosed, there were a lot of "nevers" going through my mind. You know, there would never be school ...birthday parties ... brownies

52. I'm seeing things happen more and more. Shane was crying and my brother comforted him. It was nice to know that there were other people who could comfort my child.

62. We never go alone to a meeting concerning Bruce. We always go as a couple.

APPENDIX F

APPENDIX F

Rank Order of Questionnaire Items
Low Extreme: 50% or More

TOTAL GROUP

76. I always felt there was something holding me back from totally loving Shane the way he sould be loved. I think it was the fear that he was going to die. I didn't know what to do.

Site 1

43. Sometimes its like we are against everyone, that there is just our family against the world.

13. The only hands-on support we ever had is what we bought and paid for.

76. I always felt there was something holding me back from totally loving Shane the way he sould be loved. I think it was the fear that he was going to die. I didn't know what to do.

69. I can't do one thing over the phone for Marianne. it's a meeting, then there would be another meeting and then they take it to somebody else for another meeting.

14. No one was paying attention. I felt frustrated that no one was listening to my concerns about Shane.

62. We never go alone to a meeting concerning Bruce. We always go as a couple.

45. I remember a six page report from a professional. Of six type-written pages there was not one positive thing about Marianne in it.

Site 2

76. I always felt there was something holding me back from totally loving Shane the way he should be loved. I think it was the fear that he was going to die. I didn't know what to do.

18. Sometimes it just takes a couple of words from the man (husband, father) to get them to do something that I had been talking about to them for months.

Site 3

(none)

Site 4

76. I always felt there was something holding me back from totally loving Shane the way he should be loved. I think it was the fear that he was going to die. I didn't know what to do.

43. Sometimes its like we are against everyone, that there is just our family against the world.

Site 5

76. I always felt there was something holding me back from totally loving Shane the way he should be loved. I think it was the fear that he was going to die. I didn't know what to do.

APPENDIX G

APPENDIX G
PARENTAL RESPONSIBILITY

Isolation

33. It's lonely. If you had another family with a child trying to be integrated it would be better.

43. Sometimes it's like my husband and I are against everyone, that there is just the three of us against the world.

Feeling Overwhelmed

67. I feel like I'm trying to spread myself around to everyone. There is not enough time. There's not enough time for me.

69. I can't do one thing over the phone for Marianne. It's a meeting, then there would be another meeting and then they take it to somebody else for another meeting.

70. I worry that something will get in the way of my being able to keep it all together.

72. I feel that time is running out and things aren't getting done. He has rights that are not being awarded him.

Sickness

64. Sometimes I've felt that he has been used as a guinea pig, to try out medications.

66. He was very sick. I had to give him his shots. We missed a lot of work. He cried all the time. It was a nightmare.

Negative Feelings

51. When she was diagnosed, there were a lot of "nevers" going through my mind. You know, there would never be school....birthday parties .... brownies.

74. You're frustrated with the school board and you feel you'd like to punch the principal in the mouth! A lot of parents feel guilty about that ....about feeling so angry.

76. I always felt there was something holding me back from totally loving Shane the way he should be loved. I think it was the fear that he was going to die.

79. I wish that I had started right from the first in including my husband in all the meetings with professionals; but it wasn't always possible.

Tied Down

25. Babysitting for us; well is it ever going to end?

50. There are times that I wish I had more freedom of movement. I always feel that I have to be available to whomever has Marianne, at any given moment.

PARENTS HAVE ENOUGH TO DO

38. The pressure is on us, the parents, to always see that he sees his friends after school, evenings, that sort of thing.

48 By the time you fight the issue, the semester's over and the kids have gone on to something else.

55 I'm busy keeping her busy. I can't just send her down to the rink or to swimming. I have to go too.

78 If she's going to benefit from it, it's because of our efforts to make sure she gets there and does it.

RESPITE CARE, SUPPORT, FRIENDS

Negative Statements

2 We struggle the most in trying to get the school to see that they have a role to play to help Bruce have friends.

8 We go to visit relatives; but one of us has to constantly sit with him. Nobody will say, "Well let me sit with him a while." It's easier to care for Bruce here at home.

13 The only hands-on support we ever had is what we bought and paid for.

27 Don't send me a few dollars trying to keep me happy. That's not what I'm looking for. I need someone to come in here for a few hours to give me a break. It's no good sending me the money if I don't have the person.

42 We don't get a whole lot of support unless we're willing to go out there and fight for it.

Positive Statements

47 One of my friends has been a lot of support. It's not possible to cry on her shoulder for very long. Soon you come away with positive things to do to help change the situation.

49 I have a friend that I can share confidences with.

54 Our ability to support one another builds our inner strength.

65 One of the instructors from the college is volunteering to take the load off of us. He's meeting with the school and will mediate this issue between us and the school.

ACCEPTANCE

11 She had a good year at school. There was a very understanding set of parents and she was well received.

35 The kids will talk to him even though he doesn't speak back to them.

44 I had no problem trying to get her into that program.

52 I'm seeing things happen more and more. Shane was crying and my brother comforted him. It was nice to know that there were other people who could comfort my child.

SIBLINGS

Negative Statement

28 For a long time his sister was jealous of him.

Positive Statement Overall

41 His brother has started to see Bruce differently. He is starting to notice that Bruce is really doing great.

Positive Reality

15 It's been hard on her brothers; but overall I'd say they gained more than they lost.

MOM'S O.K. TOO

Ambivalence

19 I'm no hero. There are plenty of days I said "I'm not fighting any more. I'll keep her home." That only lasted a little while. Then you start again.

40 Most of the time I'm patient; but some days I let her stubborness get the best of me.

Positive Statements

5 I have the confidence that I'm doing the best I can in this situation.

6 Most of the parents are trying their best to do a good job; otherwise they never would have shown up for the appointment.

39 Generally, I'm satisfied with my life.

Care of Self

37 I try to find time for myself each day. I go for a walk, or I listen to music. I do something that nourishes me.

31 I am optimistic. I know things will work out. I have to be.

PROFESSIONAL RESPONSIBILITY

Negative Statements

12 One professional is not supportive. I work around him.

14 No one was paying attention. I felt frustrated that no one is listening to my concerns about Shane.

16 I think there is a difference between listening to somebody and hearing somebody. Most professionals listen; but only some of them hear what we are saying.

17 If you're dealing with a bunch of professionals, you do feel that they are on one side and you are on the other.

20 We have had struggles at school for a couple years now.

22 I spent nine months trying to get that service for Shane and in the end the answer was so simple. Give me a break! So simple ... and yet they made it so complicated for me.

32 She gave me that book and said "Here, do this". I didn't know where to begin. I just put the book on the dresser. Everytime I went by it, I felt guilty.

45 I remember a six page report from a professional. Of six type-written pages there was not one positive thing about Marianne in it.

46 A lot of the professionals you deal with, you come home feeling disheartened.

57 I spent a lot of time last year, being on the receiving end of phone calls from the school ... come and get him; take him home; he shouldn't be here, all that kind of stuff.

Positive Statements

3 We decided to have Marianne repeat that year in school because she had such a terrific teacher.

9 They didn't try to take her and stick her into their system. They made their system work around her.

23 The services she has received were excellent. They accomodated her and helped me to feel good about myself, too.

56 Shane's early intervention experience was very helpful and optimistic.

58 I am finding the school very supportive.

60 The teacher was astounded that Marianne could do that. From that day forth, whatever tasks the children were getting in the classroom, Marianne got too.

68 It hasn't been a stressful situation with one professional. It's his attitude. He tries to understand and he is willing to learn things from me.

71 I have one professional who starts with the positive and then works her way around to telling you the things that are not so positive.

73 That professional made that book on language come alive to me. She showed me how to do those things with Shane in my daily work around the house.

75 I have excellent support from my family support worker. She keeps me informed; but also tries not to let me get overwhelmed by too much information.

77 One thing that really struck me was the way she interacted with Bruce. She could really "read" him. There was a lot of warmth. She took delight in his small accomplishments.

STRATEGIES

7 Education, as far as day to day living goes, is a joint effort from the whole family.

10 I really think that there should be two parts to our parent's group: an advocacy part and a part that is purely support for us parents.

26 I don't do a lot of work one-on-one with Shane at home. I want him to know there is a place to work and a place to relax. Here at home he can just be plain old Shane. He can have his own space.

30 We're trying very hard this year to get off to a good start with the school. We are trying to keep things positive.

34 I did not want his sister to feel left out, because he was getting so much attention.

53 I think it would be good if we just started a group (of parents of children with disabilities) and said, "This is a place you can share your struggles and celebrate your successes."

61 You can talk to your friends but they wouldn't understand the way another parent of a child with disabilities would understand.

62 We never go alone to a meeting concerning Bruce. We always go as a couple.

OTHER

Adult Children

4 The whole system just changes when your child reaches adulthood. You are treated differently. It is much more impersonal and you get the feeling they think you are trying to "rip off" the sytem.

59 I think the social services system abuses parents of disabled adults. We are treated like "slave labour".

Advice to Professionals

21 I am just one person. There are a lot of other people involved with this child.. Show them. Show the whole family.

24 Don't provide parents with a list of "do's and don'ts". Ask them, "Do you think this is possible? Would you have time to do that?"

29 Professionals have to realize that they have to work with parents. If they work against us, nothing will work out.

Woman/Man and Getting Services

18 Sometimes it just takes a couple of words from the man (husband/father) to get them to do something that I had been talking about to them for months.

Older Children

36 Things went well in junior high; but at senior high its been just one roadblock after another.

Mother and Paid Work

63 I went back to work part-time. I had to, I had to get back in contact with the adult world.

Foster and "Regular" parents

80 If I were a foster parent, I wouldn't have to worry about going out working to make some money.

Family Survival

1 Well I'd say our ability to deal with Marianne's disabilities as a family is pretty good, so far, nothing has done us in.

APPENDIX H

APPENDIX H
Summary: Mean Responses to Item Groups
Total Group (N=95)*

Item Group	N	$\bar{X}$ response	s.d.
Total Parental Responsibility	95	3.03	.81
- isolation	89	3.01	1.19
- feeling overwhelmed	91	3.21	.96
- sickness of child	71	2.47	1.33
- negative feelings	92	2.82	.89
- feeling tied-down	87	3.51	1.14
Respite Care, Support, Friends			
- negative experiences	92	3.14	.96
- positive experiences	94	3.61	1.00
Parents have enough to do	93	4.00	.81
Mother			
- ambivalence	94	2.90	.96
- positive self statements	96	4.22	.63
- care of self	95	3.65	.85
Others' Acceptance	92	3.66	.83
Siblings' Experience			
- negative	64	2.42	1.35
- positive	67	3.46	.93
- positive reality overall	79	3.99	1.06
Experience with Professionals			
- negative	95	2.98	.88
- positive	93	3.32	.78
- advice to professionals	91	3.71	.93
Strategies	96	3.80	.62
Other			
- adult children	63	3.13	1.47
- advice to professionals	91	3.17	.93
- getting services (man/woman)	76	2.66	1.28
- older child	20	2.95	1.32
- mother and paid work	60	3.75	1.35
- foster mother/regular mother	54	2.70	1.61
- family survival	89	4.04	1.28

1 = almost never
2 = seldom
3 = sometimes
4 = often
5 = almost always

* One mother with two children with disabilities filled out a form for each child. (Other mothers in the same situation put the "double information" on one form.)

APPENDIX H
Summary: Mean Responses to Item Groups
Site 1 (n=15)

Item Groups	n	$\bar{X}$ response	s.d.
Total Parental Responsibility	15	2.81	.68
- isolation	15	2.77	.98
- feeling overwhelmed	15	2.84	1.08
- sickness of child	13	2.38	1.49
- negative feelings	15	2.83	.82
- feeling tied-down	15	3.20	1.15
Respite Care, Support, Friends			
- negative experiences	15	2.50	.75
- positive experiences	15	3.83	.87
Parents have enough to do	15	3.82	.91
Mother			
- ambivalence	15	3.23	.86
- positive self statements	15	4.23	.71
- care of self	15	3.80	.86
Others' Acceptance	15	3.93	.71
Siblings' Experience			
- negative	11	2.64	1.12
- positive	10	2.70	.48
positive reality overall	13	3.62	.96
Experience with Professionals			
- negative	15	2.63	.68
- positive	15	3.71	.74
- advice to professionals	15	3.53	1.10
Strategies	15	3.71	.64
Other			
- adult children	5	2.80	1.10
- getting services (man/woman)	10	2.60	1.26
- older child*	-	-	-
- mother and paid work	10	3.40	1.26
- foster mother/regular mother	8	2.13	1.46
- family survival	14	4.36	1.15

1 = almost never
2 = seldom
3 = sometimes
4 = often
5 = almost always

* All the children from this site are still very young (1994).

APPENDIX H
Summary : Mean Responses to Item Groups
Site 2 (n=29)

Item Groups	n	$\bar{X}$ response	s.d.
Total Parental Responsibility	29	3.04	.91
- isolation	24	3.15	1.23
- feeling overwhelmed	25	3.10	1.08
- sickness of child	20	2.20	1.17
- negative feelings	27	2.81	1.03
- feeling tied-down	23	3.65	1.21
Respite Care, Support, Friends			
- negative experiences	26	3.11	.97
- positive experiences	28	3.67	1.09
Parents have enough to do	27	3.94	.80
Mother			
- ambivalence	29	2.81	1.18
- positive self statements	29	4.43	.60
- care of self	29	3.71	1.05
Others' Acceptance	27	3.77	.90
Siblings' Experience			
- negative	21	2.52	1.57
- positive	22	4.00	.93
- positive reality overall	26	4.35	.85
Experience with Professionals			
- negative	28	2.81	1.01
- positive	26	3.39	.85
- advice to professionals	26	3.41	1.07
Strategies	29	3.73	.75
Other			
- adult children	25	2.48	1.28
- getting services (man/woman)	24	2.33	1.49
- older child	10	2.30	1.16
- mother and paid work	15	3.47	1.55
- foster mother/regular mother	13	2.08	1.50
- family survival	27	3.78	1.67

1 = almost never
2 = seldom
3 = sometimes
4 = often
5 = almost always

APPENDIX H
Summary : Mean Responses to Item Groups
Site 3 (n=17)

Item Groups	n	$\bar{X}$ response	s.d.
Total Parental Responsibility	17	3.09	.57
- isolation	16	2.97	1.02
- feeling overwhelmed	17	3.36	.71
- sickness of child	10	2.55	1.26
- negative feelings	16	2.73	.62
- feeling tied-down	15	3.73	.82
Respite Care, Support, Friends			
- negative experiences	17	3.44	.99
- positive experiences	17	3.01	.73
Parents have enough to do	17	3.70	1.04
Mother			
- ambivalence	17	2.88	.86
- positive self statements	17	4.26	.56
- care of self	17	3.53	.78
Others' Acceptance	16	3.60	.80
Siblings' Experience			
- negative	8	2.13	1.46
- positive	12	3.25	1.06
- positive reality overall	12	3.58	1.38
Experience with Professionals			
- negative	17	3.24	.62
- positive	17	3.26	.55
- advice to professionals	16	3.51	.72
Strategies	17	3.74	.45
Other			
- adult children	11	2.86	1.76
- getting services (man/woman)	14	2.64	1.08
- older child	2	4.00	1.41
- mother and paid work	13	3.54	1.56
- foster mother/regular mother	12	3.17	1.53
- family survival	16	4.19	.91

1 = almost never
2 = seldom
3 = sometimes
4 = often
5 = almost always

APPENDIX H
Summary : Mean Responses to Item Groups
Site 4 (n=16)

Item Groups	n	$\bar{X}$ response	s.d.
Total Parental Responsibility	15	3.07	.65
- isolation	15	2.63	1.22
- feeling overwhelmed	15	3.35	.75
- sickness of child	12	3.04	1.23
- negative feelings	15	2.87	.81
- feeling tied-down	15	3.57	1.19
Respite Care, Support, Friends			
- negative experiences	15	2.92	1.04
- positive experiences	15	3.57	1.07
Parents have enough to do	15	4.42	.46
Mother			
- ambivalence	15	2.77	.78
- positive self statements	16	3.94	.63
- care of self	15	3.63	.77
Others' Acceptance	15	3.46	.82
Siblings' Experience			
- negative	12	2.75	1.29
- positive	11	3.18	.87
- positive reality overall	13	3.92	1.19
Experience with Professionals			
- negative	16	2.75	1.00
- positive	16	3.28	.93
- advice to professionals	15	3.91	.79
Strategies	16	3.76	.54
Other			
- adult children	8	3.69	.88
- getting services (man/woman)	12	2.92	1.24
- older child	3	3.00	2.00
- mother and paid work	7	4.57	.79
- foster mother/regular mother	8	3.00	1.77
- family survival	14	4.43	.94

1 = almost never
2 = seldom
3 = sometimes
4 = often
5 = almost always

APPENDIX H
Summary: Responses to Item Groups
Site 5 (n=18)*

Item Groups	n	$\bar{X}$ response	s.d.
Total Parental Responsibility	19	3.11	1.04
- isolation	19	3.34	1.39
- feeling overwhelmed	19	3.42	1.05
- sickness of child	16	2.41	1.53
- negative feelings	19	2.84	1.05
- feeling tied-down	19	3.37	1.27
Respite Care, Support, Friends			
- negative experiences	19	3.59	.71
- positive experiences	19	3.92	.99
Parents have enough to do	19	4.18	.58
Mother			
- ambivalence	18	2.89	.90
- positive self statements	19	4.07	.63
- care of self	19	3.58	.65
Others' Acceptance	19	3.52	.83
Siblings' Experience			
- negative	12	1.92	1.16
- positive	12	3.58	.51
- positive reality overall	15	4.07	.96
Experience with Professionals			
- negative	19	3.45	.72
- positive	19	3.01	.65
- advice to professionals	19	4.27	.59
Strategies	19	4.04	.56
Other			
- adult children	14	4.29	1.25
- advice to professionals	19	4.27	.59
- getting services (man/woman)	16	3.00	1.15
- older child	5	3.80	.45
- mother and paid work	15	4.07	1.10
- foster mother/regular mother	13	3.08	1.71
- family survival	18	3.78	1.17

1 = almost never
2 = seldom
3 = sometimes
4 = often
5 = almost always

* One mother with two children with disabilities filled out a form for each child. (Other mothers in the same situation put the "double information" on one form.)

APPENDIX I

APPENDIX I

Mother's Comments: Sorted by Sites

SITE 1

Briefly tell me one positive experience you have had with reference to your child with disabilities.

101 I learned to enjoy the <u>small</u> things in life because John's milestones don't happen that fast like other children.

102 We live in a small town and Kathie was born here. She has been very well accepted by the community. We bring her everywhere we go. The people downtown (grocery store, bank, drugstore) seem to look forward to her visits. They go out of their way to say hello and ask how she's doing. Kathie has a very bright personality and it is hard for people who seem afraid of her to ignore her for long -- but the people here seem to truly enjoy her.

103 I have been able to meet a lot of nice people that I would not have had an opportunity to meet otherwise. I have been made aware of needs for all children that are not being met and have started to become active in this area.

104 Even though she is severely handicapped our family, relatives and school teachers seem to all work together to take care of her, watch over her and everyone is interested in what kind of progress she has made. Everyone really loves her and try to help us work with her. We've never had any problems with the help from school or therapists. They all listen to every concern or achievement. Only one doctor gave us any problem and we were able to find a new one that was more helpful. Overall she's been a real blessing to all of us.

105 Having a child with a disability has made me much more aware of the number of people with disabilities. We are not alone. We have a wonderful support group here and a great early intervention program. We also take our daughter to therapy once a week to a local hospital for O.T and P.T. as well as once a week she gets it in the home through the early intervention program. They work well together, the hospital and school. Work on same goals and plans. Always very positive. Really work for the child. We feel very fortunate. Things could be a lot worse.

106 Each day Carl's speech grows little by little and when he hears a new word he repeats it quite a bit.

107 Everything about my son is positive to me. I am lucky to have him. He almost died on me several times. I love him so much. But life sure isn't fair to him and our family. He is such a happy child. Every accomplishment to me a big deal.

108 I'd have to say the "overall positive" experience we as a family must focus on is that how something so terribly devastating (birth of a special needs child) has turned into such an enriching experience.

109 We recently started going to a new church that is more accessible than our old one. Anne was immediately accepted there. They moved her Sunday school class to a more accessible area after we had gone there only a few times. The pastor's wife told me recently that Anne had added so much to the congregation.

110 Because of Sarah, we have met so many new wonderful people.

111 Kindergarten - The teacher was wonderful and his one-on-one management aide was superb. She knew when to step back and let the kids take charge. The first day the class was told why Harrow was in a wheelchair and how to use the wheelchair etc. They took over. He had a wonderful year!

112 She has taught me to <u>really</u> appreciate each developmental milestone with her and with her younger siblings. She's helped me count our blessings and realize how fortunate health and "normal" development are. She has taught me what patience is. I have also become more self confident in standing up for her rights and getting what she needs. We have been very successful in getting what she needs.

113 Integration (inclusion) has been a positive experience for us. When our son was in a segregated school, we would take him shopping or somewhere else in the community and he was a stranger to all. People just stared. But now with him integrated at school and socially, everywhere we go, people speak to him or say "Hi" to him. (Making our whole family more acceptable.)

114 Tabitha has taught me compassion and is working on teaching me patience. It would be a better world with more Tabitha's as she is a very loving, touching child.

115 No Response.

Briefly tell me one negative experience you have had with reference to your child with disabilities.

101 Being told by medical professionals what John would probably never do was a negative experience for me.

102 We visited a church where our parents live and sat next to a family. The teenage daughter noticed Kathie and seemed physically repulsed by her. She moved away from Kathie (we were in the same pew) and looked surreptitiously at Kathie the whole time. We ignored her and treated Kathie like we always do. Kathie even tried 'to make friends' with her but she was very put off. I grew more uncomfortable and was glad to leave. It was the first time Kathie hadn't "won over" a disability-shy person with her charm.

103 Most of the negative experiences come from 2 sources:

1. A clinic where I do not feel that I or my child were treated as people, just cattle being shuffled thru the system. I also feel our rights were violated, only I was so overwhelmed at the time I did not say anything. Next time I will.
2. My husband will not accept the fact that our child has special needs, he is convinced she is just a little behind and will out grow it. I don't know how to make him understand her DNA will never change, she is who she is. Also his family does not understand what is going on and my family is nervous when the subject is brought up.

104 Sometimes it becomes very difficult to know what she needs because she can't talk. We don't always know if she has an ear ache or the flu before its already too late. Tantrums can be a problem when she can't get her point across for what she wants.

105 It has been a very frustrating 2½ years. We have been going to doctors and running test after test to come up with a diagnosis other than cerebral palsy. We still have no answers. They will not even guess an opinion if your child will walk or not, or talk, or how disabled she will be. It's very hard to plan for the future when you don't know what to expect. As she is getting older and **bigger** things are getting harder.(e.g. Always need a stroller, too big to carry). It's also more obvious to other people that our child is disabled. More looks, more stares.

106 Carl has problems with understanding what's right and what's wrong. He doesn't listen very well like he should for his age.

107 The "Hell" we have to go through with the medical attention and surgeries for my son. He has been hurt by a doctor in the past, when he was 7 months old.

Now it still is so "hard" for "trust" for anyone in the medical field. He very much depends on Mama to pull him through.

108 Our constant battle is, of course, with the school system. I want to mainstream my child and I feel they are guiding me away from it. Worse than that, I feel a total year of my child's life was wasted with a "professional" incompetent in her job during a very important year of development.

109 Nothing really sticks out in my mind, as a negative experience. There have been many experiences with my daughter that have been unpleasant, mostly going to doctor's appointments and going to public places that were not accessible. Probably the worst time was when she was only a few weeks old she was put in the hospital. We didn't know if she would live or not. It was a very painful experience.

110 Our principal is against inclusion and has made "me" the Mom, the bad guy in the entire process.

111 Neurologist - Never explains why he's continuing with meds. Will my son ever be able to go off medication or will the injuries always be there no matter what?

112 I was told my daughter couldn't go on a field trip from the Y unless I went with her because she would get too tired. (She learned to walk late and they were walking). I was going to send a stroller. What they needed was more adult supervision, it shouldn't have had to have been me. Other parents were asked, if they wanted to come; I was told I had to come. Later they realized they were wrong.

113 There is no help or support at all to the struggles that go on in areas of family life other than school time. Two simple examples that come to mind are negative behavior at a doctor's or dental office, (what its like when that child tantrums or will not wait in the waiting room); or will not cooperate with a haircut. We had some eating problems and refusal to come to the dinner table with the family. Some of those behavior problems can almost drive a family "over the edge" and they don't fit into the neat little categories of a professional's workload. So who offers suggestions? Nobody. Generally the family would continue "over the edge". We were lucky.

114 The negative side would be that she requires so much of my time that there is nothing left for her older brother. I am forever guilty that I am missing his childhood. She will not even allow me to provide him comfort when he is sick, as he wants me.

115 When I first found out she had disabilities, I talked to <u>so many</u> people (professionals) and no one knew what was going on, who to send me to, and who could help me.

Do you have anything more that you want to say?

101 No response

102 We have an older daughter age 8, and we have always tried to treat and discipline Kathie like we did Kelly. There are, of course, certain exceptions we have made, but mostly we try to treat her as "normally" as possible. I have one comment to make in reference to the fact that the study is based on "mothers of children with disabilities". My husband is very involved in parenting both of our children, even though I spend more time with them because we have chosen for me to be home with them.

I would encourage you to be more inclusive in your language. Fathers need to be involved with their kids and need encouragement to do so, it seems.

103 When we get together in our support group sometimes there are so many handouts about different meetings, all of which are very important, I feel guilty because it is impossible for me to attend any or some. I don't have anyone to care for my child and I don't want to take her out to meetings a lot at night.

104 Overall Carol has been a positive inspiration in our lives. She tries really hard to accomplish whatever task is before her. Her determination is an inspiration to anyone. Her loving personality makes it a lot easier to deal with her handicap. No one could ever change my mind that it is worth every minute of having her in our home. All of our children help with her and know how to deal with her many moods and they all play with her and let her participate in what they are doing. I think it will help them become more understanding to others as they grow older. It takes a lot of faith and trust to get through every day. We've been blessed with many good people to work with.

105 I'm sure the real concern will start when she is school age. It's a scary thought. Sometimes I feel I'm dealing with enough already. Will I be able to handle it all? Will she fit in, have friends, understand what is going on around her?

106 Carl can be stubborn at times and do what he wants to do. He gets into things that he shouldn't be in or have. He is still not potty-trained even though I have been working with him for the past 3 years. I don't think he understands the concept of potty-training. Sometimes Carl doesn't do what he is told or asked to do. We always have to repeat things to him.

107 Family relationships suffer immensely with couples with a developmentally-delayed child with physical problems.

108 No response

109 No response

110 This whole game is set in cycles. Right now I'm in a low cycle, but other times are better. I'm bitter about medicare problems and fighting the school! It is scary to think it may never end - it probably won't.

111 I have learned to be an advocate. I also feel I'm doing the work that my son's case manager should be doing. I call him to remind him that the deadline is coming fast for certain things.
Harrow is a joy, he's changed our lives. His sister (8yrs) has been his guardian angel. She has never questioned why and understands why we do things certain ways in our home now. The only thing I feel bad for her -she's had to grow up too fast and she feels the need to take on responsibilities for her brother.

112 I think this survey was very confusing to respond to the statements. Also I answered for the present time but my feelings were often different in the past.

113 Our town really needs a full time advocate for parents, that has the time to sit down and listen to the whole story. Someone who will work together with both the school district and the family when a conflict of interest is present. Unfortunately there is a <u>huge</u> gap between what it says on the IEP and what is actually carried out. And what should a parent do then? To become overly involved and fight for what you know you deserve only creates relationship problems with staff in the future. Believe me, I know from experience.
What (we) lack here is an inclusion specialist or a very active (willing to get involved) advocate. The kids are the ones who suffer.

114 People who have a child with special needs or a disability need a weekly break to maintain sanity. At the beginning when they are first diagnosed everyone is there wanting to help. That is the time you want to be alone with that child and sort through your thoughts and feelings. Two-three-four-five years down the line when you have adjusted and need a break or some help, where are they? One should never say call me if you need anything, instead they should call you and say, "I'm coming over for — hours on --- so that you can do something you need or want."

115 No response.

SITE 2

Briefly tell me one positive experience you have had with reference to your child with disabilities.

201 My daughter has worked in supportive employment for the last few years, this could only have been done with the proper support system in place for her. I never thought she would be a productive member of society, but everyone that knows her and cared about her -- we had to give her the opportunity to try and succeed, which is no different than what you want for your normal children.

202 Finally having someone in Adult Services actually take the time to get Jake out and get him a job in the community. But until we said we were taking him out of the program and gave them a deadline -- no one did anything. Then a miracle -- Jake has a community job and is making enough each week to buy his music. Thank goodness for this one very excellent person.

203 Many positive experiences come to mind -- (1) Attending her high school prom with her and escort. (2) Going thru graduation with cap, gown. (3) Working in the community since completing high school -- same place now for 4 years, 3 months -- quite a record. (4) To share her relationship with her nephew -- he loves her dearly.

204 No response

205 She loves animals.

206 She has brought a lot of happiness and love to me and others with her willingness to learn and her care about others like her.

207 He is 41 years old, and has worked for a over a year at a part-time job. Most of the time he hates going to work and blames me because he has to! The rest of the time he loves job, and responsibility, and pay check. The positive time is when he is content!

208 Positive experiences include: local acceptance; commendation on her work-attitude. I have met some fine teachers.

209 Many people treat him very well. We had a graduation open house with all the trimmings. A good crowd from family and church came. No school people, though they were invited. Tom stood at the guest book and opened presents and cards and felt very special. He probably had more guests than the "regular graduates."

210 Marilyn was at a Jr. High School for her last 2 or 3 years of public school. This was a very open setting which she enjoyed a lot. It did great things for her self-esteem. Her teacher was wonderful.

211 Steven has taught me how to love. He will ask for a kiss or sometimes he says he loves Mom just because he does -- not because he wants anything in particular. He has no subterfuge or guile. He has no ability to dissemble. He is totally honest and innocent. It is remarkable knowing that you are loved by him just because you're you. I cannot help but love him back. Although his autism often is a barrier to meaningful social interactions, his beautiful soul shines through his disability.

212 Noted Kenneth's ability to understand complex assemblies by his seeing it done -- and based on his intense interest; he can do anything with his hands.

213 Keith was born normal. At 8 mos. old, he had double ear infection which resulted in high fever causing brain damage and epilepsy. I, his mother, have stayed in the home and taken care of him for 35 years. He went to a special school, not public school, till he was 18 yr. My husband and I taught him everyday necessities and it has been a joy to see him learn nd progress each year. Now that his Dad is deceased, we live alone and he takes care of me as well as I him. I give myself space and balance out each other's activities and pleasures, so neither of us feels neglected.

214 He is not as bad i.e. as severely disabled, as a lot of people. He's not like you and I, and he's not like others. He's in between. He relates to normal people better. If I go away to visit, he always cleans the house when I'm gone.

215 Special people who really cared provided positive experiences.

216 His accomplishments have taken on a more important meaning for all of us in the family, including him. There's real pride at doing well on a spelling test or getting a happy face on a workbook exercise. We feel happy at smaller advances than with our daughter -- everything is in perspective. And he has had marvelous teachers who went beyond their normal duties to include him and teach him as if he had no disability.

217 Marcia is a very loving child-adult. She will always say "I love you" if I have had a bad day. She is very caring about others and their feelings. She is a joy and we love her just as she is. We do many family things together and she loves them -- trips, visit friends, eating out, etc.

218 My child is now 42 years of age and I feel that almost every facet of his life has been a positive experience. At the age of 18 months (we) were told we should put him in an institution and forget we ever had him, so I feel very positive about everything he has been able to accomplish.

219 One positive experience with Dianna was her helping make her bed, vacuum her room, empty waste basket, etc. Household chores has been positive! Especially in room. I have to do rest of house. Cooking in microwave, etc. is another positive experience.

220 On his own he made the effort to go to the mall and bought me a birthday present he knew I would really enjoy. This involved him dealing with people (which he has difficulty doing), the rural transit system and spending his own money.

221 We moved a year ago and she has felt that things here are really hers and she can give her opinion on various things.

222 The fantastic physical therapist that helped Elaine to walk by age 3 1/2 -- an example of excellent, caring people who have helped Elaine.

223 She is 28 years old. She has given us 28 years of total love and joy. We feel that as parents her loving presence has completely overshadowed her disabilities. She enriches our lives every day. We are indeed fortunate to have her.

224 No Response

225 As our daughter was growing and maturing, there were little improvements all along, altho' they sometimes were minute. It is encouraging that she can live in her own apartment. She is a loving, agreeable member of our family. She frequently comes to our place to assist in yard and garden work, and we often do sewing projects together. We can share jokes and funny stories and we have a common faith in God and worship together regularly.

226 The Association and Vocational Rehabilitation have worked really hard to prepare Ken for his "outside" employment. From the beginning, I was included in every decision and was well informed. I also was able to call anytime and was treated with respect and also helped until I was satisfied.

227 We have learned and felt all the good feelings so many people have toward our daughter. We are square dancers and our daughter has gone with us lots. She has so many good friends, it is unbelievable. Also our son's friends have always been the same way.

228 After we both got cancer we had to make sure that he would be taken care of. They accepted him, after 1 1/2 years of trying, into a group home which relieved both of us for his future. His mother may have only a few more days to live that is why the first questionnaire was not filled out. I'm sure that my wife would have answered these a little different.

229 Positive experiences include: being told that he is the "highest producer" in his workshop and the best worker they've ever had; being told that he has always been the peer model in every class or group he has been in (i.e. perfect manners, appropriate behaviour, most well groomed); last, being told that I would be a good teacher of DD's, since I've done such a super job.

Briefly tell me one negative experience you have had with reference to your child with disabilities.

201 Being told to put your 5 year old autistic child in an institution and to forget her was a negative experience. I was told this by a doctor. I was determined to prove him wrong.

202 Having an attendant at the local "Fun Night" point to Jake and say, "He can't ride -- he's handicapped!"

203 The frustration of repeating instructions only to have her fail to follow. Recently told her to come home after work; no bus training that day. She went anyway, no phone call, we were frantic as I was in a business meeting for 3 hours when I got back to my desk, I discovered she was not home -- as she rides a taxi home everyday, your mind can imagine a lot of things that might go wrong. Hopefully she learned a lesson. Also, cannot get her to use a phone recorder.

204 My son is 6'3" and weighs 382 lbs; when we go into a store where toys are sold, people stare and make fun of a man his size playing with toys. You can't educate people that aren't willing to learn.

205 She seems to want us to leave her alone -- so she can be more independent.

206 Some people do not know how to accept her. Lots of people make fun of her or do not want anything to do with her.

207 His blaming me for everything that doesn't please him or he doesn't want to do at that time, in that place is a negative experience for me. He becomes angry and highly upset with his job and wants to return to the sheltered workshop.

208 Years ago the IEP's were presented in an unprofessional and negative format.

209 A pediatrician put him on Tegretal. He got very bad headaches and became violent. The pediatrician told me we'd just have to institutionalize him -- some get violent. We had done the best we could do. He denied it was the Tegretal and wouldn't change it. Another physician intervened and within 3 days Tom was an angel again. He had headaches for 6 months after going off Tegretal. The only "apology" from the first physician was when he told me later a 3 year old girl did the same thing.

210 I was actually called by a psychologist (that we had taken Marilyn to for evaluation) and told that he had found an institution that would take her. His comments were that we should put her in since she would never be an asset to our family. I hung up on him since I hadn't requested this.

211 When he was younger he had to go to the hospital to have tubes put in his ears. Despite our advance pleas to the hospital staff and our careful arrangements for timing, he was kept waiting almost 3 hours after he was scheduled for surgery -- this was intolerable for him and needlessly hard. I was so angry at the hospital staff and the doctor for not taking his disability into account when scheduling the surgery, especially after we had told them that he could not be kept waiting.

212 A negative experience for us was a Professional that told us, "Forget about it, he'll never learn anything"; Wrong!!! A neurologist that told us: they have him down as low as a dog -- you should put him in an institution -- so he won't be sitting in a corner drooling when his older sisters bring home dates. Dropped this neurologist immediately. Kenneth was 5 at the time and in kindergarten; this was when we learned he was retarded, but they kept him in kindergarten class -- since he was the most sociable child in there -- and the others could learn from him.

213 As much as I would like to see him interact with so-called "normal people," it is difficult to fit in sometimes. His speech is a hindrance to social inter-action some of time. Even if he could talk clearly, his vocabulary is limited for having a good conversation.

214 The fact that he doesn't understand the value of money is a negative experience.

215 A negative experience for us was a Public school who didn't want to provide!

216 The manner in which the team of geneticists broke the news of his rare chromosomal disorder bordered on the criminal -- The specialists never considered the impact of what they were revealing and were (more) caught up in the probability of his passing it on to another generation than our interest in the immediate impact on his own life.

217 There has not been any big negative experience with Marcia. At first, when she was little, it bothered me some when people looked at her -- the way she walks -- but that does not bother me anymore.

218 The most negative experience we have had was when he reached school age and there was absolutely no education facilities for mentally handicapped persons. We made an appointment with the superintendent of schools in our county to ask

him what we could do but when we told him our problem he got up from his desk, opened the door for us to leave, and told us there was absolutely nothing he could do for us. That was when we started trying to find some other parents of disabled children and get a support group started.

219 Dianna needs help in preparing to go places, especially, appointments. She takes hours to get dressed, etc. She often will not be ready to go when anyone asks.

220 Everyday home life is a negative experience for me. His father could not accept that something was wrong. Tension, stress. Dealing with Joe & his two younger brothers.

221 No Response

222 The drs. told me to put Elaine in an institution and forget her -- this was at age 1 1/2 yrs -- they said there was no hope.

223 From time to time another family has not wanted their child to associate with Mary because of her disabilities.

224 No Response

225 I guess the thing that has frustrated me most over the years is her inability to get ready on time when we all need to be some place at a certain time. On the other hand when it is time for a certain program on TV or radio that she wants to watch, she knows exactly when to turn on the set.

226 At birth -- shortly after he came home from hospital -- doctor suggested he be put in institution, that there was no hope. After changing doctors, I have been blessed with professionals that truly care about my son and myself.

227 The negative part has always come from adults that should know better, such as schools, teachers. We were told our daughter could not go to one school. We moved and enrolled her in another school, bought a house and less than 2 weeks later, school authority brought her home and said she could not go to school there. This was a special education class, and we talked with the leaders before we ever moved, and placed her in this class.

228 No Response

Do you have anything more that you want to say?

201 A parent cannot just be a parent -- they must always be an advocate for their child. Expectations should always be there as long as you are realistic in your expectation. Parents do not realize the power they have in working with the system to get what is needed for their child. It's been a long, rocky road the last 25 years of my life, but what an experience I've had that many people will never know -- I have met the most wonderful people thru having a child with a disability and I've sure met a few jack-asses, too, but I forget them.

202 Jake is my stepson. He has been "my son" for 10 years now. One day I had absolutely no experience with a handicapped child and the next a 16 year old who could not feed, dress, bathe or go to the bathroom without help moved in. Well what a year we had! I jumped straight into a whole new world of limitations and physical therapy and lots of struggles and tears. We survived that first year and each year Jake has blossomed. How much we have all learned and how much I have enjoyed seeing Jake learn to be more independent. I have four children (all grown) of my own and they all love Jake and have learned a lot about just being grateful and an appreciation of how hard it is sometimes for Jake to do simple things they do with ease. Didn't mean to write a book -- I've tried. I've screamed, I've been so frustrated -- but I've laughed more than any of these! Jake is a joy and a blessing. Jake travels with us -- he and I go to country music concerts, to concerts, to ball games, you name it -- we all have been on a learning expedition this past 10 years.
Early on I was told by a professional that since "I didn't have a degree" I couldn't possibly know what I was talking about! Being totally ignorant was probably a good thing -- I used my experience as a mother and my common sense and only used the "professional stuff" that worked. Much of it is not realistic and is merely idealistic -- it plain doesn't work in real life. I hear a lot of jargon and endless talk spouting rhetoric but very little of it is useful in day to day living. For 10 years professionals have been insisting Jake can learn to handle money and other related ideas -- we know him -- he does not understand the complexities of 1.75 out of two dollars leaves a quarter and why should he? It would be better to spend this time on something he can learn! But they are so afraid to admit they might be wrong.

203 Only that I hope the future will provide more training, available residential placement, transportation help as we have fought since day one for all of these and gained very little to nothing. Too much politics involved in some residential programs. I have very little time for myself, my husband or my other child and grandchild which makes me feel like a failure at times. There needs to be recognition that these children grow up and grow old. We do not have social programs or placement geared to this life change. Community clients are totally left out of most activities. If the parent does not create a social activity, no one else will.

Residential clients are on-the-go constantly -- with planned activity and a hired staff to supervise. Working parents have a tough time competing.

204 In our 31 years we have become so overly protective with Randy that we don't trust just anyone with him. When my son hurts, "I hurt," and when someone abuses him it is me on the receiving end. I plan on writing a short story on "Life with Randy."

205 The reason I didn't fill out the first questionnaire you sent was because I didn't think the questions applied to Lori, since she is older and on her own pretty much.

206 Yes, if it wasn't for the Center I do not know what I would have done. I did not know how to train her about learning to get by in the world. These centers are the best t hing that ever happen for us with child disabilities. Now they have a chance in life also.

207 It's sure not easy.

208 I am grateful to the Center.

209 No early intervention services were available to us. It was impossible to get help of any kind. The hospital just kept giving me students who would stand back and tell me to keep doing what I was doing -- it was working. I begged for help with motor skills and never did get anything, not even advice! The Association center has provided him some place to go each day, sport activities for the first time where he can not just be a spectator, and friends of his own. Friends of his own has been very important to him -- not his brother's friends! The school system fired his best teacher. Jr. High and High School classes were useless!

210 I'm trying to remember what went on during her public school years. It has been 17 years since she attend public school. She never was in an inclusion situation. There were times when it was very difficult to make the school personnel understand that Marilyn needed special education. Marilyn has made great strides now that she's out of school. She loves to work and loves to be around people she works with. She is active in church, loves to shop and is working toward more independence. She has worked so hard. Her father and I are so very proud of her. She has given our family an empathy for others. Marilyn has a younger sister and brother and 4 nephews. This (research project) has stirred up so many negative memories!

211 M y son lives in a group home in our community during the week and comes home on weekends. We are in close contact with the group home and the

classroom teacher at school, but it is always a struggle to get everyone to carry out his program. I am getting older and it is getting harder and harder to fight for good programming and good living conditions for him. We are constantly at the mercy of legislators who see aid to those with disabilities as expendable.

212 No Response

213 I have found having a child with brain-damage and learning disability has helped me to be more caring, considerate, compassionate, and accepting of all kinds of people we encounter in our lives. I don't look at what he cannot do or the person he isn't but I am thankful he can do many things that I never expected and that he has a heart bigger than life itself which touches a lot of people with more love than we could ever hope to have. I have learned much from Neville and I have never regretted the time I have given him. The same applies to Neville's father when he was alive and his sister and 2 brothers.

214 It will be a good experience for him to be on his own, and to do things for himself, because I won't always be here. He needs to learn to cope with the real world.

215 Parents should be provided the same money as group homes etc. are provided. Sure group home's can do a job. Who couldn't on $3,000 to $6,000 per month? We could also hire someone to do the little things that never seem to get done!

216 No amount of written information can ever prepare parents for having a child with a disability. Once the issue is reality, the written guidance, advice, support groups, etc. can help, but as a culture, new mothers aren't sufficiently prepared for the possibility of a "special" child. In a culture where so much emphasis is now placed on prenatal care and preventative measures, a pregnant woman has the false sense that as long as you're "going by the book," nothing is apt to go wrong. Physicians need to be more realistic about congenital problems and not shy away when they're suspicious that something is not quite "right."

217 No. Thanks! I hope I filled this out o.k. Marcia would be considered having cerebral palsy. Not real bad -- as she walks -- and can do many things. She loves working at the Center in Medium City. We have to take her half way -- from our little town – the rural transit takes her on. Then we have to get her each evening at the pick up point.

218 Most of the statements in this survey were not applicable for me since my son is older and was not fortunate enough to have been able to attend a public school. I feel that parents are very fortunate to have the facilities that are available to them

now. My son is now working in the community thru a rehabilitation program and rides a city bus by himself to and from work. I feel very proud of him for this accomplishment.

219 Dianna is presently getting rehabilitation services which only allows 2 days\week for her. She could use more services more often as she needs people who can work with her! When the people do come they are quite positive with her and very friendly. They try to work with her by conversation, etc. I am pleased with this as her progress is very important to me. Dianna will soon have a household and live in an apartment, etc. She has been looking forward to doing this.

220 My son was diagnosed at 19. His school experience was total frustration. Teachers didn't know how to deal with him. Students making fun of him. Barely passing. Sometimes failing. There were a couple of good teachers. The professionals we have dealt with have been very good to Joe and are working towards his independence.

221 There needs to be someone or somewhere we can turn when we need a break.

222 I guess I'll have to fight for her best interests forever. I thought when she left the school system it would be easier, but with cuts in medical services we are continually on the offensive to protect and safeguard her.

223 Thank you for doing this study. I'm certain that services to our special children will benefit from it.

224 No response

225 We feel very fortunate that our daughter is capable of living in her own apartment. We are very grateful for the assistance from the X program and the competent counselors and job coaches that work with her. They found her a very appropriate job which she loves, and have checked on her frequently to make sure things are going satisfactorily.

226 It is very hard to cope sometimes -- especially in the beginning. Support needs to come from every direction. If you are in a position to help someone -- in any way whatsoever -- please do so.

227 I think parents with children with disabilities learn very much the true character of people they have to deal with in order to raise a child like this. I know we have. I believe physicians are also included in with these negative people to an extent. We had one physician tell us the only thing to do was to put her in an institution.

228 No Response

SITE 3

Briefly tell me one positive experience you have had with reference to your child with disabilities.

301 Since Andrew was 5 we enrolled him in the local soccer programs. He was able to participate well. It was a real thrill when his team came first place in the championship the year before last.

302 Ray enjoys going to the sheltered workshop and the staff there are very co-operative and caring. In the summer of 1992, he worked with a car salesman, cleaning cars inside and out, cutting grass with riding lawn mowers at his place and at all his apartments. It meant great social growth and much happiness for Ray.

303 Rather I enjoy taking her to the malls where she can meet some of her friends which she enjoys. What I don't like is the way some people stare and talk behind your back about her disability and feel sorry for her being in the wheelchair. She has accepted this in her life and does have pride in herself and doesn't need anyone's pity for being in a wheelchair.

304 Nathan has met some beautiful people in his life, people who really cared about his health. He has come close to death so many times, and was sent on a wish trip to see Billy Rae Cyrus, the singer. We went as a family and it was beautiful. Nathan loves to sing - he has a Karaoke machine at home and enjoys it immensely.

305 My positive experience given to me by my children (with disabilities) is the personal growth and strength that they have instilled in me. I diagnosed my own children with a very rare disorder. I have travelled to lecture to geneticists in the U.S., I have been in contact with Nobel prize winning geneticists, lectured at universities, contacted other children's families around the world, who also have this syndrome, and I work closely with 8 organizations and committees that deal with disability issues. All of which has been opened up to me by my children.

306 Barbara works at a sheltered adult workshop. When she got in there and got settled and as time went on it was a positive experience for her. She's now 27 years old and very happy with her work and friends.

307 The most positive experience was the day my daughter took her first steps with leg braces on.

308 Nick is generally a very likable boy. He has his way of getting into people's hearts, with his smile, and the way he looks at you. People bond to him very easily, (he also is very cute, which helps). Because of this, the people working with him always go the extra mile for Nick. He brings out the best in them, without knowingly manipulating, which always works to his advantage. I'd say that the most positive experience of having a handicapped child is getting to know all those really wonderful, caring people who chose to be involved with handicapped persons, not for the money (there's never enough) but because their hearts are in the right place.

309 No response.

310 My child was diagnosed as severely retarded. She did not walk till she was nearly four years old. My physio worker was very helpful to me in trying various ways to help her walk. She also did not like to touch things so had to be desensitized. Also any trips I've gone on to the children's hospital in Capital City...they have been great.

311 The physician told us that Jack was hopeless - there was no hope - would never walk, talk, sit up, hear have no control over his elimination, take seizure, he is total and complete care - put him in an institution. I was 8 weeks pregnant for my little girl who is 11 months younger. I told that doctor to go to hell and if it was the last thing I ever done I would prove him wrong. That was September 1991. September 1993 I took Jack to him as we regularly do. Jack can hear a minute drop. I put him in the floor and he sat up all on his own. He smiled and hugged his mother. He responded to my praise and put his hands together to clap. I was so happy and proud of my boy. The doctor couldn't believe his eyes. He said I am happy for you and your husband, I really am, if I didn't see it I wouldn't believe it. My response "Love can work miracles."

312 No response

313 With Sam there has been many. One comes to mind. His music teacher taught Sam to play a cymbol on a drum, his right hand was good. At Xmas Sam did a solo on this drum with the music teacher playing along on the piano, and he did a great job. And when he finished his arm went up in the air with the biggest smile on his face.

314 Grade one has been a wonderfully positive experience for Paul and everyone involved in his life. He is fully integrated into a regular classroom and spends only 20-30 minutes/day out of class working on computer skills. He has a 1-1 aide who (next to his parents) is the greatest "break" he ever got. They have been together in daycare, kindergarten, preschool, and now school since 1991. She also does respite. Paul has learned and been able to show he knows the

grade one work. He gets most of his cues from his classmates and models their behaviour. He can type, print some (independently) but most exciting of all he has began to speak.

315 School has been a positive experience for us. For the most part he has had good teachers and assistants. We have kept a good line of communication between the assistant, teacher and myself. Flexibility in program and teaching methods is very important. The best teacher assistants he had were the ones who became more involved with us as a family. This goes back to communication - you have to keep the lines open by inquiring what kind of program they are following.

316 My two sons are both hearing impaired, they also have X disease. We also lost one little boy to X disease. We have had lots of support from our school. My positive experience is to see my children accomplish so much in such a short period of time.

317 I have three sons with disabilities. When my eldest son was 3 1/2 years old I was going through a lot of denial and felt very angry. A worker started to visit our home twice a week. She played with David (it was a stimulation program). She accepted David as he was. She helped to show me that the most important part of our relationship is love. David needed my love and I needed his. Through the years (and difficulties) remembering her and the lesson learned sustained me many times.

Briefly tell me one negative experience you have had with reference to your child with disabilities.

301 My biggest disappointment was 2 years ago. I discovered quite by accident. that Andrew was being punished at school by being confined to a very small room, no windows, door closed and no activities. He had been there every recess, noon and break for a period of two weeks before my discovery, and it was to continue until the end of the school year which was about another month. I might add the people enforcing this punishment were told by the principle that I hade been notified, which I had not been.

302 Ray is very determined in what he does, what he wears, etc. and getting worse. He bothers me in that he is so very curious, who I am talking to on the phone, what people are doing, where I go, what time I got home, etc. and spreads all our goings-on thus we feel we have no privacy. Ray always helped evenings on the farm with his brother, but this past winter had several falls on the ice while transferring from one bus to another, hurt his back, and lost all interest in the farm.

303 It occurred in the mall one day and occurred in the front yard as people would call her retarded which she is not but some people are just plain arrogant. Too bad they couldn't change places with Debra Anne and realize what she needs is support.

304 This past two years have been the worst to say the least. My son was abused by two teachers in different schools. On one occasion, he came home with his jogging suit ripped down the middle (front). When I confronted them, it was all hushed up. He was diagnosed with Tourette's this year. Also attention deficit disorder. When under stress, the tics erupt, then he has seizures. I have had to call (X television program) besides K.M. and MLA, to get help to remove him from school after he collapsed on 5 different occasions and was hospitalized each time. They would not listen to me as a parent, were ignorant and I have never, and do not ever intend to go thru that again with any school system. I saw "abuse" that makes me sick, I am presently in human services course myself and thank God for TS, KC and JM, because I knew (I) was OK, otherwise those school professionals would have convinced me I were the crazy one. In order for you to change society, we have to listen to parents, to our clients (mentally handicapped) who never seem to have a say, and the abuse has to stop because innocent people are getting hurt by professionals who themselves are abusive. I've seen it. It's a power trip with them. I will never let them hurt my son again. I'll go where I have to. The X television program would have taken our story, but by then, they changed schools for him. I wanted him with his aide. It's hard for me as a single parent to believe what is going on with our system. I truly hope there will be more help with respite care, because

I for one have been with my son alone for years. It would be nice to have some free time, something we as parents do not have. Social services is supporting me (with money) to get through my course, but they do not support us with our handicapped children. We are the minority not having a voice. I hope someday to be able to help other children not to have to go through what my son went through - or my family - to get help. Our handicapped adults and parents are being abused by professionals who don't know or care what it's all about. Let them walk in our shoes for awhile.

305 It's hard enough coping with the fact that I have 2 children with disabilities, and as a mother I'm always fighting to attain or retain services that are basic for their quality of life. I'm always spreading myself thin; trying to be involved educationally and medically. Just 3 weeks ago I almost lost my oldest daughter to a blood disease, and at the same time I'm battling with government over the closure of our regional school for the blind and hearing impaired, and with the local school boards and professionals over my youngest daughter starting school this fall, to mention a few ongoing issues. It's exasperating!

306 When she made the change from a child development class where she was quite sheltered, to a junior high situation. That was quite negative for both of us at first. However, she settled in, had a great special education teacher and things worked out well.

307 The most negative experience was the day my daughter blamed herself for having spina bifida - since then she has very low self esteem/confidence in herself.

308 It has been far more difficult for me to deal with schools and trying to get services which I felt necessary for my child than it is to deal with all his disabilities (which are numerous). It was easier for us to move our family (which we did twice in three years) to get a better situation for Nick, than the stress, and aggravation of inadequate services and schooling.

309 There is a "neighbour" in our neighbourhood who cannot accept our boy as "special needs". She goes out of her way to be nasty and say hurtful things. She calls him "Satan" and told him the reason he was adopted was because his own family couldn't stand him.

310 I would have liked more input from speech therapy. It is very hard to get any help in this area.

311 At physio-therapy, the therapist never telling Jack who she is, what she is about to do, or change of position. Always complaining of his size and how heavy he is. Been very hard and rough with Jack, letting him fall and not being told. I was

not happy with her behaviour towards my son. She asked to be removed from the case. Never giving Jack any praise or reassurance.

312 No response.

313 He's lucky he has 3 close friends that come over quite a bit, but its sad when he asks why he's hardly ever invited back. Its not the kids, but the parents. I know they don't owe him anything, but he's a kid who also wants to go out.

314 Our most negative experience would have to be dealing with the 1 week in the hospital in Capital City. It took over a year just to see these people who were supposed to know a thing or two but, sadly, they are still in the dark ages as far as autism is concerned, and if I'd followed their advice I'm sure he wouldn't be doing as well as he is.

315 The one thing that really sticks out in my mind is the attitude of some physicians and therapists. I constantly get the feeling that I am not pushing my son hard enough. I hate going back for a spina bifida clinic for example if: He is not putting on pants or tying shoes like they said he should be. The problem is that I don't feel the therapists can empathisize with the situation. My child has to want to do these things. They don't have to be with him everyday and watch the struggles or hear the crying. I do, and somedays it is more than I can take. I have other things to think about, a husband and another child. Our lives cannot revolve around Peter anymore than they already do. One physician actually went over my head and tried to book a 2 week stay at hospital in the middle of the summer. She made me feel like whatever I was doing was just not enough. Thank heavens, I do not have to deal with her anymore. I wish professionals would stop and think what they are saying. How would they like someone to came into their home and try to tell them that they needed to be a better parent? I would like to see someone in our area as a support person for parents. A sort of middle man would be great. Parents need a lot of support and encouragement. It is very long and winding road with a lot of bumps along the way. We, the parents struggle with all kinds of fears and problems meanwhile trying to keep our sanity and live a happy life. Please remember we had a life before our disabled child came along.

316 My negative experience - because we also have foster children and one of our children is profoundly deaf - is people who stare at her "especially adults" because she doesn't talk like other people. Also people's ignorance about children who are hearing impaired. Always talking about them as if there not there or couldn't hear a thing.

317 When my son David was to start school I took him to the school for a pre-test to Grade 1 (in May). What they expected him to do was way beyond him. Still when he started school in September there was no extra help for him. He repeated Grade 1 but still didn't know the material. He was then transferred to another school into a special education class. By this time his self-esteem was very low. He felt stupid. He started to act out. No one seemed to understand what the child was going through.

Do you have anything more that you want to say?

301 If Andrew could only speak better I'm sure my troubles would be over. It is so hard to get speech therapy once your child is in school.

302 This survey did not really apply to us as Ray is 41 yrs old and where school is mentioned, I tried to apply the workshop. We are pleased he can travel on the school bus, but transportation in the summer months and on school holidays is a real problem.

303 The government should give her a disability pension when she becomes an adult. Her job prospects with limited use of her body are not very good but she has to work two years before she can receive disability. Social Services won't give her enough to fulfil a lifestyle she deserves as I will be her support for as long as she resides home (probably her whole lifetime). I know of several people who are receiving disability pensions and there is nothing wrong with them. Why should they get one and Debra who needs it, not be entitled to it? P.S. My MP can't help us!

304 No response

305 On the front of this questionnaire I put down my occupation as a homemaker, however I am so much more than that. I am often referred as the "non" professional when I sit on boards or committees, and I quickly correct them, because as far as my children are concerned I am "their" professional, and although I did not attend college as a student, I am now asked to speak to college students, so as I can teach them about my schooling... the college of "Live it and Learn it".

306 Barbara is happy with her work and with her friends (other mentally handicapped persons). She especially enjoys the summer recreation program set up by our local of the Association. However, all of this happens 30 km away. So transportation at times is a problem. Since I'm a teacher, I'm able to transport her in the summer months. I'll be retiring in the fall of '94 so I hope to be able to do more for her. So far I'm doing the best I can.

307 Will the day ever come when I won't still get very angry that my little girl (all children in fact) has these disabilities and I feel her life will be even more of a struggle than so called "normal children".

308 Thank you for your attention.

309 Leonard was diagnosed as an Attention Deficit child almost two years ago. After all the physicians and going through all the red tape he is now on medication

and closely watched by the family doctor. He has burned so many bridges beforehand with neighbours and peer groups, we find the finger pointed at him first, when something goes wrong, whether it's his fault or not.
We adopted Leonard when he was 11 days old. He was one month premature. Very little background information came with him.

310 Her teacher's aide has been very supportive to my child. They both have a great relationship. Hope when she goes to Junior High that her aide can go.

311 I would like to say we love our son and he has made us better people and stronger than we ever thought we were. There has been a lot of doors slammed in our faces but we keep on fighting for our son and his rights.

312 No response

313 Overall on the most part we are very lucky with help and support from professionals. Peter's integration is going well except for the area of teacher's assistant's not wanting to integrate his communication device into his every day work. She has help from myself and a speech therapist, but says she's using it when really she isn't. I find the school tends to side with the assistant too much. She's been at the school for 2 years. I sometimes get emotional because I know Peter is a child who wants to answer, if everything was normal, he'd be quite talkative and he does well at home, but he needs to push at school. I wish I had a mediator or a social worker on a personal basis that I can go to. So when I do talk to schools, I could leave my emotions out of it - in other areas - teacher assists do well.

314 No response.

315 No response.

316 My sons are both the tops in their classes and because of professional people who believed that children that are hearing impaired can talk as well as you and me and have succeeded.

317 Many times I wondered what was best for my children. I learnt what to avoid by experience. I try to avoid pessimistic professionals. I need to have support, not someone who adds more worries to my mind. I like positive thinkers. I find the school system very rigid. Little individuality is tolerated. You must conform. I wish someone knew how to teach these people to relax around my children. I wish there were more people to help them at school and at home. But only if they are people who really care about the child and not just their paycheck.

SITE 4

Briefly tell me one positive experience you have had with reference to your child with disabilities.

401 There are many positive experiences: when she smiles and laughs - they are real. She also started to say "Mom" 2 years ago when she was 18!!! I know she loves me too.

402 I've learned more about various mental and physical disabilities, and am not afraid of them or so curious about individuals with differences now. Because I've spent so much time in hospitals, rehabilitation centres, developmental centres, group homes, Association meetings, parent to parent support group meetings etc. And therefore my children have learned to be more caring, open and expecting of others with differences than say my generation was.

403 I have had many professionals involved with Naomi since her birth and so many of them could not do enough for her. I never knew how many people really care when something happens that is difficult in your life.

404 One positive experience was Joseph's involvement in Dr. Merton's language class where Pat Gray worked with Joseph's language development, daily for 6 weeks, in 1984. Joseph's work placements via his high school have all been excellent, productive and individualized and Special Olympics soccer has been excellent.

405 All of our positive experiences come to us in the regular, non-disabled world. Here are two:

1. When Thomas started nursery school (not a special one, but our neighbourhood preschool where emphasis is learning thru play) his teacher observed that, at age 3, he was quite mature socially - more so than several other 3 yr olds in the class. She always minimizes his differentness and enjoys his progress.
2. At church school the team of teachers and assistants have taken seriously their role in Thomas's spiritual life, including him in every way and keen to help prepare him for Kindergarten. Teachers (who are remarkable women) have told me how much they're learning from him and how glad they are that he is there.

406 Beverly has a younger sister, whom we have brought up, with the openness of various handicaps. Neighbour has a child with cerebral palsy, parents we know have other children with Downs Syndrome and Beverly's sister thinks no differently

of these children, than her sister. She is not afraid, nor ashamed. This I feel is because of Beverly. She shows her sister true love. She has taught her sister how to love unconditionally.

407 The school has been great and the children are extremely friendly to our daughter. Our physiotherapist, Helen, can handle my anxieties amazingly well. I never want to give her up.

408 After childhood and teen/early twenties years of self-abusive behaviours, irritability at just about everything, to see and hear Stewart, albeit with a heavy daily drug dosage, enjoying life at least a little - teasing and enjoying being tickled and smiling! After years and years of those terrible alone look in his eyes or no expression at all, this has been wonderful! and is wonderful he really enjoys coming home but spends majority of time asleep unless cajoled into action!

409 I remember the nurses from the well-baby clinic coming to the farm and talking with me about problems I had dealing with my child. For many years they were the only ones who understood the problems I was having. There was one older nurse who was especially good, her name was Mrs. Jones, she kept turning up whenever things were going down hill - I will be eternally grateful to her.

410 Can I please tell you at least three positive experiences?
1. Having Wayne. We love him to pieces and he has really brought our family even closer. 2. Having a good physiotherapist right from the beginning. She was excellent for giving us ideas of activities to do at home. That's what we wanted. She was good at including Wayne's twin in the activities too. 3. Going to the "Institutes for the Achievement of Human Potential" in Philadelphia - now there were professionals who cared and believed in your child and in you as parents. They had excellent ideas too with explanations of why you were doing the activities. The professionals worked together as a team in Philadelphia - unlike here at home where you see the professionals, if you're lucky, separately and they all have different ideas - no correlation!

411 We have a wonderful speech pathologist. She treats Carla and me with dignity and tries to improve Carla's speech although there's often little improvement.

412 There have been many positive experiences. Martha's acceptance and treatment as one of the children by our friends, people at church (children's Liturgy group), at the daycare, at school, at the grocery store, has been very positive. We hope Martha's integration into society will continue to be this positive. We are trying to insure this by teaching her appropriate behaviour and language skills.

413 When my youngest son, whose prognosis in infancy was to be an "autistic vegetable", first learned to play, then walk (age 4), talk (5+) and then read (7+). He now reads at his age level, talks very well, climbs and runs, and has emerged from most of the symptoms of his early autism. He is now very sociable, friendly and outgoing - seeking human contact, cuddles and has friends. He's apparently making up for lost time in early childhood.

414 No response

415 No response

416 No response

417 No response

418 Anytime someone truly listens or treats me with respect I feel hopeful that we can make some progress

Briefly tell me one negative experience you have had with reference to your child with disabilities.

401 Being frustrated with her mood and not knowing why she is so upset about something is a negative experience. Too many messy pants. Not being able to take her with me to some places because she gets upset. Then having to stay home instead. My parents not understanding. When I mention how frustrated she is or having a hard time with her the answer is "When do you think you could put her in a home!". People not noticing her very small accomplishments and the joy her smile can bring.

402 Having a child with multiple handicaps knowing he is totally dependent on you for his entire life is scary mind-bending (sad). It's like you're in mourning for "years", for the whole and full life of your son that can never be. You'll never see him walk, drive, graduate, marry, raise a family of his own.....

403 I had one physician come in to see Naomi after her heart surgery when she was having some breathing problems. He walked in took one look at her and said " Oh all these kids have this problem" and then he walked out.

404 Several months ago, I accompanied our 21 year old son to an Association dance at school. It was most discouraging to witness unecessary humiliation and overt neglect of the mentally challenged. The "guests" were given a "snack" at 8.30. The "snack" consisted of Mc Donald's drink and dry sugar cookies. No choices were available. Only days earlier I had accompanied "normal" high school students to a drama function. The snack consisted of an array of fresh fruit, cakes, three kinds of pop, cheese and crackers etc. Every single ("normal") function whether preschool, art openings, soccer meetings have always provided guests with at least two choices of refreshments. Our son is allergic to McDonald's drink and sugar cookies so he went without any refreshments. We could have brought him his own snack but the other "guests" would have felt badly. Our son is not capable of performing a range of tasks. However, he can select food and pour his own drink and is pleased when he can get a sense of control by performing such tasks. The people at the Association dance were treated like cattle and expected to drink stale sugar water that had been poured several hours earlier. Please let us not necessarily humiliate the less fortunate members of our community. I would be very happy to take turns bringing a variety of snacks and supervise a crew of mentally challenged people who could serve the snack themselves. They may not be capable of driving a car but they can definitely pour refreshments and select food. They also deserve healthy refreshing apple juice or at least no-name pop (adults drink it). Mc Donald's drink smacks too much of `little children'.

405 Speech assessment/therapy was a big downer. They use inappropriate tools, environment etc. and got a really bad" read" on Thomas. They knew nothing about our family culture but were very directive about how we should interact with Thomas. They didn't want to work on his articulation, wouldn't let us have access to XYZ software- just wanted to assess him every 6-12 months. This was useless so we quit speech.

406 We, right from her birth, have constantly been asked how much money do you get for keeping her? This has often been asked yet our response has always been nothing. Why should we? She is ours, she is a part of our family. They say well you should, other provinces pay families an amount to keep their handicapped children at home.

407 The psychologists we had, initially, never said anything positive, no matter what we saw in terms of progress. Finally we realised that we were much better off without them. I cried for hours every time we saw them. I now rely on "informal" advice from professionals who are friends, acquaintances or family.

408 It has been negative to hear Dr.L talk about the gradual reduction of drugs which have been prescribed for many mentally handicapped adults (in particular) which may not be necessary and indeed pose additional side-effect problems. The medications are just continued without review unless there is a particular emergency. To be granted an appointment with this same doctor who was extremely interested in Stewart's case as an example of a particular genetic syndrome - an "M.T."? scan a must - absolutely no reason for all the drugs - see you next month. The next month arrives (overheard from secretary's office, Dr.L on route to clinic - "Oh I'll have to have a word with Mrs. Z. The words were "Yes what can I do for you?" Something must have happened for this change of attitude between appointments. Hopes dashed.

409 I remember being at the swimming pool one afternoon with my three daughters we were all laying on the grass (their ages were maybe 6,7 and 9). Karen the handicapped daughter got up to go to the bathroom. She only made it halfway there and ended up peeing on the grass. Another young woman (whom I did not know) was so mad about that, she ended up grabbing her two kids and stalking out of the pool.

410 Only one negative experience? That's Difficult! Overall the most negative experience would be trying to get OT and speech therapy services for Wayne without having to drive 1-2 hours. I also feel such services only two times a month are not sufficient. We have four sons and it is not easy to be on the road all the time. We even called health services to see if we could get training as parents from all the professionals at once so we could do home therapy. We just asked if we

could meet with these professionals for 2-3 days so we could formulate a home program that would cover all of Wayne's needs. We were told by health services that there was no place in our province where this could be done. This is when we decided to go to Philadelphia despite all the expenses (which health services would not help us at all with).

411 Most experiences with the "outside world" are negative. Carla's abilities are discounted because people focus on the disabilities. Carla is organized, careful, caring and forgiving. She has a wonderful sense of humour which most people have never seen. I also hate the fact she's allowed to behave in socially inappropriate ways because she's "handicapped".

412 When Martha was born the pediatrician who was called in was very negative about her potential. The doctor gave us an old medical text for information. We had to find our own information and learn through experience that her life would not be that bad. Martha has no serious medical problems and is a delightful child. The pediatrician's attitude and behaviour towards our daughter and us has been the worst experience we have had since she was born. Our family doctor was very supportive and helpful in guiding us to other agencies.

413 Having to resuscitate my daughter in the cafeteria of a ferry boat in the middle of the English channel. I was alone with her and her next younger brother. Everybody just stared. Nobody helped me. The ship's doctor did not come for about 10 minutes.(By that time if I hadn't managed to revive her, she would have been dead). It was a nightmare and one of the key events leading up to my mini-breakdown, at least regarding my ability to care for (i.e.look after) my daughter. I still care for my sons but have totally burnt out my strength to meet my daughter's needs.

414 No response

415 No response

416 No response

417 No response

418 A resident chastized me for not adequately nourishing my child. We were visiting the pediatrician for the umpteenth time because my child was unable to nurse or bottle feed without experiencing pain. My son was about 5 months old and weighed less than six pounds in spite of my efforts.

Do you have anything more that you want to say?

401 What bugs me is people not understanding that sometimes when she is "bad" she is only frustrated and we don't understand why. It's hard when you are unable to communicate.

402 Our province, our hometown in particular, has no group homes in place for the multi-handicapped young adults, once their parents are no longer able to care for them at home due to physical stress and ageing etc. We don't want our children institutionalized or put in nursing homes. We want them to go on living in a home-like environment, in perhaps group homes with extended families that care about them, where they can have their own rooms, personal effects, visitors, outings and vacations with their families.

403 In my opinion, raising Naomi will be like raising any child. There are always challenges and hers will be different from my other children just as theirs were different from each other. I'm as proud of her or maybe more so with each milestone. She has added so much to my life and I thank God everyday for letting me have her for my child.

404 The difficulties with the "community-based" services like Special Olympics and the Association, are that such activities are segregating the mentally challenged from the main stream of society. Whenever our son participates in Special Olympics, soccer or bowling he comes homes with an array of unusual behaviours (we still encourage him to participate and drive him to the functions). In contrast, when he returns from working at the university dining hall, he displays adult-like strategies and mannerisms which are socially acceptable. Our son is becoming increasingly frustrated by his inability to enjoy a healthy social life with genuine friends. We parents feel very helpless with his dilemna. We used to be able to create a good social life for him when he was young. We can still buy him the latest walkman with appropriate dials for his awkward hands and his impatient tendencies. We can drive him to a dairy farm to milk cows, but we are apparently unable to find him a friend. His health problems, asthma, allergies, and frequent pneumonia compound our challenges.

405 By the time Thomas was three (he's 5 1/2 now) we had taken charge and eliminated the contacts/experiences that drained us the most. We are angry about how families are treated. We are angry about ill-informed or under-informed professionals who think they can mess with lives with impunity. We continue to have a lot of medical involvement though now. It's mostly follow-up (Thomas has had surgery on his bowels, heart, ears and eye). We have learned how to manage this and go where we get the kind of service we want and where Thomas is treated with respect. We are working with the school re kindergarten entrance this fall.

Rehab services is not involved in any way. There has been and will be no psych assessment. I believe I went through a terrible crisis in Thomas's third year when I realized that the "experts" were fallible that often I knew more than they did about child development, about good child care. We were being pushed to accept a preschool placement that would have been mediocre at best - in fact it would have caused Thomas to regress and would have completely squelched my boy's inventive, exploring spirit. (I could go on about this for hours!!). We determined that the therapeutic agenda was not going to dominate Thomas's preschool experience. That attitude has carried on ever since. As much as possible, Thomas is treated like our other children (he's one of four). We believe it is best for him. So we don't see speech, OT, psych. We see PT once a year. We go to the clinic every year or two, just to maintain that he is (or could be) a recipient of services. We do get the best medical care and advice we can. We attend conferences etc. to inform us re the education journey ahead. Of course, we fantasize about just sitting back and letting others be in charge, about not having to be so involved - so vigilant. But this is a family commitment for us now - our older children expect us to advocate for and protect Thomas.

406 I feel the school boards should be open to each family who has a child with a disability, to allow them to attend whichever system (public or alternative) the family wishes. I would also very much like and have been trying for years to have the high school mentally handicapped school program changed to suit our child's abilities. For example, she is able to do academics, reading, typing, math, computer and Phys Ed, yet the high school program offers 80% to 90% lifeskills and only functional academics pertaining to the lifeskills. Our child has proved herself to be able to be taught, to read,do math on a calculator and work on computers. Why does this have to stop at age 14 or 15? We get NO answers, only that this is the Curriculum.

407 Please give a research number next time so confidentiality could be assured. In small communities confidentiality is sadly lacking. Recent experience with same. Feel violated.

408 There is indeed, but I really find it difficult on paper. I feel there is great damage done to many severly handicapped older people by the impressions of complete "desirable" integration into the community being possible for all. Here's a story from a medium sized town which is sad ---- The local special school for the handicapped was built quite a few years ago by volunteers and funding from the community (and the school's club in particular). Very well equipped building - large playground - gym - wheel chair accessability - beautifully appointed kitchen for learning. Because it is wrong to segregrate, the School has been purchased by the local school boards and is used for storage or occasional meetings or conventions. What a sad and inexcusable waste of a facility. Oh sorry - just rambling. I was so

pleased you phoned. Still feel very guilty about Stewart. He is the oldest of seven children. When he was fourteen the baby, (now 15 yrs old) cried suddenly - Stewart picked up the playpen he was lying in and hurled David across the room. At this time the nightmare became too much and Stewart started living in the community group home. Since that time he has been home for several visits and now every weekend and holidays. We were told by the Consultant who diagnosed Stewart in England aged 8 months that we should go ahead with plans to emigrate to Canada - go and have a large family in a "large" country. This will not happen to you again (he had told us Stewart would never do anything but lie flat on his back, most likely.) How could he know if no one follows up on the adults with a given diagnosis?. Anyway we arrived in Canada two days after Christmas in 1964. We had our large family and it is wonderful for me to be able to talk to the girls in particular as friends and tremendous support and fun but the early days were very, very touchy with regard to Stewart and his future. Because my husband cannot bring himself to be involved with Stewart in any way, even now, he will go for a walk and never ever suggest that first maybe Stewart would like to go or should go. Perhaps this accounts for the gush of words on my part that seldom have an outlet. Forgive me. There is no reason why Stewart could not live at home now but I feel that he is well settled in the group home with five other young men. He knows well if anything happens to me, I know he'll be OK in familiar surroundings. I have a grand mal seisure myself during the night approx. every six weeks and am virtually incapable the following day. Stewart has both grand mal and petit mal seisures probably only about once every three weeks - perhaps attributed to the control by the drugs. Tremors now noticeable since Haldol.

Professional people have been very kind and well meaning over the years. No complaints there - Have just felt sometimes that they had as much difficulty in being constructive as we.

409 My retarded adult has a sister 2 yrs. younger and another sister 18 months younger than that. I was expecting the third child when I found out that the oldest was handicapped. One of the first big problems we had with my retarded child was when the youngest child learned to do more than the retarded child could (things like colouring,numbers etc.) She played with her first sister, then later she would spend more time with the second sister. Karen seemed to really feel it when the youngest sister outgrew her (for want of a better word). This was a very difficult time for Karen and for my whole family.

410 I feel that home therapy is the answer for those that live far away from services. We enjoy doing all kinds of therapy with Wayne in our home - everyone helps out! Wayne works and performs better in familiar surroundings too. This way, we can also work with him when he's at his prime. Wayne would often not do well at his appointments when we were travelling because he'd be too tired to perform. We feel we're being more fair to Wayne's twin, too, working at home because then

we can include him too. For home therapy to be the answer though, there would have to be a place where one could meet with all types of professionals at once so that a program using all their ideas could be put to use in the home. Feel free to call with any questions!

411 This survey was difficult to fill out. The scale should have gone NA Disagree <---------------> Agree

412 Since my husband and I are part of the school system here we feel in control of the educational system Martha is in. And we are very pleased with her progress. Having Martha has been a very positive experience for my husband and me as well as our family. Martha is developmentally delayed but there are so many things she can do. Her brothers and sisters are as proud of her accomplishments as we are. Martha has brought a lot of love into our lives. The future will not always be easy but I feel we are priveledged to have Martha in our family.

413 I think somebody should write a book or research study about my children. In all my reading and networking I have never heard or seen a family who has such a combination of unrelated syndromes and conditions, ranging so widely amongst physical disability, psychological disorders (autism & hyperactivity /challenging behaviour),sensory impairment (both boys partial deafness and daughter's visual impairment) plus the added dimension of the middle son's giftedness and younger son's islands of very high functioning.
The family ecology, parental management, problems, sibling mutual effects, bilingualism (French/English) and immense battles for services (court cases, appeals etc.) would surely provide fertile ground for study!
Meanwhile I managed to go back for an MA degree and my husband for a management degree.

414 No response

415 No response

416 No response

417 No response

418 If you would like to use any comments I've made in my presentations in any way, feel free.

Site 5

Briefly tell me one positive experience you have had with reference to your child with disabilities.

501 Harry P. and the Recreation Association. I cannot praise them highly enough. For years they have been a tremendous support helping my son integrate into their regular programs. Our contact with Social services/ Dept. of Ed/ Vocational Services have gone very smoothly. Sam is in the food services course - he has a teacher assistant. The cooperation from all the participants has been beyond our expectations.

502 Matthew has made our world look different since his birth, his special smile and way he makes our life happy in different ways , he truly is an " Angel on Earth". Our other son Brady who is six also feels this way. I think Matthew has made a lot of positive differences in people's lives, not just our own. His strength and happiness and will to overcome gives others strength to do the same. I will continue to look after him, for as long as he is on this earth, also I will continue to fight for the rights and supports of these special children in this province.

503 When Virginia and I are together, she smiles continuously. Her non-verbal communication has improved and rewarding her efforts to communicate gives me a great deal of satisfaction. Virginia is determined and truly terrific. She is a fighter, like her mom. We've fought the system and for the most part have gotten services.

504 This is hard to list only one positive experience as Edward is a "positive experience", by his wonderful loving manner, friendly nature, tremendous personality and a gift from God that my family and I would not have wanted to miss.

505 Everyone needs to be cared for and loved unconditionally! Do you really need to walk, talk and eat like the majority of us do? There are other ways to do these things. My son does not walk, he strolls. My son does not talk "normally" he laughs. My son does not eat "normally" he's tube fed. Marshall is a big part of my life as I am a big part of his.

506 I assume you are referring to experiences dealing with the "system". I could only account for two in all my son's 18 years. It was the year he attended X Day care (integrated)- 4yrs. old. The other was 1993, when I had a teacher work one on one with Chester for the whole year at home. He had regressed to the point of not leaving his bed and after a long "battle", I required financial help to have someone come into the home and work with Chester to lift up his self esteem and gradually get him out of the house and back to school. Many road blocks were put in place by the "powers" that be, but I fought all the way for my son. Needless to say I have no "friends" in the system (government or school).

507 Graduation from daycare. He took his part as the Doctor in "Miss Polly" and Jack in "Jack be Nimble" with all the "Normal" children and was accepted without a second thought. It made me proud but also gave me hope.

508 That is a hard question. I feel that our family tries more to concentrate on Stanley's abilities more so than his disabilities. By doing this I feel that Stanley becomes more like them unlike his peers and friends, so Stanley's everyday accomplishments such as getting up, bathing, brushing teeth, hair etc. independently as possible makes us all feel good and ensures us that he is growing and developing at a nice rate.

509 Watching her during this last year of school has been a positive experience: integrated fully in our neighbourhood school; making progress in many aspects. She's happier, more content, more aware! Watching how the other children - her peers - interact and include her in the activities - make and send home "tactile artwork" for her, that they've done on their own time at home! She does not stand apart from her classmates but belongs!

510 He is a pleasure to have! I find it difficult to separate our life into positives and negatives. He's a dynamic, independently minded child who fills us with all sorts of positive experiences. He rises in the morning with a smile and a warm hug, he often sits on a lap and holds your cheeks in his hands and smiles at you with his sky blue eyes. He tries to be funny and challenges himself to be courageous and daring. He finds ways (his own signs, or taking your hand) to communicate his message, to get what he wants. He is a joy to have as are his two sisters.

511 Megan was chosen princess for Valentine in her classroom this year and competed with the other kids in junior high for Queen. As each one's name was called she clapped and cheered for that participant and was satisfied with being a class rep and receiving her rose and box of chocolates.

512 There certainly have been many positive experiences but the one that stands out the most is when Dennis started communicating via facilitated communication. His knowledge and insight never ceases to amaze us. The individual we always suspected was there is now coming to the forefront.

513 One extremely positive experience was after my daughter was integrated in her neighbourhood school in year 2. I had several parents come to me and tell how much their children were learning from Rachel and how great it was that she was in their class. It made all our struggles seem worthwhile.

514 Probably the most positive experience we have had (one of many) with Russell has been the surgeon he has had for his bowel and stomach surgeries.

This doctor is exceptional in that he sees Russell as a disabled child who has endless "secrets" to share with us and we are never to ever try to guess what his limits are as he is capable of surpassing and achieving what we are sure he is not capable of. Even when I gave up hope on the operations done on Russell and the pain he was going through, this doctor made me see that Russell has every right to a "normal" life as any other child. He never ceased to be amazed by Russell's progress and shared his faith in Russell with us. Most important he really listened to what we said!

515 One of the first professionals to work with him was an "occupational therapist". At first I was sceptical about what her profession could do for him, but it turned out to be one of the most beneficial "therapies". She worked hand-over-hand with him and demonstrated clearly how to achieve certain goals.

516 We had two fantastic teachers, one in Primary and one a "special educator" who taught Phillip from Grades 3-7. The second lady made sure that Phillip was included where and whenever it was possible. She made sure that I didn't feel responsible for every mis-behaviour - the "fault" was not mine. She was knowledgable and caring. That combination made a difference.

517 Nancy's removal from the training center happened as a result of a very negative experience; but she went into a group home and then a small option home. A planning team and then a transition team were set up around Nancy to plan for her future. This proved to be very positive and successful because I was given leeway to choose the team members and to set it up in such a way that I addressed Nancy's needs. With the help of the Minister of community services, all road blocks were removed. Nancy now has many caring, supportive and dedicated individuals around her.

518 A formal "circle" of friends was established for Paul in high school that lasted for 3 1/2 years and over time developed into more natural friendships. Lots of in-school and out-of-school activities - dances, hockey games, hanging out at the mall etc. One friendship continues two years after graduation. David, Paul's brother, worked two summers job shadowing a meter reader for the Power company and one summer for a municipal parks and recreation service. The boost to his confidence and self-esteem were incredible. He gained a maturity and sense of responsibility that really surprised us.

Briefly tell me one negative experience you have had with reference to your child with disabilities.

501 School System They gave/give lip service to integration. They provided a teacher assistant - but also created a dependency on this TA. High school was terrible. The individual teachers gave an honest effort to integrate him within the classroom but he did not have any social integration into life at the school. No one took responsibility for him. They left him on his own at lunch time - he would get in trouble. The last year he usually ate his lunch in the resource room. Because he was on his own he copied the worse behaviour in the school- we ended up with terrible behaviour problems at home - went to child guidance as a result - still didn't get much help - child guidance doesn't know how to deal with young people who are mentally handicapped. Also to be fair junior high was better than high school and elementary. We think this is because the Principal at the time was very supportive of what we were doing.

502 The lack of adequate support in our province for these children is a negative experience. We as parents are frustrated by the lack of support that is given to families that wish to keep their children at home. What supports that are available are inadequate for the survival of these families. The provincial government pays $11,000 to $15,000 or more per month to institutionalise children like mine at cost to us, but when it comes to support for people keeping their children home, well it's just not there! The provincial government must take a proactive role in the survival of these families. They should encourage and enable families with children with severe disabilities or chronic illnesses to nurture and enjoy their children in their homes, rather than supplanting the family's primary caregiver role by expanding public funds to place the children in institutions or out-of-home placements! All children regardless of the severity of their disability belong with and do best with their family.

503 Negative experiences: fighting for everything. Fighting for services, for financial support, for her place in the community. Basically I had to say to the government "O.K., I can't cope anymore" and then I got it all. Virginia lives on the next street over from us , attends her community school, comes home at other days and on weekends. We have the best of both worlds. Virginia has her family and a life in the community. We still have a lot of work to do but we are making some in-roads.

504 Finding negative experiences: this is not hard. When I had Edward enrolled in a horseback riding club through Capital City summer recreation, he was to encounter blatant discrimination. Parents were going to remove their children from the class. The manager and others involved totally discriminated against my son.

505 When he was first born. That famous annoying, hurtful, demeaning word "Don't expect!" It was to the point that even when we take Marshall home," Don't expect him to know who you are." Well did Marshall teach them a thing or two! You said one negative experience but I have two. The department of community services. I have to battle with this department almost daily to get some services for Marshall. Marshall was 3 1/2 years old before they began to help with his high medical and physical costs. He just turned five in July.

506 There are so many negative ones I can't begin to write about one in particular. I have had negative experiences with the physicians when Peter was first diagnosed, negative experiences all through the school system. Negative experience dealing with in-home support through the government. Sometimes if it wasn't for sharing these experiences with other parents who have felt the same frustrations, I'd think there was something wrong with me. But all I want is what is best for my son and my whole family. It's terrible when the little bit of help you get is only because you had to fight very hard to get it.

507 A doctor who had seen my son once in a year spoke in a way that made me feel he thought this child who he knew very little about had no future. It felt as though he was labelling and stifling any self esteem and positive reinforcement that we worked so hard to build. I felt angry and I think it set us back quite a bit. It made me wonder if I had imagined all the progress I had seen.

508 Negative - Is the sudden shock after our son was born. We knew nothing about Down Syndrome and had no close family members around us. We lived out west at that time. It would have to be the not knowing, the fear and wondering what we did wrong. There were a lot of negative thoughts at that time, wondering if he would walk, eat, play, talk etc., what his life would be like and how he would fit into our family. Lots of bad advice from some friends at that time, a very lonely, scary time for us.

509 The continuous battle with community services, school board etc. in recognizing our needs as a family unit and Marjorie's right as a human being. The abuse she suffered while residing at a children's institution has been the worst possible experience any parent can have.

510 Our employee child-care-giver was sitting at the table reading him a book - saying each word in an unusually slow, mechanical manner as though he was a robot and hard of hearing. I was angry because she had worked and cared for him (and his older sister) since his birth and she obviously couldn't see beyond his labelled disability, that he could and did comprehend every spoken word, in regular language and normal voice tone.

511 When Megan was 8 years, the system decided that she be moved (along with some others) to a regular classroom from her segregated special ed. class - 6 kids and 2 adults - (to a class of 31 kids - 1 teacher - no support - in a new school - no orientation). When this didn't work out they told us our child had a problem. Here the whole system failed Megan - teachers, professionals, school - all! It took little old parents to do their job!

512 There certainly are many in this area as well. One of the biggest disappointments was with the medical profession at the children's hospital. For years I thought Dennis to be autistic but they did not diagnose Dennis as such until age 8. What seemed to make the difference were photos of Dennis as a baby & toddler showing him very aware and drinking out of a cup independently at 4 months. Even though we told them what Dennis was like they obviously didn't listen to us. Those pictures said a thousand words but what we were saying for years didn't amount too much. We were " the parents who wanted to see those things in our child".

513 There seems to be so many negative experiences that it seems difficult to choose only one. Dealing with so many professionals there have been numerous negative situations. One that stands out in my mind was the time I was called into the Principal's office of the school where my daughter was being partially integrated. She was only integrated for things like Music, Phys. Ed. Library etc. but the parents of the "normal" children had formed a group to get her out of the regular class. The principal had called me in to tell me of this. I found it a very stressful year because there was little support from the teachers and very little from the principal. (Thankfully this was not her neighbourhood school and when she finally moved to where she should have been, her integration experience was very positive.)

514 My daughter would say a negative experience for her it was when she was pushing Russell in the stroller through the mall and a lady walked up to her, looked at Russell and said to her face "My what an ugly baby". For me a negative experience was a doctor (specialist) who showed no regard for the pain Russell was suffering from a raw, bleedy, sore bottom and told me to accept that he'd always have a raw, sore bottom <u>so get used to it</u>. The pain was so chronic that he stopped making any sound (even crying). Took another specialist only a short time to help find a cure and prescribe pain killers for 3 weeks or until he spoke again. Took him 6 weeks to talk again and cry.

515 He was "expelled" from pre-school for pulling hair and other anti-social behaviour which was potentially harmful to the other children. The director and teachers did not know how to deal with him, and allowed panic to prevail whenever an incident occurred. This was supposed to be a "developmental" center. This event was our invitation into the world of fighting for his rights and a taste of the

struggles that may be ahead. This was done without notice or discussion, the motives for the expulsion are still questionable. It partly relates to the Director being uncomfortable with people with special needs.

516 Recently Kevin finished school, there was no program where he "fit in". The social service worker did not support us, return phone calls or recognize my stress. I have just returned to work full time and was not willing to give that up again. It was not until I started to make arrangements for an expensive group home I told them that I would put my son out of our home that we received a <u>response.</u> Within 2 weeks of my saying that he would not have a home, and <u>all</u> my savings were spent, an apartment and an attendant became available. It was very stressful. Things are not perfect now - we need to change the attendant and that will be difficult. More stress.

517 The most negative and devastating experience was the issue of abuse which possibly happened at the centre where she lived. The insensitive treatment we received by the very people who were responsible for Nancy's care was unforgivable. The investigation which was carried out was incomplete and unsatisfactory. We are still dealing with the effects of this abuse and will for a long time to come. To date, nobody has been held accountable.

518 At an IEP meeting for Paul in high school, two teachers verbally attacked me with loud angry voices for wanting him integrated (even though the statement had already been agreed to and was a continuation of 4 years of integrated ed. in his previous school). I was told that I was just holding on to the latest philosophy and was on the bandwagon, I did not care I was harming all the other children, I was selfish, I was demanding something that was impossible for teachers to do, etc. etc. The worst of it was that the principal who was (and is) very supportive of integrating my son and others, just sat there and did nothing to intervene or to refocus the meeting on developing the IEP. I was devastated and ended up crying uncontrollably and left the meeting after 45 minutes of continuous abuse. Surprisingly the IEP got put in place and he had four quite successful years in that school. Why did they need to put me through that? Why could they not see that Paul's presence could enrich the lives of others rather than harm them?

Do you have anything more that you want to say?

501 Parents who have a child with a disability need to know what resources are out there. This information must be kept up to date and readily available for all parents and professionals. As a professional myself and trying to obtain the appropriate information i.e. resources for families, I can tell you that within the system itself (various Gov't depts.) the right hand doesn't know what the left hand is doing. You have to dig to get what you want. How many parents are too worn out or don't have the ability to do this digging?

502 No Response.

503 I hope the inequities of services being provided will be more fairly distributed in the future. I also pray the province will honor its intention to close children's institutions in this province. When I compare Virginia's quality of life to those still in institutions there is no comparison. Parents have to lobby hard to ensure their kids/families get what they need to survive.

504 I must add that Edward has older sisters (30/32) and that questions related to siblings were not relevant. Much success.

505 I know I have another battle now that he is 5. I wish things could be more accessible to meet Marshall's needs eg. Developmental Day care (hasn't been able to go), Physiotherapy (cut back to 3 times/year, 1 hour each time), Augmentive skills/Communication skills, Occupational therapy, Dept. of Education. I wish our province could make our lives less stressful by meeting our needs as a family. I find the medical problems much more difficult to deal with, (25 hospital stays in 5 years). Constant chest/lung problems making it difficult to travel/visit. I feel the Dept. of health needs to take some responsibility for Marshall's medical costs. They also need to give guidance when families take their infants home; i.e. support groups; other families' names who are in similar situations; where you can get financial support for all of the extraordinary costs for the infant's/child's care; etc. They should never send the families home with nothing.

506 While receiving respite money from the province, myself and other parents were subjected to quite a few remarks that were very objectionable. For example - you are so lucky to be receiving "all this money" - "you're getting more than anyone else"- make sure you use it for respite and don't waste it - You're up for review soon and it will probably be reduced or cut off. They try to make us feel we're getting welfare and draining the system. I'm sure some parents feel guilty and are intimidated by some government workers.

507 Early intervention was a God send to my son and our family. Not only did it help socially and making me aware of what was available to us but also we could meet others who were in similar or "worse" situations.

508 The most positive thing about having Stanley in our family life started while we were in the hospital with Stanley. Our daughter then was very excited about her new brother but unsure about why we were all crying etc. So being perceptive enough to see the so-called wise adults talking, Sharon jumped in the bed looked us in the eye and calmly said Stanley is our baby no one else's,"Right?" We smiled and said yes not really ready for her next statement."Well then we will just have to take him home and love him no matter what he has because he's ours, right Mummy?" Wise words from such a little girl and we have tried to follow it even since it was delivered to us. Having a child with special needs is no cake walk but with the right supports in place, family members and good friends, your path in life can go a little more smoothly for you. It's hard to reach out at times but after the first time you do this it will become a little easier, there is no shame in needing help. Once we learned this, life did get a little easier for us.

509 Marjorie, as Marjorie does not pose a problem. She is perfect as she is! It is the system that we as a family must endure and battle with that can pull families apart, because to date the barriers still exist to exclude Marjorie from full citizenship - which as her mother I see is her right to access equality along with the rest of the population - in all aspects of her life.

510 Our son is "categorized" as possessing a mild degree of the disability, Down syndrome. I believe however that the context of family in which he is being raised has played a significant part in his "incredible" development. I expect that we will encounter a whole new set of obstacles and barriers - generated from peoples attitudes - when he goes to school.

511 Despite a rocky start- Megan has turned out to be a lovely young lady who is interested in everything around her and is confident that she can do or be anything she sets her mind to. If we as parents hadn't pushed for everything that she wanted or needed, she would never have come as far as she has. Just this spring a school board member told me that all of the "professionals" who thought we were looking for the impossible now think we have done an absolutely wonderful job. They sure had a lot to learn.

512 I like to think I have come a long way since those early years. I've stayed involved with the National Association and have always tried to keep up with new things coming along (which would help us understand and deal with living with a high need child). I believe its possible for my son to have a meaningful life and be a contributing member of the community.

513 Having a child with a disability is both a joy and a curse. It is a joy because of the person Rachel is, the good experiences we've had, the things we've learned and the people we've been so fortunate to meet because of her. It's a curse because of constantly having to fight for what other people take for granted (school experiences, friends, leisure activities etc.) We feel tired of it all and lonely because it seems there are so few people who really care about Rachel and her quality of life and what her family must face daily. I worry constantly about her future and at times resent that we will always require "baby-sitting" for her. It seems to bring out the best in me and the worst in me. Reading the comments from the parents used in this questionnaire helps me realize(remember) that we're really not alone in our struggle and the way we feel.

514 We see Russell as a great gift entrusted to us by God. He has been an unbelievable joy to our whole family. The learning is endless and the gifts he has given to all of us to see inside ourselves and become better people is an experience I never dreamed of. Our 19 year old learning disabled/ADD child; Russell's sister was a daily stress and burnout on our family but in the long run made us strong and showed us how little we knew about living. Because of her we had the courage... and want to raise another special needs child. This time around there is no burnout and we've learned how to live from hour to hour and day to day and to find endless enjoyment within our family.

515 Barry was not diagnosed until he was nearly two. The G.P. kept saying don't worry; he's just slow; now he'll catch up. I feel G.P.'s need more education in child development so as to be able to spot problems earlier. Neurologists (or whoever breaks the news to the parents re the child's condition) need to consider how to do this in a compassionate way. I believe they give you the worse case scenario and make things seem pretty bleak. After I left the neurological assessment he had told me that my son would be very slow all his life, etc., I was devastated and didn't know what to do; I didn't know whether to believe him, as his manner was not very personable toward the child and he was judgemental on issues that seemed relevant. I was upset and angry at him, the neurologist. How can they learn to be a little gentler in breaking the news?

516 I have had advantages that many other parents didn't have - supportive parents, an education and financial resources (sometimes). Last year was our first holiday without Kevin (one week). I am so worried about what will happen when I can't be responsible. Last winter I had a bad car accident. That made me realize that I need to have plans made and in place - just in case. But always I seem to struggle alone, even when I'm getting help, I am the responsible person, the one in charge. I need someone to take over the responsibility - maybe I need someone to worry for me.

517 There are many negative attitudes, even among the people working with children with disabilities (teachers, doctors, social workers, politicians, community service personnel) and these attitudes need to be challenged. Parents need to be listened to, their ideas and view points respected and they must have a say in what happens to their child.

518 Now that both Paul and David have finished high school (integrated for the last nine years) there is nothing available to them except the sheltered workshop. It seems ludicrous and unacceptable to me to spend years fighting for and supporting integrated education only to graduate into a segregated work center. The few supported work programs that exist cannot provide the level of support either of them needs. On the other hand, staying at home doing nothing is also unacceptable. So as a family we start again -- fighting to develop a desperately needed service and if necessary (as in our case) you do it yourself. We have started a small family-based cottage industry as a place for our sons to work. It seems that at each transition stage you have to go back to square one and start all over again. It's the same song, second verse (or 20th verse!). Although you can celebrate the successes, it is not easy to come to grips with the fact that it will never end. Life is a series of transitions from one stage to another and with each new stage you are confronted with the same issues over and over again. Hard as it is, you don't dare allow yourself the luxury of getting discouraged because if you do, you might give up the struggle. And if we as parents and families give up, there is no one else (least of all government) you can depend on to ensure that our children's rights and well-being are protected. So life goes on !!

APPENDIX J

APPENDIX J

Mother's Comments: Sorted by Questionss

Question 1

SITE 1

Briefly tell me one positive experience you have had with reference to your child with disabilities.

101 I learned to enjoy the <u>small</u> things in life because John's milestones don't happen that fast like other children.

102 We live in a small town and Kathie was born here. She has been very well accepted by the community. We bring her everywhere we go. The people downtown (grocery store, bank, drugstore) seem to look forward to her visits. They go out of their way to say hello and ask how she's doing. Kathie has a very bright personality and it is hard for people who seem afraid of her to ignore her for long -- but the people here seem to truly enjoy her.

103 I have been able to meet a lot of nice people that I would not have had an opportunity to meet otherwise. I have been made aware of needs for all children that are not being met and have started to become active in this area.

104 Even though she is severely handicapped our family, relatives and school teachers seem to all work together to take care of her, watch over her and everyone is interested in what kind of progress she has made. Everyone really loves her and try to help us work with her. We've never had any problems with the help from school or therapists. They all listen to every concern or achievement. Only one doctor gave us any problem and we were able to find a new one that was more helpful. Overall she's been a real blessing to all of us.

105 Having a child with a disability has made me much more aware of the number of people with disabilities. We are not alone. We have a wonderful support group here and a great early intervention program. We also take our daughter to therapy once a week to a local hospital for O.T and P.T. as well as once a week she gets it in the home through the early intervention program. They work well together, the hospital and school. Work on same goals and plans. Always very positive. Really work for the child. We feel very fortunate. Things could be a lot worse.

106 Each day Carl's speech grows little by little and when he hears a new word he repeats it quite a bit.

107 Everything about my son is positive to me. I am lucky to have him. He almost died on me several times. I love him so much. But life sure isn't fair to him and our family. He is such a happy child. Every accomplishment to me a big deal.

108 I'd have to say the "overall positive" experience we as a family must focus on is that how something so terribly devastating (birth of a special needs child) has turned into such an enriching experience.

109 We recently started going to a new church that is more accessible than our old one. Anne was immediately accepted there. They moved her Sunday school class to a more accessible area after we had gone there only a few times. The pastor's wife told me recently that Anne had added so much to the congregation.

110 Because of Sarah, we have met so many new wonderful people.

111 Kindergarten - The teacher was wonderful and his one-on-one management aide was superb. She knew when to step back and let the kids take charge. The first day the class was told why Harrow was in a wheelchair and how to use the wheelchair etc. They took over. He had a wonderful year!

112 She has taught me to <u>really</u> appreciate each developmental milestone with her and with her younger siblings. She's helped me count our blessings and realize how fortunate health and "normal" development are. She has taught me what patience is. I have also become more self confident in standing up for her rights and getting what she needs. We have been very successful in getting what she needs.

113 Integration (inclusion) has been a positive experience for us. When our son was in a segregated school, we would take him shopping or somewhere else in the community and he was a stranger to all. People just stared. But now with him integrated at school and socially, everywhere we go, people speak to him or say "Hi" to him. (Making our whole family more acceptable.)

114 Tabitha has taught me compassion and is working on teaching me patience. It would be a better world with more Tabitha's as she is a very loving, touching child.

115 No Response.

SITE 2

Briefly tell me one positive experience you have had with reference to your child with disabilities.

201 My daughter has worked in supportive employment for the last few years, this could only have been done with the proper support system in place for her. I never thought she would be a productive member of society, but everyone that knows her and cared about her -- we had to give her the opportunity to try and succeed, which is no different than what you want for your normal children.

202 Finally having someone in Adult Services actually take the time to get Jake out and get him a job in the community. But until we said we were taking him out of the program and gave them a deadline -- no one did anything. Then a miracle -- Jake has a community job and is making enough each week to buy his music. Thank goodness for this one very excellent person.

203 Many positive experiences come to mind -- (1) Attending her high school prom with her and escort. (2) Going thru graduation with cap, gown. (3) Working in the community since completing high school -- same place now for 4 years, 3 months -- quite a record. (4) To share her relationship with her nephew -- he loves her dearly.

204 No response

205 She loves animals.

206 She has brought a lot of happiness and love to me and others with her willingness to learn and her care about others like her.

207 He is 41 years old, and has worked for a over a year at a part-time job. Most of the time he hates going to work and blames me because he has to! The rest of the time he loves job, and responsibility, and pay check. The positive time is when he is content!

208 Positive experiences include: local acceptance; commendation on her work-attitude. I have met some fine teachers.

209 Many people treat him very well. We had a graduation open house with all the trimmings. A good crowd from family and church came. No school people, though they were invited. Tom stood at the guest book and opened presents and cards and felt very special. He probably had more guests than the "regular graduates."

210 Marilyn was at a Jr. High School for her last 2 or 3 years of public school. This was a very open setting which she enjoyed a lot. It did great things for her self-esteem. Her teacher was wonderful.

211 Steven has taught me how to love. He will ask for a kiss or sometimes he says he loves Mom just because he does -- not because he wants anything in particular. He has no subterfuge or guile. He has no ability to dissemble. He is totally honest and innocent. It is remarkable knowing that you are loved by him just because you're you. I cannot help but love him back. Although his autism often is a barrier to meaningful social interactions, his beautiful soul shines through his disability.

212 Noted Kenneth's ability to understand complex assemblies by his seeing it done -- and based on his intense interest; he can do anything with his hands.

213 Keith was born normal. At 8 mos. old, he had double ear infection which resulted in high fever causing brain damage and epilepsy. I, his mother, have stayed in the home and taken care of him for 35 years. He went to a special school, not public school, till he was 18 yr. My husband and I taught him everyday necessities and it has been a joy to see him learn nd progress each year. Now that his Dad is deceased, we live alone and he takes care of me as well as I him. I give myself space and balance out each other's activities and pleasures, so neither of us feels neglected.

214 He is not as bad i.e. as severely disabled, as a lot of people. He's not like you and I, and he's not like others. He's in between. He relates to normal people better. If I go away to visit, he always cleans the house when I'm gone.

215 Special people who really cared provided positive experiences.

216 His accomplishments have taken on a more important meaning for all of us in the family, including him. There's real pride at doing well on a spelling test or getting a happy face on a workbook exercise. We feel happy at smaller advances than with our daughter -- everything is in perspective. And he has had marvelous teachers who went beyond their normal duties to include him and teach him as if he had no disability.

217 Marcia is a very loving child-adult. She will always say "I love you" if I have had a bad day. She is very caring about others and their feelings. She is a joy and we love her just as she is. We do many family things together and she loves them -- trips, visit friends, eating out, etc.

218 My child is now 42 years of age and I feel that almost every facet of his life has been a positive experience. At the age of 18 months (we) were told we should put him in an institution and forget we ever had him, so I feel very positive about everything he has been able to accomplish.

219 One positive experience with Dianna was her helping make her bed, vacuum her room, empty waste basket, etc. Household chores has been positive! Especially in room. I have to do rest of house. Cooking in microwave, etc. is another positive experience.

220 On his own he made the effort to go to the mall and bought me a birthday present he knew I would really enjoy. This involved him dealing with people (which he has difficulty doing), the rural transit system and spending his own money.

221 We moved a year ago and she has felt that things here are really hers and she can give her opinion on various things.

222 The fantastic physical therapist that helped Elaine to walk by age 3 1/2 -- an example of excellent, caring people who have helped Elaine.

223 She is 28 years old. She has given us 28 years of total love and joy. We feel that as parents her loving presence has completely overshadowed her disabilities. She enriches our lives every day. We are indeed fortunate to have her.

224 No Response

225 As our daughter was growing and maturing, there were little improvements all along, altho' they sometimes were minute. It is encouraging that she can live in her own apartment. She is a loving, agreeable member of our family. She frequently comes to our place to assist in yard and garden work, and we often do sewing projects together. We can share jokes and funny stories and we have a common faith in God and worship together regularly.

226 The Association and Vocational Rehabilitation have worked really hard to prepare Ken for his "outside" employment. From the beginning, I was included in every decision and was well informed. I also was able to call anytime and was treated with respect and also helped until I was satisfied.

227 We have learned and felt all the good feelings so many people have toward our daughter. We are square dancers and our daughter has gone with us lots. She has so many good friends, it is unbelievable. Also our son's friends have always been the same way.

228 After we both got cancer we had to make sure that he would be taken care of. They accepted him, after 1 1/2 years of trying, into a group home which relieved both of us for his future. His mother may have only a few more days to live that is why the first questionnaire was not filled out. I'm sure that my wife would have answered these a little different.

229 Positive experiences include: being told that he is the "highest producer" in his workshop and the best worker they've ever had; being told that he has always been the peer model in every class or group he has been in (i.e. perfect manners, appropriate behaviour, most well groomed); last, being told that I would be a good teacher of DD's, since I've done such a super job.

SITE 3

Briefly tell me one positive experience you have had with reference to your child with disabilities.

301 Since Andrew was 5 we enrolled him in the local soccer programs. He was able to participate well. It was a real thrill when his team came first place in the championship the year before last.

302 Ray enjoys going to the sheltered workshop and the staff there are very co-operative and caring. In the summer of 1992, he worked with a car salesman, cleaning cars inside and out, cutting grass with riding lawn mowers at his place and at all his apartments. It meant great social growth and much happiness for Ray.

303 Rather I enjoy taking her to the malls where she can meet some of her friends which she enjoys. What I don't like is the way some people stare and talk behind your back about her disability and feel sorry for her being in the wheelchair. She has accepted this in her life and does have pride in herself and doesn't need anyone's pity for being in a wheelchair.

304 Nathan has met some beautiful people in his life, people who really cared about his health. He has come close to death so many times, and was sent on a wish trip to see Billy Rae Cyrus, the singer. We went as a family and it was beautiful. Nathan loves to sing - he has a Karaoke machine at home and enjoys it immensely.

305 My positive experience given to me by my children (with disabilities) is the personal growth and strength that they have instilled in me. I diagnosed my own children with a very rare disorder. I have travelled to lecture to geneticists in the U.S., I have been in contact with Nobel prize winning geneticists, lectured at universities, contacted other children's families around the world, who also have this syndrome, and I work closely with 8 organizations and committees that deal with disability issues. All of which has been opened up to me by my children.

306 Barbara works at a sheltered adult workshop. When she got in there and got settled and as time went on it was a positive experience for her. She's now 27 years old and very happy with her work and friends.

307 The most positive experience was the day my daughter took her first steps with leg braces on.

308 Nick is generally a very likable boy. He has his way of getting into people's hearts, with his smile, and the way he looks at you. People bond to him very easily,

(he also is very cute, which helps). Because of this, the people working with him always go the extra mile for Nick. He brings out the best in them, without knowingly manipulating, which always works to his advantage. I'd say that the most positive experience of having a handicapped child is getting to know all those really wonderful, caring people who chose to be involved with handicapped persons, not for the money (there's never enough) but because their hearts are in the right place.

309 No response.

310 My child was diagnosed as severely retarded. She did not walk till she was nearly four years old. My physio worker was very helpful to me in trying various ways to help her walk. She also did not like to touch things so had to be desensitized. Also any trips I've gone on to the children's hospital in Capital City...they have been great.

311 The physician told us that Jack was hopeless - there was no hope - would never walk, talk, sit up, hear have no control over his elimination, take seizure, he is total and complete care - put him in an institution. I was 8 weeks pregnant for my little girl who is 11 months younger. I told that doctor to go to hell and if it was the last thing I ever done I would prove him wrong. That was September 1991. September 1993 I took Jack to him as we regularly do. Jack can hear a minute drop. I put him in the floor and he sat up all on his own. He smiled and hugged his mother. He responded to my praise and put his hands together to clap. I was so happy and proud of my boy. The doctor couldn't believe his eyes. He said I am happy for you and your husband, I really am, if I didn't see it I wouldn't believe it. My response "Love can work miracles."

312 No response

313 With Sam there has been many. One comes to mind. His music teacher taught Sam to play a cymbol on a drum, his right hand was good. At Xmas Sam did a solo on this drum with the music teacher playing along on the piano, and he did a great job. And when he finished his arm went up in the air with the biggest smile on his face.

314 Grade one has been a wonderfully positive experience for Paul and everyone involved in his life. He is fully integrated into a regular classroom and spends only 20-30 minutes/day out of class working on computer skills. He has a 1-1 aide who (next to his parents) is the greatest "break" he ever got. They have been together in daycare, kindergarten, preschool, and now school since 1991. She also does respite. Paul has learned and been able to show he knows the grade one work. He gets most of his cues from his classmates and models their

behaviour. He can type, print some (independently) but most exciting of all he has began to speak.

315 School has been a positive experience for us. For the most part he has had good teachers and assistants. We have kept a good line of communication between the assistant, teacher and myself. Flexibility in program and teaching methods is very important. The best teacher assistants he had were the ones who became more involved with us as a family. This goes back to communication - you have to keep the lines open by inquiring what kind of program they are following.
316 My two sons are both hearing impaired, they also have X disease. We also lost one little boy to X disease. We have had lots of support from our school. My positive experience is to see my children accomplish so much in such a short period of time.

317 I have three sons with disabilities. When my eldest son was 3 1/2 years old I was going through a lot of denial and felt very angry. A worker started to visit our home twice a week. She played with David (it was a stimulation program). She accepted David as he was. She helped to show me that the most important part of our relationship is love. David needed my love and I needed his. Through the years (and difficulties) remembering her and the lesson learned sustained me many times.

SITE 4

Briefly tell me one positive experience you have had with reference to your child with disabilities.

401 There are many positive experiences: when she smiles and laughs - they are real. She also started to say "Mom" 2 years ago when she was 18!!! I know she loves me too.

402 I've learned more about various mental and physical disabilities, and am not afraid of them or so curious about individuals with differences now. Because I've spent so much time in hospitals, rehabilitation centres, developmental centres, group homes, Association meetings, parent to parent support group meetings etc. And therefore my children have learned to be more caring, open and expecting of others with differences than say my generation was.

403 I have had many professionals involved with Naomi since her birth and so many of them could not do enough for her. I never knew how many people really care when something happens that is difficult in your life.

404 One positive experience was Joseph's involvement in Dr. Merton's language class where Pat Gray worked with Joseph's language development, daily for 6 weeks, in 1984. Joseph's work placements via his high school have all been excellent, productive and individualized and Special Olympics soccer has been excellent.

405 All of our positive experiences come to us in the regular, non-disabled world. Here are two:

1. When Thomas started nursery school (not a special one, but our neighbourhood preschool where emphasis is learning thru play) his teacher observed that, at age 3, he was quite mature socially - more so than several other 3 yr olds in the class. She always minimizes his differentness and enjoys his progress.
2. At church school the team of teachers and assistants have taken seriously their role in Thomas's spiritual life, including him in every way and keen to help prepare him for Kindergarten. Teachers (who are remarkable women) have told me how much they're learning from him and how glad they are that he is there.

406 Beverly has a younger sister, whom we have brought up, with the openness of various handicaps. Neighbour has a child with cerebral palsy, parents we know have other children with Downs Syndrome and Beverly's sister thinks no differently of these children, than her sister. She is not afraid, nor ashamed. This I feel is

because of Beverly. She shows her sister true love. She has taught her sister how to love unconditionally.

407 The school has been great and the children are extremely friendly to our daughter. Our physiotherapist, Helen, can handle my anxieties amazingly well. I never want to give her up.

408 After childhood and teen/early twenties years of self-abusive behaviours, irritability at just about everything, to see and hear Stewart, albeit with a heavy daily drug dosage, enjoying life at least a little - teasing and enjoying being tickled and smiling! After years and years of those terrible alone look in his eyes or no expression at all, this has been wonderful! and is wonderful he really enjoys coming home but spends majority of time asleep unless cajoled into action!

409 I remember the nurses from the well-baby clinic coming to the farm and talking with me about problems I had dealing with my child. For many years they were the only ones who understood the problems I was having. There was one older nurse who was especially good, her name was Mrs. Jones, she kept turning up whenever things were going down hill - I will be eternally grateful to her.

410 Can I please tell you at least three positive experiences?
1. Having Wayne. We love him to pieces and he has really brought our family even closer. 2. Having a good physiotherapist right from the beginning. She was excellent for giving us ideas of activities to do at home. That's what we wanted. She was good at including Wayne's twin in the activities too. 3. Going to the "Institutes for the Achievement of Human Potential" in Philadelphia - now there were professionals who cared and believed in your child and in you as parents. They had excellent ideas too with explanations of why you were doing the activities. The professionals worked together as a team in Philadelphia - unlike here at home where you see the professionals, if you're lucky, separately and they all have different ideas - no correlation!

411 We have a wonderful speech pathologist. She treats Carla and me with dignity and tries to improve Carla's speech although there's often little improvement.

412 There have been many positive experiences. Martha's acceptance and treatment as one of the children by our friends, people at church (children's Liturgy group), at the daycare, at school, at the grocery store, has been very positive. We hope Martha's integration into society will continue to be this positive. We are trying to insure this by teaching her appropriate behaviour and language skills.

413 When my youngest son, whose prognosis in infancy was to be an "autistic vegetable", first learned to play, then walk (age 4), talk (5+) and then read (7+). He

now reads at his age level, talks very well, climbs and runs, and has emerged from most of the symptoms of his early autism. He is now very sociable, friendly and outgoing - seeking human contact, cuddles and has friends. He's apparently making up for lost time in early childhood.

414 No response

415 No response

416 No response

417 No response

418 Anytime someone truly listens or treats me with respect I feel hopeful that we can make some progress

SITE 5

Briefly tell me one positive experience you have had with reference to your child with disabilities.

501 Harry P. and the Recreation Association. I cannot praise them highly enough. For years they have been a tremendous support helping my son integrate into their regular programs. Our contact with Social services/ Dept. of Ed/ Vocational Services have gone very smoothly. Sam is in the food services course - he has a teacher assistant. The cooperation from all the participants has been beyond our expectations.

502 Matthew has made our world look different since his birth, his special smile and way he makes our life happy in different ways , he truly is an " Angel on Earth". Our other son Brady who is six also feels this way. I think Matthew has made a lot of positive differences in people's lives, not just our own. His strength and happiness and will to overcome gives others strength to do the same. I will continue to look after him, for as long as he is on this earth, also I will continue to fight for the rights and supports of these special children in this province.

503 When Virginia and I are together, she smiles continuously. Her non-verbal communication has improved and rewarding her efforts to communicate gives me a great deal of satisfaction. Virginia is determined and truly terrific. She is a fighter, like her mom. We've fought the system and for the most part have gotten services.

504 This is hard to list only one positive experience as Edward is a "positive experience", by his wonderful loving manner, friendly nature, tremendous personality and a gift from God that my family and I would not have wanted to miss.

505 Everyone needs to be cared for and loved unconditionally! Do you really need to walk, talk and eat like the majority of us do? There are other ways to do these things. My son does not walk, he strolls. My son does not talk "normally" he laughs. My son does not eat "normally" he's tube fed. Marshall is a big part of my life as I am a big part of his.

506 I assume you are referring to experiences dealing with the "system". I could only account for two in all my son's 18 years. It was the year he attended X Day care (integrated)- 4yrs. old. The other was 1993, when I had a teacher work one on one with Chester for the whole year at home. He had regressed to the point of not leaving his bed and after a long "battle", I required financial help to have someone come into the home and work with Chester to lift up his self esteem and gradually get him out of the house and back to school. Many road blocks were put in place by the "powers" that be, but I fought all the way for my son. Needless to say I have no "friends" in the system (government or school).

507 Graduation from daycare. He took his part as the Doctor in "Miss Polly" and Jack in "Jack be Nimble" with all the "Normal" children and was accepted without a second thought. It made me proud but also gave me hope.

508 That is a hard question. I feel that our family tries more to concentrate on Stanley's abilities more so than his disabilities. By doing this I feel that Stanley becomes more like them unlike his peers and friends, so Stanley's everyday accomplishments such as getting up, bathing, brushing teeth, hair etc. independently as possible makes us all feel good and ensures us that he is growing and developing at a nice rate.

509 Watching her during this last year of school has been a positive experience: integrated fully in our neighbourhood school; making progress in many aspects. She's happier, more content, more aware! Watching how the other children - her peers - interact and include her in the activities - make and send home "tactile artwork" for her, that they've done on their own time at home! She does not stand apart from her classmates but belongs!

510 He is a pleasure to have! I find it difficult to separate our life into positives and negatives. He's a dynamic, independently minded child who fills us with all sorts of positive experiences. He rises in the morning with a smile and a warm hug, he often sits on a lap and holds your cheeks in his hands and smiles at you with his sky blue eyes. He tries to be funny and challenges himself to be courageous and daring. He finds ways (his own signs, or taking your hand) to communicate his message, to get what he wants. He is a joy to have as are his two sisters.

511 Megan was chosen princess for Valentine in her classroom this year and competed with the other kids in junior high for Queen. As each one's name was called she clapped and cheered for that participant and was satisfied with being a class rep and receiving her rose and box of chocolates.

512 There certainly have been many positive experiences but the one that stands out the most is when Dennis started communicating via facilitated communication. His knowledge and insight never ceases to amaze us. The individual we always suspected was there is now coming to the forefront.

513 One extremely positive experience was after my daughter was integrated in her neighbourhood school in year 2. I had several parents come to me and tell how much their children were learning from Rachel and how great it was that she was in their class. It made all our struggles seem worthwhile.

514 Probably the most positive experience we have had (one of many) with Russell has been the surgeon he has had for his bowel and stomach surgeries.

This doctor is exceptional in that he sees Russell as a disabled child who has endless "secrets" to share with us and we are never to ever try to guess what his limits are as he is capable of surpassing and achieving what we are sure he is not capable of. Even when I gave up hope on the operations done on Russell and the pain he was going through, this doctor made me see that Russell has every right to a "normal" life as any other child. He never ceased to be amazed by Russell's progress and shared his faith in Russell with us. Most important he really listened to what we said!

515 One of the first professionals to work with him was an "occupational therapist". At first I was sceptical about what her profession could do for him, but it turned out to be one of the most beneficial "therapies". She worked hand-over-hand with him and demonstrated clearly how to achieve certain goals.

516 We had two fantastic teachers, one in Primary and one a "special educator" who taught Phillip from Grades 3-7. The second lady made sure that Phillip was included where and whenever it was possible. She made sure that I didn't feel responsible for every mis-behaviour - the "fault" was not mine. She was knowledgable and caring. That combination made a difference.

517 Nancy's removal from the training center happened as a result of a very negative experience; but she went into a group home and then a small option home. A planning team and then a transition team were set up around Nancy to plan for her future. This proved to be very positive and successful because I was given leeway to choose the team members and to set it up in such a way that I addressed Nancy's needs. With the help of the Minister of community services, all road blocks were removed. Nancy now has many caring, supportive and dedicated individuals around her.

518 A formal "circle" of friends was established for Paul in high school that lasted for 3 1/2 years and over time developed into more natural friendships. Lots of in-school and out-of-school activities - dances, hockey games, hanging out at the mall etc. One friendship continues two years after graduation. David, Paul's brother, worked two summers job shadowing a meter reader for the Power company and one summer for a municipal parks and recreation service. The boost to his confidence and self-esteem were incredible. He gained a maturity and sense of responsibility that really surprised us.

Question 2

SITE 1

Briefly tell me one negative experience you have had with reference to your child with disabilities.

101 Being told by medical professionals what John would probably never do was a negative experience for me.

102 We visited a church where our parents live and sat next to a family. The teenage daughter noticed Kathie and seemed physically repulsed by her. She moved away from Kathie (we were in the same pew) and looked surreptitiously at Kathie the whole time. We ignored her and treated Kathie like we always do. Kathie even tried 'to make friends' with her but she was very put off. I grew more uncomfortable and was glad to leave. It was the first time Kathie hadn't "won over" a disability-shy person with her charm.

103 Most of the negative experiences come from 2 sources:

1. A clinic where I do not feel that I or my child were treated as people, just cattle being shuffled thru the system. I also feel our rights were violated, only I was so overwhelmed at the time I did not say anything. Next time I will.
2. My husband will not accept the fact that our child has special needs, he is convinced she is just a little behind and will out grow it. I don't know how to make him understand her DNA will never change, she is who she is. Also his family does not understand what is going on and my family is nervous when the subject is brought up.

104 Sometimes it becomes very difficult to know what she needs because she can't talk. We don't always know if she has an ear ache or the flu before its already too late. Tantrums can be a problem when she can't get her point across for what she wants.

105 It has been a very frustrating 2½ years. We have been going to doctors and running test after test to come up with a diagnosis other than cerebral palsy. We still have no answers. They will not even guess an opinion if your child will walk or not, or talk, or how disabled she will be. It's very hard to plan for the future when you don't know what to expect. As she is getting older and bigger things are getting harder.(e.g. Always need a stroller, too big to carry). It's also more obvious to other people that our child is disabled. More looks, more stares.

106 Carl has problems with understanding what's right and what's wrong. He doesn't listen very well like he should for his age.

107 The "Hell" we have to go through with the medical attention and surgeries for my son. He has been hurt by a doctor in the past, when he was 7 months old. Now it still is so "hard" for "trust" for anyone in the medical field. He very much depends on Mama to pull him through.

108 Our constant battle is, of course, with the school system. I want to mainstream my child and I feel they are guiding me away from it. Worse than that, I feel a total year of my child's life was wasted with a "professional" incompetent in her job during a very important year of development.

109 Nothing really sticks out in my mind, as a negative experience. There have been many experiences with my daughter that have been unpleasant, mostly going to doctor's appointments and going to public places that were not accessible. Probably the worst time was when she was only a few weeks old she was put in the hospital. We didn't know if she would live or not. It was a very painful experience.

110 Our principal is against inclusion and has made "me" the Mom, the bad guy in the entire process.

111 Neurologist - Never explains why he's continuing with meds. Will my son ever be able to go off medication or will the injuries always be there no matter what?

112 I was told my daughter couldn't go on a field trip from the Y unless I went with her because she would get too tired. (She learned to walk late and they were walking). I was going to send a stroller. What they needed was more adult supervision, it shouldn't have had to have been me. Other parents were asked, if they wanted to come; I was told I had to come. Later they realized they were wrong.

113 There is no help or support at all to the struggles that go on in areas of family life other than school time. Two simple examples that come to mind are negative behavior at a doctor's or dental office, (what its like when that child tantrums or will not wait in the waiting room); or will not cooperate with a haircut. We had some eating problems and refusal to come to the dinner table with the family. Some of those behavior problems can almost drive a family "over the edge" and they don't fit into the neat little categories of a professional's workload. So who offers suggestions? Nobody. Generally the family would continue "over the edge". We were lucky.

114 The negative side would be that she requires so much of my time that there is nothing left for her older brother. I am forever guilty that I am missing his

childhood. She will not even allow me to provide him comfort when he is sick, as he wants me.

115 When I first found out she had disabilities, I talked to <u>so many</u> people (professionals) and no one knew what was going on, who to send me to, and who could help me.

SITE 2

Briefly tell me one negative experience you have had with reference to your child with disabilities.

201 Being told to put your 5 year old autistic child in an institution and to forget her was a negative experience. I was told this by a doctor. I was determined to prove him wrong.

202 Having an attendant at the local "Fun Night" point to Jake and say, "He can't ride -- he's handicapped!"

203 The frustration of repeating instructions only to have her fail to follow. Recently told her to come home after work; no bus training that day. She went anyway, no phone call, we were frantic as I was in a business meeting for 3 hours when I got back to my desk, I discovered she was not home -- as she rides a taxi home everyday, your mind can imagine a lot of things that might go wrong. Hopefully she learned a lesson. Also, cannot get her to use a phone recorder.

204 My son is 6'3" and weighs 382 lbs; when we go into a store where toys are sold, people stare and make fun of a man his size playing with toys. You can't educate people that aren't willing to learn.

205 She seems to want us to leave her alone -- so she can be more independent.

206 Some people do not know how to accept her. Lots of people make fun of her or do not want anything to do with her.

207 His blaming me for everything that doesn't please him or he doesn't want to do at that time, in that place is a negative experience for me. He becomes angry and highly upset with his job and wants to return to the sheltered workshop.

208 Years ago the IEP's were presented in an unprofessional and negative format.

209 A pediatrician put him on Tegretal. He got very bad headaches and became violent. The pediatrician told me we'd just have to institutionalize him -- some get violent. We had done the best we could do. He denied it was the Tegretal and wouldn't change it. Another physician intervened and within 3 days Tom was an angel again. He had headaches for 6 months after going off Tegretal. The only "apology" from the first physician was when he told me later a 3 year old girl did the same thing.

210 I was actually called by a psychologist (that we had taken Marilyn to for evaluation) and told that he had found an institution that would take her. His comments were that we should put her in since she would never be an asset to our family. I hung up on him since I hadn't requested this.

211 When he was younger he had to go to the hospital to have tubes put in his ears. Despite our advance pleas to the hospital staff and our careful arrangements for timing, he was kept waiting almost 3 hours after he was scheduled for surgery -- this was intolerable for him and needlessly hard. I was so angry at the hospital staff and the doctor for not taking his disability into account when scheduling the surgery, especially after we had told them that he could not be kept waiting.

212 A negative experience for us was a Professional that told us, "Forget about it, he'll never learn anything"; Wrong!!! A neurologist that told us: they have him down as low as a dog -- you should put him in an institution -- so he won't be sitting in a corner drooling when his older sisters bring home dates. Dropped this neurologist immediately. Kenneth was 5 at the time and in kindergarten; this was when we learned he was retarded, but they kept him in kindergarten class -- since he was the most sociable child in there -- and the others could learn from him.

213 As much as I would like to see him interact with so-called "normal people," it is difficult to fit in sometimes. His speech is a hindrance to social inter-action some of time. Even if he could talk clearly, his vocabulary is limited for having a good conversation.

214 The fact that he doesn't understand the value of money is a negative experience.

215 A negative experience for us was a Public school who didn't want to provide!

216 The manner in which the team of geneticists broke the news of his rare chromosomal disorder bordered on the criminal -- The specialists never considered the impact of what they were revealing and were (more) caught up in the probability of his passing it on to another generation than our interest in the immediate impact on his own life.

217 There has not been any big negative experience with Marcia. At first, when she was little, it bothered me some when people looked at her -- the way she walks -- but that does not bother me anymore.

218 The most negative experience we have had was when he reached school age and there was absolutely no education facilities for mentally handicapped persons. We made an appointment with the superintendent of schools in our county to ask

him what we could do but when we told him our problem he got up from his desk, opened the door for us to leave, and told us there was absolutely nothing he could do for us. That was when we started trying to find some other parents of disabled children and get a support group started.

219 Dianna needs help in preparing to go places, especially, appointments. She takes hours to get dressed, etc. She often will not be ready to go when anyone asks.

220 Everyday home life is a negative experience for me. His father could not accept that something was wrong. Tension, stress. Dealing with Joe & his two younger brothers.

221 No Response

222 The drs. told me to put Elaine in an institution and forget her -- this was at age 1 1/2 yrs -- they said there was no hope.

223 From time to time another family has not wanted their child to associate with Mary because of her disabilities.

224 No Response

225 I guess the thing that has frustrated me most over the years is her inability to get ready on time when we all need to be some place at a certain time. On the other hand when it is time for a certain program on TV or radio that she wants to watch, she knows exactly when to turn on the set.

226 At birth -- shortly after he came home from hospital -- doctor suggested he be put in institution, that there was no hope. After changing doctors, I have been blessed with professionals that truly care about my son and myself.

227 The negative part has always come from adults that should know better, such as schools, teachers. We were told our daughter could not go to one school. We moved and enrolled her in another school, bought a house and less than 2 weeks later, school authority brought her home and said she could not go to school there. This was a special education class, and we talked with the leaders before we ever moved, and placed her in this class.

228 No Response

SITE 3

Briefly tell me one negative experience you have had with reference to your child with disabilities.

301 My biggest disappointment was 2 years ago. I discovered quite by accident. that Andrew was being punished at school by being confined to a very small room, no windows, door closed and no activities. He had been there every recess, noon and break for a period of two weeks before my discovery, and it was to continue until the end of the school year which was about another month. I might add the people enforcing this punishment were told by the principle that I hade been notified, which I had not been.

302 Ray is very determined in what he does, what he wears, etc. and getting worse. He bothers me in that he is so very curious, who I am talking to on the phone, what people are doing, where I go, what time I got home, etc. and spreads all our goings-on thus we feel we have no privacy. Ray always helped evenings on the farm with his brother, but this past winter had several falls on the ice while transferring from one bus to another, hurt his back, and lost all interest in the farm.

303 It occurred in the mall one day and occurred in the front yard as people would call her retarded which she is not but some people are just plain arrogant. Too bad they couldn't change places with Debra Anne and realize what she needs is support.

304 This past two years have been the worst to say the least. My son was abused by two teachers in different schools. On one occasion, he came home with his jogging suit ripped down the middle (front). When I confronted them, it was all hushed up. He was diagnosed with Tourette's this year. Also attention deficit disorder. When under stress, the tics erupt, then he has seizures. I have had to call (X television program) besides K.M. and MLA, to get help to remove him from school after he collapsed on 5 different occasions and was hospitalized each time. They would not listen to me as a parent, were ignorant and I have never, and do not ever intend to go thru that again with any school system. I saw "abuse" that makes me sick, I am presently in human services course myself and thank God for TS, KC and JM, because I knew (I) was OK, otherwise those school professionals would have convinced me I were the crazy one. In order for you to change society, we have to listen to parents, to our clients (mentally handicapped) who never seem to have a say, and the abuse has to stop because innocent people are getting hurt by professionals who themselves are abusive. I've seen it. It's a power trip with them. I will never let them hurt my son again. I'll go where I have to. The X television program would have taken our story, but by then, they changed schools for him. I wanted him with his aide. It's hard for me as a single parent to believe what is going on with our system. I truly hope there will be more help with respite care, because

282

I for one have been with my son alone for years. It would be nice to have some free time, something we as parents do not have. Social services is supporting me (with money) to get through my course, but they do not support us with our handicapped children. We are the minority not having a voice. I hope someday to be able to help other children not to have to go through what my son went through - or my family - to get help. Our handicapped adults and parents are being abused by professionals who don't know or care what it's all about. Let them walk in our shoes for awhile.

305 It's hard enough coping with the fact that I have 2 children with disabilities, and as a mother I'm always fighting to attain or retain services that are basic for their quality of life. I'm always spreading myself thin; trying to be involved educationally and medically. Just 3 weeks ago I almost lost my oldest daughter to a blood disease, and at the same time I'm battling with government over the closure of our regional school for the blind and hearing impaired, and with the local school boards and professionals over my youngest daughter starting school this fall, to mention a few ongoing issues. It's exasperating!

306 When she made the change from a child development class where she was quite sheltered, to a junior high situation. That was quite negative for both of us at first. However, she settled in, had a great special education teacher and things worked out well.

307 The most negative experience was the day my daughter blamed herself for having spina bifida - since then she has very low self esteem/confidence in herself.

308 It has been far more difficult for me to deal with schools and trying to get services which I felt necessary for my child than it is to deal with all his disabilities (which are numerous). It was easier for us to move our family (which we did twice in three years) to get a better situation for Nick, than the stress, and aggravation of inadequate services and schooling.

309 There is a "neighbour" in our neighbourhood who cannot accept our boy as "special needs". She goes out of her way to be nasty and say hurtful things. She calls him "Satan" and told him the reason he was adopted was because his own family couldn't stand him.

310 I would have liked more input from speech therapy. It is very hard to get any help in this area.

311 At physio-therapy, the therapist never telling Jack who she is, what she is about to do, or change of position. Always complaining of his size and how heavy he is. Been very hard and rough with Jack, letting him fall and not being told. I was

not happy with her behaviour towards my son. She asked to be removed from the case. Never giving Jack any praise or reassurance.

312 No response.

313 He's lucky he has 3 close friends that come over quite a bit, but its sad when he asks why he's hardly ever invited back. Its not the kids, but the parents. I know they don't owe him anything, but he's a kid who also wants to go out.

314 Our most negative experience would have to be dealing with the 1 week in the hospital in Capital City. It took over a year just to see these people who were supposed to know a thing or two but, sadly, they are still in the dark ages as far as autism is concerned, and if I'd followed their advice I'm sure he wouldn't be doing as well as he is.

315 The one thing that really sticks out in my mind is the attitude of some physicians and therapists. I constantly get the feeling that I am not pushing my son hard enough. I hate going back for a spina bifida clinic for example if: He is not putting on pants or tying shoes like they said he should be. The problem is that I don't feel the therapists can empathisize with the situation. My child has to want to do these things. They don't have to be with him everyday and watch the struggles or hear the crying. I do, and somedays it is more than I can take. I have other things to think about, a husband and another child. Our lives cannot revolve around Peter anymore than they already do. One physician actually went over my head and tried to book a 2 week stay at hospital in the middle of the summer. She made me feel like whatever I was doing was just not enough. Thank heavens, I do not have to deal with her anymore. I wish professionals would stop and think what they are saying. How would they like someone to came into their home and try to tell them that they needed to be a better parent? I would like to see someone in our area as a support person for parents. A sort of middle man would be great. Parents need a lot of support and encouragement. It is very long and winding road with a lot of bumps along the way. We, the parents struggle with all kinds of fears and problems meanwhile trying to keep our sanity and live a happy life. Please remember we had a life before our disabled child came along.

316 My negative experience - because we also have foster children and one of our children is profoundly deaf - is people who stare at her "especially adults" because she doesn't talk like other people. Also people's ignorance about children who are hearing impaired. Always talking about them as if there not there or couldn't hear a thing.

317 When my son David was to start school I took him to the school for a pre-test to Grade 1 (in May). What they expected him to do was way beyond him. Still

when he started school in September there was no extra help for him. He repeated Grade 1 but still didn't know the material. He was then transferred to another school into a special education class. By this time his self-esteem was very low. He felt stupid. He started to act out. No one seemed to understand what the child was going through.

SITE 4

Briefly tell me one negative experience you have had with reference to your child with disabilities.

401 Being frustrated with her mood and not knowing why she is so upset about something is a negative experience. Too many messy pants. Not being able to take her with me to some places because she gets upset. Then having to stay home instead. My parents not understanding. When I mention how frustrated she is or having a hard time with her the answer is "When do you think you could put her in a home!". People not noticing her very small accomplishments and the joy her smile can bring.

402 Having a child with multiple handicaps knowing he is totally dependent on you for his entire life is scary mind-bending (sad). It's like you're in mourning for "years", for the whole and full life of your son that can never be. You'll never see him walk, drive, graduate, marry, raise a family of his own.....

403 I had one physician come in to see Naomi after her heart surgery when she was having some breathing problems. He walked in took one look at her and said " Oh all these kids have this problem" and then he walked out.

404 Several months ago, I accompanied our 21 year old son to an Association dance at school. It was most discouraging to witness unecessary humiliation and overt neglect of the mentally challenged. The "guests" were given a "snack" at 8.30. The "snack" consisted of Mc Donald's drink and dry sugar cookies. No choices were available. Only days earlier I had accompanied "normal" high school students to a drama function. The snack consisted of an array of fresh fruit, cakes, three kinds of pop, cheese and crackers etc. Every single ("normal") function whether preschool, art openings, soccer meetings have always provided guests with at least two choices of refreshments. Our son is allergic to McDonald's drink and sugar cookies so he went without any refreshments. We could have brought him his own snack but the other "guests" would have felt badly. Our son is not capable of performing a range of tasks. However, he can select food and pour his own drink and is pleased when he can get a sense of control by performing such tasks. The people at the Association dance were treated like cattle and expected to drink stale sugar water that had been poured several hours earlier. Please let us not necessarily humiliate the less fortunate members of our community. I would be very happy to take turns bringing a variety of snacks and supervise a crew of mentally challenged people who could serve the snack themselves. They may not be capable of driving a car but they can definitely pour refreshments and select food. They also deserve healthy refreshing apple juice or at least no-name pop (adults drink it). Mc Donald's drink smacks too much of `little children'.

405 Speech assessment/therapy was a big downer. They use inappropriate tools, environment etc. and got a really bad" read" on Thomas. They knew nothing about our family culture but were very directive about how we should interact with Thomas. They didn't want to work on his articulation, wouldn't let us have access to XYZ software- just wanted to assess him every 6-12 months. This was useless so we quit speech.

406 We, right from her birth, have constantly been asked how much money do you get for keeping her? This has often been asked yet our response has always been nothing. Why should we? She is ours, she is a part of our family. They say well you should, other provinces pay families an amount to keep their handicapped children at home.

407 The psychologists we had, initially, never said anything positive, no matter what we saw in terms of progress. Finally we realised that we were much better off without them. I cried for hours every time we saw them. I now rely on "informal" advice from professionals who are friends, acquaintances or family.

408 It has been negative to hear Dr.L talk about the gradual reduction of drugs which have been prescribed for many mentally handicapped adults (in particular) which may not be necessary and indeed pose additional side-effect problems. The medications are just continued without review unless there is a particular emergency. To be granted an appointment with this same doctor who was extremely interested in Stewart's case as an example of a particular genetic syndrome - an "M.T."? scan a must - absolutely no reason for all the drugs - see you next month. The next month arrives (overheard from secretary's office, Dr.L on route to clinic - "Oh I'll have to have a word with Mrs. Z. The words were "Yes what can I do for you?" Something must have happened for this change of attitude between appointments. Hopes dashed.

409 I remember being at the swimming pool one afternoon with my three daughters we were all laying on the grass (their ages were maybe 6,7 and 9). Karen the handicapped daughter got up to go to the bathroom. She only made it halfway there and ended up peeing on the grass. Another young woman (whom I did not know) was so mad about that, she ended up grabbing her two kids and stalking out of the pool.

410 Only one negative experience? That's Difficult! Overall the most negative experience would be trying to get OT and speech therapy services for Wayne without having to drive 1-2 hours. I also feel such services only two times a month are not sufficient. We have four sons and it is not easy to be on the road all the time. We even called health services to see if we could get training as parents from all the professionals at once so we could do home therapy. We just asked if we

could meet with these professionals for 2-3 days so we could formulate a home program that would cover all of Wayne's needs. We were told by health services that there was no place in our province where this could be done. This is when we decided to go to Philadelphia despite all the expenses (which health services would not help us at all with).

411 Most experiences with the "outside world" are negative. Carla's abilities are discounted because people focus on the disabilities. Carla is organized, careful, caring and forgiving. She has a wonderful sense of humour which most people have never seen. I also hate the fact she's allowed to behave in socially inappropriate ways because she's "handicapped".

412 When Martha was born the pediatrician who was called in was very negative about her potential. The doctor gave us an old medical text for information. We had to find our own information and learn through experience that her life would not be that bad. Martha has no serious medical problems and is a delightful child. The pediatrician's attitude and behaviour towards our daughter and us has been the worst experience we have had since she was born. Our family doctor was very supportive and helpful in guiding us to other agencies.

413 Having to resuscitate my daughter in the cafeteria of a ferry boat in the middle of the English channel. I was alone with her and her next younger brother. Everybody just stared. Nobody helped me. The ship's doctor did not come for about 10 minutes.(By that time if I hadn't managed to revive her, she would have been dead). It was a nightmare and one of the key events leading up to my mini-breakdown, at least regarding my ability to care for (i.e.look after) my daughter. I still care for my sons but have totally burnt out my strength to meet my daughter's needs.

414 No response

415 No response

416 No response

417 No response

418 A resident chastized me for not adequately nourishing my child. We were visiting the pediatrician for the umpteenth time because my child was unable to nurse or bottle feed without experiencing pain. My son was about 5 months old and weighed less than six pounds in spite of my efforts.

SITE 5

Briefly tell me one negative experience you have had with reference to your child with disabilities.

501 School System They gave/give lip service to integration. They provided a teacher assistant - but also created a dependency on this TA. High school was terrible. The individual teachers gave an honest effort to integrate him within the classroom but he did not have any social integration into life at the school. No one took responsibility for him. They left him on his own at lunch time - he would get in trouble. The last year he usually ate his lunch in the resource room. Because he was on his own he copied the worse behaviour in the school- we ended up with terrible behaviour problems at home - went to child guidance as a result - still didn't get much help - child guidance doesn't know how to deal with young people who are mentally handicapped. Also to be fair junior high was better than high school and elementary. We think this is because the Principal at the time was very supportive of what we were doing.

502 The lack of adequate support in our province for these children is a negative experience. We as parents are frustrated by the lack of support that is given to families that wish to keep their children at home. What supports that are available are inadequate for the survival of these families. The provincial government pays $11,000 to $15,000 or more per month to institutionalise children like mine at cost to us, but when it comes to support for people keeping their children home, well it's just not there! The provincial government must take a proactive role in the survival of these families. They should encourage and enable families with children with severe disabilities or chronic illnesses to nurture and enjoy their children in their homes, rather than supplanting the family's primary caregiver role by expanding public funds to place the children in institutions or out-of-home placements! All children regardless of the severity of their disability belong with and do best with their family.

503 Negative experiences: fighting for everything. Fighting for services, for financial support, for her place in the community. Basically I had to say to the government "O.K., I can't cope anymore" and then I got it all. Virginia lives on the next street over from us , attends her community school, comes home at other days and on weekends. We have the best of both worlds. Virginia has her family and a life in the community. We still have a lot of work to do but we are making some in-roads.

504 Finding negative experiences: this is not hard. When I had Edward enrolled in a horseback riding club through Capital City summer recreation, he was to encounter blatant discrimination. Parents were going to remove their children from the class. The manager and others involved totally discriminated against my son.

505 When he was first born. That famous annoying, hurtful, demeaning word "Don't expect!" It was to the point that even when we take Marshall home," Don't expect him to know who you are." Well did Marshall teach them a thing or two! You said one negative experience but I have two. The department of community services. I have to battle with this department almost daily to get some services for Marshall. Marshall was 3 1/2 years old before they began to help with his high medical and physical costs. He just turned five in July.

506 There are so many negative ones I can't begin to write about one in particular. I have had negative experiences with the physicians when Peter was first diagnosed, negative experiences all through the school system. Negative experience dealing with in-home support through the government. Sometimes if it wasn't for sharing these experiences with other parents who have felt the same frustrations, I'd think there was something wrong with me. But all I want is what is best for my son and my whole family. It's terrible when the little bit of help you get is only because you had to fight very hard to get it.

507 A doctor who had seen my son once in a year spoke in a way that made me feel he thought this child who he knew very little about had no future. It felt as though he was labelling and stifling any self esteem and positive reinforcement that we worked so hard to build. I felt angry and I think it set us back quite a bit. It made me wonder if I had imagined all the progress I had seen.

508 Negative - Is the sudden shock after our son was born. We knew nothing about Down Syndrome and had no close family members around us. We lived out west at that time. It would have to be the not knowing, the fear and wondering what we did wrong. There were a lot of negative thoughts at that time, wondering if he would walk, eat, play, talk etc., what his life would be like and how he would fit into our family. Lots of bad advice from some friends at that time, a very lonely, scary time for us.

509 The continuous battle with community services, school board etc. in recognizing our needs as a family unit and Marjorie's right as a human being. The abuse she suffered while residing at a children's institution has been the worst possible experience any parent can have.

510 Our employee child-care-giver was sitting at the table reading him a book - saying each word in an unusually slow, mechanical manner as though he was a robot and hard of hearing. I was angry because she had worked and cared for him (and his older sister) since his birth and she obviously couldn't see beyond his labelled disability, that he could and did comprehend every spoken word, in regular language and normal voice tone.

511 When Megan was 8 years, the system decided that she be moved (along with some others) to a regular classroom from her segregated special ed. class - 6 kids and 2 adults - (to a class of 31 kids - 1 teacher - no support - in a new school - no orientation). When this didn't work out they told us our child had a problem. Here the whole system failed Megan - teachers, professionals, school - all! It took little old parents to do their job!

512 There certainly are many in this area as well. One of the biggest disappointments was with the medical profession at the children's hospital. For years I thought Dennis to be autistic but they did not diagnose Dennis as such until age 8. What seemed to make the difference were photos of Dennis as a baby & toddler showing him very aware and drinking out of a cup independently at 4 months. Even though we told them what Dennis was like they obviously didn't listen to us. Those pictures said a thousand words but what we were saying for years didn't amount too much. We were " the parents who wanted to see those things in our child".

513 There seems to be so many negative experiences that it seems difficult to choose only one. Dealing with so many professionals there have been numerous negative situations. One that stands out in my mind was the time I was called into the Principal's office of the school where my daughter was being partially integrated. She was only integrated for things like Music, Phys. Ed. Library etc. but the parents of the "normal" children had formed a group to get her out of the regular class. The principal had called me in to tell me of this. I found it a very stressful year because there was little support from the teachers and very little from the principal. (Thankfully this was not her neighbourhood school and when she finally moved to where she should have been, her integration experience was very positive.)

514 My daughter would say a negative experience for her it was when she was pushing Russell in the stroller through the mall and a lady walked up to her, looked at Russell and said to her face "My what an ugly baby". For me a negative experience was a doctor (specialist) who showed no regard for the pain Russell was suffering from a raw, bleedy, sore bottom and told me to accept that he'd always have a raw, sore bottom so get used to it. The pain was so chronic that he stopped making any sound (even crying). Took another specialist only a short time to help find a cure and prescribe pain killers for 3 weeks or until he spoke again. Took him 6 weeks to talk again and cry.

515 He was "expelled" from pre-school for pulling hair and other anti-social behaviour which was potentially harmful to the other children. The director and teachers did not know how to deal with him, and allowed panic to prevail whenever an incident occurred. This was supposed to be a "developmental" center. This event was our invitation into the world of fighting for his rights and a taste of the

struggles that may be ahead. This was done without notice or discussion, the motives for the expulsion are still questionable. It partly relates to the Director being uncomfortable with people with special needs.

516 Recently Kevin finished school, there was no program where he "fit in". The social service worker did not support us, return phone calls or recognize my stress. I have just returned to work full time and was not willing to give that up again. It was not until I started to make arrangements for an expensive group home I told them that I would put my son out of our home that we received a <u>response.</u> Within 2 weeks of my saying that he would not have a home, and <u>all</u> my savings were spent, an apartment and an attendant became available. It was very stressful. Things are not perfect now - we need to change the attendant and that will be difficult. More stress.

517 The most negative and devastating experience was the issue of abuse which possibly happened at the centre where she lived. The insensitive treatment we received by the very people who were responsible for Nancy's care was unforgivable. The investigation which was carried out was incomplete and unsatisfactory. We are still dealing with the effects of this abuse and will for a long time to come. To date, nobody has been held accountable.

518 At an IEP meeting for Paul in high school, two teachers verbally attacked me with loud angry voices for wanting him integrated (even though the statement had already been agreed to and was a continuation of 4 years of integrated ed. in his previous school). I was told that I was just holding on to the latest philosophy and was on the bandwagon, I did not care I was harming all the other children, I was selfish, I was demanding something that was impossible for teachers to do, etc. etc. The worst of it was that the principal who was (and is) very supportive of integrating my son and others, just sat there and did nothing to intervene or to refocus the meeting on developing the IEP. I was devastated and ended up crying uncontrollably and left the meeting after 45 minutes of continuous abuse. Surprisingly the IEP got put in place and he had four quite successful years in that school. Why did they need to put me through that? Why could they not see that Paul's presence could enrich the lives of others rather than harm them?

Question 3
SITE 1
Do you have anything more that you want to say?

101 No response

102 We have an older daughter age 8, and we have always tried to treat and discipline Kathie like we did Kelly. There are, of course, certain exceptions we have made, but mostly we try to treat her as "normally" as possible. I have one comment to make in reference to the fact that the study is based on "mothers of children with disabilities". My husband is very involved in parenting both of our children, even though I spend more time with them because we have chosen for me to be home with them.
I would encourage you to be more inclusive in your language. Fathers need to be involved with their kids and need encouragement to do so, it seems.

103 When we get together in our support group sometimes there are so many handouts about different meetings, all of which are very important, I feel guilty because it is impossible for me to attend any or some. I don't have anyone to care for my child and I don't want to take her out to meetings a lot at night.

104 Overall Carol has been a positive inspiration in our lives. She tries really hard to accomplish whatever task is before her. Her determination is an inspiration to anyone. Her loving personality makes it a lot easier to deal with her handicap. No one could ever change my mind that it is worth every minute of having her in our home. All of our children help with her and know how to deal with her many moods and they all play with her and let her participate in what they are doing. I think it will help them become more understanding to others as they grow older. It takes a lot of faith and trust to get through every day. We've been blessed with many good people to work with.

105 I'm sure the real concern will start when she is school age. It's a scary thought. Sometimes I feel I'm dealing with enough already. Will I be able to handle it all? Will she fit in, have friends, understand what is going on around her?

106 Carl can be stubborn at times and do what he wants to do. He gets into things that he shouldn't be in or have. He is still not potty-trained even though I have been working with him for the past 3 years. I don't think he understands the concept of potty-training. Sometimes Carl doesn't do what he is told or asked to do. We always have to repeat things to him.

107 Family relationships suffer immensely with couples with a developmentally-delayed child with physical problems.

108 No response

109 No response

110 This whole game is set in cycles. Right now I'm in a low cycle, but other times are better. I'm bitter about medicare problems and fighting the school! It is scary to think it may never end - it probably won't.

111 I have learned to be an advocate. I also feel I'm doing the work that my son's case manager should be doing. I call him to remind him that the deadline is coming fast for certain things.
Harrow is a joy, he's changed our lives. His sister (8yrs) has been his guardian angel. She has never questioned why and understands why we do things certain ways in our home now. The only thing I feel bad for her -she's had to grow up too fast and she feels the need to take on responsibilities for her brother.

112 I think this survey was very confusing to respond to the statements. Also I answered for the present time but my feelings were often different in the past.

113 Our town really needs a full time advocate for parents, that has the time to sit down and listen to the whole story. Someone who will work together with both the school district and the family when a conflict of interest is present. Unfortunately there is a <u>huge</u> gap between what it says on the IEP and what is actually carried out. And what should a parent do then? To become overly involved and fight for what you know you deserve only creates relationship problems with staff in the future. Believe me, I know from experience.
What (we) lack here is an inclusion specialist or a very active (willing to get involved) advocate. The kids are the ones who suffer.

114 People who have a child with special needs or a disability need a weekly break to maintain sanity. At the beginning when they are first diagnosed everyone is there wanting to help. That is the time you want to be alone with that child and sort through your thoughts and feelings. Two-three-four-five years down the line when you have adjusted and need a break or some help, where are they? One should never say call me if you need anything, instead they should call you and say, "I'm coming over for — hours on --- so that you can do something you need or want."

115 No response.

SITE 2

Do you have anything more that you want to say?

201 A parent cannot just be a parent -- they must always be an advocate for their child. Expectations should always be there as long as you are realistic in your expectation. Parents do not realize the power they have in working with the system to get what is needed for their child. It's been a long, rocky road the last 25 years of my life, but what an experience I've had that many people will never know -- I have met the most wonderful people thru having a child with a disability and I've sure met a few jack-asses, too, but I forget them.

202 Jake is my stepson. He has been "my son" for 10 years now. One day I had absolutely no experience with a handicapped child and the next a 16 year old who could not feed, dress, bathe or go to the bathroom without help moved in. Well what a year we had! I jumped straight into a whole new world of limitations and physical therapy and lots of struggles and tears. We survived that first year and each year Jake has blossomed. How much we have all learned and how much I have enjoyed seeing Jake learn to be more independent. I have four children (all grown) of my own and they all love Jake and have learned a lot about just being grateful and an appreciation of how hard it is sometimes for Jake to do simple things they do with ease. Didn't mean to write a book -- I've tried. I've screamed, I've been so frustrated -- but I've laughed more than any of these! Jake is a joy and a blessing. Jake travels with us -- he and I go to country music concerts, to concerts, to ball games, you name it -- we all have been on a learning expedition this past 10 years.
Early on I was told by a professional that since "I didn't have a degree" I couldn't possibly know what I was talking about! Being totally ignorant was probably a good thing -- I used my experience as a mother and my common sense and only used the "professional stuff" that worked. Much of it is not realistic and is merely idealistic -- it plain doesn't work in real life. I hear a lot of jargon and endless talk spouting rhetoric but very little of it is useful in day to day living. For 10 years professionals have been insisting Jake can learn to handle money and other related ideas -- we know him -- he does not understand the complexities of 1.75 out of two dollars leaves a quarter and why should he? It would be better to spend this time on something he can learn! But they are so afraid to admit they might be wrong.

203 Only that I hope the future will provide more training, available residential placement, transportation help as we have fought since day one for all of these and gained very little to nothing. Too much politics involved in some residential programs. I have very little time for myself, my husband or my other child and grandchild which makes me feel like a failure at times. There needs to be recognition that these children grow up and grow old. We do not have social programs or placement geared to this life change. Community clients are totally left out of most activities. If the parent does not create a social activity, no one else will.

Residential clients are on-the-go constantly -- with planned activity and a hired staff to supervise. Working parents have a tough time competing.

204 In our 31 years we have become so overly protective with Randy that we don't trust just anyone with him. When my son hurts, "I hurt," and when someone abuses him it is me on the receiving end. I plan on writing a short story on "Life with Randy."

205 The reason I didn't fill out the first questionnaire you sent was because I didn't think the questions applied to Lori, since she is older and on her own pretty much.

206 Yes, if it wasn't for the Center I do not know what I would have done. I did not know how to train her about learning to get by in the world. These centers are the best t hing that ever happen for us with child disabilities. Now they have a chance in life also.

207 It's sure not easy.

208 I am grateful to the Center.

209 No early intervention services were available to us. It was impossible to get help of any kind. The hospital just kept giving me students who would stand back and tell me to keep doing what I was doing -- it was working. I begged for help with motor skills and never did get anything, not even advice! The Association center has provided him some place to go each day, sport activities for the first time where he can not just be a spectator, and friends of his own. Friends of his own has been very important to him -- not his brother's friends! The school system fired his best teacher. Jr. High and High School classes were useless!

210 I'm trying to remember what went on during her public school years. It has been 17 years since she attend public school. She never was in an inclusion situation. There were times when it was very difficult to make the school personnel understand that Marilyn needed special education. Marilyn has made great strides now that she's out of school. She loves to work and loves to be around people she works with. She is active in church, loves to shop and is working toward more independence. She has worked so hard. Her father and I are so very proud of her. She has given our family an empathy for others. Marilyn has a younger sister and brother and 4 nephews. This (research project) has stirred up so many negative memories!

211 M y son lives in a group home in our community during the week and comes home on weekends. We are in close contact with the group home and the classroom teacher at school, but it is always a struggle to get everyone to carry out

his program. I am getting older and it is getting harder and harder to fight for good programming and good living conditions for him. We are constantly at the mercy of legislators who see aid to those with disabilities as expendable.

212 No Response

213 I have found having a child with brain-damage and learning disability has helped me to be more caring, considerate, compassionate, and accepting of all kinds of people we encounter in our lives. I don't look at what he cannot do or the person he isn't but I am thankful he can do many things that I never expected and that he has a heart bigger than life itself which touches a lot of people with more love than we could ever hope to have. I have learned much from Neville and I have never regretted the time I have given him. The same applies to Neville's father when he was alive and his sister and 2 brothers.

214 It will be a good experience for him to be on his own, and to do things for himself, because I won't always be here. He needs to learn to cope with the real world.

215 Parents should be provided the same money as group homes etc. are provided. Sure group home's can do a job. Who couldn't on $3,000 to $6,000 per month? We could also hire someone to do the little things that never seem to get done!

216 No amount of written information can ever prepare parents for having a child with a disability. Once the issue is reality, the written guidance, advice, support groups, etc. can help, but as a culture, new mothers aren't sufficiently prepared for the possibility of a "special" child. In a culture where so much emphasis is now placed on prenatal care and preventative measures, a pregnant woman has the false sense that as long as you're "going by the book," nothing is apt to go wrong. Physicians need to be more realistic about congenital problems and not shy away when they're suspicious that something is not quite "right."

217 No. Thanks! I hope I filled this out o.k. Marcia would be considered having cerebral palsy. Not real bad -- as she walks -- and can do many things. She loves working at the Center in Medium City. We have to take her half way -- from our little town -- the rural transit takes her on. Then we have to get her each evening at the pick up point.

218 Most of the statements in this survey were not applicable for me since my son is older and was not fortunate enough to have been able to attend a public school. I feel that parents are very fortunate to have the facilities that are available to them now. My son is now working in the community thru a rehabilitation program and

rides a city bus by himself to and from work. I feel very proud of him for this accomplishment.

219 Dianna is presently getting rehabilitation services which only allows 2 days\week for her. She could use more services more often as she needs people who can work with her! When the people do come they are quite positive with her and very friendly. They try to work with her by conversation, etc. I am pleased with this as her progress is very important to me. Dianna will soon have a household and live in an apartment, etc. She has been looking forward to doing this.

220 My son was diagnosed at 19. His school experience was total frustration. Teachers didn't know how to deal with him. Students making fun of him. Barely passing. Sometimes failing. There were a couple of good teachers. The professionals we have dealt with have been very good to Joe and are working towards his independence.

221 There needs to be someone or somewhere we can turn when we need a break.

222 I guess I'll have to fight for her best interests forever. I thought when she left the school system it would be easier, but with cuts in medical services we are continually on the offensive to protect and safeguard her.

223 Thank you for doing this study. I'm certain that services to our special children will benefit from it.

224 No response

225 We feel very fortunate that our daughter is capable of living in her own apartment. We are very grateful for the assistance from the X program and the competent counselors and job coaches that work with her. They found her a very appropriate job which she loves, and have checked on her frequently to make sure things are going satisfactorily.

226 It is very hard to cope sometimes -- especially in the beginning. Support needs to come from every direction. If you are in a position to help someone -- in any way whatsoever -- please do so.

227 I think parents with children with disabilities learn very much the true character of people they have to deal with in order to raise a child like this. I know we have. I believe physicians are also included in with these negative people to an extent. We had one physician tell us the only thing to do was to put her in an institution.

228 No Response

SITE 3
Do you have anything more that you want to say?

301 If Andrew could only speak better I'm sure my troubles would be over. It is so hard to get speech therapy once your child is in school.

302 This survey did not really apply to us as Ray is 41 yrs old and where school is mentioned, I tried to apply the workshop. We are pleased he can travel on the school bus, but transportation in the summer months and on school holidays is a real problem.

303 The government should give her a disability pension when she becomes an adult. Her job prospects with limited use of her body are not very good but she has to work two years before she can receive disability. Social Services won't give her enough to fulfil a lifestyle she deserves as I will be her support for as long as she resides home (probably her whole lifetime). I know of several people who are receiving disability pensions and there is nothing wrong with them. Why should they get one and Debra who needs it, not be entitled to it? P.S. My MP can't help us!

304 No response

305 On the front of this questionnaire I put down my occupation as a homemaker, however I am so much more than that. I am often referred as the "non" professional when I sit on boards or committees, and I quickly correct them, because as far as my children are concerned I am "their" professional, and although I did not attend college as a student, I am now asked to speak to college students, so as I can teach them about my schooling... the college of "Live it and Learn it".

306 Barbara is happy with her work and with her friends (other mentally handicapped persons). She especially enjoys the summer recreation program set up by our local of the Association. However, all of this happens 30 km away. So transportation at times is a problem. Since I'm a teacher, I'm able to transport her in the summer months. I'll be retiring in the fall of '94 so I hope to be able to do more for her. So far I'm doing the best I can.

307 Will the day ever come when I won't still get very angry that my little girl (all children in fact) has these disabilities and I feel her life will be even more of a struggle than so called "normal children".

308 Thank you for your attention.

309 Leonard was diagnosed as an Attention Deficit child almost two years ago. After all the physicians and going through all the red tape he is now on medication and closely watched by the family doctor. He has burned so many bridges beforehand with neighbours and peer groups, we find the finger pointed at him first, when something goes wrong, whether it's his fault or not.
We adopted Leonard when he was 11 days old. He was one month premature. Very little background information came with him.

310 Her teacher's aide has been very supportive to my child. They both have a great relationship. Hope when she goes to Junior High that her aide can go.

311 I would like to say we love our son and he has made us better people and stronger than we ever thought we were. There has been a lot of doors slammed in our faces but we keep on fighting for our son and his rights.

312 No response

313 Overall on the most part we are very lucky with help and support from professionals. Peter's integration is going well except for the area of teacher's assistant's not wanting to integrate his communication device into his every day work. She has help from myself and a speech therapist, but says she's using it when really she isn . I find the school tends to side with the assistant too much. She's been at the school for 2 years. I sometimes get emotional because I know Peter is a child who wants to answer, if everything was normal, he'd be quite talkative and he does well at home, but he needs to push at school. I wish I had a mediator or a social worker on a personal basis that I can go to. So when I do talk to schools, I could leave my emotions out of it - in other areas - teacher assists do well.

314 No response.

315 No response.

316 My sons are both the tops in their classes and because of professional people who believed that children that are hearing impaired can talk as well as you and me and have succeeded.

317 Many times I wondered what was best for my children. I learnt what to avoid by experience. I try to avoid pessimistic professionals. I need to have support, not someone who adds more worries to my mind. I like positive thinkers. I find the school system very rigid. Little individuality is tolerated. You must conform. I wish someone knew how to teach these people to relax around my children. I wish there were more people to help them at school and at home. But only if they are people who really care about the child and not just their paycheck.

SITE 4

Do you have anything more that you want to say?

401 What bugs me is people not understanding that sometimes when she is "bad" she is only frustrated and we don't understand why. It's hard when you are unable to communicate.

402 Our province, our hometown in particular, has no group homes in place for the multi-handicapped young adults, once their parents are no longer able to care for them at home due to physical stress and ageing etc. We don't want our children institutionalized or put in nursing homes. We want them to go on living in a home-like environment, in perhaps group homes with extended families that care about them, where they can have their own rooms, personal effects, visitors, outings and vacations with their families.

403 In my opinion, raising Naomi will be like raising any child. There are always challenges and hers will be different from my other children just as theirs were different from each other. I'm as proud of her or maybe more so with each milestone. She has added so much to my life and I thank God everyday for letting me have her for my child.

404 The difficulties with the "community-based" services like Special Olympics and the Association, are that such activities are segregating the mentally challenged from the main stream of society. Whenever our son participates in Special Olympics, soccer or bowling he comes homes with an array of unusual behaviours (we still encourage him to participate and drive him to the functions). In contrast, when he returns from working at the university dining hall, he displays adult-like strategies and mannerisms which are socially acceptable. Our son is becoming increasingly frustrated by his inability to enjoy a healthy social life with genuine friends. We parents feel very helpless with his dilemna. We used to be able to create a good social life for him when he was young. We can still buy him the latest walkman with appropriate dials for his awkward hands and his impatient tendencies. We can drive him to a dairy farm to milk cows, but we are apparently unable to find him a friend. His health problems, asthma, allergies, and frequent pneumonia compound our challenges.

405 By the time Thomas was three (he's 5 1/2 now) we had taken charge and eliminated the contacts/experiences that drained us the most. We are angry about how families are treated. We are angry about ill-informed or under-informed professionals who think they can mess with lives with impunity. We continue to have a lot of medical involvement though now. It's mostly follow-up (Thomas has had surgery on his bowels, heart, ears and eye). We have learned how to manage this and go where we get the kind of service we want and where Thomas is treated with respect. We are working with the school re kindergarten entrance this fall.

Rehab services is not involved in any way. There has been and will be no psych assessment. I believe I went through a terrible crisis in Thomas's third year when I realized that the "experts" were fallible that often I knew more than they did about child development, about good child care. We were being pushed to accept a preschool placement that would have been mediocre at best - in fact it would have caused Thomas to regress and would have completely squelched my boy's inventive, exploring spirit. (I could go on about this for hours!!). We determined that the therapeutic agenda was not going to dominate Thomas's preschool experience. That attitude has carried on ever since. As much as possible, Thomas is treated like our other children (he's one of four). We believe it is best for him. So we don't see speech, OT, psych. We see PT once a year. We go to the clinic every year or two, just to maintain that he is (or could be) a recipient of services. We do get the best medical care and advice we can. We attend conferences etc. to inform us re the education journey ahead. Of course, we fantasize about just sitting back and letting others be in charge, about not having to be so involved - so vigilant. But this is a family commitment for us now - our older children expect us to advocate for and protect Thomas.

406 I feel the school boards should be open to each family who has a child with a disability, to allow them to attend whichever system (public or alternative) the family wishes. I would also very much like and have been trying for years to have the high school mentally handicapped school program changed to suit our child's abilities. For example, she is able to do academics, reading, typing, math, computer and Phys Ed, yet the high school program offers 80% to 90% lifeskills and only functional academics pertaining to the lifeskills. Our child has proved herself to be able to be taught, to read,do math on a calculator and work on computers. Why does this have to stop at age 14 or 15? We get NO answers, only that this is the Curriculum.

407 Please give a research number next time so confidentiality could be assured. In small communities confidentiality is sadly lacking. Recent experience with same. Feel violated.

408 There is indeed, but I really find it difficult on paper. I feel there is great damage done to many severly handicapped older people by the impressions of complete "desirable" integration into the community being possible for all. Here's a story from a medium sized town which is sad ---- The local special school for the handicapped was built quite a few years ago by volunteers and funding from the community (and the school's club in particular). Very well equipped building - large playground - gym - wheel chair accessability - beautifully appointed kitchen for learning. Because it is wrong to segregrate, the School has been purchased by the local school boards and is used for storage or occasional meetings or conventions. What a sad and inexcusable waste of a facility. Oh sorry - just rambling. I was so

pleased you phoned. Still feel very guilty about Stewart. He is the oldest of seven children. When he was fourteen the baby, (now 15 yrs old) cried suddenly - Stewart picked up the playpen he was lying in and hurled David across the room. At this time the nightmare became too much and Stewart started living in the community group home. Since that time he has been home for several visits and now every weekend and holidays. We were told by the Consultant who diagnosed Stewart in England aged 8 months that we should go ahead with plans to emigrate to Canada - go and have a large family in a "large" country. This will not happen to you again (he had told us Stewart would never do anything but lie flat on his back, most likely.) How could he know if no one follows up on the adults with a given diagnosis?. Anyway we arrived in Canada two days after Christmas in 1964. We had our large family and it is wonderful for me to be able to talk to the girls in particular as friends and tremendous support and fun but the early days were very, very touchy with regard to Stewart and his future. Because my husband cannot bring himself to be involved with Stewart in any way, even now, he will go for a walk and never ever suggest that first maybe Stewart would like to go or should go. Perhaps this accounts for the gush of words on my part that seldom have an outlet. Forgive me. There is no reason why Stewart could not live at home now but I feel that he is well settled in the group home with five other young men. He knows well if anything happens to me, I know he'll be OK in familiar surroundings. I have a grand mal seisure myself during the night approx. every six weeks and am virtually incapable the following day. Stewart has both grand mal and petit mal seisures probably only about once every three weeks - perhaps attributed to the control by the drugs. Tremors now noticeable since Haldol.

Professional people have been very kind and well meaning over the years. No complaints there - Have just felt sometimes that they had as much difficulty in being constructive as we.

409 My retarded adult has a sister 2 yrs. younger and another sister 18 months younger than that. I was expecting the third child when I found out that the oldest was handicapped. One of the first big problems we had with my retarded child was when the youngest child learned to do more than the retarded child could (things like colouring,numbers etc.) She played with her first sister, then later she would spend more time with the second sister. Karen seemed to really feel it when the youngest sister outgrew her (for want of a better word). This was a very difficult time for Karen and for my whole family.

410 I feel that home therapy is the answer for those that live far away from services. We enjoy doing all kinds of therapy with Wayne in our home - everyone helps out! Wayne works and performs better in familiar surroundings too. This way, we can also work with him when he's at his prime. Wayne would often not do well at his appointments when we were travelling because he'd be too tired to perform. We feel we're being more fair to Wayne's twin, too, working at home because then

we can include him too. For home therapy to be the answer though, there would have to be a place where one could meet with all types of professionals at once so that a program using all their ideas could be put to use in the home. Feel free to call with any questions!

411 This survey was difficult to fill out. The scale should have gone NA Disagree <----------------> Agree

412 Since my husband and I are part of the school system here we feel in control of the educational system Martha is in. And we are very pleased with her progress. Having Martha has been a very positive experience for my husband and me as well as our family. Martha is developmentally delayed but there are so many things she can do. Her brothers and sisters are as proud of her accomplishments as we are. Martha has brought a lot of love into our lives. The future will not always be easy but I feel we are priveledged to have Martha in our family.

413 I think somebody should write a book or research study about my children. In all my reading and networking I have never heard or seen a family who has such a combination of unrelated syndromes and conditions, ranging so widely amongst physical disability, psychological disorders (autism & hyperactivity /challenging behaviour),sensory impairment (both boys partial deafness and daughter's visual impairment) plus the added dimension of the middle son's giftedness and younger son's islands of very high functioning.
The family ecology, parental management, problems, sibling mutual effects, bilingualism (French/English) and immense battles for services (court cases, appeals etc.) would surely provide fertile ground for study!
Meanwhile I managed to go back for an MA degree and my husband for a management degree.

414 No response

415 No response

416 No response

417 No response

418 Barbara, if you would like to use any comments I've made in my presentations in any way, feel free.

SITE 5
Do you have anything more that you want to say?

501 Parents who have a child with a disability need to know what resources are out there. This information must be kept up to date and readily available for all parents and professionals. As a professional myself and trying to obtain the appropriate information i.e. resources for families, I can tell you that within the system itself (various Gov't depts.) the right hand doesn't know what the left hand is doing. You have to dig to get what you want. How many parents are too worn out or don't have the ability to do this digging?

502 No Response.

503 I hope the inequities of services being provided will be more fairly distributed in the future. I also pray the province will honor its intention to close children's institutions in this province. When I compare Virginia's quality of life to those still in institutions there is no comparison. Parents have to lobby hard to ensure their kids/families get what they need to survive.

504 I must add that Edward has older sisters (30/32) and that questions related to siblings were not relevant. Much success.

505 I know I have another battle now that he is 5. I wish things could be more accessible to meet Marshall's needs eg. Developmental Day care (hasn't been able to go), Physiotherapy (cut back to 3 times/year, 1 hour each time), Augmentive skills/Communication skills, Occupational therapy, Dept. of Education. I wish our province could make our lives less stressful by meeting our needs as a family. I find the medical problems much more difficult to deal with, (25 hospital stays in 5 years). Constant chest/lung problems making it difficult to travel/visit. I feel the Dept. of health needs to take some responsibility for Marshall's medical costs. They also need to give guidance when families take their infants home; i.e. support groups; other families' names who are in similar situations; where you can get financial support for all of the extraordinary costs for the infant's/child's care; etc. They should never send the families home with nothing.

506 While receiving respite money from the province, myself and other parents were subjected to quite a few remarks that were very objectionable. For example - you are so lucky to be receiving "all this money" - "you're getting more than anyone else"- make sure you use it for respite and don't waste it - You're up for review soon and it will probably be reduced or cut off. They try to make us feel we're getting welfare and draining the system. I'm sure some parents feel guilty and are intimidated by some government workers.

507 Early intervention was a God send to my son and our family. Not only did it help socially and making me aware of what was available to us but also we could meet others who were in similar or "worse" situations.

508 The most positive thing about having Stanley in our family life started while we were in the hospital with Stanley. Our daughter then was very excited about her new brother but unsure about why we were all crying etc. So being perceptive enough to see the so-called wise adults talking, Sharon jumped in the bed looked us in the eye and calmly said Stanley is our baby no one else's,"Right?" We smiled and said yes not really ready for her next statement."Well then we will just have to take him home and love him no matter what he has because he's ours, right Mummy?" Wise words from such a little girl and we have tried to follow it even since it was delivered to us. Having a child with special needs is no cake walk but with the right supports in place, family members and good friends, your path in life can go a little more smoothly for you. It's hard to reach out at times but after the first time you do this it will become a little easier, there is no shame in needing help. Once we learned this, life did get a little easier for us.

509 Marjorie, as Marjorie does not pose a problem. She is perfect as she is! It is the system that we as a family must endure and battle with that can pull families apart, because to date the barriers still exist to exclude Marjorie from full citizenship - which as her mother I see is her right to access equality along with the rest of the population - in all aspects of her life.

510 Our son is "categorized" as possessing a mild degree of the disability, Down syndrome. I believe however that the context of family in which he is being raised has played a significant part in his "incredible" development. I expect that we will encounter a whole new set of obstacles and barriers - generated from peoples attitudes - when he goes to school.

511 Despite a rocky start- Megan has turned out to be a lovely young lady who is interested in everything around her and is confident that she can do or be anything she sets her mind to. If we as parents hadn't pushed for everything that she wanted or needed, she would never have come as far as she has. Just this spring a school board member told me that all of the "professionals" who thought we were looking for the impossible now think we have done an absolutely wonderful job. They sure had a lot to learn.

512 I like to think I have come a long way since those early years. I've stayed involved with the National Association and have always tried to keep up with new things coming along (which would help us understand and deal with living with a high need child). I believe its possible for my son to have a meaningful life and be a contributing member of the community.

513 Having a child with a disability is both a joy and a curse. It is a joy because of the person Rachel is, the good experiences we've had, the things we've learned and the people we've been so fortunate to meet because of her. It's a curse because of constantly having to fight for what other people take for granted (school experiences, friends, leisure activities etc.) We feel tired of it all and lonely because it seems there are so few people who really care about Rachel and her quality of life and what her family must face daily. I worry constantly about her future and at times resent that we will always require "baby-sitting" for her. It seems to bring out the best in me and the worst in me. Reading the comments from the parents used in this questionnaire helps me realize(remember) that we're really not alone in our struggle and the way we feel.

514 We see Russell as a great gift entrusted to us by God. He has been an unbelievable joy to our whole family. The learning is endless and the gifts he has given to all of us to see inside ourselves and become better people is an experience I never dreamed of. Our 19 year old learning disabled/ADD child; Russell's sister was a daily stress and burnout on our family but in the long run made us strong and showed us how little we knew about living. Because of her we had the courage... and want to raise another special needs child. This time around there is no burnout and we've learned how to live from hour to hour and day to day and to find endless enjoyment within our family.

515 Barry was not diagnosed until he was nearly two. The G.P. kept saying don't worry; he's just slow; now he'll catch up. I feel G.P.'s need more education in child development so as to be able to spot problems earlier. Neurologists (or whoever breaks the news to the parents re the child's condition) need to consider how to do this in a compassionate way. I believe they give you the worse case scenario and make things seem pretty bleak. After I left the neurological assessment he had told me that my son would be very slow all his life, etc., I was devastated and didn't know what to do; I didn't know whether to believe him, as his manner was not very personable toward the child and he was judgemental on issues that seemed relevant. I was upset and angry at him, the neurologist. How can they learn to be a little gentler in breaking the news?

516 I have had advantages that many other parents didn't have - supportive parents, an education and financial resources (sometimes). Last year was our first holiday without Kevin (one week). I am so worried about what will happen when I can't be responsible. Last winter I had a bad car accident. That made me realize that I need to have plans made and in place - just in case. But always I seem to struggle alone, even when I'm getting help, I am the responsible person, the one in charge. I need someone to take over the responsibility - maybe I need someone to worry for me.

517 There are many negative attitudes, even among the people working with children with disabilities (teachers, doctors, social workers, politicians, community service personnel) and these attitudes need to be challenged. Parents need to be listened to, their ideas and view points respected and they must have a say in what happens to their child.

518 Now that both Paul and David have finished high school (integrated for the last nine years) there is nothing available to them except the sheltered workshop. It seems ludicrous and unacceptable to me to spend years fighting for and supporting integrated education only to graduate into a segregated work center. The few supported work programs that exist cannot provide the level of support either of them needs. On the other hand, staying at home doing nothing is also unacceptable. So as a family we start again -- fighting to develop a desperately needed service and if necessary (as in our case) you do it yourself. We have started a small family-based cottage industry as a place for our sons to work. It seems that at each transition stage you have to go back to square one and start all over again. It's the same song, second verse (or 20th verse!). Although you can celebrate the successes, it is not easy to come to grips with the fact that it will never end. Life is a series of transitions from one stage to another and with each new stage you are confronted with the same issues over and over again. Hard as it is, you don't dare allow yourself the luxury of getting discouraged because if you do, you might give up the struggle. And if we as parents and families give up, there is no one else (least of all government) you can depend on to ensure that our children's rights and well-being are protected. So life goes on !!

APPENDIX K

APPENDIX K

CHILDREN

1. Positive Parental Feelings

104 Overall she's been a real blessing to all of us.

107 Everything about my son is positive to me. I am lucky to have him. He almost died on me several times. I love him so much. But life sure isn't fair to him and our family. He is such a happy child. Every accomplishment to me a big deal.

211 Steven has taught me how to love. He will ask for a kiss or sometimes he says he loves Mom just because he does -- not because he wants anything in particular. He has no subterfuge of guile. He has no ability to dissemble. He is totally honest and innocent. It is remarkable knowing that you are loved by him just because you're you. I cannot help but love him back. Although his autism often is a barrier to meaningful social interactions, his beautiful soul shines through his disability.

217 Marcia is a very loving child-adult. She will always say "I love you" if I have had a bad day. She is very caring about others and their feelings. She is a joy and we love her just as she is. We do many family things together and she loves them --trips, visit friends, eating out, etc.

218 My child is now 42 years of age and I feel that almost every facet of his life has been a positive experience. At the age of 18 months (we) were told we should put him in an institution and forget we ever had him, so I feel very positive about everything he has been able to accomplish.

223 She is 28 years old. She has given us 28 years of total love and joy. We feel that as parents her loving presence has completely overshadowed her disabilities. She enriches our lives every day. We are indeed fortunate to have her.

225 As our daughter was growing and maturing, there were little improvements all along, although they sometimes were minute. It is encouraging that she can live in her own apartment. She is a loving, agreeable member of our family. She frequently comes to our place to assist in yard and garden work, and we often do sewing projects together. We can share jokes and funny stories and we have a common faith in God and worship together regularly.

229 (Positive experiences include): Being told that he is the "highest producer" in his workshop and the best worker they've ever had; being told that he has always been the peer model in every class or group he has been in (i.e. perfect manners, appropriate behaviour, most well groomed); last, being told that I would be a good teacher of DD's, since I've done such a super job.

304 Nathan has met some beautiful people in his life, people who really cared about his health. He has come close to death so many times, and was sent on a wish trip to see Billy Rae Cyrus, the singer. We went as a family and it was beautiful. Nathan loves to sing - he has a karaoke machine at home and enjoys it immensely.

307 The most positive experience was the day my daughter took her first steps with leg braces on.

313 With Sam there has been many. One comes to mind. His music teacher taught Sam to play a cymbal on a drum, his right hand was good. At Xmas Sam did a solo on this drum with the music teacher playing along on the piano, and he did a great job. And when he finished his arm went up in the air with the biggest smile on his face.

314 Paul has learned and been able to show he knows the grade one work. He gets most of his cues from his classmates and models their behaviour. He can type, print some (independently) but most exciting of all he has begun to speak.

316 My two sons are both hearing impaired, they also have X disease. We also lost one little boy to X disease. We have had lots of support from our school. My positive experience is to see my children accomplish so much in such a short period of time.

401 There are many (positive experiences): when she smiles and laughs - they are real. She also started to say "Mom" 2 years ago when she was 18!!! I know she loves me too.

410 Can I please tell you at least three (positive experiences)? 1.) Having Wayne. We love him to pieces and he has really brought our family even closer. 2.) and 3.) See "Services: Positive Experiences (General)".

502 Matthew has made our world look different since his birth, his special smile and the way he makes our life happy in different ways. He truly is an "Angel on Earth". Our other son Brady who is six also feels this way. I think Matthew has made a lot of positive differences in people's lives, not just our own. His strength and happiness and will to overcome gives others strength to do the same. I will

continue to look after him, for as long as he is on this earth, also I will continue to fight for the rights and supports of these special children in this province.

503 When Virginia and I are together, she smiles continuously. Her non-verbal communication has improved and rewarding her efforts to communicate gives me a great deal of satisfaction. Virginia is determined and truly terrific.

504 This is hard (to list only one positive experience) as Edward is a "positive experience", by his wonderful loving manner, friendly nature, tremendous personality and a gift from God that my family and I would not have wanted to miss.

510 He is a pleasure to have! I find it difficult to separate our life into positives and negatives. He's a dynamic, independently minded child who fills us with all sorts of positive experiences. He rises in the morning with a smile and a warm hug, he often sits on a lap and holds your cheeks in his hands and smiles at you with his sky blue eyes. He tries to be funny and challenges himself to be courageous and daring. He finds ways (his own signs, or taking your hand) to communicate his message, to get what he wants. He is a joy to have as are his two sisters.

2. Growth, Learning, and Knowing

205 She seems to want us to leave her alone -- so she can be more independent.

210 She loves to work and loves to be around (the) people she works with. She is active in church, loves to shop and is working toward more independence. She has worked so hard. Her father and I are so very proud of her. She has given our family an empathy for others. Marilyn has a younger sister and brother and 4 nephews. This (research project) has stirred up so many negative memories!

212 Noted Kenneth's ability to understand complex assemblies by his seeing it done; and based on his intense interest; he can do anything with his hands.

213 I don't look at what he cannot do or the person he isn't but I am thankful he can do many things that I never expected and that he has a heart bigger than life itself which touches a lot of people with more love than we could ever hope to have.

214 He is not as bad (i.e. as severely disabled) as a lot of people. He's not like you and I, and he's not like others. He's in between. He relates to normal people better. If I go away to visit, he always cleans the house when I'm gone.

214 It will be a good experience for him to be on his own, and to do things for himself, because I won't always be here. He needs to learn to cope with the real world.

217 She loves working at the Center in Medium City. We have to take her half way from our little town -- the rural transit takes her on. Then we have to get her each evening at the pick up point.

219 One positive experience with Dianna was her helping make her bed, vacuum her room, empty waste basket, etc. Household chores has been positive! Especially in room. I have to do rest of house. Cooking in microwave, etc. is another positive experience.

220 On his own he made the effort to go to the mall and bought me a birthday present he knew I would really enjoy. This involved him dealing with people (which he has difficulty doing), the rural transit system and spending his own money.

221 We moved a year ago and she has felt that things here are really hers and she can give her opinion on various things.

306 Barbara works at a sheltered adult workshop. When she got in there and got settled and as time went on it was a positive experience for her. She's now 27 years old and very happy with her work and friends.

408 After childhood and teen/early twenties years of self-abusive behaviours, irritability at just about everything, to see and hear Stewart, albeit with a heavy daily drug dosage, enjoying life at least a little - teasing and enjoying being tickled and smiling! After years and years of those terrible alone look in his eyes or no expression at all, this has been wonderful! and it is wonderful he really enjoys coming home but spends majority of time asleep unless cajoled into action!

409 My retarded adult has a sister 2 yrs. younger and another sister 18 months younger than that. I was expecting the third child when I found out that the oldest was handicapped. One of the first big problems we had with my retarded child was when the youngest child learned to do more than the retarded child could (things like colouring, numbers etc.) She played with her first sister, then later she would spend more time with the second sister. Karen seemed to really feel it when the youngest sister outgrew her (for want of a better word). This was a very difficult time for Karen and for my whole family.

413 When my youngest son, whose prognosis in infancy was to be an "autistic vegetable", first learned to play, then walk (age 4), talk (5+) and then read (7+). He now reads at his age level, talks very well, climbs and runs, and has emerged from most of the symptoms of his early autism. He is now very sociable, friendly and

outgoing - seeking human contact, cuddles and has friends. He's apparently making up for lost time in early childhood.

511 Megan was chosen princess for Valentine's in her classroom this year and competed with the other kids in junior high for Queen. As each one's name was called she clapped and cheered for that participant and was satisfied with being a class rep and receiving her rose and box of chocolates.

3. Learning and Knowing (Negative)

106 Carl has problems with understanding what's right and what's wrong. he doesn't listen very well like he should for his age.

213 As much as I would like to see him interact with so-called "normal people," it is difficult to fit in sometimes. His speech is a hindrance to social interaction some of time. Even if he could talk clearly, his vocabulary is limited for having a good conversation.

214 The fact that he doesn't understand the value of money (is a negative).

219 Dianna needs help in preparing to go places, especially, appointments. She takes hours to get dressed, etc. She often will not be ready to go when anyone asks.

225 I guess the thing that has frustrated me most over the years is her inability to get ready on time when we all need to be some place at a certain time. (On the other hand) when it is time for a certain program on TV or radio that she wants to watch, she knows exactly when to turn on the set.

307 The most negative experience was the day my daughter blamed herself for having spina bifida - since then she has very low self esteem/confidence in herself.

4. Communication

106 Each day Carl's speech grows little by little and when he hears a new word he repeats it quite a bit.

301 If Andrew could only speak better I'm sure my troubles would be over. It is so hard to get speech therapy once your child is in school.

308 Nick is generally a very likable boy. He has his way of getting into people's hearts, with his smile, and the way he looks at you. People bond to him very easily,

(he also is very cute, which helps). Because of this, the people working with him always go the extra mile for Nick. He brings out the best in them, without knowingly manipulating, which always works to his advantage.

401 What bugs me is people not understanding that sometimes when she is "bad" she is only frustrated and we don't understand why. It's hard when you are unable to communicate.

512 There certainly have been many (positive experiences) but the one that stands out the most is when Dennis started communicating via facilitated communication. His knowledge and insight never ceases to amaze us. The individual we always suspected was there is now coming to the forefront.

5. Other Descriptions

205 She loves animals.

207 He is 41 years old, and has worked for over a year at a part-time job. Most of the time he hates going to work and blames me because he has to! The rest of the time he loves job, and responsibility, and pay check. The positive time is when he is content!

505 Everyone needs to be cared for and loved unconditionally! Do you really need to walk, talk and eat like the majority of us do? There are other ways to do these things. My son does not walk, he strolls. My son does not talk "normally", he laughs. My son does not eat "normally", he's tube fed. Marshall is a big part of my life as I am a big part of his.

STRESS/ANXIETY

1. General

105 I'm sure the real concern will start when she is school age. It's a scary thought. Sometimes I feel I'm dealing with enough already. Will I be able to handle it all? Will she fit in, have friends, understand what is going on around her?

106 Carl can be stubborn at times and do what he wants to do. He gets into things that he shouldn't be in or have. He is still not potty-trained even though I have been working with him for the past 3 years. I don't think he understands the concept of potty-training. Sometimes Carl doesn't do what he is told or asked to do. We always have to repeat things to him.

107 Family relationships suffer immensely with couples with a developmentally-delayed child with physical problems.

204 In our 31 years we have become so overly protective with Randy that we don't trust just anyone with him. When my son hurts, "I hurt," and when someone abuses him it is me on the receiving end. I plan on writing a short story on "Life with Randy."

207 It's sure not easy.

220 Everyday home life (is a negative experience for me). His father could not accept that something was wrong. Tension, stress, dealing with Joe & his two younger brothers.

307 Will the day ever come when I won't still get very angry that my little girl (all children in fact) has these disabilities and I feel her life will be even more of a struggle than so called "normal children".

309 Leonard was diagnosed as an Attention Deficit child almost two years ago. After all the physicians and going through all the red tape he is now on medication and closely watched by the family doctor. He has burned so many bridges before hand with neighbours and peer groups; we find the finger pointed at him first, when something goes wrong, whether it's his fault or not. We adopted Leonard when he was 11 days old. He was one month premature. Very little background information came with him.

317 I wish there were more people to help them at school and at home. But only if they are people who really care about the child and not just their paycheck.

407 Our province, our hometown in particular, has no group homes in place for the multi-handicapped young adults, once their parents are no longer able to care for them at home due to physical stress and aging etc. We don't want our children institutionalized or put in nursing homes. We want them to go on living in a home-like environment, in perhaps group homes with extended families that care about them, where they can have their own rooms, personal effects, visitors, outings and vacations with their families.

408 Stewart is the oldest of seven children. When he was fourteen the baby, (now 15 years old) cried suddenly. Stewart picked up the playpen he was lying in and hurled David across the room. At this time the nightmare became too much and Stewart started living in the community group home. Since that time he has been home for several visits and now every weekend and holidays.

505 I know I have another battle now that he is 7. I wish things could be more accessible to meet Marshall's needs, for example: Developmental Day care (hasn't been able to go); Physiotherapy (cut back to 3 times/year, 1 hour each time); Augmentive skills/Communication skills; Occupational therapy; Dept. of Education. I wish our province could make our lives less stressful by meeting our needs as a family. I find the medical problems much more difficult to deal with, (25 hospital stays in 5 years). Constant chest/lung problems making it difficult to travel/visit. If feel the Dept. of Health needs to take some responsibility for Marshall's medical costs. They also need to give guidance when families take their infants home (i.e. support groups; other families' names who are in similar situations; where you can get financial support for all of the extraordinary costs for the infant's/child's care; etc.) They should never send the families home with nothing.

508 Negative - Is the sudden shock after our son was born. We knew nothing about Down syndrome and had no close family members around us. We lived out West at that time. It would have to be the not knowing, the fear and wondering what we did wrong. There were a lot of negative thoughts at that time, wondering if he would walk, eat, play, talk etc., what his life would be like and how he would fit into our family. Lots of bad advice from some friends at that time, a very lonely, scary time for us.

2. Lack of Support

101 Being told by medical professionals what John would probably never do (was a negative experience for me).

103 When we get together in our support group sometimes there are so many handouts about different meetings, all of which are very important, I feel guilty because it is impossible for me to attend any or some. I don't have anyone to care for my child and I don't want to take her out to meetings a lot at night.

103 My husband will not accept the fact that our child has special needs, he is convinced she is just a little behind and will outgrow it. I don't know how to make him understand her DNA will never change. She is who she is. Also, his family does not understand what is going on and my family is nervous when the subject is brought up.

113 There is no help or support at all to the struggles that go on in areas of family life other than school time. Two simple examples that come to mind are negative behavior at a doctor's or dental office, (what its like when that child tantrums or will not wait in the waiting room); or will not cooperate with a haircut. We had some eating problems and refusal to come to the dinner table with the family. Some of those behaviour problems can almost drive a family "over the edge" and they don't

fit into the neat little categories of a professional workload. So who offers suggestions? Nobody. Generally the family would continue "over the edge". We were lucky.

114 People who have a child with special needs or a disability need a weekly break to maintain sanity. At the beginning when they are first diagnosed everyone is there wanting to help. That is the time you want to be alone with that child and sort through your thoughts and feelings. Two-three-four-five years down the line when you have adjusted and need a break or some help, where are they? One should never say call me if you need anything, instead they should call you and say, "I'm coming over for — hours on --- so that you can do something you need or want."

215 (A negative experience for us was a) public school who didn't want to provide!

218 The most negative experience we have had was when he reached school age and there was absolutely no education facilities for mentally handicapped persons. We made an appointment with the superintendent of schools in our county to ask him what we could do but when we told him our problem he got up from his desk, opened the door for us to leave, and told us there was absolutely nothing he could do for us. That was when we started trying to find some other parents of disabled children and get a support group started.

221 There needs to be someone or somewhere we can turn when we need a break.

222 The doctors. told me to put Elaine in an institution and forget her -- this was at age 1 1/2 yrs -- they said there was no hope.

226 It is very hard to cope sometimes -- especially in the beginning. Support needs to come from every direction. If you are in a position to help someone -- in any way whatsoever -- please do so.

227 I think parents with children with disabilities learn very much the true character of people they have to deal with in order to raise a child like this. I know we have. I believe physicians are also included in with these negative people to an extent. We had one physician tell us the only thing to do was to put her in an institution.

302 We are pleased he can travel on the school bus, but transportation in the summer months and on school holidays is a real problem.

303 The government should give her a disability pension when she becomes an adult. Her job prospects with limited use of her body are not very good but she has to work two years before she can receive disability. Social Services won't give her enough to fulfil a lifestyle she deserves as I will be her support for as long as she resides home (probably her whole lifetime). I know of several people who are receiving disability pensions and there is nothing wrong with them. Why should they get one and Debra who needs it, not be entitled to it? P.S. My Member of Parliament can't help us!

315 The one thing that really sticks out in my mind is the attitude of some physicians and therapists. I constantly get the feeling that I am not pushing my son hard enough. I hate going back for a spina bifida clinic, for example, if he is not putting on pants or tying shoes like they said he should be. The problem is that I don't feel the therapists can empathisize with the situation. My child has to want to do these things. . . One physician actually went over my head and tried to book a 2 week stay at hospital in the middle of the summer. She made me feel like whatever I was doing was just not enough. Thank heavens, I do not have to deal with her anymore.

401 My parents not understanding. When I mention how frustrated she is or having a hard time with her the answer is "When do you think you could put her in a home!". People not noticing her very small accomplishments and the joy her smile can bring.

412 When Martha was born the pediatrician who was called in was very negative about her potential. The doctor gave us an old medical text for information. We had to find our own information and learn through experience that her life would not be that bad. Martha has no serious medical problems and is a delightful child. The pediatrician's attitude and behaviour towards our daughter and us has been the worst experience we have had since she was born. Our family doctor was very supportive and helpful in guiding us to other agencies.

413 Having to resuscitate my daughter in the cafeteria of a ferry boat in the middle of the English channel. I was alone with her and her next younger brother. Everybody just stared. Nobody helped me. The ship's doctor did not come for about 10 minutes. (By that time if I hadn't managed to revive her, she would have been dead). It was a nightmare and one of the key events leading up to my mini-breakdown, at least regarding my ability to care for her (i.e. look after) my daughter. I still care for my sons but have totally burnt out my strength to meet my daughter's needs.

418 A resident chastized me for not adequately nourishing my child. We were visiting the pediatrician for the umpteenth time because my child was unable to

nurse or bottle feed without experiencing pain. My son was about 5 months old and weighed less than six pounds in spite of my efforts.

505 When he was first born. Those famous annoying, hurtful, demeaning words "Don't expect!" (was a negative experience). It was to the point that even when we (would) take Marshall home (we would hear), "Don't expect him to know who you are." Well did Marshall teach them a thing or two!

507 A doctor who had seen my son once in a year spoke in a way that made me feel he thought this child, who he knew very little about, had no future. It felt as thought he was labelling and stifling any self esteem and positive reinforcement that we worked so hard to build. I felt angry and I think it set us back quite a bit. It made me wonder if I had imagined all the progress I had seen.

510 Our employee child-care-giver was sitting at the table reading him a book, saying each word in an unusually slow, mechanical manner as though he was a robot and hard of hearing. I was angry because she had worked and cared for him (and his older sister) since his birth and she obviously couldn't see beyond his labelled disability. (She couldn't see) that he could and did comprehend every spoken word, in regular language and normal voice tone.

512 One of the biggest disappointments was with the medical profession at the children's hospital. For years I thought Dennis to be autistic but they did not diagnose Dennis as such until age 8. What seemed to make the difference were photos of Dennis as a baby & toddler showing him very aware and drinking out of a cup independently at 4 months. Even though we told them what Dennis was like they obviously didn't listen to us. Those pictures said a thousand words but what we were saying for years didn't amount too much. We were "the parents who wanted to see those things in our child".

513 We feel tired of it all and lonely because it seems there are so few people who really care about Rachel and her quality of life and what her family must face daily. I worry constantly about her future and at times resent that we will always require "babysitting" for her.

513 There seems to be so many negative experiences that it seems difficult to choose only one. Dealing with so many professionals there have been numerous negative situations. One that stands out in my mind was the time I was called into the Principal's office of the school were my daughter was being partially integrated. She was only integrated for things like Music, Phys. Ed. Library etc. but the parents of the "normal" children had formed a group to get her out of the regular class. The principal had called me in to tell me of this. I found it a very stressful year because there was little support from the teachers and very little from the principal.

(Thankfully this was not her neighborhood school and when she finally moved to where she should have been, her integration experience was very positive.)

515 Barry was not diagnosed until he was nearly two. The G.P. kept saying don't worry; he's just slow; now he'll catch up. I feel G.P.'s need more education in child development so as to be able to spot problems earlier. Neurologists (or whoever breaks the news to the parents re: the child's condition) need to consider how to do this in a compassionate way. I believe they give you the worse case scenario and make things seem pretty bleak. After I left the neurological assessment he had told me that my son would be very slow all his life, etc., I was devastated and didn't know what to do; I didn't know whether to believe him, as his manner was not very personable toward the child and he was judgemental on issues that seemed relevant. I was upset and angry at him, the neurologist. How can they learn to be a little gentler in breaking the news?

516 I have had advantages that many other parents didn't have: supportive parents, an education and financial resources (sometimes). Last year was our first holiday without Kevin (one week). I am so worried about what will happen when I can't be responsible. Last winter I had a bad car accident. That made me realize that I need to have plans made and in place - just in case. But always I seem to struggle alone, even when I'm getting help, I am the responsible person, the one in charge. I need someone to take over the responsibility - maybe I need someone to worry for me.

518 Now that both Paul and David have finished high school (integrated for the last nine years) there is nothing available to them except the sheltered workshop. It seems ludicrous and unacceptable to me to spend years fighting for and supporting integrated education only to graduate into a segregated work center. The few supported work programs that exist cannot provide the level of support either of them needs. On the other hand, staying at home doing nothing is also unacceptable.

3. Demands on Parents

110 This whole game is set in cycles. Right now I'm in a low cycle, but other times are better. I'm bitter about medicare problems and fighting the school! It is scary to think it may never end - it probably won't.

111 I have learned to be an advocate. I also feel I'm doing the work that my son's case manager should be doing. I call him to remind him that the deadline is coming fast for certain things.

114 The negative side would be that she requires so much of my time that there is nothing left for her older brother. I am forever guilty that I am missing his childhood. She will not even allow me to provide him comfort when he is sick, as he wants me.

203 I have very little time for myself, my husband or my other child and grandchild which makes me feel like a failure at times.

203 The frustration of repeating instructions only to have her fail to follow. Recently told her to come home after work; no bus training that day. She went anyway, no phone call, we were frantic as I was in a business meeting for 3 hours. When I got back to my desk, I discovered she was not home -- as she rides a taxi home everyday, your mind can imagine a lot of things that might go wrong. Hopefully she learned a lesson. Also, cannot get her to use a phone recorder.

203 Community clients are totally left out of most activities. If the parent does not create a social activity, no one else will. Residential clients are on-the-go constantly -- with planned activities and a hired staff to supervise. Working parents have a tough time competing.

207 His blaming me for everything that doesn't please him or he doesn't want to do at that time, in the place (is a negative experience for me). He becomes angry and highly upset with his job and wants to return to the sheltered workshop.

222 I guess I'll have to fight for her best interests forever. I thought when she left the school system it would be easier, but with cuts in medical services we are continually on the offensive to protect and safeguard her.

302 Ray is very determined in what he does, what he wears, etc. and getting worse. He bothers me in that he is so very curious: who I am talking to on the phone; what people are doing; where I go; what time I got home; etc. and spreads all our goings-on. Thus we feel we have no privacy. Ray always helped evenings on the farm with his brother, but this past winter had several falls on the ice while transferring from one bus to another, hurt his back, and lost all interest in the farm.

306 Barbara is happy with her work and with her friends (other mentally handicapped persons). She especially enjoys the summer recreation program set up by our local of the Association. However, all of this happens 30 km away. So transportation at times is a problem. Since I'm a teacher, I'm able to transport her in the summer months. I'll be retiring in the fall of '94 so I hope to be able to do more for her. So far I'm doing the best I can.

315 It is a very long and winding road with a lot of bumps along the way. We, the parents struggle with all kinds of fears and problems meanwhile trying to keep our sanity and live a happy life. Please remember, we had a life before our disabled child came along.

316 It is a very long and winding road with a lot of bumps along the way. We, the parents struggle with all kinds of fears and problems meanwhile trying to keep our sanity and live a happy life. Please remember we had a life before our disabled child came along.

401 Being frustrated with her mood and not knowing why she is so upset about something (is a negative experience). Too many messy pants. Not being able to take her with me to some places because she gets upset. Then having to stay home instead.

405 Of course, we fantasize about just sitting back and letting others be in charge, about not having to be so involved - so vigilant. But this is a family commitment for us now - our older children expect us to advocate for and protect Thomas.

503 I hope the inequities of services being provided will be more fairly distributed in the future. I also pray the province will honor its intention to close children's institutions in this province. When I compare Virginia's quality of life to those still in institutions there is no comparison. Parents have to lobby hard to ensure their kids/families get what they need to survive.

513 It's a curse because of constantly having to fight for what other people take for granted (school experiences, friends, leisure activities etc.)

518 So as a family we start again -- fighting to develop a desperately needed service and if necessary (as in our case) you do it yourself. We have started a small family-based cottage industry as a place for our sons to work. It seems that at each transition stage you have to go back to square one and start all over again. It's the same song, second verse (or 20th verse!). Although you can celebrate the successes, it is not easy to come to grips with the fact that it will never end. Life is a series of transitions from one stage to another and with each new stage you are confronted with the same issues over and over again. Hard as it is, you don't dare allow yourself the luxury of getting discouraged because if you do, you might give up the struggle. And if we as parents and families give up, there is no one else (least of all government) you can depend on to ensure that our children's rights and well-being are protected. So life goes on!!

4. Illness and Stress

104 Sometimes it becomes very difficult to know what she needs because she can't talk. We don't always know if she has an earache or the flu before its already too late. Tantrums can be a problem when she can't get her point across for what she wants.

105 It has been a very frustrating 2 1/2 years. We have been going to doctors and running test after test to come up with a diagnosis other than cerebral palsy. We still have no answers. They will not even guess an opinion if your child will walk or not, or talk, or how disabled she will be. It's very hard to plan for the future when you don't know what to expect. As she is getting older and bigger things are getting harder (e.g. always need a stroller, too big to carry). It's also more obvious to other people that our child is disabled. More looks, more stares.

107 The "Hell" we have to go through with medical attention and surgeries for my son. He has been hurt by a doctor in the past, when he was 7 months old. Now it still is so "hard" for "trust" for anyone in the medical field. He very much depends on mama to pull him through.

109 Probably the worst time was when she was only a few weeks old she was put in the hospital. We didn't know if she would live or not. It was a very painful experience.

5. Lack of Friendship

404 The difficulties with the "community-based" services like Special Olympics and the Association, are that such activities are segregating the mentally challenged from the main stream of society. Whenever our son participates in Special Olympics, soccer or bowling he comes homes with an array of unusual behaviours. (We still encourage him to participate and drive him to the functions). In contrast, when he returns from working at the university dining hall, he displays adult-like strategies and mannerisms which are socially acceptable. Our son is becoming increasingly frustrated by his inability to enjoy a healthy social life with genuine friends. We parents feel very helpless with his dilemma. We used to be able to create a good social life for him when he was young. We can still buy him the latest walkman with appropriate dials for his awkward hands and his impatient tendencies. We can drive him to a dairy farm to milk cows, but we are apparently unable to find him a friend. His health problems, asthma, allergies, and frequent pneumonia compound our challenges.

6. Miscellaneous Parental Emotions

402 Having a child with multiple handicaps, knowing he is totally dependent on you for his entire life, is scary mind-bending (sad). It's like you're in mourning for "years", for the whole and full life of your son that can never be. You'll never see him walk, drive, graduate, marry, raise a family of his own......

SERVICES

1. Positive Experiences (General)

105 We are not alone. We have a wonderful support group here and a great early intervention program.

201 My daughter has worked in supportive employment for the last few years, this could only have been done with the proper support system in place for her. I never thought she would be a productive member of society, but everyone that knows her and cared about her -- we had to give her the opportunity to try and succeed, which is no different than what you want for your normal children.

206 If it wasn't for the Center I do not know what I would have done. I did not know how to train her about learning to get by in the world. These centers are the best thing that ever happen for us with child disabilities. Now they have a chance in life also.

208 I am grateful to the Center.

219 Dianna is presently getting rehabilitation services which only allows 2 days/week for her. She could use more services more often as she needs people who can work with her! When the people do come, they are quite positive with her and very friendly. They try to work with her by conversation, etc. I am pleased with this as her progress is very important to me. Dianna will soon have a household and live in an apartment, etc. She has been looking forward to doing this.

220 The professionals we have dealt with have been very good to Joe and are working towards his independence.

222 The fantastic physical therapist that helped Elaine to walk by age 3 1/2 (has been a positive experience), an example of excellent caring people who have helped Elaine.

225 We feel very fortunate that our daughter is capable of living in her own apartment. We are very grateful for the assistance from the X program and the competent counsellors and job coaches that work with her. They found her a very appropriate job which she loves, and have checked on her frequently to make sure things are going satisfactorily.

226 The Association and Vocational Rehabilitation have worked really hard to prepare Ken for his "outside" employment. From the beginning, I was included in every decision and was well informed. I also was able to call any time and was treated with respect and also helped until I was satisfied.

304 I am presently in human services course myself and thank God for TS, KC and JM, because I knew (I) was OK, otherwise those school professionals would have convinced me I were the crazy one.

310 My child was diagnosed as severely retarded. She did not walk till she was nearly four years old. My physio worker was very helpful to me in trying various ways to help her walk. She also did not like to touch things so had to be desensitized. Also any trips I've gone on to the children's hospital in Capital City ... they have been great.

403 I have had many professionals involved with Naomi since her birth and so many of them could not do enough for her. I never knew how many people really care when something happens that is difficult in your life.

404 (One positive experience was) Joseph's involvement in Dr. Merton's language class where Pat Gray worked with Joseph's language development, daily for 6 weeks, in 1984. Joseph's work placements via his high school have all been excellent, productive and individualized. Special Olympics soccer has been excellent.

409 I remember the nurses from the well-baby clinic coming to the farm and talking with me about problems I had dealing with my child. For may years they were the only ones who understood the problems I was having. There was one older nurse who was especially good, her name was Mrs. Jones, she kept turning up whenever things were going down hill. I will be eternally grateful to her.

410 Having a good physiotherapist right from the beginning. She was excellent for giving us ideas of activities to do at home. That's what we wanted. She was good at including Wayne's twin in the activities too. Going to the "Institutes for the Achievement of Human Potential" in Philadelphia - now there were professionals who cared and believed in your child and in you as parents. They had excellent ideas too with explanations of why you were doing the activities.

411 We have a wonderful speech pathologist. She treats Carla and me with dignity and tries to improve Carla's speech although there's often little improvement.

501 Harry P. and the Recreation Association (have been a positive experience). I cannot praise them highly enough. For years they have been a tremendous support helping my son integrate into their regular programs. Our contact with Social services/ Dept. of Ed/ Vocational Services have gone very smoothly. Sam is in the food services course - he has a teacher assistant. The cooperation from all the participants has been beyond our expectations.

501 Also to be fair, junior high was better than high school and elementary. We think this is because the Principal at the time was very supportive of what we were doing.

507 Early intervention was a Godsend to my son and our family. Not only did it help socially and making me aware of what was available to us but also we could meet others who were in similar or "worse" situations.

514 Probably the most positive experience we have had (one of many) with Russell has been the surgeon he has had for his bowel and stomach surgeries. This doctor is exceptional in that he sees Russell as a disabled child who has endless "secrets" to share with us and we are never to ever try to guess what his limits are as he is capable of surpassing and achieving what we are sure he is not capable of. Even when I gave up hope on the operations done on Russell and the pain he was going through, this doctor made me see that Russell has every right to a "normal" life as any other child. He never ceased to be amazed by Russell's progress and shared his faith in Russell with us. Most important he really listened to what we said!

515 One of the first professionals to work with him was an "occupational therapist". At first I was sceptical about what her profession could do for him, but it turned out to be one of the most beneficial "therapies". She worked hand-over-hand with him and demonstrated clearly how to achieve certain goals.

517 Nancy's removal from the training center happened as a result of a very negative experience; (but) she went into a group home and then a small option home. A planning team and then a transition team were set up around Nancy to plan for her future. This proved to be very positive and successful because I was given leeway to choose the team members and to set it up in such a way that I addressed Nancy's needs. With the help of the minister of community services, all road blocks were removed. Nancy now has many caring, supportive and dedicated individuals around her.

518 A formal "circle" of friends was established for Paul in high school that lasted for 3 1/2 years and over time developed into more natural friendships. Lots of in-school and out-of-school activities - dances, hockey games, hanging out at the mall etc. One friendship continues two years after graduation. David (Paul's brother) worked two summer jobs shadowing a meter reader for the Power company and one summer for a municipal parks and recreation service. The boost to his confidence and self-esteem were incredible. He gained a maturity and sense of responsibility that really surprised us.

2. Negative Experiences (General)

103 Most of the negative experiences come from 2 sources: 1.) A clinic (where) I do not feel that I or my child were treated as people, just cattle being shuffled through the system. I also feel our rights were violated, only I was so overwhelmed at the time I did not say anything. Next time I will. 2.) See "Lack of Support" (above).

104 Only one doctor gave us any problem and we were able to find a new one that was more helpful.

111 Neurologist - Never explains why he's continuing with meds. Will my son ever be able to go off medication or will the injuries always be there no matter what?

115 When I first found out she had disabilities, I talked to <u>so many</u> people (professionals) and no one knew what was going on; who to send me to; and who could help me.

212 (A negative experience for us was) a professional that told us, "Forget about it, he'll never learn anything", Wrong!!! A neurologist that told us: they have him down as low as a dog – you should put him in an institution -- so he won't be sitting in a corner drooling when his older sisters bring home dates. Dropped this neurologist immediately. Kenneth was 5 at the time and in kindergarten; this was when we learned he was retarded, but they kept him in kindergarten class -- since he was the most sociable child in there -- and the others could learn from him.

216 The manner in which the team of geneticists broke the news of his rare chromosomal disorder bordered on the criminal – The specialists never considered the impact of what they were revealing and were (more) caught up in the probability of his passing it on to another generation than our interest in the immediate impact on his own life.

310 I would have liked more input from speech therapy. It is very hard to get any help in this area.

311 At physiotherapy, (we have negative experiences): the therapist never telling Jack who she is; what she is about to do; or change of position; complaining of his size and how heavy he is. She has been very hard and rough with Jack, letting him fall and not being told. I was not happy with her behavior towards my son. She asked to be removed from the case. Also never giving Jack any praise or reassurance.

314 Our most negative experience would have to be dealing with the 1 week in the hospital in Capital City. It took over a year just to see these people who were supposed to know a thing or two but, sadly, they are still in the dark ages as far as autism is concerned, and if I'd followed their advice I'm sure he wouldn't be doing as well as he is.

315 One physician actually went over my head and tried to book a 2 week stay at the hospital in the middle of the summer. She made me feel like whatever I was doing was just not enough. Thank heavens, I do not have to deal with her anymore.

403 I had one physician come in to see Naomi after her heart surgery when she was having some breathing problems. He walked in, took one look at her and said "Oh all these kids have this problem" and then he walked out.

410 The professionals worked together as a team in Philadelphia - unlike here at home where you see the professionals, if you're lucky, separately and they all have different ideas - no correlation!

506 There are so many negative ones I can't begin to write about one in particular. I have had negative experiences with the physicians when Peter was first diagnosed, negative experiences all through the school system. Negative experience dealing with in-home support through the government.

514 (A negative experience) for me was a doctor (specialist) who showed no regard for the pain Russell was suffering from a raw, bleedy, sore bottom and told me to accept that he'd always have a raw, sore bottom <u>so get used to it</u>. The pain was so chronic that he stopped making any sound (even crying). Took another specialist only a short time to find a cure and prescribe pain killers for 3 weeks or until he spoke again. Took him 6 weeks to talk again and cry.

3. Positive Experiences (Schooling)

210 Marilyn was at a Jr. High School for her last 2 or 3 years of public school. This was a very open setting which she enjoyed a lot. It did great things for her self-esteem. Her teacher was wonderful.

216 And he has had marvellous teachers who went beyond their normal duties to include him and teach him as if he had no disability.

220 ...There were a couple of good teachers.

310 Her teacher's aide has been very supportive to my child. They both have a great relationship. Hope when she goes to Junior High that her aide can go.

314 Grade one has been a wonderfully positive experience for Paul and everyone involved in his life. He is fully integrated into a regular classroom and spends only 20-30 minutes/day out of class working on computer skills. He has a 1-1 aide who (next to his parents) is the greatest "break" he ever got. They have been together in daycare, kindergarten, preschool, and now school since 1991. She also does respite.

315 School has been a positive experience for us. For the most part he has had good teachers and assistants. We have kept a good line of communication between the assistant, teacher and myself. Flexibility in program and teaching methods is very important. The best teacher assistants he had were the ones who became more involved with us as family. This goes back to communication - you have to keep the lines open by inquiring what kind of program they are following.

516 We had two fantastic teachers, one in Primary and one a "special educator" who taught Phillip from Grades 3-7. The second lady made sure that Phillip was included where and whenever it was possible. She made sure that I didn't feel responsible for every mis-behaviour - the "fault" was not mine. She was knowledgable and caring. That combination made a difference.

4. Negative Experiences (Schooling)

208 Years ago the IEP's were presented in an unprofessional and negative format.

210 I'm trying to remember what went on during her public school years. It has been 17 years since she attended public school. She never was in an inclusion situation. There were times when it was very difficult to make the school personnel

understand that Marilyn needed special education. Marilyn has made great strides now that she's out of school.

220 My son was diagnosed at 19. His school experience was total frustration. Teachers didn't know how to deal with him. Students making fun of him. Barely passing. Sometimes failing...

301 My biggest disappointment was 2 years ago. I discovered quite by accident. that Andrew was being punished at school by being confined to a very small room, no windows, door closed and no activities. He had been there every recess, noon and break for a period of two weeks before my discovery, and it was to continue until the end of the school year, which was about another month. I might add the people enforcing the punishment were told by the principal that I had been notified, which I had not been.

304 This past two years have been the worst to say the least. My son was abused by two teachers in different schools. On one occasion, he came home with his jogging suit ripped down the middle (front). When I confronted them, it was all hushed up. He was diagnosed with Tourette's this year. Also attention deficit disorder. When under stress, the tics erupt, then he has seizures. I have had to call (X television program) besides K.M. and Member of the Legislative Assembly, to get help to remove him from school after he collapsed on 5 different occasions and was hospitalized each time. They would not listen to me as a parent, were ignorant and I have never, and do not ever intend to go through that again with any school system. I saw "abuse" that makes me sick.

317 When my son David was to start school I took him to the school for a pre-test to Grade 1 (in May). What they expected him to do was way beyond him. Still when he started school in September there was no extra help for him. He repeated Grade 1 but still didn't know the material. He was then transferred to another school into a special education class. By this time his self-esteem was very low. He felt stupid. He started to act out. No one seemed to understand what the child was going through.

317 I find the school system very rigid. Little individuality is tolerated. You must conform. I wish someone knew how to teach these people to relax around my children.

408 I feel there is great damage done to many severely handicapped older people by the impressions of complete "desirable" integration into the community being possible for all. Here's a story from a medium sized town which is sad ---- The local special school for the handicapped was built quite a few years ago by volunteers and funding from the community (and the school's club in particular).

Very well equipped building - large playground - gym - wheel chair accessibility - beautifully appointed kitchen for learning. Because it is wrong to segregate, the school has been purchased by the local school boards and is used for storage or occasional meetings or conventions. What a sad and inexcusable waste of a facility.

501 School System They gave/give lip service to integration. They provided a teacher assistant - but also created a dependency on this TA. High school was terrible. The individual teachers gave an honest effort to integrate him within the classroom but he did not have any social integration into life at the school. No one took responsibility for him. They left him on his own at lunch time - he would get in trouble. The last year he usually ate his lunch in the resource room. Because he was on his own he copied the worse behaviour in the school - we ended up with terrible behaviour problems at home - went to child guidance as a result - still didn't get much help - child guidance doesn't know how to deal with young people who are mentally handicapped.

511 When Megan was 8 years, the system decided that she be moved (along with some others) to a regular classroom from her segregated special ed. class - 6 kids and 2 adults - (to a class of 31 kids - 1 teacher - no support - in a new school - no orientation). When this didn't work out they told us our child had a problem. Here the whole system failed Megan - teachers, professionals, school -all! It took little old parents to do their job!

5. Struggles

108 Our constant battle is, of course, with the school system. I want to mainstream my child and I feel they are guiding me away from it. Worse than that, I feel a total year of my child's life was wasted with a "professional" incompetent in her job during a very important year of development.

109 Nothing really sticks out in my mind, as a negative experience. There have been many experiences with my daughter that have been unpleasant, mostly going to doctor's appointments and going to public places that were not accessible.

110 Our principal is against inclusion and has made "me", the mom, the bad guy in the entire process.

201 Being told to put your 5 year old autistic child in an institution and to forget her (was a negative experience). I was told this by a doctor. I was determined to prove him wrong.

202 Finally having someone in Adult Services actually take the time to get Jake out and get him a job in the community. But until we said we were taking him out of the program and gave them a deadline -- no one did anything. Then a miracle -- Jake has a community job and is making enough each week to buy his music. Thank goodness for this one very excellent person.

203 ...I hope the future will provide more training, available residential placement, transportation help as we have fought since day one for all of these and gained very little to nothing. Too much politics involved in some residential programs.

209 No early intervention services were available to us. It was impossible to get help of any kind. The hospital just kept giving me students who would stand back and tell me to keep doing what I was doing -- it was working. I begged for help with motor skills and never did get anything, not even advice! The Association center has provided him some place to go each day, sport activities for the first time where he can not just be a spectator, and friends of his own. Friends of his own has been very important to him -- not his brother's friends! The school system fired his best teacher. Jr. High and High School classes were useless!

209 A pediatrician put him on Tegretal. He got very bad headaches and became violent. The pediatrician told me we'd just have to institutionalize him -- some get violent. We had done the best we could do. He denied it was the Tegretal and wouldn't change it. Another physician intervened and within 3 days Tom was an angel again. He had headaches for 6 months after going off Tegretal. The only "apology" from the first physician was when he told me later a 3 year old girl did the same thing.

210 I was actually called by a psychologist (that we had taken Marilyn to for evaluation) and told that he had found an institution that would take her. His comments were that we should put her in since she would never be an asset to our family. I hung up on him since I hadn't requested this.

211 My son lives in a group home in our community during the week and comes home on weekends. We are in close contact with the group home and the classroom teacher at school, but it is always a struggle to get everyone to carry out his program. I am getting older and it is getting harder and harder to fight for good programming and good living conditions for him. We are constantly at the mercy of legislators who see aid to those with disabilities as expendable.

211 When he was younger he had to go to the hospital to have tubes put in his ears. Despite our advance pleas to the hospital staff and our careful arrangements for timing, he was kept waiting almost 3 hours after he was scheduled for surgery -- this was intolerable for him and needlessly hard. I was so angry at the hospital staff

and the doctor for not taking his disability into account when scheduling the surgery, especially after we had told them that he could not be kept waiting.

226 At birth -- shortly after he came home from hospital -- doctor suggested he be put in institution, that there was no hope. After changing doctors, I have been blessed with professionals that truly care about my son and myself.

227 The negative part has always come from adults that should know better, such as schools, teachers. We were told our daughter could not go to one school. We moved and enrolled her in another school, bought a house and less than 2 weeks later, school authority brought her home and said she could not go to school there. This was a special education class, and we talked with the leaders before we ever moved, and placed her in this class.

228 After we both got cancer we had to make sure that he would be taken care of. They accepted him, after 1 1/2 years of trying, into a group home which relieved both of us for his future. His mother may have only a few more days to live that is why the first questionnaire was not filled out. I'm sure that my wife would have answered these a little different.

304 In order for us to change society, we have to listen to parents, to our clients (mentally handicapped) who never seem to have a say, and the abuse has to stop because innocent people are getting hurt by professionals who themselves are abusive. I've seen it. It's a power trip with them. I will never let them hurt my son again. I'll go where I have to. The X television program would have taken our story, but by then, they changed schools for him. I wanted him with his aide. It's hard for me as a single parent to believe what is going on with our system. I truly hope there will be more help with respite care, because I for one have been with my son alone for years. It would be nice to have some free time, something we as parents do not have. Social Services is supporting me (with money) to get through my course, but they do not support us with our handicapped children. We are the minority not having a voice. I hope someday to be able to help other children not have to go through what my son went through - or my family - to get help. Our handicapped adults and parents are being abused by professionals who don't know or care what it's all about. Let them walk in our shoes for awhile.

305 It's hard enough coping with the fact that I have 2 children with disabilities, and as a mother I'm always fighting to attain or retain services that are basic for their quality of life. I'm always spreading myself thin; trying to be involved educationally and medically. Just 3 weeks ago I almost lost my oldest daughter to a blood disease, and at the same time I'm battling with government over the closure of our regional school for the blind and hearing impaired, and with the local school

boards and professionals over my youngest daughter starting school this fall, to mention a few ongoing issues. It's exasperating!

305 On the front of this questionnaire I put down my occupation as a homemaker, however I am so much more than that. I am often referred as the "non" professional when I sit on boards or committees, and I quickly correct them, because as far as my children are concerned I am "their" professional, and although I did not attend college as a student, I am now asked to speak to college students, so as I can teach them about my schooling. . . the college of "Live It and Learn It".

308 It has been far more difficult for me to deal with schools and trying to get services which I felt necessary for my child than it is to deal with all his disabilities (which are numerous). It was easier for us to move our family (which we did twice in three years) to get a better situation for Nick, than the stress, and aggravation of inadequate services and schooling.

311 The physician told us that Jack was hopeless - there was no hope - would never walk, talk, sit up, hear have no control over his elimination, take seizures - he is total and complete care - put him in an institution. I was 8 weeks pregnant for my little girl who is 11 months younger. I told that doctor to go to hell and if was the last thing I ever did I would prove him wrong. That was September 1991. September 1993 I took Jack to him as we regularly do. Jack can hear a minute drop. I put him in the floor and he sat up all on his own. He smiled and hugged his mother. He responded to my praise and put his hands together to clap. I was so happy and proud of my boy. The doctor couldn't believe his eyes. He said I am happy for you and your husband, I really am, if I didn't see it I wouldn't believe it. My response "Love can work miracles."

315 They (professionals) don't have to be with him every day and watch the struggles or hear the crying. I do, and some days it is more than I can take. I have other things to think about, a husband and another child. Our lives cannot revolve around Peter any more than they already do.

404 Several months ago, I accompanied our 21 year old son to an Association dance at school. It was most discouraging to witness necessary humiliation and overt neglect of the mentally challenged. The "guests" were given a "snack" at 8:30. The "snack" consisted of Mc Donald's drink and dry sugar cookies. No choices were available. Only days earlier I had accompanied "normal" high school students to a drama function. The snack consisted of an array of fresh fruit, cakes, three kinds of pop, cheese and crackers etc. Every single ("normal") function whether preschool, art openings, soccer meetings have always provided guests with at least two choices of refreshments. Our son is allergic to McDonald's drink and sugar cookies so he went without any refreshments. We could have brought

him his own snack but the other "guests" would have felt badly. Our son is not capable of performing a range of tasks. However, he can select food and pour his own drink and is pleased when he can get a sense of control by performing such tasks. The people at the Association dance were treated like cattle and expected to drink stale sugar water that had been poured several hours earlier. Please let us not necessarily humiliate the less fortunate members of our community. I would be very happy to take turns bringing variety of snacks and supervise a crew of mentally challenged people who could serve the snack themselves. They may not be capable of driving a car but they can definitely pour refreshments and select food. They also deserve healthy refreshing apple juice or at least no-name pop (adults drink it). Mc Donalds's drink smacks too much of little 'children'

405 Speech assessment/therapy was a big downer. They use inappropriate tools, environment etc. and got a really bad "read" on Thomas. They knew nothing about our family culture but were very directive about how we should interact with Thomas. They didn't want to work on his articulation, wouldn't let us have access to XYZ software- just wanted to assess him every 6-12 months. This was useless so we quit speech.

406 I feel the school boards should be open to each family who has a child with a disability, to allow them to attend whichever system (public or alternative) the family wishes. I would also very much like and have been trying for years to have the high school mentally handicapped school program changed to suit our child's abilities. For example, she is able to do academics, reading, typing, math, computer and Phys Ed, yet the high school program offers 80% to 90% lifeskills and only functional academics pertaining to the lifeskills. Our child has proved herself to be able to be taught, to read, do math on a calculator and work on computers. Why does this have to stop at age 14 or 15? We get NO answers, only that this is the Curriculum.

407 The psychologists we had, initially, never said anything positive, no matter what we saw in terms of progress. Finally we realised that we were much better off without them. I cried for hours every time we saw them. I now rely on "informal" advice from professionals who are friends, acquaintances or family.

408 (It has been negative) to hear Dr. L talk about the gradual reduction of drugs which have been prescribed for many mentally handicapped adults (in particular) which may not be necessary and indeed pose additional side-effect problems. The medications are just continued without review unless there is a particular emergency. To be granted an appointment with this same doctor who was extremely interested in Stewart's case as an example of a particular genetic syndrome - an "M.T."? scan a must - absolutely no reason for all the drugs - see you next month. The next month arrives (overheard from secretary's office, Dr. L

on route to clinic - "Oh I'll have a word with Mrs. Z. The words were "Yes what can I do for you?" Something must have happened for this change of attitude between appointments. Hopes dashed.

408 Professional people have been very kind and well meaning over the years. No complaints there - Have just felt sometimes that they had as much difficulty in being constructive as we.

408 We were told by the Consultant who diagnosed Stewart in England aged 8 months that we should go ahead with plans to emigrate to Canada - go and have a large family in a "large" country. This will not happen to you again (he had told us Stewart would never do anything but lie flat on his back, most likely.) How could he know if no one follows up on the adults with a given diagnosis?

410 Only one (negative experience)? That's Difficult! Overall the most negative experience would be trying to get OT and speech therapy services for Wayne without having to drive one to two hours. I also feel such services only two times a month are not sufficient. We have four sons and it is not easy to be on the road all the time. We even called health services to see if we could get training as parents from all the professionals at once so we could do home therapy. We just asked if we could meet with these professionals for 2-3 days so we could formulate a home program that would cover all of Wayne's needs. We were told by health services that there was no place in our province where this could be done. This is when we decided to go to Philadelphia despite all the expenses (which health services would not help us at all with).

502 The lack of adequate support in our province for these children (is a negative experience). We as parents are frustrated by the lack of support that is given to families that wish to keep their children at home. What supports that are available are inadequate for the survival of these families. The provincial government pays $11,000 to $15,000 or more per month to institutionalize children like mine at a cost (taxes) to us, but when it comes to support for people keeping their children home, well it's just not there! The provincial government must take a proactive role in the survival of these families. They should encourage and enable families with children with severe disabilities or chronic illnesses to nurture and enjoy their children in their homes, rather than supplanting the family's primary caregiver role by expanding public funds to place the children in institutions or out-of-home placements! All children regardless of the severity of their disability belong with and do best with their family.

503 Fighting for everything. Fighting for services, for financial support, for her place in the community

505 . . . The department of community services. . . I have to battle with this department almost daily to get some services for Marshall. Marshall was 3 1/2 years old before they began to help with his high medical and physical costs. He just turned five in July.

506 While receiving respite money from the province, myself and other parents were subjected to quite a few remarks that were very objectionable. For example - "You are so lucky to be receiving all this money," - "You're getting more than anyone else." - "Make sure you use it for respite and don't waste it." - "You're up for review soon and it will probably be reduced or cut off." They try to make us feel we're getting welfare and draining the system. I'm sure some parents feel guilty and are intimidated by some government workers.

509 The continuous battle with community services, school board etc. in recognizing our needs as a family unit and Marjorie's right as a human being. The abuse she suffered while residing at a children's institution has been the worst possible experience any parent can have.

509 As Marjorie does not pose a problem. She is perfect as she is! It is the system that we as a family must endure and battle with that can pull families apart, because to date the barriers still exist to exclude Marjorie from full citizenship which, as her mother, I see as her right to access equality along with the rest of the population, in all aspects of her life.

515 He was "expelled" from pre-school for pulling hair and other anti-social behaviour which was potentially harmful to the other children. The director and teachers did not know how to deal with him, and allowed panic to prevail whenever an incident occurred. This was supposed to be a "developmental" center. This event was our invitation into the world of fighting for his rights and a taste of the struggles that may be ahead. This was done without notice or discussion. The motives for the expulsion are still questionable. It partly relates to the Director being uncomfortable with people with special needs.

516 Recently Kevin finished school, there was no program where he "fit in". The social service worker did not support us, return phone calls or recognize my stress. I have just returned to work full time and was not willing to give that up again. It was not until I started to make arrangements for an expensive group home . . . I told them that I would put my son out of our home... that we received a <u>response</u>. Within 2 weeks of my saying that he would not have a home, and <u>all</u> my savings were spent, an apartment and an attendant became available. It was very stressful. Things are not perfect now - we need to change the attendant and that will be difficult. More stress.

517 The most negative and devastating experience was the issue of abuse which possibly happened at the centre where she lived. The insensitive treatment we received by the very people who were responsible for Nancy's care was unforgivable. The investigation which was carried out was incomplete and unsatisfactory. We are still dealing with the effects of this abuse and will for a long time to come. To date, nobody has been held accountable.

518 At an IEP meeting for Paul in high school, two teachers verbally attacked me with loud angry voices for wanting him integrated (even though the statement had already been agreed to and was a continuation of 4 years of integrated education in his previous school). I was told that I was just holding on to the latest philosophy and was on the bandwagon I did not care I was harming all other children, I was selfish, I was demanding something that was impossible for teachers to do, etc. etc. The worst of it was that the principal who was (and is) very supportive of integrating my son and others just sat there and did nothing to intervene or to refocus the meeting on developing the IEP. I was devastated and ended up crying uncontrollably and left the meeting after 45 minutes of continuous abuse. Surprisingly the IEP got put in place and he had four quite successful years in that school. Why did they need to put me through that? Why could they not see that Paul's presence could enrich the lives of others rather than harm them?

6. Positive Support

104 We've never had any problems with the help from school or therapists. They all listen to every concern or achievement.

105 We also take our daughter to therapy once a week to a local hospital for O.T and P.T. as well as once a week she gets it in the home through the early intervention program. They work well together, the hospital and school. Work on same goals and plans. Always very positive. Really work for the child. We feel very fortunate. Things could be a lot worse.

308 I'd say that the most positive experience of having a handicapped child is getting to know all those really wonderful, caring people who chose to be involved with handicapped persons, not for the money (there's never enough) but because their hearts are in the right place.

317 I have three sons with disabilities. When my eldest son was 3 1/2 years old I was going through a lot of denial and felt very angry. A worker started to visit our home twice a week. She played with David (it was a stimulation program). She accepted David as he was. She helped to show me that the most important part of

our relationship is love. David needed my love and I needed his. Through the years (and difficulties) remembering her and the lesson learned sustained me many times.

7. Positive and Negative Support

313 Overall, for the most part, we are very lucky with help and support from professionals. Peter's integration is going well except for the area of teacher's assistant's not wanting to integrate his communication device into his everyday work. She has help from myself and a speech therapist, but says she's using it when really she isn't. I find the school tends to side with the assistant too much. She's been at the school for 2 years. I sometimes get emotional because I know Peter is a child who wants to answer. If everything was normal, he'd be quite talkative and he does well at home, but he needs a push at school. . .

8. "The System"

503 She is a fighter, like her mom. We've fought the system and for the most part have gotten services.

506 I assume you are referring to (positive) experiences dealing with the system. I could only account for two in all my son's 18 years. It was the year he attended X day care (integrated) - 4 yrs. old. The other was 1993, when I had a teacher work one on one with Chester for the whole year at home. He had regressed to the point of not leaving his bed and after a long "battle", I required financial help to have someone come into the home and work with Chester to lift up his self esteem and gradually get him out of the house and back to school. Many road blocks were put in place by the "powers that be", but I fought all the way for my son. Needless to say I have no "friends" in the system (government or school).

PERSONAL

408 (I) still feel very guilty about Stewart.

408 Because my husband cannot bring himself to be involved with Stewart in any way, even now, he will go for a walk and never ever suggest that first maybe Stewart would like to go or should go. Perhaps this accounts for the gush of words on my part that seldom have an outlet. Forgive me. There is no reason why Stewart could not live at home now but I feel that he is well settled in the group home with five other young men he knows well. If anything happens to me, I know he'll be OK in familiar surroundings. I have a grand mal seizure myself during the night approximately every six weeks and am virtually incapable the following day.

Stewart has both grand mal and petit mal seizures probably only about once every three weeks - perhaps attributed to the control by the drugs. Tremors now noticeable since Haldol.

408 Anyway we arrived in Canada two days after Christmas in 1964. We had our large family and it is wonderful for me to be able to talk to the girls, in particular, as friends and tremendous support and fun; but the early days were very, very touchy with regard to Stewart and his future.

SURVIVAL

1. Interface with Community (Positive)

102 We live in a small town and Kathie was born here. She has been very well accepted by the community. We bring her everywhere we go. The people downtown (grocery store, bank, drugstore) seem to look forward to her visits. They go out of their way to say hello and ask how she's doing. Kathie has a very bright personality and it is hard for people who seem afraid of her or ignore her for long -- but people here seem to truly enjoy her.

109 We recently started going to a new church that is more accessible than our old one. Anne was immediately accepted there. They moved her Sunday School class to a more accessible area after we had gone there only a few times. The pastor's wife told me recently that Anne had added so much to the congregation.

111 Kindergarten - The teacher was wonderful and his one-on-one management aide was superb. She knew when to step back and let the kids take charge. The first day the class was told why Harrow was in a wheelchair and how to use the wheelchair etc. They took over. He had a wonderful year.

113 Integration (inclusion) has been a positive experience for us. When our son was in a segregated school, we would take him shopping or somewhere else in the community and he was a stranger to all. People just stared. But now with him integrated at school and socially, everywhere we go, people speak to him or say "Hi" to him. (Making our whole family more acceptable.)

203 Many (positive experiences) come to mind -- (1) Attending her high school prom with her and escort. (2) Going through graduation with cap, gown. (3) Working in the community since completing high school -- same place now for 4 years, 3 months -- quite a record. (4) To share her relationship with her nephew -- he loves her dearly.

208 (positive experiences include): Local acceptance; Commendation on her work-attitude. I have met some fine teachers.

209 Many people treat him very well. We had a graduation open house with all the trimmings. A good crowd from family and church came. No school people, though they were invited. Tom stood at the guest book and opened presents and cards and felt very special. he probably had more guests than the "regular graduates."

215 Special people who really cared (provided positive experiences).

227 We have learned and felt all the good feelings so many people have toward our daughter. We are square dancers and our daughter has gone with us lots. She has so many good friends, it is unbelievable. Also our son's friends have always been the same way.

301 Since Andrew was 5 we enrolled him in the local soccer programs. He was able to participate well. It was a real thrill when his team came first place in the championship the year before last.

302 Ray enjoys going to the sheltered workshop and the staff there are very co-operative and caring. In the summer of 1992, he worked with a car salesman, cleaning cars inside and out, cutting grass with riding lawn mowers at his place and at all his apartments. It meant great social growth and much happiness for Ray.

405 All of our experiences come to us in the regular, non-disabled world. Here are two: 1.) When Thomas started nursery school (not a special one, but our neighbourhood preschool where emphasis is learning through play) his teacher observed that, at age 3, he was quite mature socially - more so than several other three year olds in the class. She always minimizes his differentness and enjoys his progress. 2.) At church school the team of teachers and assistants have taken seriously their role in Thomas's spiritual life, including him in every way and keen to help prepare him for Kindergarten. Teachers (who are remarkable women) have told me how much they're learning from him and how glad they are that he is there.

407 The school has been great and the children are extremely friendly to our daughter. Our physiotherapist, Helen, can handle my anxieties amazingly well. I never want to give her up.

412 There have been many positive experiences. Martha's acceptance and treatment as one of the children by our friends, people at church (children's liturgy group), at the daycare, at school, at the grocery store, has been very positive. We

hope Martha's integration into society will continue to be this positive. We are trying to insure this by teaching her appropriate behaviour and language skills.

509 Watching her during this last year of school (has been a positive experience): integrated fully in our neighbourhood school; making progress in many aspects. She's happier, more content, more aware! Watching how the other children - her peers - interact and include her in the activities - make and send home "tactile artwork" for her, that they've done on their own time at home! She does not stand apart from her classmates but belongs!

513 One extremely positive experience was after my daughter was integrated in her neighbourhood school in year 2. I had several parents come to me and tell how much their children were learning from Rachel and how great it was that she was in their class. It made all our struggles seem worthwhile.

2. Interface with Community (Negative)

102 We visited a church where our parents live and sat next to a family. The teenage daughter noticed Kathie and seemed physically repulsed by her. She moved away from Kathie (we were in the same pew) and looked surreptitiously at Kathie the whole time. We ignored her and treated Kathie like we always do. Kathie even tried to "make friends" with her but she was very put off. I grew more uncomfortable and was glad to leave. It was the first time Kathie hadn't "won over" a disability-shy person with her charm.

112 I was told my daughter couldn't go on a field trip from the X group unless I went with her because she would get too tired. (She learned to walk late and they were walking). I was going to send a stroller. What they needed was more adult supervision; it shouldn't have had to have been me. Other parents were asked, if they wanted to come; I was told I had to come. Later they realized they were wrong.

202 Having an attendant at the local "Fun Night" point to Jake and say, "He can't ride. He's handicapped!" (was a negative experience).

204 My son is 6'3" and weighs 382 lbs; when we go into a store where toys are sold, people stare and make fun of a man his size playing with toys. You can't educate people that aren't willing to learn.

206 Some people do not know how to accept her. Lots of people make fun of her or do not want anything to do with her.

223 From time to time another family has not wanted their child to associate with Mary because of her disabilities.

303 I enjoy taking her to the malls where she can meet some of her friends which she enjoys. What I don't like is the way some people stare and talk behind your back about her disability and feel sorry for her being in the wheelchair. She has accepted this in her life and does have pride in herself and doesn't need anyone's pity for being in a wheelchair.

303 It occurred in the mall one day and occurred in the front yard as people would call her retarded which she is not but some people are just plain arrogant. Too bad they couldn't change places with Debra Anne and realize what she needs is support.

306 When she made the change from a child development class where she was quite sheltered, to a junior high situation, that was quite negative for both of us at first. However, she settled in, had a great special education teacher and things worked out well.

309 There is a "neighbour" in our neighbourhood who cannot accept our boy as "special needs". She goes out of her way to be nasty and say hurtful things. She calls him "Satan" and told him the reason he was adopted was because his own family couldn't stand him.

313 He's lucky he has 3 close friends that come over quite a bit, but its sad when he asks why he's hardly ever invited back. Its not the kids, but the parents. I know they don't owe him anything, but he's a kid who also wants to go out.

316 My negative experience - because we also have foster children and one of our children is profoundly deaf - is people who stare at her, especially adults, because she doesn't talk like other people. Also people's ignorance about children who are hearing impaired. Always talking about them as if they are not there or couldn't hear a thing.

406 We, right from her birth, have constantly been asked, "How much money do you get for keeping her?" This has often been asked yet our response has always been "Nothing." Why should we? She is ours, she is part of our family. They say, "Well you should. Other provinces pay families an amount to keep their handicapped children at home."

409 I remember being at the swimming pool one afternoon with my three daughters we were all laying on the grass (their ages were maybe 6, 7 and 9). Karen the handicapped daughter got up to go to the bathroom. She only made it

halfway there and ended up peeing on the grass. Another young woman (whom I did not know) was so mad about that, she ended up grabbing her two kids and stalking out of the pool.

411 Most experiences with the "outside world" are negative. Carla's abilities are discounted because people focus on the disabilities. Carla is organized, careful, caring and forgiving. She has a wonderful sense of humour which most people have never seen. I also hate the fact she's allowed to behave in socially inappropriate ways because she's "handicapped".

504 (Finding negative experiences): this is not hard. When I had Edward enrolled in a horseback riding club through Capital city summer recreation, he was to encounter blatant discrimination. Parents were going to remove their children from the class. The manager and others involved totally discriminated against my son.

510 Our son is "categorized" as possessing a mild degree of the disability, Down syndrome. I believe however that the context of family in which he is being raised has played a significant part in his "incredible" development. I expect that we will encounter a whole new set of obstacles and barriers - generated from peoples attitudes - when he goes to school.

514 My daughter would say (a negative experience) for her was when she was pushing Russell in the stroller through the mall and a lady walked up to her, looked at Russell and said to her face "My what an ugly baby".

3. Personal Growth

101 I learned to enjoy the small things in life because John's milestones don't happen that fast, like other children.

103 I have been able to meet a lot of nice people that I would not have had an opportunity to meet, otherwise. I have been made aware of needs for all children that are not being met and have started to become active in this area.

105 Having a child with a disability has made me much more aware of the number of people with disabilities.

108 I'd have to say the "overall positive experience" we as a family must focus on, is that how something so terribly devastating (birth of a special needs child) has turned into such an enriching experience.

110 Because of Sarah, we have met so many new wonderful people.

112 She has taught me to really appreciate each developmental milestone with her and with her younger siblings. She's helped me count our blessings and realize how fortunate health and "normal" development are. She has taught me what patience is. I have also become more self confident in standing up for her rights and getting what she needs. We have been very successful in getting what she needs.

114 Tabitha has taught me compassion and is working on teaching me patience. It would be a better world with more Tabitha's as she is a very loving, touching child.

201 A parent cannot just be a parent -- they must always be an advocate for their child. Expectations should always be there as long as you are realistic in your expectation. Parents do not realize the power they have in working with the system to get what is needed for their child. It's been a long, rocky road the last 25 years of my life, but what an experience I've had that many people will never know -- I have met the most wonderful people through having a child with a disability and I've sure met a few jack-asses, too, but I forget them.

202 Jake is my stepson. He has been "my son" for 10 years now. One day I had absolutely no experience with a handicapped child and the next a 16 year old who could not feed, dress, bathe or go to the bathroom without help moved in. Well what a year we had! I jumped straight into a whole new world of limitations and physical therapy and lots of struggles and tears. We survived that first year and each year Jake has blossomed. How much we have all learned and how much I have enjoyed seeing Jake learn to be more independent. I have four children (all grown) of my own and they all love Jake and have learned a lot about just being grateful and an appreciation of how hard it is sometimes for Jake to do simple things they do with ease. Didn't mean to write a book -- I've tried. I've screamed I've been so frustrated -- but I've laughed more than any of these! Jake is a joy and a blessing. Jake travels with us -- he and I go to country music concerts, to concerts, to ball games, you name it -- we all have been on a learning expedition this past 10 years.

206 She has brought a lot of happiness and love to me and others with her willingness to learn and her care about others like her.

213 I have found having a child with brain-damage and learning disability has helped me to be more caring, considerate, compassionate, and accepting of all kinds of people we encounter in our lives.

213 I have learned much from Neville and I have never regretted the time I have given him. The same applies to Neville's father when he was alive and his sister and 2 brothers.

213 Keith was born normal. At 8 mos. old, he had double ear infection which resulted in high fever causing brain damage and epilepsy. I, his mother, have stayed in the home and taken care of him for 35 years. He went to a special school, not public school, until he was 18 years old. My husband and I taught him everyday necessities and it has been a joy to see him learn and progress each year. Now that his Dad is deceased, we live alone and he takes care of me as well as I him. I give myself space and balance out each other's activities and pleasures, so neither of us feels neglected.

216 His accomplishments have taken on a more important meaning for all of us in the family, including him. There's real pride at doing well on a spelling test or getting a happy face on a workbook exercise. We feel happy at smaller advances than with our daughter -- everything is in perspective.

217 There has not been any big negative experience with Marcia. At first, when she was little, it bothered me some when people looked at her -- the way she walks -- but that does not bother me anymore.

218 My son is now working in the community through a rehabilitation program and rides a city bus by himself to and from work. I feel very proud of him for this accomplishment.

305 My positive experience given to me by my children (with disabilities) is the personal growth and strength that they have instilled in me. I diagnosed my own children with a very rare disorder. I have travelled to lecture to geneticists in the U.S., I have been in contact with Nobel prize winning geneticists, lectured at universities, contacted other children's families around the world, who also have this syndrome, and I work closely with 8 organizations and committees that deal with disability issues. All of which has been opened up to me by my children.

311 I would like to say we love our son and he has made us better people and stronger than we ever thought we were. There has been a lot of doors slammed in our faces but we keep on fighting for our son and his rights.

402 I've learned more about various mental and physical disabilities, and am not afraid of them or so curious about individuals with differences now because I've spent so much time in hospitals, rehabilitation centres, developmental centres, group homes, Association meetings, parent to parent support group meetings etc.

And therefore, my children have learned to be more caring, open and accepting of others with differences than say my generation was.

403 In my opinion, raising Naomi will be like raising any child. There are always challenges and hers will be different from my other children just as theirs were different from each other. I'm as proud of her or maybe more so with each milestone. She has added so much to my life and I thank God every day for letting me have her for my child.

405 I believe I went through a terrible crisis in Thomas's third year when I realized that the "experts" were fallible, that often I knew more than they did about child development, about good child care. We were being pushed to accept a preschool placement that would have been mediocre at best - in fact it would have caused Thomas to regress and would have completely squelched my boy's inventive, exploring spirit. (I could go on about this for hours!!).

412 Having Martha has been a very positive experience for my husband and me as well as our family. Martha is developmentally delayed but there are so many things she can do. Her brothers and sisters are as proud of her accomplishments as we are. Martha has brought a lot of love into our lives. The future will not always be easy but I feel we are priveledged to have Martha in our family.

508 The most positive thing about having Stanley in our family life started while we were in the hospital with Stanley. Our daughter then was very excited about her new brother but unsure about why we were all crying etc. So being perceptive enough to see the so-called wise adults talking, Sharon jumped in the bed looked us in the eye and calmly said Stanley is our baby no one else's, "Right?" We smiled and said yes not really ready for her next statement. "Well then we will just have to take him home and love him no matter what he has because he's ours, right Mummy?" Wise words from such a little girl and we have tried to follow it even since it was delivered to us. Having a child with special needs is no cake walk but with the right supports in place, family members and good friends, your path in life can go a little more smoothly for you. It's hard to reach out at times but after the first time you do this it will become a little easier, there is no shame in needing help. Once we learned this, life did get a little easier for us.

511 Despite a rocky start- Megan has turned out to be a lovely young lady who is interested in everything around her and is confident that she can do or be anything she sets her mind to. If we as parents hadn't pushed for everything that she wanted or needed, she would never have come as far as she has. Just this spring a school board member told me that all of the "professionals" who thought we were looking for the impossible now think we have done an absolutely wonderful job. They sure had a lot to learn.

512 I like to think I have come a long way since those early years. I've stayed involved with the National Association and have always tried to keep up with new things coming along (which would help us understand and deal with living with a high needs child). I believe its possible for my son to have a meaningful life and be a contributing member of the community.

513 Having a child with a disability is both a joy and a curse. It is a joy because of the person Rachel is, the good experiences we've had, the things we've learned and the people we've been so fortunate to meet because of her.

513 It (Rachel's disability) seems to bring out the best in me and the worst in me. Reading the comments from the parents used in this questionnaire helps me realize (remember) that we're really not alone in our struggle and the way we feel.

514 We see Russell as a great gift entrusted to us by God. He has been an unbelievable joy to our whole family. The learning is endless and the gifts he has given to all of us to see inside ourselves and become better people is an experience I never dreamed of. Our 19 year old learning disabled/ADD child (Russell's sister) was a daily stress and burnout on our family but in the long run made us strong and showed us how little we knew about living. Because of her we had the courage. . . and want to raise another special needs child. This time around there is no burnout and we've learned how to live from hour to hour and day to day and to find endless enjoyment within our family.

4. Personal Growth (Siblings)

406 Beverly has a younger sister whom we have brought up with an openness to various handicaps. Neighbour has a child with cerebral palsy, parents we know have other children with Down syndrome and Beverly's sister thinks no differently of these children, than her sister. She is not afraid, nor ashamed. This I feel is because of Beverly. She shows her sister true love. She has taught her sister how to love unconditionally.

5. Positive Support

104 Even though she is severely handicapped our family, relatives and school teachers, seem to all work together to take care of her, watch over her and everyone is interested in what kind of progress she has made. Everyone really loves her and (they) try to help us work with her.

506 Sometimes if it wasn't for sharing these experiences with other parents who have felt the same frustrations, I'd think there was something wrong with me. But

all I want is what is best for my son and my whole family. It's terrible when the little bit of help you get is only because you had to fight very hard to get it.

6. Strategies

102 We have an older daughter, age 8, and we have always tried to treat and discipline Kathie like we did Kelly. There are, of course, certain exceptions we have made, but mostly we try to treat her as "normally" as possible.

317 Many times I wondered what was best for my children. I learnt what to avoid by experience. I try to avoid pessimistic professionals. I need to have support, not someone who adds more worries to my mind. I like positive thinkers.

405 By the time Thomas was three (he's 5 1/2 now) we had taken charge and eliminated the contacts/experiences that drained us the most. We are angry about how families are treated. We are angry about ill-informed or under-informed professionals who think they can mess with lives with impunity. We continue to have a lot of medical involvement though now. It's mostly follow-up (Thomas has had surgery on his bowels, heart, ears and eye). We have learned how to manage this and go where we get the kind of service we want and where Thomas is treated with respect. We are working with the school re kindergarten entrance this fall. Rehab services is not involved in any way. There has been and will be no psychological assessment.

405 We determined that the therapeutic agenda was not going to dominate Thomas's preschool experience. That attitude has carried on ever since. As much as possible, Thomas is treated like our other children (he's one of four). We believe it is best for him. So we don't see speech, OT, psych. We see PT once a year. We go to the clinic every year or two, just to maintain that he is (or could be) a recipient of services. We do get the best medical care and advice we can. We attend conferences etc. to inform us re: the education journey ahead.

410 I feel that home therapy is the answer for those that live far away from services. We enjoy doing all kinds of therapy with Wayne in our home - everyone helps out! Wayne works and performs better in familiar surroundings, too. This way, we can also work with him when he's at his prime. Wayne would often not do well at his appointments when we were travelling because he'd be too tired to perform. We feel we're being more fair to Wayne's twin, too, working at home because then we can include him too.

412 Since my husband and I are part of the school system here we feel in control of the educational system Martha is in. And we are very pleased with her progress.

503 Basically I had to say to the government "O.K., I can't cope anymore" and then I got it all. Virginia lives on the next street over from us attends her community school, comes home at other days and on weekends. We have the best of both worlds. Virginia has her family and a life in the community. We still have a lot of work to do but we are making some inroads.

508 I feel that our family tries more to concentrate on Stanley's abilities more so than his disabilities. By doing this I feel that Stanley becomes more like then unlike his peers and friends, so Stanley's everyday accomplishments such as getting up, bathing, brushing teeth, hair etc. independently as possible makes us all feel good and ensures us that he is growing and developing at a nice rate.

7. Changes That Give Hope

316 My sons are both the tops in their classes and because of professional people who believed that children that are hearing impaired can talk as well as you and me (they) have succeeded.

418 Anytime someone truly listens or treats me with respect I feel hopeful that we can make some progress.

507 (At) graduation from daycare, he took his part as the Doctor in "Miss Polly" and Jack in "Jack be Nimble" with all the "normal" children and was accepted without a second thought. It made me proud but also gave me hope.

8. Characteristics of Family Members

104 Overall Carol has been a positive inspiration in our lives. She tries really hard to accomplish whatever task is before her. Her determination is an inspiration to anyone. Her loving personality makes it a lot easier to deal with her handicap. No one could ever change my mind that it is worth every minute of having her in our home. All of our children help with her and know how to deal with her many moods and they all play with her and let her participate in what they are doing. I think it will help them become more understanding to others as they grow older. It takes a lot of faith and trust to get through every day. We've been blessed with many good people to work with.

111 Harrow is a joy, he's changed our lives. His sister (8yrs) has been his guardian angel. She has never questioned why and understands why we do things certain ways in our home, now. The only thing, I feel bad for her. She's had to grow up too fast and she feels the need to take on responsibilities for her brother.

9. Advice to Professionals

102 I have one comment to make in reference to the fact that the study is based on "mothers of children with disabilities". My husband is very involved in parenting both of our children, even though I spend more time with them because we have chosen for me to be home with them. I would encourage you to be more inclusive in your language. Fathers need to be involved with their kids and need encouragement to do so, it seems.

113 Our town really needs a full time advocate for parents, (who) has the time to sit down and listen to the whole story. Someone who will work together with both the school district and the family when a conflict of interest is present. Unfortunately there is a huge gap between what it says on the IEP and what is actually carried out. And what should a parent do then? To become overly involved and fight for what you know you deserve only creates relationship problems with staff in the future. Believe me, I know from experience. What (we) lack here is an inclusion specialist or a very active (willing to get involved) advocate. The kids are the ones who suffer.

202 Early on I was told by a professional that since "I didn't have a degree" I couldn't possibly know what I was talking about! Being totally ignorant was probably a good thing -- I used my experience as a mother and my common sense and only used the "professional stuff" that worked. Much of it is not realistic and is merely idealistic -- it plain doesn't work in real life. I hear a lot of jargon and endless talk spouting rhetoric but very little of it is useful in day to day living. For 10 years professionals have been insisting Jake can learn to handle money and other related ideas -- we know him -- he does not understand the complexities of 1.75 out of two dollars leaves a quarter and why should he? It would be better to spend this time on something he can learn! But they are so afraid to admit they might be wrong.

203 There needs to be recognition that these children grow up and grow old. We do not have social programs or placement geared to this life change.

215 Parents should be provided the same money as group homes etc. are provided. Sure group home's can do a job. Who couldn't on $3,000 to $6,000 per month? We could also hire someone to do the little things that never seem to get done!

216 No amount of written information can ever prepare parents for having a child with a disability. Once the issue is reality, the written guidance, advice, support groups, etc. can help, but as a culture, new mothers aren't sufficiently prepared for the possibility of a "special" child. In a culture where so much emphasis is now placed on prenatal care and preventative measures, a pregnant woman has the false sense that as long as you're "going by the book," nothing is apt to go wrong. Physicians need to be more realistic about congenital problems and not shy away when they're suspicious that something is not quite "right."

313 . . . I wish I had a mediator or a social worker on a personal basis that I can go to. So when I do talk to schools, I could leave my emotions out of it -in other areas - teacher assists do well.

315 I would like to see someone in our area as a support person for parents ... a sort of middle man would be great. Parents need a lot of support and encouragement.

315 I wish professionals would stop and think what they are saying. How would they like someone to come into their home and try to tell them that they needed to be a better parent?

410 For home therapy to be the answer, though, there would have to be a place where one could meet with all types of professionals at once so that a program using all their ideas could be put to use in the home.

501 Parents who have a child with a disability need to know what resources are out there. This information must be kept up to date and readily available for all parents and professionals. As a professional myself and trying to obtain the appropriate information (i.e. resources for families) I can tell you that within the system itself (various Gov't depts.) the right hand doesn't know what the left is doing. You have to dig to get what you want. How many parents are too worn out or don't have the ability to do this digging?

517 There are many negative attitudes, even among the people working with children with disabilities (teachers, doctors, social workers, politicians, community service personnel) and these attitudes need to be challenged. Parents need to be listened to, their ideas and view points respected and they must have a say in what happens to their child.

MISCELLANEOUS

112 I think this survey was very confusing to respond to the statements. Also I answered for the present time but my feelings were often different in the past.

205 The reason I didn't fill out the first questionnaire you sent was because I didn't think the questions applied to Lori, since she is older and on her own, pretty much.

217 No. Thanks! I hope I filled this out OK. Marcia would be considered having cerebral palsy. Not real bad -- as she walks -- and can do many things.

218 Most of the statements in this survey were not applicable for me since my son is older and was not fortunate enough to have been able to attend a public school. I feel that parents are very fortunate to have the facilities that are available to them now.

223 Thank you for doing this study. I'm certain that services to our special children will benefit from it.

302 This survey did not really apply to us as Ray is 41 yrs. old and where school is mentioned, I tried to apply the workshop.

308 Thank you for your attention.

407 Please give a research number next time so confidentiality could be assured. In small communities confidentiality is sadly lacking. Recent experience with same. Feel violated.

408 Oh sorry -- just rambling. I was so pleased you phoned.

411 This survey was difficult to fill out. The scale should have gone
NA Disagree <--------------> Agree.

413 I think somebody should write a book or research study about my children. In all my reading and networking I have never heard or seen a family who has such a combination of unrelated syndromes and conditions, ranging so widely amongst physical disability, psychological disorders (autism & hyperactivity/challenging behaviour), sensory impairment (both boys partial deafness and daughters visual impairment) plus the added dimension of the middle son's giftedness and younger son's islands of very high functioning. The family ecology, parental management, problems, sibling mutual effects, bilingualism (French/English) and immense battles for services (court cases, appeals etc.) surely provide fertile ground for study! Meanwhile I managed to go back for an MA degree and my husband for a management degree.

418 If you would like to use any comments I've made in my presentations in any way, feel free.

504 I must add that Edward has older sisters (30/32) and that questions related to siblings were not relevant. Much success.