

**FAMILIES IN TRANSITION: AN EXPLORATORY
STUDY OF PARENTS' PERCEPTIONS OF THE
SCHOOL-TO-WORK TRANSITION OF THEIR
CHILDREN WITH COGNITIVE DISABILITIES**

by

Harold R. Hoffmann

**A thesis submitted to the
Faculty of Graduate Studies
in partial fulfillment
of the requirements for the degree of
Master of Education**

**Faculty of Education
University of Manitoba**

Winnipeg, Manitoba

March, 1997



**National Library
of Canada**

**Acquisitions and
Bibliographic Services**

**395 Wellington Street
Ottawa ON K1A 0N4
Canada**

**Bibliothèque nationale
du Canada**

**Acquisitions et
services bibliographiques**

**395, rue Wellington
Ottawa ON K1A 0N4
Canada**

Your file Votre référence

Our file Notre référence

The author has granted a non-exclusive licence allowing the National Library of Canada to reproduce, loan, distribute or sell copies of this thesis in microform, paper or electronic formats.

The author retains ownership of the copyright in this thesis. Neither the thesis nor substantial extracts from it may be printed or otherwise reproduced without the author's permission.

L'auteur a accordé une licence non exclusive permettant à la Bibliothèque nationale du Canada de reproduire, prêter, distribuer ou vendre des copies de cette thèse sous la forme de microfiche/film, de reproduction sur papier ou sur format électronique.

L'auteur conserve la propriété du droit d'auteur qui protège cette thèse. Ni la thèse ni des extraits substantiels de celle-ci ne doivent être imprimés ou autrement reproduits sans son autorisation.

0-612-23342-1

**THE UNIVERSITY OF MANITOBA
FACULTY OF GRADUATE STUDIES

COPYRIGHT PERMISSION PAGE**

**FAMILIES IN TRANSITION:
AN EXPLORATORY STUDY OF PARENTS'
PERCEPTIONS OF THE SCHOOL-TO-WORK TRANSITION OF THEIR
CHILDREN WITH COGNITIVE DISABILITIES**

BY

HAROLD R. HOFFMAN

**A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University
of Manitoba in partial fulfillment of the requirements of the degree
of
MASTER OF EDUCATION**

Harold R. Hoffman 1997 (c)

Permission has been granted to the Library of The University of Manitoba to lend or sell copies of this thesis/practicum, to the National Library of Canada to microfilm this thesis and to lend or sell copies of the film, and to Dissertations Abstracts International to publish an abstract of this thesis/practicum.

The author reserves other publication rights, and neither this thesis/practicum nor extensive extracts from it may be printed or otherwise reproduced without the author's written permission.

Abstract

The perceptions of parents of children with cognitive disabilities, with respect to their children's transition from school to employment, were examined in this thesis. These perceptions were ascertained through the use of a survey, through individual interviews with parents, and through discussion groups between parents. The experiences parents have had with respect to the school-to-work transitions of their children varied. The results suggest that parents have concerns about the preparation and implementation of the transition from school to work and adult life. There is further evidence to suggest that the school-to-work transition is a trying period for parents and that they have certain preferences, expectations, and needs.

Implications for schools and adult service agencies are discussed and recommendations for improving the school-to-work transition process from a parental perspective are provided. A better understanding of parental perceptions by the professionals involved in the transition process may lead to smoother school-to-work transitions for young people with cognitive disabilities.

Acknowledgements

The completion of this thesis would not have been possible without the input of many people. I wish to express my gratitude to the following:

- to my advisor, Dr. Richard Freeze whose constant guidance and support was invaluable and much appreciated,
- to Dr. Zana Lutfiyya and Dr. Rod Kueneman for being on my thesis committee and for providing their time and insights,
- to the parents who participated in this project for sharing their experiences and thoughts and without whom this study would not have been possible.

Finally, I would like to thank my wife Marlene for being a steady source of encouragement and inspiration, to my daughter Shaylyn for being a constant joy, and finally, to my daughter Chelsea whose short life so enriched mine. To my family, I dedicate this thesis.

TABLE OF CONTENTS

ABSTRACT	i
ACKNOWLEDGEMENTS	ii
LIST OF TABLES	vii
Chapter One - INTRODUCTION	1
Purpose of the Study	2
Statement of the Problem	3
Educational Significance	4
Definitions of Terms	8
Limitations of the Study	15
Chapter Two - REVIEW OF THE LITERATURE	18
Parents of Individuals with Disabilities	18
Stress and Grief of Parents	18
Vocational Aspirations and Expectations	
of Parents	27
Parents' Experiences with School and	
Service Agencies	36
Parents' Concerns	39
Research Implications	46
Summary and Conclusions of	
Literature Review	53
Research Questions	57
Chapter Three - RESEARCH METHODOLOGY	63
Participants of the Study	63
Research Design and Procedure	65

Instrumentation	67
Phase II Discussion Groups and Interviews	68
A Word On Qualitative Research	73
Chapter Four - RESEARCH FINDINGS	76
Response Rate	76
Interview and Discussion Groups Data	
Analysis: What the Parents Said	109
Category Identification	111
Work Experience	112
Parent Involvement	113
Positive Experiences	113
Negative Experiences	115
Support Groups and Networks	118
Frustration	118
Transportation and Mobility	121
Integration	121
Quality of Life	123
Residential Concerns	
and Opportunities	124
Community Involvement	125
Friendships	125
Expectations	127
Concerns	129
Matching	130
Importance of Work	130

Lack of Follow-up and Commitment	132	
Lack of Cooperation Between Key Groups	136	
Sense of Not Being Listened to	138	
Advocacy and Parental Input	139	
Funding	141	
Information Wanted	142	
Cooperation and Collaboration with Parents	147	
Human Element	147	
Feelings of Stress	148	
Intimidation	149	
Contact	150	
The "System"	150	
What the Parents Want	151	
Parents' Recommendations and Solutions	153	
Chapter Five - CONCLUSIONS AND RECOMMENDATIONS	158	
Conclusions and Implications	158	
Recommendations	164	
Considerations for Future Research	170	
Summary	171	
REFERENCES	173	
APPENDIX A	Introductory Letter to Parents and Consent Form	200
APPENDIX B	Reminder to Parents	202

APPENDIX C	Parent Questionnaire	204
APPENDIX D	Glossary of Terms	209
APPENDIX E	Letter to Parents Concerning Discussion Groups, Interviews and Consent Form	211
Appendix F	Letter to Parents Concerning Discussion Groups	214
Appendix G	Discussion Issues Given Parents	215
Appendix H	Ethics Approval Form	217

LIST OF TABLES

TABLE	PAGE NUMBERS
1. Parent participation in interviews	78-79
2. Parent participation in discussion groups	79-80
3. Total participation in interviews and discussion groups	81
4. Gender of respondent	81
5. Relationship to child	82
6. Age of parent	82
7. Degree to which child's independence is limited	83
8. School placement of child	94
9. Type of work expected after graduation	94
10. Type of work preferred after graduation	95
11. Importance of work after graduation	96
12. Extent of concern of employment situation	97
13. Extent of satisfaction with schools	98
14. Extent of parent's involvement	105
15. Extent of involvement parent would like	106
16. Extent parents believe views/wishes are taken into account	107
17. Extent parents have been involved in the advocacy or training of students with disabilities	108

Chapter One

INTRODUCTION

Employment is an important aspect of an individual's life. The premise that employment is necessary to gain full acceptance in society underscores its importance (McDonnell, Hardman, & Hightower, 1989). There is a growing assumption that all students with disabilities should be prepared for employment and that preparation should begin in school (Chadsey-Rusch, 1990; Rusch, Chadsey-Rusch, & Lagomarcino, 1987).

The importance of employment for students with disabilities means that high school programs likely will focus increasingly on the skills and knowledge that these students need to live as independently as possible in the adult world. Vocational education and training and employment experiences likely will assume larger roles in the overall curriculum. These roles increasingly will include a variety of options, such as community-based vocational training, vocational education classes, and paid work experiences. Regular education, special education, and vocational education ideally should work together to promote successful employment options for youth with disabilities.

A cooperative relationship between the parents of students with disabilities, education personnel, and adult service delivery providers is integral to school-to-work

transition planning. In order to develop relevant and functional curricula for students with disabilities it is necessary to know the instructional priorities of parents (Epps & Myers, 1989). Unfortunately, most professionals have had a lack of understanding of what it means to be a parent of a child with a disability (Anderegg, Vergason, & Smith, 1992). This lack of understanding contributes to what Anderegg, Vergason, and Smith (1992) call a barrier to improving communications between professionals and parents. Hardman, Drew, Egan, and Wolf (1991) referred to the relationship between parents and professionals as one "marked by confusion, dissatisfaction, disappointment, and anger" (p.48).

The period prior to, during, and following the transition from school to adult life can be a trying one for parents of youth and young adults with disabilities. The school-to-work experience is a time of transition for them as much as it is for their children.

Purpose of The Study

The insights parents can offer about the positive or negative aspects of the transition process from school to work and adult life are valuable. An awareness of the perspectives, concerns, needs, and priorities of parents may lead to a better understanding by school personnel and adult service workers of the school-to-work process.

To try and understand what experiences parents and their children have had and how these experiences have influenced their perceptions, it was imperative to offer parents opportunities to share their insights and their stories. This study was a two stage process. In the first stage, parents completed a questionnaire concerning their perceptions. In the second stage, parents were given the opportunity to elaborate on their perceptions in individual interviews, as well as to share their thoughts through discussion groups.

Statement of the Problem

The problem investigated in this study was the affect the planning and implementation of the school-to-work transition has on the concerns, desires, preferences, and needs of parents of youth and young adults with cognitive disabilities. In essence, parents' perceptions on the transition from school to work was investigated. The views of parents were explored to ascertain their beliefs, the foundations of those beliefs, and their views on the school-to-work process.

Furthermore, the relationships between certain vocational preparation strategies, parental experiences, and variables such as mainstreaming and support networks were investigated to determine their affects on parental perceptions. The information gleaned may enhance the

school-to-work transition process.

There is still a paucity of research on why parents have the perceptions they do within the realm of transitioning from school to employment and adult life for their children with cognitive disabilities. However, researchers contributing to the literature on parents of children with disabilities suggest that many parents have experienced a lack of services, assistance, and supports from school systems (Ferguson, Ferguson, & Jones, 1988; Waggoner & Wilgosh, 1990) and that parents have real concerns about the transition of their children to adult life and employment (Chadsey-Rusch, 1990; Davis, 1988; Fourqurean & LaCourt, 1990; Hill, Seyfarth, Banks, & Wehman, 1987).

Before education personnel and community service delivery workers can accommodate parents' needs in the transition process, parents' perceptions, including the basis for them, need to be known and understood.

Educational Significance

It has been said that the opportunity to work is extremely important to people with cognitive disabilities in their quest for respect and achievement (Stark & Goldsbury, 1988). Considering this, a major goal of high school education for students with cognitive disabilities should be placement in competitive or supported employment. Ideally,

a long-range vocational goal for every individual with a cognitive impairment should be placement in some kind of employment situation (Hasazi & Clark, 1988).

Pilley (1988) summed up the educational significance of employment by stating that if the ultimate goal of education is employment and independent living to the greatest extent possible, it is vital to assess the level of success of graduates in these areas. Wisniewski, Alper, and Schloss (1991) take Pilley's view one step further by contending that the ultimate goal for all students should be, not just employment, but competitive employment. There are studies indicating that many individuals with disabilities do not find, or are not able to maintain, employment in the community (Will, 1984a; Agran, 1987; Edger, 1987). This is due to a myriad of factors, including: job market conditions, the extent of family and friendship networks, the gender of the individual, a lack of inter-agency cooperation and coordination, the level of disability of the individual, and parental influence and attitudes (Brickey, Campbell, & Browning, 1985; Chang, 1988; Hoisch, Karen, & Franzini, 1992; Kiernan, McGaughey, & Schalock, 1988). Suggestions have been made which might reverse the lack of employment for individuals with disabilities. These include more emphasis on vocational training and work exposure, better linkages with appropriate service providers, an

increased focus on placement in community-based employment during career/vocational programming, increased follow-up and follow-along contact and support during the post-school stages of transition, good job matching, a solid and energetic transitional team effort, and the empowerment of families to be active participants in the transition planning process (Frank & Sitlington, 1993; Heal, Copher, De Stefano, & Rusch, 1989; Roesser, Brolin, & Johnson, 1990).

While vocational training programs have evolved to reflect the current philosophy of inclusion in which the importance of community integration is stressed, the movement from school to successful employment often results in unemployment or underemployment for individuals with disabilities (Hasazi, Gordon, Roe, Hull, Finck, & Salembier, 1985; Weisenstein, Stowitschek & Affleck, 1991). It should be a function of the school system to improve the transition systems, if improvements are warranted.

The role of the parents in the process of transition for youth with disabilities is one of great importance. Their input into school-to-work program planning is vital for a smooth transition and increased chances for success. The need and necessity of parental participation in program planning has been well documented (Brantlinger, 1991; Elksnin & Elksnin, 1990; Everson, 1990; Miller, La Follette, & Green, 1990; Haring, Lovett, & Saren, 1991; Steere,

Pancsofar, Wood & Hecimovic, 1990).

However, despite a strong emphasis on the need for parental participation, a chasm remains between school systems and adult service personnel and parents. There have been discrepancies between the priorities and desired outcomes valued by professionals and parents. In addition, parents have reported needs that were not being met and concerns that were not addressed (Ferguson, Ferguson & Jones, 1988; Penner, Douglas & Van Lieshout, 1992; Waggoner & Wilgosh, 1990). As such, the perception of success in school-to-work transitioning by professionals is dubious. Brantlinger (1991) argues that the frequently encouraged notion of parents as partners is mere rhetoric because parental involvement is somewhat of a formality which lacks substance, and that the opinions of parents are not valued, but rather dismissed.

The educational significance of the problem is that parents, the ultimate advocates and case managers for their children (Goodall & Bruder, 1986), may not be satisfied with the school or adult services provided in the realm of transitioning from school to the adult world. On a similar note, parents may not be satisfied due to a lack of services. Their perceptions need to be understood to better accommodate their needs as well as those of individuals with disabilities who are leaving school.

Understanding the situations and views of the parents of youth with cognitive disabilities in transition is essential if parental needs are to be met successfully.

Definitions of Terms

The population of people with disabilities which is referred to in this paper is not confined to those with any specific disability, unless otherwise noted. They include those with mental, physical, visual and hearing impairments, as well as those with multiple disabilities. The definitions for the various disabilities are a means to identify groups of individuals, but we are cautioned to remember that "categories are simply terms used to confirm that individuals in our society differ from each other" (Ysseldyke & Algozzine, 1982, p. 43). Values and attitudes of society evolve and, as such, so do the definitions of disabilities (Brown, 1987).

Despite the variability in form and severity of disabilities among the children of the parents involved in this research study, they each have a cognitive disability to some degree. Cognitive disabilities can be described as those which can include memory deficits, problems in processing abstract information, poor retrieval of stored information, and impaired processing, initiating, and carrying out of actions (Wehman, 1992). A cognitive disability can also result in reasoning deficits, poor

judgement, difficulty in generalization, problems with attention and concentration, and problems with processing and sequencing information (Wehman, 1992). Cognition has been described as "...the process of acquiring a conscious awareness that helps us know and understand in a wide spectrum of activities, such as remembering, learning, thinking, and attending" (Bailey, Jr. & Wolery, 1989, p. 276). In broader terms, Bailey, Jr. and Wolery (1989) stated that cognition is composed of mental processes by which individuals acquire knowledge.

Included among children who have been referred to as "exceptional" are those with disabilities (Kirk & Gallagher, 1985). In the educational sense, children are considered exceptional "if their development deviates in kind and degree to such an extent that they require educational provisions not needed by most children for maximum development" (Kirk & Gallagher, 1985, p. 3). This term can be relevant in school-to-work transition practices as particular vocational training and school-to-work transition programs are tailored for individuals by virtue of their disability.

The terms "disability" and "handicap" are often used interchangeably (Davis & Bullis, 1990) and not necessarily appropriately, as they do not necessarily refer to the same concept. Wright (1983) described both concepts as they have

been delineated by the World Health Organization in 1980. A disability refers to a limitation of function that results from an impairment of a specific organ or body system. A handicap describes the actual obstacles encountered by the individual in real life resulting from a disability. By reason of that distinction, a disability might or might not result in a handicap. As Stewart (1974) points out, whether a handicap results from a disability depends not only on the severity of the disability, but also on the environment, the situation, and the individual's adaptation. The term "impairment" refers to the damage, injury, or incapacity that an individual has (Peterson, 1987). The term impairment has been used synonymously with disability (Peterson, 1987).

However, as Davis and Bullis (1990) indicate, the terms have been misused. Therefore, although the distinction will be adhered to as closely as possible in this paper, the usage of either "disability" or "handicap" as used by other writers and researchers cited in this paper will not be altered. To do so would be to presume their intentions and inevitably lead to erroneous assumptions.

The definition for mental retardation has recently been changed. Currently, "mental retardation refers to substantial limitations in present functioning. It is characterized by significantly subaverage intellectual

functioning, existing concurrently with related limitations in two or more of the following applicable adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure and work. Mental retardation manifests before age 18" (Seiter, 1992, p. iii). The term mentally handicapped will refer to individuals who are mildly, moderately and severely mentally retarded unless specifically indicated.

There have been a number of terms used synonymously by educators and researchers with vocational training, such as vocational education, work education, work experience, vocational skills training, job training, and so on. The terms are often used loosely and they are not often defined. White, Smith, Meers, and Callahan (1985) referred to vocational skills training as preparing special needs youth for employment through instructional formats which utilize proven special and vocational education procedures.

The term "work training" was defined by Peck and Hong (1988) as a "medium through which work-related skills such as punctuality, concentration, persistence, and stamina are developed; the actual task is unimportant in relation to the development of desirable attributes" (p. 149). This implies that training encompasses a wide spectrum of related behaviours other than the specific, vocational tasks. The

terms work experience, work training, and vocational training are often used synonymously in the literature, as they will be in this paper.

There are several other terms used in the world of school-to-work transition and vocational preparation for people with disabilities which require clarification. As defined by Schalock, McGaughey, and Kiernan (1989) they are as follows:

(a) sheltered employment: "employment in a controlled environment, where payment is typically less than the minimum wage" (p. 81)

(b) transition training/employment: "employment that provides time limited support leading to competitive employment, where payment is typically at less than the minimum wage" (p.81)

(c) competitive employment: "unsubsidized employment where payment is at or above the minimum wage including certain enclaves, work crews, and employment in regular jobs, even when follow-along services are provided." (p.81)

(d) supported employment: "employment that requires intensive ongoing support, utilizing worksites where persons without disabilities are employed, where payment is most often at less than minimum wage" (p.81).

Supported employment has also been defined as "paid employment for persons with developmental disabilities for whom competitive employment at or above the minimum wage is unlikely and who, because of their disabilities, need ongoing support to perform the work. Support is provided through activities such as training, supervision, and transportation. Supported employment is conducted in a variety of settings, particularly, work sites in which persons without disabilities are employed" (Wehman, Sale, & Parent, 1992, p.4). While the wages earned may depend on the amount of work performed or the output, Wehman, Sale and Parent (1992) note that one of the key characteristics of supported employment is that of receiving reasonable pay for real work.

In an article by Griffin and Lowry (1989), supported employment was described as having the components of competitive work in an integrated work site, ongoing support on the job, an emphasis on creating real work opportunities, social integration, and variety and flexibility. In addition, no one is excluded from supported employment on the basis of severity of the disability. Rather, the ongoing support is adjusted to accommodate the needs of each individual.

While Schalock, McGaughey, and Kiernan (1989) state that certain enclaves and work crews can be part of

competitive employment, Griffin and Lowry (1989) indicate that mobile work crews and enclaves can be a part of a supported employment service delivery model. Depending on the nature and location of the work, the enclaves and work crews could also be operated in isolation, and segregated from individuals without disabilities. The primary difference between the two approaches is that, while mobile work crews operate out of a van and hold several contracts (typically in lawn maintenance, farm work, janitorial work, landscaping, etc.), enclaves pursue only one contract per group of workers with disabilities who are matched to one or more jobs within a company.

The term "community employment" has several of the components which are associated with supported and competitive employment. It has been defined as paid work which takes place in natural settings (i.e. settings not designed for special populations) and includes ongoing interactions with other employees, the overwhelming majority of whom neither receive nor provide habilitation services (Nisbet & Hagner, 1988).

The term "transition" is indicative of change (Knowlton & Clark, 1987). It could be a change from one set of circumstances to another or from one environment to another (Meers, 1992). Transition has been defined as:

...a carefully planned process which may be initiated

either by school personnel or adult service providers to establish and implement a plan for either employment or additional vocational training of a handicapped student who will graduate or leave school in three to five years; such a process must involve special educators, vocational educators, parents and/or the students, and an adult service system representative, and possibly an employer (Wehman, 1984, pp. 23-24).

Transition has also been defined as "a bridge between the security and structure offered by the school and the risks of adult life" (Goodall & Bruder, 1986, p. 23).

From a service-planning perspective, transition is a process that includes high school, graduation, additional post-secondary education or adult services and the first few years of employment (Will, 1984b).

Limitations of the Study

There are some variables which could have distorted the findings of this study. Not all parents initially invited to participate in the study responded or wished to participate. For parents who completed the questionnaire, the possibility remains that their true perceptions were not listed among the choices. To compensate for this the questionnaire contained space for comments or elaboration. However, not all parents elaborated or made comments on all questionnaire components. Some parents who completed the

questionnaire did not participate in a discussion group or interview, thereby limiting their opportunities to seek clarification about the questions or provide elaboration to their responses.

Parents who participated in the discussion groups or interviews may have been hesitant to respond to some questions or they may have chosen not to disclose some information. Since much of the data gathered from this study was narrative in nature and disclosed in close proximity, there was an added possibility that the interviewee responded according to unconscious cues or reactions by the interviewer, however unintentional, or to the cues or reactions of other participants in the discussion groups. Due to the nature of the discussion groups and the personalities involved in each of them, the discussions did not unfold in quite the same way in each case. However, efforts were made to prevent wide digressions by distributing the discussion issues. However, some parents did want to pursue certain areas. There were digressions and elaborations of issues which may have had a bearing on the responses of the participants.

Some participants in the interview had originally indicated a preference for a discussion group but were unable to attend. Their responses and how they contributed to the data may have been dependent on whether they

participated in a discussion group or in an interview.

The parents who participated in the second phase of the study, that is, in the discussion groups or interviews, were not randomly selected. Some parents chose to take part while others did not. As such, the perceptions of those who did not take part in the second phase of the study were not probed and the full extent of their perceptions remains unknown.

There are three additional limitations to this study. First, the sample of interview respondents was small. Second, there was no control group used. Finally, the respondents varied with respect to ethnicity, socioeconomic status, access to support groups, and the type and severity of disability of their child.

Chapter Two

REVIEW OF THE LITERATURE

In this section previous literature on parents of individuals with disabilities is examined. The section will be divided into areas pertaining to the stress and grief of parents, parents' aspirations and expectations for their children, parents' experiences with schools and service agencies and, finally, parents' concerns. The research implications of the literature review will be discussed as will the research questions to be asked.

Parents of Individuals with Disabilities

Stress and grief of parents. Much has been written about the differences between parents and families of sons or daughters with disabilities and parents and families of children who do not have a disability. Previous findings differentiate parents of children with disabilities from other parents on the basis of increased caregiving demands (Harris & McHale, 1989; Erickson & Upshur, 1989). Children with disabilities make demands on a family's time, psychological well-being, relationships, resources and freedom of movement (Brantlinger, 1991). This may contribute to the common theme of social isolation connected with families of children with disabilities which Brantlinger refers to.

The notion that increased stress is experienced by

parents or families of a child with a disability has been well documented (Beckman, 1983; Dyson, 1991; Dyson & Fewell, 1986; Friedrich & Friedrich, 1981; Kazak & Marvin, 1984; Krauss, 1993; Mahoney, O'Sullivan & Robinson, 1992; Minnes, 1988; Waisbren, 1980). Flynt and Wood (1989) found the age of the child was not relevant to stress levels of mothers of children with a mental handicap. The notion that stress in families increases with the age of a child with a disability is not supported in a recent research study on this topic (Orr, Cameron, Dobson & Day, 1993).

Stress levels have been found to be related to the child's need for special care, the difficulty of the child's behaviour, and the child's ability to communicate (Beckman, 1983; Erickson & Upshur, 1989; Frey, Greenberg, & Fewell, 1989). The severity of the disability has also been found to be related to the degree of stress and family difficulties. Families with a child with severe mental retardation were found to have more difficulties with family adjustment and daily life than families with a child who had less severe mental retardation (Blacher, Nihira & Meyers, 1987). Cohen, Agosta, Cohen and Warren (1989) reported that the severity of the disability and the family's capacity for coping are related to the difficulties experienced by families of individuals with disabilities. Some evidence suggests that families who have children with more severe

disabilities are more likely to be identified as "distressed" (Mahoney, O'Sullivan & Robinson, 1992).

Parents might also be under added stress due to the attention the child brings to himself/herself (Baxter, 1989). Dyson (1991) and Frey, Fewell, and Vadasy (1989) suggest factors which seem to be associated with stress are uncertainty about the child's future and a lack of information and understanding about the child's condition.

Periods of transition in families with a child with a disability are often times of increased stress and challenge for families (Crnic, Friedrich, & Greenberg, 1983; Ferguson, Ferguson, & Jones, 1988; Goodall & Bruder, 1986; Turnbull, Summers, & Brotherson, 1986). Adolescence may also be a trying time for parents. During adolescence parents may confront the realization of long-term dependency and be facing numerous life issues, such as the youth's potential and vocational options (Hanline, 1991).

The time of transition from school to the adult world is a particularly stressful time for parents of children with disabilities (Brotherson, Turnbull, & Bronicki, 1988; Hanline, 1991; Wikler, 1986b). The stress on families with children with mental disabilities entering adolescence or entering adulthood have been alluded to by Konanc and Warren (1984) and Wikler (1986a, 1986b).

The degree of social supports available to parents has

been found to influence the stress and difficulties they experience (Todis & Singer, 1991). Flynt, Wood and Scott (1992) found a relationship between the level of social support and the perceptions of stress by mothers of children with mental handicaps. Social supports can help parents cope with the changes they experience (Hanline, 1991; Unger & Powell, 1991). Seltzer, Begun, Seltzer and Krauss (1991) reported that the support provided by siblings toward their brother or sister with a disability had a positive impact on the well-being of the mothers.

Other researchers have not found evidence to support the notion that families with a child who has a disability experience more stress (Frey, Fewell, & Vadasy, 1989). Houser and Seligman (1991) found no difference in levels of stress between fathers of adolescents with mental retardation and fathers of adolescents without mental retardation, but they did report certain coping strategies by the fathers of the mentally handicapped adolescents. There is recognition that families of children with handicaps do cope well with the demands experienced by having a child with a disability (Noh, Dumas, Wolf & Fisman, 1989; Erickson & Upshur, 1989).

Some researchers have examined the influences the child and family have on each other. Harris and McHale (1989) examined the amount of time parents spend with their

children. Their results suggest that the more time mothers spend with a child with a mental handicap the more difficulty they experience in family life. Some evidence suggests that mothers may experience more stress than fathers (Beckman, 1991). However, Rousey, Best, and Blacher's (1992) research on perceptions of stress and coping between mothers and fathers of children with severe disabilities who live at home found no major differences.

Friedrich and Friedrich (1981) reported deterioration of family relationships when there is a child with a disability in the family while Dyson (1991) and Mahoney, O'Sullivan and Robinson (1992) indicate that, other than high levels of stress, families with a child with a disability differed very little from other families in family functioning. It appears that the majority of the families adapt to difficulties. Kazak and Marvin (1984) found evidence from their research that the marital bonds of mothers of children with spina bifida were stronger than those of a comparison group of families without children with a disability.

The work of Kubler-Ross (1969) on mourning after the death of a child has prompted research on the feelings of parents who have a child with a disability. In essence, when the disability is revealed parents undergo a grieving process.

Blacher (1984) presented a model of the grieving process which incorporated levels or stages of grief. In Blacher's three-phase model parents go through a) shock and denial, b) reactions which may include a variety of feelings, such as anger, hopelessness and shame, and c) acceptance and adjustment. According to this theory, parents of children with a disability go through predictable stages of adjustment and emotions over time. This stage theory is not accepted by everyone. There have been assertions that predictable, sequential patterns of reaction by parents to having a son or daughter with a disability may not exist for many families (Allen & Affleck, 1985; Crnic, Friedrich & Greenberg, 1983). Crnic, Friedrich, and Greenberg (1983) presented a different notion of coping. According to their perspective, the way parents of children with disabilities cope with problems and difficulties is related to their perceptions of stress, the resources available to them, and the school, work, and neighbourhood environments in which they live.

Olshansky (1962; 1966) attributed the term "chronic sorrow" to the experiences of parents of children with mental handicaps who were thought to be experiencing grief throughout their lives due to the birth of a child with a disability. One of the variables influencing the type and degree of these emotions is the type of disability (Harper,

1984; Harris, 1984; Harvey, 1984).

In a research study designed to examine how chronic, disabling illness in a child affected the daily lives of three families, Martin, Brady, and Kotarba (1992) reported low vitality, restricted social life, and a preoccupation with decisions related to their social lives. The findings indicated the great impact the child's illness had on family members.

Events, either positive or negative in nature, such as a change in school placement or a special event in the life of the child or family, can cause the recurrence of emotions of grief (Anderegg, Vergason & Smith, 1992; Gargiulo & Graves, 1991). Witcher (1989) cautions professionals not to think that once any of the emotions in the grieving process are played out they are laid to rest. As the adjustment process unfolds, these emotions may resurface. There may be no conclusion to an adjustment process. Rather, it may continue taking on different forms.

Ormerod and Huebner (1988) reiterated many of the previous research issues related to parent's reactions when they realized their child's disability was revealed. They noted that the reactions of parents vary in intensity depending in part on factors such as the severity of the handicap, socioeconomic status, religious orientation, and the quality of internal/external support systems.

Flagg-Williams (1991) identifies three trends that have influenced literature on the perspectives on children with a disability. While the chronic stress and stage theories have left their mark, the third trend, and the one becoming increasingly prominent in research, involves the interaction of families and the environment. The areas included in this approach are not just family life, but social life, school life, and employment. The variables within these environments influence families' perceptions and behaviours.

Despite the research indicating levels of stress, the grieving process, and family life difficulties of parents who have children with a disability, caution should be taken not to stereotype them as being in continuous distress by virtue of having a child with a disability. The stages of the grieving process do not always occur in a predictable order and not all parents are affected to the same extent by a particular emotional phase of the grieving process (Witcher, 1989).

Gallimore, Weisner, Kaufman and Bernheimer (1989), using an ecological perspective in their study of families, found great variations between families. There were differences in the extent families were involved in organizations, in the division of labour among members, and in the way they constructed their environments to accommodate their child's needs and circumstances. Also,

the complexity and diversity of environmental influences on families where there is a child with a disability should be kept in mind. The influence of environmental factors such as parents' emotional attitudes and time spent with the child might influence one family but would not necessarily influence another family in a similar way (Flagg-Williams, 1991). The dynamics of families are far too complex. Further, Glidden (1993) asserts that although there is a notion that a family with a child with a disability is a family with a disability, the extent of their adjustment is influenced by the presence or absence of positive outcomes.

Much of the research on parents' reactions and feelings deal with the early years of the child and much of the research focuses on the diagnosis of a disability of a child. In some ways, the circumstances are repeated years later during the transition from school to work. The variables that play such a prominent role in shaping parent's feelings in the early years appear to reemerge in the high school years as the student prepares to leave the school system.

In summary, the factors associated with families of individuals with disabilities have been identified as social isolation and increased stress. The stress of the families have been identified to be related to:

- the severity of the disability,

- the difficulty of the child's behaviour,
- the child's ability to communicate,
- changes in school placement or special events,
- periods of transition such as into adolescence or from school to adulthood, and
- the degree of social supports available to parents.

There is also some evidence to suggest that parents of children with disabilities do not, generally, have more stress and problems in family functioning. Rather, the way parents cope is situation specific and depends on a variety of variables, such as:

- their perceptions of stress,
- the resources available to them (from school, work, and neighbourhood), and
- the interaction of the family and the social, school, and employment environments.

Vocational aspirations and expectations of parents.

Parents' views on high school preparation for employment for students with disabilities have revealed concern. In a study conducted by Benz and Halpern (1986), 40% of the parents indicated vocational preparation for students with disabilities was the weakest part of the curriculum.

Epps and Meyers (1989) surveyed the parents of children

with severe and profound disabilities with regards to the their priorities in the domestic, vocational, community, and leisure domains. The vocational domain was rated as most important for most age levels, despite few parents anticipating either part-time or full-time employment for their children. These findings may be misleading. The vocational domain pertained to work responsibilities at home and not necessarily in actual paid employment. Also, the concept of supported employment was not presented, which perhaps led to lower work expectations.

In a study conducted in Virginia, Seyfarth, Hill, Orelove, and McMillan (1987) examined the vocational aspirations that parents of individuals with mental handicaps had for their children. The parents' aspirations were influenced by a number of factors. Parents of older individuals and parents of children with more severe disabilities had lower aspirations than parents who had younger children and children who had higher developmental functioning.

A relationship between expectations and the severity of the disability was reported by others. Sowers and Powers (1989) reported that parents of youth with severe and multiple disabilities believed their sons or daughters were unlikely to work in nonsheltered work sites.

Pilley (1988) found parents of students with moderate

mental handicaps were more likely to indicate satisfaction with the job placement of their sons or daughters than parents of children who were mildly mentally handicapped. Also, parents' expectations of type of placement differed between the two groups of parents. In Pilley's study, fifteen of twenty parents (75%) of moderately handicapped young adults anticipated sheltered employment, whereas sixteen of twenty-seven (59.2%) parents of the mildly handicapped people planned to be in competitive employment. While the parents of mildly mentally handicapped students had greater expectations, they also had greater disappointment with job placement. Parents of moderately mentally handicapped students had lower expectations but also reported more satisfaction with job placement.

Other factors considered important by most parents were autonomy on the job and the opportunity to advance to positions with more pay. Seyfarth, Hill, Orelove, McMillan, and Wehman (1987) suggested that parents might adjust the vocational aspirations they have for their son/daughter according to available vocational opportunities, labour market conditions, the demonstrated potential of their child, and with an increase in information upon which to base their judgements.

Sowers and Powers (1989) suggested that support and involvement from parents can be attained by sharing the

success of individuals who have disabilities similar to those of their children and by giving parents the opportunity to see their child in a community work site. It was not known whether these strategies would also influence parents' vocational aspirations.

There is some evidence to suggest that gender differences influence the employment situations anticipated by parents, with males expected to be employed more than females (Epps & Meyers, 1989).

Low vocational expectations from parents have been reported by Hill, Seyfarth, Banks, Wehman, and Orelove (1987). In their survey of 660 parents/guardians of mentally handicapped individuals who were receiving adult services from agencies for the mentally handicapped, only 12% of the respondents expressed a preference for competitive employment for their child. Parents of individuals with mild or moderate mental retardation preferred a placement in a sheltered workshop, whereas parents of children with severe/profound disabilities selected activity centres as the optimal placement. An interesting finding is that improving working conditions or increasing wages was of little interest to all parents, a finding not supported by the research of McNair and Rusch (1991). The evidence from the study by Hill, Seyfarth, Banks, Wehman, and Orelove (1987) suggests parents have low

vocational expectations.

Somewhat higher expectations and higher aspirations from parents of children with disabilities of various kinds were reported in other research. Haring, Lovett and Saren (1991) reported only 40% of the parents of 129 high school graduates with a variety of disabilities believed their son/daughter would not function with competence in a community setting. Sixty per cent of the parents wanted their child to be as independent as possible in terms of social, vocational, and residential independence. Although two-fifths of the parents did not express this desire, 21% indicated a preference for having their children stay at home instead of going to work. One suggestion was that this was a reflection of an overprotectionist attitude (Haring, Lovett, & Saren, 1991). Vocational aspirations by parents for their children with disabilities have been found to exceed their expectations (McNair & Rusch, 1991).

Turnbull and Turnbull (1988) have suggested that low expectations may be due to a lack of awareness of vocational options, overprotection, or an unwillingness to let go. They further suggest that a shift from specialized settings, special classes, and sheltered workshops will raise expectations.

An emphasis on the development of friendships, increased opportunities for decision-making, and future

planning are inherent in raising expectations. Evidence suggests that parents whose children attend special schools believe that placement in a more integrated environment would prove a negative experience, whereas parents of children who attended integrated programs had positive feelings about integrated environments (McDonnell, 1987). Fear of unknown environments or environments with which one has had little experience could lead to caution and avoidance. Foley (1988) reported how parents, once fearful of community-based employment, were delighted at the progress their children were making and became committed to the concept.

Brickey, Campbell, and Browning (1985) examined the vocational backgrounds of 53 sheltered workshop employees, 51 of whom were mentally handicapped, and who were placed in competitive jobs several years later. Of the 53 adults, three were identified as being severely mentally handicapped, 23 were moderately handicapped, and 25 were mildly handicapped. The results suggested that those individuals still employed after four or five years had parents who wanted them in competitive employment and had much influence over them. The individuals who returned to the sheltered workshop had parents who were not as supportive of competitive employment. The point made is that parents who desire competitive employment for their

children are more likely to achieve that outcome. The issue of why parents preferred competitive employment, while others were not as inclined, was not fully addressed. It was noted, however, that parents provided a more effective support system for competitive employment if the handicapped adults in the study lived with their parents, as opposed to having other residential arrangements.

The particular vocational aspirations parents have may be influenced by what parents do not know. Wehman (1988) suggests that many parents do not understand the concept of supported employment and many do not wish to accept the risks of work.

Raising the expectations of parents is important as they can have a great impact on the employment potential of youth with disabilities (Sowers & Powers, 1989). In all likelihood, the vocational expectations of parents are influenced by what parents experience and perceive. Parents' expectations for the particular program they desire can be raised by programs that demonstrate that young people with disabilities can experience more integration, higher paying jobs, and success on the job (Hill, Seyfarth, Banks, Wehman & Orelove, 1987).

Through-out the literature on parents' vocational expectations and aspirations for their children with disabilities, the message, however subtle, is that low

expectations and aspirations represent sheltered workshops and high expectations and aspirations represent supported/competitive employment. However, this distinction may be one made by only educators and adult service system personnel.

The vocational aspirations, expectations, and priorities of parents may differ from those of educators, rehabilitation, and adult service personnel. The meaning of success in a work placement may be different for parents as well. Wisniewski, Alper, and Schloss (1991) noted that the basis for making decisions on the quality of a work experience program is the ability to successfully provide a student with the skills needed to become successfully employed.

In one study, success was defined as paid employment of at least minimum wage, for at least 10 hours a week and lasting 6 months (Heal, Copher, De Stefano, & Rusch, 1989). Falvey (1986) suggests that in determining the success of a school program for students with severe disabilities, educators should take into account the type of job the graduate is doing, whether he/she gets a paycheque, how much he/she gets paid, whether he/she gets to work on his/her own, and whether the graduate likes the job. The parental definition of a successful job placement may incorporate additional features, or it might be more narrowly defined by

them. As for the student, it is important to determine what the definition of a successful school-to-work transition is for parents.

In summary, parents are concerned with high school employment preparation programs for their children with disabilities. However, the vocational expectations and aspirations parents have for their children vary. The variables influencing the vocational expectations and aspirations parents have may be:

- the age of the children,
- the severity of the disability,
- parents' attitude toward work as a normal part of life,
- the extent of parents' knowledge of vocational programs and options,
- parents' experiences with having children in specialized settings,
- vocational opportunities available,
- labour market conditions,
- the demonstrated potential of the child,
- the extent of the information with which parents can base their judgements, and
- the gender of the child.

There is evidence to suggest that parents of children with more severe disabilities have lower expectations, more

satisfaction with job placement, and a greater anticipation of sheltered vocational placements for their children than parents of children with less severe disabilities. The reasons for these differences in expectations is not clear. There is conflicting evidence regarding the extent to which parents desire improved working conditions and increased wages.

Generally, vocational expectations may be heightened by parental experiences involving the transition from school to competitive employment, an emphasis on the development of friendships, increased vocational opportunities, a departure from specialized settings, and future planning and more knowledge of vocational programs and options.

Parents' experiences with schools and service agencies. Parents of children with disabilities have encountered difficulties in their interactions with school systems. Frustration with school personnel and school boards, lack of external supports, social concerns, and a concern about the child's future are issues parents of children with learning disabilities have expressed (Waggoner & Wilgosh, 1990).

In one study, parents described their feelings during the transition from school to adult life (Ferguson, Ferguson, & Jones, 1988). They commented on a lack of services and lack of assistance by professionals. A sense

of abandonment was also experienced when their son or daughter turned 21 because the services suddenly ended. As a parent, Davis (1988) described the difficulties she encountered and her concerns during a school-to-work transition process for her child with a mental disability. In a study by Morgan-Redshaw, Wilgosh, and Bibby (1990), five mothers of hearing-impaired adolescents indicated that, while they all reported positive experiences, they were still concerned with the negative quality of many parent-professional relationships. Employment was not one of the major themes which emerged. Epps and Meyers (1989), and Meyers and Blacher (1987), however, have reported a high level of parental satisfaction with the educational programming provided to their severely handicapped children.

Young adults with disabilities or their parents have indicated they had little input into the development of their employment opportunities (Penner, Douglas & Van Lieshout, 1992). Haring, Lovett, and Saren (1991) interviewed the parents of 129 high school special education graduates with a range of disabilities to learn their perceptions on various issues. Almost one-quarter of the parents interviewed indicated no involvement in their child's education.

Parents want more involvement in the transition program for their children than they have had in the past (McNair &

Rusch, 1991). While parents want to participate in transition planning, Miller, La Follette, and Green (1990) have indicated that parents continue to feel unprepared to assume a leadership role in transition planning. A lack of knowledge or awareness of community services for their children with handicaps has also been reported (Kornblatt & Heinrich, 1985).

The importance of parental involvement has been echoed to the extent that the absence of parental involvement can be perceived as wrong and in need of change. However, MacMillan and Turnbull (1983) suggest that parental involvement should be determined more by individual cases than generalizations. Their premise is that some parents have good reasons for no formal involvement in school matters and, therefore, school staff should not view noninvolvement as comparable to disinterest.

In summary, parents have had varied experiences with schools and service agencies. Parents have indicated these experiences and the emotions produced by them. These are:

- feelings of frustration,
- lack of supports,
- social and vocational concerns,
- feelings of abandonment,
- negative parent/professional relationships,
- a lack of input in the development of employment

opportunities, yet a desire for more input, and
- a lack of awareness and knowledge of services.

Conversely, there is some evidence that parents of children with severe disabilities have reported high satisfaction with educational programming. Parental involvement is widely considered to be of great importance.

Parents' concerns. A number of investigations into the concerns of parents of children with disabilities have been undertaken. Wilgosh (1990) reported on research involving parents of children with disabilities to learn more about their lives and of issues of great concern to them. Several themes emerged which included the parents' search for the best educational opportunities, the parents' advocacy for their child, the concern for the child's future, and the importance of support services. Dawson and Kierney (1988) also reported on concerns about having adequate support services expressed by parents of children with moderate learning disabilities.

In the area of employment, indications are that parents might be more concerned with employment retention, safety, job advancement, continued guarantees for financial aid, and other work-related issues (Hill, Seyfarth, Banks, Wehman & Orelove, 1987).

In an investigation conducted in Texas, Fourqurean and LaCourt (1990) endeavoured to determine the opinions and

concerns of 215 young adults with handicaps and their parents with regards to high school experiences and the transition to adult life. Sixty-eight per cent were learning disabled, 17% were emotionally disturbed, 12% were mentally handicapped and 5% were physically disabled, hearing impaired or visually impaired. The concerns varied with the type of disability. For individuals with mental handicaps and their parents, vocational success and personal independence were of concern, as were affective issues such as self-esteem. Securing competitive employment was also a concern. For individuals with learning disabilities and their parents, job retention and job advancement were main concerns. Parents indicated a need for more vocational preparation, especially for those individuals who had a mental handicap.

Chadsey-Rusch (1990) interviewed nine parents/guardians of students with severe and profound handicaps involved in community-based vocational training experiences. Only four respondents believed that what the young adults were learning would prepare them for work. Most indicated a preference for integrated employment and five of the nine parents/guardians disclosed anxiety and uncertainty about the individual's future once school ends.

There is evidence to suggest that parents of young adults with disabilities prefer to have their sons and

daughters live at home rather than in some other living arrangement (Haring & Lovett, 1990b; Turnbull & Turnbull, 1988). In one longitudinal study of placement tendency of severely mentally handicapped and multiply handicapped children aged six to thirteen years, one-half of the parents indicated they gave no thought to residential placement outside the home (Blacher, 1990). The majority of adults with mental handicaps live at home or under the supervision of their families (Amado, Lakin & Menke, 1990; Seltzer, Begun, Seltzer, & Krauss, 1991). Despite this, Blacher and Baker (1992) note that the number of people with mental handicaps living outside the home is reported to be higher than it has ever been. Therefore, social aspects might be of concern to many parents of children with mental handicaps. This may be even more true for parents of offspring with severe mental retardation, as family members predominate as the only social networks for these individuals (Landesman-Dwyer, Berkson & Romer, 1989; Krauss, Seltzer & Goodman, 1992).

Frey, Fewell, and Vadasy, (1989) found that social networks were an important part of life for mothers of physically and mentally handicapped children. Evidence suggests that adults who are mentally handicapped and who lived at home with their parents, in comparison with mentally handicapped adults in other living arrangements,

had smaller social support networks which were composed mainly of family members (Krauss & Erickson, 1988; Krauss, Seltzer & Goodman, 1992). Social support refers to interpersonal transactions involving aid, affect, or affirmation (Antonucci, 1985). Krauss and Erickson (1988) noted that the individuals who lived at home also tended to spend most of their time with family members.

The importance of internal resources to families of children with disabilities has been documented. Cole and Meyer (1989) surveyed 166 parents of children who were severely mentally handicapped with regards to their plans for the future residential placement of their children.

Black, Molaison, and Smull (1990) reported that community living services were one of the greatest needs expressed by families caring for individuals with mental retardation during the transition to adulthood. However, the results also indicate that the family requests for community living were related to stressors more than to the characteristics of the person with the disability.

Botuck and Winsberg (1991) found that respites from school age children and adults with severe disabilities benefitted mothers with increased feelings of well-being and lowered feelings of depression. It has been suggested that being in school may act as a form of respite care (Bromley & Blacher, 1989). This may intensify the concerns of parents

over their child's future as they prepare to leave school.

As parents age, permanency planning for offspring with disabilities becomes a major issue for them (Heller & Factor, 1991; Kaufman, Adams, & Campbell, 1991).

Haring, Lovett, and Saren (1991) noted that parents of young adults with disabilities have many concerns about the possible social, occupational, and sexual exploitation of their sons and daughters. Haring and Lovett (1991b) did suggest that some ways to alleviate parents' concerns are to provide more information, and discuss programs and options and research results, as well as exposing parents to successful work sites.

Parents also have concerns over nonsheltered employment. Sowers (1989) reported that parents are concerned about the availability of transportation, loss of financial benefits, and job retention in community-based nonsheltered employment. Low paying jobs, employer's expectations, problems with co-workers, poor benefits, and lack of work are all personal concerns expressed by one mother of a mentally handicapped person (Davis, 1988).

In a study designed to determine the concerns of families of children with disabilities, parents disclosed worries about the future prospects for their children (Wilgosh, 1990). Whereas parents of mildly handicapped children may feel optimism about the future, parents of more

severely handicapped children worried about vocational training, community employment and opportunities for independent living. If concerns can be prioritized, perhaps the greatest general concern of parents of children who are mentally handicapped revolves around the uncertainty of what the future holds (Chinn, Drew, & Logan, 1979).

Some studies have found differences between mothers and fathers of children with disabilities. Some evidence suggests mothers are more likely than fathers to be involved in parent-professional relationships (Epps & Meyers, 1989). The lack of participation by fathers may simply be due to their not being as available as the mothers, but professionals should be cognizant of the possibility that a father's perceptions may or may not be similar to the mother's. It has been suggested that the degree some parents do participate in the education of their child is indicative of the degree they accept the situation (Gargiulo & Graves, 1991). There is also some evidence to suggest differences in expressed needs of mothers and fathers of handicapped children (Bailey, Blasco & Simeonsson, 1992).

Parents may have valid reasons for harbouring a number of concerns over their son's or daughter's move from high school to adulthood. Miller, La Follette, and Green (1990) suggest that the belief of many parents that schools have transition planning under control is far from true.

In summary, parents have indicated many concerns. There are a number of issues emerging from the literature on parents' concerns. These concerns revolve around:

- educational opportunities,
- concerns for the future which intensify as the child nears his/her exit from school,
- employment retention,
- safety on the job,
- vocational advancement,
- continued guarantees for financial aid,
- availability of job training programs (such as supported employment),
- social aspects,
- exploitation (social, occupational, and sexual),
- availability of transportation,
- loss of financial benefits, and
- job retention in community-based nonsheltered employment.

Residential arrangements were also of concern to parents. There is evidence to suggest that social networks are linked to residential arrangements. Parents may plan to keep their children residing at home based on the extent of their internal resources. As parents age, permanency planning increases in importance for them. Finally, there is some evidence to suggest that there are differences in

the extent of participation, perceptions, and expressed needs between mothers and fathers.

Research Implications

Increased attention has been directed towards the families of children with disabilities. Glidden (1993) reported that since 1988, 21% of the articles published in the American Journal on Mental Retardation described research relating to family issues. School personnel who teach students with disabilities should know how important educational programming within the various domains is viewed by parents in terms of importance (Epps & Myers, 1989). Therefore, it is crucial to gain insight into parents' concerns and desires, and their perceptions of living and employment situations.

Turnbull and Turnbull (1988) noted that research on family expectations for vocational opportunities is extremely limited. Just a few years ago, Hill, Seyfarth Banks, Wehman, and Orelove (1987), after a review of the literature, found not one study that directly surveyed the attitudes of parents of people with disabilities toward adult vocational services.

The need for information on families' views is evident. The perceptions of parents can provide information which may positively influence the vocational preparation and service delivery to youth with disabilities. Goodall and Bruder

(1986) contend that there is a need for information pertaining to the search for appropriate services for adolescents with disabilities during the transition from high school.

Numerous researchers have alluded to the importance of learning what the parental perceptions are of children who have disabilities when they are in the transition process (Bullis & Egelston-Dodd, 1990; Ferguson, Ferguson, & Jones, 1988; Moon & Beale, 1985). Obtaining information about parents' needs and desires relating to work placement can increase family involvement in the support of job placement and maintenance (Sowers, 1989).

Despite the increased awareness of the importance of parental involvement in the school-to-work transition of people with disabilities, there remain concerns that parents' needs and wishes are not being met and are often not taken into account (Sowers, 1989).

Much of the research on the grief of parents with a child with a disability focuses on the diagnosis of a disability. In some ways, the experiences and emotions repeat themselves years later during adolescence and young adulthood when the individual is preparing to leave the school system. It has been documented that periods of transition are worrisome times. The feelings resurface because twelve years of education is being replaced by a new

phase. The reality of the inevitability of exiting from school may rekindle familiar emotions and produce new concerns. For instance, parents may have financial worries about having to pay for respite which was previously available while their child was in school.

One of the reasons the transition into adulthood can be a very stressful time for families is due to moving from a familiar situation to an unfamiliar and uncertain adult service system (Brotherson, Turnbull, & Bronicki, 1988). Given this, it would stand to reason that familiarity with, and information about, services and supports would reduce the sense of fear and anxiety as perceived by parents.

The transition services offered to young adults with disabilities and their parents must be in tune with the demands the parents are facing and with their wishes. The services themselves could become a part of a family's support network. A wide-ranging partnership between various people are important to plan and implement transition from school to employment.

Gill (1988) makes the point that high school students with mental disabilities benefit from a vocational and special education partnership. Follow-up studies of special education graduates have not precisely established and described what components are critical in an effective special education program, nor have they identified the

factors that differentiate special education graduates (Haring & Lovett, 1990a).

With the input from many people involved in students' individual education plans comes the practice of interdisciplinary meetings during which plans are developed. Warren and Warren (1989) suggest that for a smooth transition from school to work, continued contact and coordination between parents, and places of employment, transportation and housing services is necessary. However, such large meetings may only serve to intimidate parents and lead them to not disclose their true feelings (Ormerod & Huebner, 1988). Therefore, accurate perceptions of the views of parents may not be formed by the transition team.

There is evidence to suggest that there are differences in opinion between parents and professionals on various issues of transition planning. Baumgart, Filler and Askvig (1991) investigated the importance rating and rankings of social skills by 263 parents, teachers, and other professionals. Results indicate that teachers and other professionals rated social skills as more important than the parents did, regardless of the disability. Baumgart, Filler, and Askvig (1991) suggested the reasons the parents' perceptions of social skills differed may be due to a lack of information available to parents on research findings and changes in the field, as well as parents seeing their

children in familiar or less socially demanding situations. The results of this study may indicate differences of opinion between parents and professionals on other matters.

It appears that exposure to, or familiarity with, experiences can influence attitudes as suggested by previous research on the attitudes of parents of people with handicaps on the institutionalization of their offspring. Spreat, Telles, Conroy, and Feinstein (1987) found parents were generally not receptive to the idea of community placement as compared to residing in an institution, but this belief was more pronounced for parents who had no experience with group homes.

Larson and Laken (1991), in their review of 27 studies of attitudes of people on the deinstitutionalization of family members, found an overwhelming satisfaction with institutional placement and opposition to deinstitutionalization. However, results also suggest that opposition to deinstitutionalization and high levels of community satisfaction are related to community living. Reasons suggested for family members' initial desire for institutionalization included the supposed lack of potential, vulnerability, and risk of exploitation of the individual with a disability. A fear of the unknown may have influenced these beliefs. Therefore, parents' aspirations and expectations may be influenced by what they

do not know and what they do not experience. It would be useful to learn what prior experiences influence the perceptions parents have.

Hanline and Halvorsen (1989) have also reported concerns and a lack of optimism by parents of children with disabilities on transitioning from a segregated educational setting to an integrated one. Parents indicated concerns that their children would not develop friendships, that they would fail, or that they would come to physical harm.

The results of these studies on families' perceptions of segregation and institutionalization could have ramifications in the area of employment for people with disabilities as well. Parents may harbour fears and concerns about the vocational placement of their sons or daughters based on a lack of awareness and knowledge of options and their potential for success. Parents want more information on career options for their children (McNair & Rusch, 1991). By the same token, familiarity with, and witnessing a successful transition from school to work may raise optimism, reduce concerns, and lessen fears. The views parents have can be shaped by their experiences, as some of the research by Wilgosh (1990) reveals. It is important to alleviate the concerns of parents and help families prepare for future transitioning (Hanline, 1991), but to do so necessitates the knowledge of what constitutes

those concerns.

Flagg-Williams (1991), in a summation of her review of the perspectives of parents of children with disabilities, indicated other issues of importance to parents which could be explored. They relate to the stressors families face, their coping abilities, and their social networks. Flagg-Williams suggested such information could be of importance to school psychologists when dealing with families. By the same token, however, parents' responses to such issues may help ease the school-to-work transition period for the parents themselves. If educators and other personnel involved in the transition process knew and understood what issues parents were concerned with, and what outcomes they wanted, the provision of information to parents and the improvement to school-to-work transition practices might be enhanced.

Research is increasingly focused on understanding the factors associated with more effectively dealing with crisis situations from a parenting perspective (Krauss, 1993). While Krauss was referring to the stress experienced by parents upon learning their child has a disability, periods of transition could also have parallels with a crisis situation.

Halvorsen, Doering, Farron-Davis, Usilton, and Sailor (1989) proposed an emphasis on individual families, during

transitioning, and one based on parent needs, preferences, and resources. This individualization of the transition caters to the uniqueness of each family. Halvorsen, Doering, Farrow-Davis, Usilton, and Sailor assert that educators need to be aware of transition issues of concern to parents and endeavour to alleviate their concerns and bring about change in the service delivery system.

Turnbull and Turnbull (1988) suggest that what is missing in planning for children with disabilities of all ages and their families is for families and professionals to be able and willing to develop great expectations and then to work together to transform expectations into reality. This requires a better understanding of parents' perspectives.

As already discussed, research exists on what parents of children with disabilities perceive, and, in terms of the stages of the grief cycle, what emotions they have. However, there is a paucity of research on the reasons why parents have the perceptions they do. Suggestions have been made, but much of it is conjecture. It would be useful to acquire insight from parents on their perspectives as well as on their experiences.

Summary and Conclusions of Literature Review

Vocational training or employment preparation for high school students with disabilities is one of the issues in

the forefront of their preparation for community living.

Several vocational training and placement programs have been designed and utilized to enhance the employment success and transition from the school to the community.

There is some contrasting evidence concerning the success rates of individuals with disabilities in their work sites. Although some studies have indicated high success rates, especially in supported employment programs, there is a great deal of evidence to suggest that individuals with a disability have difficulty procuring and maintaining employment. Several factors have been suggested as being important in employment, such as social skills, communication, and adequate work habits.

The role of parents of children with disabilities is a unique and important one. Several themes have emerged from previous examinations of the perceptions and concerns of parents of children with disabilities. Parents have indicated concerns about their child's future and a belief that the children face an uncertain future in the employment world.

Parents, more than anyone, know their children. Parents' perceptions can be instrumental in determining the educational opportunities for students with disabilities (Haring, Lovett, & Saren, 1991). Preparation for the adult world entails preparation for employment. This is an

integral part of secondary education for students with disabilities.

These differences in perception and opinion between parents and professionals are indicative of a need for further investigation. More information is needed to determine not only if parent's perceptions are different, but why they are different. Baumgart, Filler, and Askvig (1991) recommend more in-depth probing of parents' perceptions and barriers to implementing social skills training.

Goodall and Bruder (1986) suggested parents likely have many questions regarding the transition process. It is important to know what the parents' role is in the transition process as parents perceive it, and whether it is the role they would like to have.

Many researchers have indicated that parents have expressed their desire for involvement in the education and planning for their child with a disability and many professionals have emphasized the necessity of this involvement.

It is important to constantly reevaluate the transition process and make changes where warranted. Parents can offer valuable insight into the positive and negative aspects of the process. Transitions can also be worrisome and trying times for parents. A better understanding of parents'

perspectives on school-to-work transition may provide a more effective transition not only for parents, but for transition personnel, and above all, for their children.

In conclusion, the underemployment of students with disabilities and the difficulties they encounter form a basis for why parents have concerns over the vocational opportunities, eventual work placement, and future of their child.

The concerns and perceptions parents have vary in degree and form. There are numerous variables and components that influence and shape these perceptions. As such, the perceptions and views of parents may not be static and may continually evolve.

It is widely accepted that the involvement of parents is of crucial importance in the transition process, especially for students with cognitive disabilities. Understanding the perceptions of parents and the variables which influence these perceptions requires further investigation.

Many issues and variables have surfaced in a review of the literature. Many of these were incorporated into a questionnaire as well as discussion issues which parents elaborated on.

The questions or issues selected for the questionnaire to parents, and the discussion group or interviews with

parents, revolved around six general areas:

- parents' expectations,
- parents' preferences,
- parents' ratings of importance of various issues,
- parents' concerns,
- parents' experiences and satisfaction with service delivery and education personnel, and
- parents' participation and involvement

The information gleaned from the questionnaire formed the basis and established the direction for more in-depth probing of parents' perceptions in the form of parent discussion groups and interviews.

Research Questions

The fundamental purpose of this study was to examine the perceptions and attitudes of parents of youth or young adults with cognitive disabilities toward high school employment preparation and program planning for their sons and daughters. Within the context of this broad area there is a need to examine the variables and experiences which a review of the literature has found to be pertinent in influencing parents' perceptions.

The intent of this study was to gather insight into what parents perceive about the school-to-work transition and why. Some of the issues to be addressed and questions to be asked are as follows:

1) What are the vocational aspirations and expectations of parents for their children with cognitive disabilities? Previous research suggests that vocational aspirations and expectations are influenced by the severity of the disability (Pilley, 1988; Sowers & Powers, 1989), the extent of integration (Foley, 1988; Turnbull & Turnbull, 1988), and by vocational training experiences (Hill, Seyfarth, Banks, Wehman & Orelove 1987), such as community-based experiences versus sheltered work sites. Do parents with children taking part in supportive/competitive employment experiences have greater vocational expectations and aspirations for their children than parents who have not been involved with this form of work training?

It stands to reason that the severity of the disability may also greatly influence the parents' perception of the child's options in addition to work or work training experiences. It is important to learn from parents what their judgments are and what the basis of those judgements are.

2) What are the concerns parents of children with cognitive disabilities have regarding the school-to-work transition for their children? In previous research, parents have indicated concerns involving the uncertainty of the future, residential concerns, social networks, job retention, employment benefits, support services, lack of

vocational preparation, safety and exploitation (Chadsey-Rusch, 1990; Davis, 1988; Fourqurean & LaCourt, 1990; Hill, Seyfarth, Banks, & Wehman, 1987; Sowers, 1989). Since previous research suggest parents have experienced a sense of helplessness and uncertainty, the question to be asked is to what extent do community and educational services inform parents of community living and vocational options for their children? Are parents sufficiently assisted and prepared with knowledge, options and information as their children prepare to exit the school system?

Do parents of children with cognitive disabilities who have received vocational training in community-based work sites for eventual supported/competitive employment perceive themselves to have better support systems and more positive transition planning and implementation experiences than parents of children who have received vocational training in sheltered work sites, simulated work environments or related instruction in the school? While parents may not be able to make such a comparison, they can provide insight and information about their specific situation.

3) Are parents' perceptions of their experiences in the school-to-work transition process influenced by the extent of their involvement or noninvolvement in the process? In essence, is there a relationship between parents who perceive they had generally positive and

satisfactory school-to-work transition experiences with school personnel regarding their children, both in terms of perceived quantity and quality? In previous research parents have indicated a variety of experiences and emotions such as a sense of abandonment, frustration with school personnel, difficulties encountered during the school-to-work transition, as well as reports of high satisfaction. Does the degree of involvement actually influence the amount of satisfaction parents experience or is parent satisfaction linked to a parent's possible limited knowledge of the possibilities of involvement?

Parents have indicated little input into their child's education and parents have expressed a need for more involvement in transition programs (McNair & Rusch, 1991). Perhaps greater parental involvement is linked with parents' perceptions of greater satisfaction in the school-to-work process.

4) Are parents of children with cognitive disabilities who have participated in vocational training in a community-based work site more satisfied with and optimistic about the vocational preparation their children receive than parents of children with disabilities who have experienced the traditional route of vocational training involving sheltered work sites, simulated work environments or related vocational instruction within the schools? It has been

suggested that experiences with, and exposure to, more integration and deinstitutionalization positively changes attitudes (Foley, 1988; Hill, Seyfarth, Banks & Wehman, 1987, McDonnell, 1987). It appears that uncertainty and a debilitating fear of the unknown can be eroded by familiarity with experiences.

On the other hand, the degree of satisfaction and optimism a parent experiences may be related to factors more complex than simply the type of work experience their child is involved with. Parents' perceptions may be influenced by factors such as the child's level of functioning, the readiness for work of the child, and the child's attitude towards work.

5) What school-to-work transition procedures or components would enhance the school-to-adult transition process for young adults with cognitive disabilities, as well as for their parents? It is generally accepted that parental input into a child's education is desirable and necessary (Goodall & Bruder, 1986; Wehman, 1990). It also stands to reason that school-to-work-to-adulthood transitioning for high school youth or young adults with disabilities is an evolving process and, as with many processes, there is room for enhancement and improvements. This study proposed to ask parents what, in their view, would make school-to-work for their children more effective,

more successful and, generally, better.

Essentially, I endeavoured to determine, from the perspectives of parents of adolescents or young adults with disabilities whether their needs were being met, their concerns addressed, and how best to do so. School personnel involved in the transition process need to be aware of issues that concern parents and also try to address their concerns so as to improve upon the service delivery system (Halvorsen, Doering, Farrow-Davis, Usilton, & Sailor, 1989).

Also, the intent of this study, given the particular needs of the students, was to determine which employment preparation strategies best served the needs of youth and young adults and whether parents are, or have been, satisfied with the education and adult services rendered.

Chapter Three

RESEARCH METHODOLOGY

Participants of the Study

The subjects for this study were the parents of youth and young adults with cognitive disabilities who were participating in a three-year research project entitled "Manitoba Transition Project: From School to Work and Adult Life". The project was funded through the Social Sciences and Humanities Research Council of Canada. Included in the designation of parents were the legal guardians. At the time the parents began participating in the study their children ranged in age from 16 to 21 years.

The children of the parents who participated in the Manitoba Transition Project: From School to Work and Adult Life were drawn from five Manitoba urban school divisions. The primary objective of the research project was to describe an experimental approach beginning in junior high school and continuing after graduation as a community supported employment program and incorporating the systematic cooperation of schools, adult agencies, employers, and the private sector in transition planning and service delivery. The students' disabilities included a wide range. In addition to cognitive disabilities, these included learning, sensory, emotional, behavioral, and medical disabilities, as well as those with severe or

multiple disabilities.

The parents in the population were identified by the investigators implementing the research project. Almost all of the parents of the 64 students who were participating in The Manitoba Transition Project: From School to Work and Adult Life project were approached for their participation in my study which was designed to examine parents' perceptions of the school-to-work transition experiences of their children as well as their perceptions of the transition process. It was understood that all participants would be asked to complete a questionnaire pertaining to their perceptions. Parents who participated in the study and, subsequently, completed the questionnaire phase of the study were invited to participate further in a second phase of the study. This consisted of their participation in either one of two discussion groups with other parents in the study or in a personal, informal interview process with the researcher.

In addition to eliciting some demographic information about the parent and the child, the questionnaire focussed on the major issues identified from a review of the literature on parents of children with disabilities and the school-to-work transition. The questionnaire items were selected to reflect variability in the disability level of the child, the type of school placement of the child, the

school experiences and views of the parents, and the vocational expectations and preferences the parents have for their children.

Research Design and Procedure

This study consisted of two parts. In the second part a qualitative approach was utilized. Part of the design of the study was adapted in part from the design, guidelines and recommendations of previous literature on qualitative or naturalistic study (Biklin & Moseley, 1988; Ferguson, Ferguson, & Jones, 1988; Morgan-Redshaw, Wilgosh, & Bibby, 1990; Odom & Shuster, 1988; Stainback & Stainback, 1989, Summet al., 1990).

The first phase of the research consisted of a questionnaire of forced-choice and open-ended questions designed to elicit some demographic information of the parents and the student, as well as information on parents' perceptions and views on employment, vocational preparation and other issues (see Appendix C for complete questionnaire). The second phase consisted of a semi-structured discussion group format as well as individual interviews.

All of the parents of the 64 students participating in the Manitoba Transition Project: From School to Work and Adult Life were initially contacted by letter to inform them of the nature and design of this research study and to

request their consent to participate (see Appendix A for information letter and consent form). Parents were informed that they may be invited to participate in a follow-up discussion group or, if they preferred, an informal interview process.

After parental consent to participate was obtained the initial letter was followed up with a questionnaire and a self-addressed, stamped envelope with which to return the completed questionnaire.

Parents were made aware of their rights and my obligations to them. Namely, parents were informed that they could, at any time, refuse to participate or to discontinue their participation in the study. Parents were informed that their true names would not be used in the write-up of the study and their identities would not be divulged to anyone other than the investigators of the Manitoba Transition Project: From School to Work and Adult Life. It was also emphasized that no one, other than research investigators within the Manitoba Transition Project: From School to Work and Adult Life, in which the parents were already participating, would have access to data which could be traced to them. Parents were also made aware that all participants would eventually be provided with general information pertaining to the study's findings. It was understood that the topic of the study, in general,

was to be school-to-work transition experiences surrounding their child, as well as their own perceptions of the transition experience, past, present and future.

Parents were requested to complete the questionnaire within two weeks and return it to me by mail. They were given the opportunity to contact me by telephone in order to answer any questions pertaining to the questionnaire. A reminder to return the questionnaire was sent to the parents after a response was not received within two weeks.

Consent to participate was received from 38 parents along with the subsequently completed questionnaires.

Instrumentation

The instrumentation of this proposed study consisted of two parts. The first part was designed to elicit background or demographic information and the second part was designed to elicit parents' perceptions. The four-page questionnaire consisted of open-ended and closed choice questions to elicit the demographic information as well as parents' perceptions and views on a variety of issues which have surfaced in a review of the literature (see Appendix C for complete questionnaire). This questionnaire was partly constructed to develop strata for the construction of the discussion groups and to select interviewees. It was initially intended that strata would be used to group parents according to one or more variables and was to be

determined by the nature of the parents' responses on the questionnaire.

Also included with the questionnaire was a glossary of terms on a loose page which parents were able to peruse (see Appendix D for Glossary of Terms).

The questionnaire was designed to gather information on areas pertinent to the school-to-work transition for parents of young people with disabilities as evidenced in a review of the literature. Literature pertaining to parents and families of children with disabilities, particularly with respect to the transition from high school, was reviewed. Questions were formulated that revolved around themes and issues which surfaced in the literature.

Phase Two - Discussion Groups and Interviews

Parents who had participated in the questionnaire phase of the study were contacted again by letter with information pertaining to the content of the study and its progress (See Appendix E). They were then invited to participate in a discussion group with other parents or, if they preferred, to participate in an informal interview with the researcher.

In a departure from the original plan, parents were not grouped into discussion groups or interviews according to strata as determined by the questionnaire responses as originally planned. This change in the methodology is attributed primarily to the availability of parents for the

interviews and discussion groups. In addition, for some of the interviews or discussion groups the participation was by both parents, whereas only one of the two completed the questionnaire.

Parents were again informed that the purpose of the discussion group or interview was to provide an opportunity for parents to discuss their views on the school-to-work transition of their children and to elaborate on issues which surfaced on the questionnaires. The topic, in general, was school-to-work transition experiences surrounding their child as well as their perceptions of the transition process. As in in the first introduction and information letter, parents were again reminded that further participation in this study was entirely voluntary, that confidentiality of identities would be maintained, and that they may refuse to participate at any time. Parents were asked to return a consent form which was sent to them in a stamped, self-addressed envelope. They were asked to indicate whether they would prefer to participate in either the discussion group or in the interview or whether they preferred not to participate further.

Parents who agreed to participate in either the interview or in the discussion group were sent a copy of discussion issues (please see Appendix G) with several, representative open-ended questions which they were asked to

think about. These were sent at least several days prior to the scheduled discussion group or individual interview. The questions were representative in nature of the information provided on the questionnaire and from issues which had arisen. Further, the issues would form the basis for the questions to be asked and the areas to be explored in the discussion groups and in the interviews. The format of the interview was quite similar to that of the discussion group. Parents, whether they participated in the discussion or in the interview, were sent identical discussion issues.

Although the general questions were somewhat structured, the sequence of more specific follow-up questions was determined by context and by the experiences of the families together with the judgement of the interviewer on how best to proceed. For instance, incomplete or unclear responses were often followed up with more questions seeking clarification or elaboration. Parents were naturally given leeway to proceed with what they wanted to say. Some parents had more to say about certain issues than others. The perceptions and the experiences of parents were all of relevance as the focus was on their perceptions on the school-to-work transition in general.

The day and time of the discussion group and interviews was agreed upon and the parents had their choice of location, either in the home of the interviewer or at a

location mutually acceptable to all participants. The discussion groups and the interviews were audiotaped with the consent of the parents. The tapes were listened to and transcribed by the researcher. All of the research data, that is completed questionnaires, audiotapes and transcriptions of the audiotapes, were kept secure by the researcher. When there is no longer a need to access the data for research purposes, the documentation and the audiotapes will be destroyed.

The tapes were then content-analyzed for major themes and other issues. Based on a review of the literature, pertinent issues with regard to parents, children with disabilities, and the transition from school were used to categorize the data from the interviews. Some of the issues derived from the literature and which were used in the content analysis were support networks, parental input, feelings of stress, positive and negative experiences with the school system, preferences for certain vocational preparation models, satisfaction or disappointment with job placement, and vocational expectations.

Discussion groups. As previously indicated, parents who consented to participate in the study by completing the questionnaire were invited, by letter, to participate in either a discussion group with other parents, in an interview with the researcher, or not to participate

further. They were asked to indicate their preference on a consent form and to mail it in a stamped, self-addressed envelope. A reminder by telephone was made to those parents who did not respond.

Ten parents indicated a clear preference for participation in a discussion group with other parents. Six parents indicated they would like to take part in either an interview or in a discussion group without indicating a clear preference. All sixteen parents were contacted by telephone. Parents were given a choice of one of three evenings - a Wednesday, a Thursday, or a Saturday on which to participate. The intention was to conduct three separate discussion groups. One of the evenings was eliminated, the Saturday, due to a lack of responses for that evening.

It was acceptable to all participants for the discussions to take place at my house. Due to some cancellations or scheduling obstacles some of the parents were unable to attend the discussion groups. The majority of these parents offered to take part in an interview format. The first discussion group was held on Wednesday, May 29th, 1996 and it consisted of, in addition to the researcher, the mother of a young adult and both parents of a young adult - three parents in all. Some parents were unable to attend but opted to take part in an interview instead.

The second discussion group was conducted on Thursday, May 30th, 1996 in the evening and it consisted of two couples and two mothers for a total of six parents. Each discussion group lasted slightly over ninety minutes. Both discussion groups were audio recorded with the consent of all participants. It was emphasized that the recordings would be used only by the researcher.

Interviews. Seventeen separate interviews were conducted. Five parents preferred to be interviewed over the telephone. One or both of the parents of twelve youth or young adults were interviewed in person. All but one of the in-person interviews were conducted at the homes of the parents. The one exception was conducted in a cafeteria.

The interviews lasted approximately thirty minutes to ninety minutes. All in-person interviews were audio-recorded with the consent of the interviewee. Written notes were made by the interviewer during the telephone interviews.

A Word on Qualitative Research

The practice of using qualitative research to obtain parents' perceptions will be addressed.

As with any methodology, there are, of course, some limitations to using this form of research. The results can be difficult to analyze and, given the length of some studies, the findings can be difficult to replicate and the

research can be costly and labour-intensive (Gay, 1987).

Also, the number of subjects are generally few.

However, qualitative research can also provide insights not obtainable with other approaches. It can reveal a wealth of information due to its volume and detail and allow researchers to gain a deeper understanding of how people interpret situations or events than they could from traditional approaches (Odom & Shuster, 1988; Stainback & Stainback, 1989). The open-ended interviewing technique is suitable for studying individuals' perspectives, as is, although to a lesser extent, the discussion group. The approaches can document the patterns of people's lives and reveal how they construct meaning around those patterns (Biklen & Moseley, 1988).

Although qualitative research can be criticized for lack of control groups, they have been found to be reliable and even desirable. Wilgosh (1990), in her interview-style qualitative research on families, noted there is consistency among families on the major themes. In addition, there are indications that qualitative research on families is desired by families over alternative research methods. Summers, Dell'Oliver, Turnbull, Benson, Santelli, Campbell and Siegel-Causey (1990) found families preferred informal approaches and open-ended interviews and conversations to determine families' needs and desires for program services

as opposed to other methods.

The methodology used for this study incorporates, in part, a qualitative approach in the discussion groups and interviews. The approach is one which was invaluable to gaining a better understanding of the perceptions of people. For this reason the qualitative component of the methodology for this study was a desirable one.

Chapter Four
RESEARCH FINDINGS

Response Rate

Sixty-one of the sixty-four parents participating in "The Manitoba Transition Project: From School to Work to Adult Life" were approached to participate in this study. The three parents who were not approached could not be contacted.

The actual number of participants taking part in the questionnaire phase of my research was thirty-eight. Twenty parents did not respond to either the initial information/consent form or to the reminder letter. Some of the parents were contacted by telephone and were non-committal while others could not be reached. Three parents responded in writing but indicated that they preferred not to participate.

Of the 60 parents who received the letters of information and consent forms, 41 responded. Of these 41, 38 parents or sets of parents agreed to participate in the questionnaire part of the study. Of these, 2 parents indicated they did not wish to participate beyond the questionnaire phase. This left 36 parents or sets of parents who potentially could have agreed to participate in the discussion groups or interviews. Twenty parents or sets of parents, that is from 20 families, took part in either an

interview or in a discussion group with other parents.

In some cases, participation of parents in both the interviews and the discussion groups involved both parents, whereas some involved only one of the parents. Table 1 gives some perspective of the participation in terms of numbers.

Here is a summary and analysis of the results of the questionnaire which was mailed to the parents participating in the study. It is a breakdown of the parent responses from the questionnaire. The number of responses for each item on the parent questionnaire is presented. Beside each count and (in parenthesis) are the percentage values for each count.

The background or demographic information, as shown in tables 4-6, indicates that the majority of respondents were female. Twenty-nine (78.4%) of the respondents were female as compared with eight males (21.6%). Thirty-four (89.5%) of the respondents were parents, one (2.6%) was a guardian, two (5.3%) respondents were foster parents and one (2.6%) was a sister.

Seven (18.4%) respondents were under 41 years of age. Fourteen (36.8%) respondents were in the 41 - 50 age group, fourteen (36.8%) respondents were in the 51 -60 age group, and three (7.9%) respondents were in the 61 -70 age group.

Table 1

Parent Participation in the Interviews

Telephone Interviews	
	<u>n</u>
Individual Parent Participation	5
Parent Couple Participation	0
Total Number of Parents Participating	5
Telephone Interviews Conducted	5
Number of Families Involved	5

In-Person Interviews	
	<u>n</u>
Individual Parent Participation	6
Parent Couple Participation	3 (x 2)
Total Number of Parents Participating	12
In-Person Interviews Conducted	9
Number of Families Involved	9

Table 1 (Continued)

Combined Telephone and In-Person Interviews

	n
Individual Parent Participation	11
Parent Couple Participation	3 (x 2)
Total Number of Parents Participating	17
Total Interviews Conducted	14
Number of Families Involved	14

Table 2

Parent Participation in the Discussion Groups

Discussion Group I

	n
Individual Parent Participation	1
Parent Couple Participation	1
Total Number of Parents Participating	3
Number Families Involved	2

Table 2 (Continued)

Discussion Group II	
	n
Individual Parent Participation	2
Parent Couple Participating	2
Total Number of Parents Participating	6
Number of Families Involved	4
Combined Discussion Groups	
	n
Individual Parent Participation	3
Parent Couple Participation	3 (x 2)
Total Number of Parents Participating	9
Number of Families Involved	6

Table 3

Total Participation from Interviews and Discussion Groups

	Number of Responses
	n
Individual Parent Participation	14
Parent Couple Participation	6 (x2)
Total Number of Parents Participating	26
Number of Families Involved	20

Table 4

Gender of Respondents

	Number of Responses
Gender	n (%)
Male	8 (21.6%)
Female	29 (78.4%)
Total	37

Table 5

Relationship to Child

Number of Responses	
<u>Relationship</u>	<u>n (%)</u>
Parent	34 (89.5%)
Guardian	1 (2.6%)
Foster Parent	2 (5.3%)
Other	1 (2.6%)
<hr/>	
Total	38

Table 6

Age of Parent

Number of Responses	
<u>Age (years)</u>	<u>n (%)</u>
Under 41	7 (18.4%)
41 - 50	14 (36.8%)
51 - 60	14 (36.8%)
61 - 70	3 (7.9%)
<hr/>	
Total	38

Table 7

Degree to Which Child's Independence is Limited By
His or Her Disability

		Number of Responses
<u>Degree of Limitation</u>		<u>n (%)</u>
Not limited	1	1 (2.6%)
	2	2 (5.3%)
	3	18 (47.4%)
	4	11 (28.9%)
Very limited	5	6 (15.8%)
<hr/>		
Total		38
<hr/>		

As shown in Table 7, the severity and range of disabilities varied from not limiting (2.6%) to very limiting (15.8%) in terms of independence. Almost half of the parents (44.7%) indicated the disability was closer to "very limited" as opposed to "not limiting."

Parents provided some elaboration on their ratings by providing some comments. The majority of the comments consisted, at least in part, of the nature of the child's disability including strengths and weaknesses. The disabilities were of a wide range including, learning, emotional, sensory, behavioural, medical and physical, as well as those with multiple disabilities. The comments also indicated a range of severity of disability and limitation of independence. Several parents in their comments described some of the individual characteristics of their child as well as specific situations in which the limitation is more or less prominent.

On the questionnaire, parents were asked to indicate the type of school placement that best described their child's program. As shown in Table 8 the placements ranged from regular class to special school. One third of the respondents (34.2%) described their child's placement as a combination regular/special class placement. Three respondents (8.1%) indicated "other". All three elaborated with a comment: "supported work program", "not in school,

he's working", and "graduated from [school] on modified program". Some parents indicated one of the five options but expanded with a more specific description of the child's present or recent school program.

One of the components on the questionnaire surveyed the work expectation parents had for the child after graduation (see Table 9). One half of the parents (52.6%) indicated they expected supported employment, at least for a while, for their child following graduation. Parents who did not expect their children to be working after graduation or had other expectations may have been influenced by the severity of their child's disability. The following comments provided by these parents indicate their views are influenced by the severity of the disability:

"I would like to see her continue in [the] physiotherapy program. That is all that is really important [for] her and ourselves."

"[Child] will hopefully be placed in a program with an aide that will involve physical activity to keep her limber, [as well as] mental stimulation."

"I do not see how [child] will be able to do any job."

"I really can't think of anything he could possibly do, even with someone beside him."

These parents indicated that their child's independence was severely limited by their child's disability.

Parents overwhelmingly indicated a preference for competitive or supported employment for their children. Ten parents (26.3%) indicated a preference for competitive employment. Only one parent made a comment to elaborate on their choice:

"It bothers me that persons with his high functioning abilities (within their disability) would have to rely upon the government for the rest of their lives when, with minimum support, they could be self-supporting financially."

More than half of the parents indicated a preference for supported employment. Some of the comments made are as follows:

"[Child] has already graduated and is in supported employment already."

"Hopefully, supported for a while and then graduate to competitive."

"Not sheltered employment. Not not working."

Some parents made comments describing their child's learning characteristics or situations in which the child would best function.

Five parents indicated a preference for sheltered employment. The comments they made are as follows:

"Supervision would allow me peace of mind".

"Cannot work by himself. Needs direction always. He cannot answer any mail he receives."

Six parents indicated a preference for "not working" following graduation or "other". One comment which accompanied these selections was as follows:

"We first want him to be happy, safe and loved."

Another parent indicated that the reason for her preference was due to the severity of the disability.

The vast majority of parents (71.1 %) indicated that work for the child following graduation is very important. Some of the comments these parents made to accompany their choice are as follows:

"essential for his well being"

"[Child] is not that mentally handicapped that she doesn't have aspirations. She just doesn't realize what she cannot do."

"I feel that much of an adult's sense of self-worth comes from working, be it paid employment or volunteering. [Child's] handicap is minimal enough she is unaware of her differences. Unemployment would only emphasize the differences."

"Self-esteem and independence are very directly related to being self-supporting."

"For a sense of self-esteem. Also it will give us freedom from constant supervision."

"I want her to get the message that after school finishes she is ready for work. Work is a part of life."

"As important as everyone else to work after grad."

"It is important to [child] that she either works or continues her studies. She very much dislikes staying at home, doing nothing. She likes to be out and around."

Other parents also indicated the importance of work on the 5-point scale. Further comments made are as follows:

"He needs to have some activity or outside involvement for his well being."

"especially for her self-image and independence"

Only five parents (13.2%) indicated that work was not important. The comments they made are as follows:

"Reasons: she can't do anything."

"It isn't important as long as our son remains happy."

Another parent indicated that the child was unable to do anything independently. Parents who did not consider work as important also indicated the disability was severe and limited independence. For these parents work was less of a priority.

The majority of parents (68.4%) were very concerned about the employment situation after graduation. The comments some of these parents made to support their choice are as follows:

"Where? At what? Where will she live because our home is out of town."

"Because of her weakness we are very concerned as to

how well she would fit in an employment situation."

"She needs to have a job placement [so] as to help her learn about life and life skills so she may be able to cope with living alone and on her own."

"There will be some plan in place for [child] immediately after graduation. I have concerns about long term possibilities, job satisfaction and types of work that are typically available to young people with disabilities."

"How will he function on his own?"

"Due to economic restraints, the future for the handicapped looks very gloomy."

"We wonder what and how much he can do."

"Was very concerned. This is why I got involved with [a supported employment organization]."

"Even though I have worked very hard in the field I see changes coming that could very easily prevent him from accessing the supports he needs to get and maintain employment."

"Limited abilities in today's job market will yield limited to no placements in the employment field. Too many employers do not have patience to successfully employ and train the handicapped."

Other parents who also indicated a concern made these comments:

"[Child] has one year left of school. To date he has

had very little amount of work experience. He still lacks a work ethic, is easily distracted, so without support his chances of getting and keeping a job are very slim."

"The longer they wait, the greater the incentive to go is diminished. I would rather have her work as a helper than do nothing...I would also consider her going back to school or [a supported employment organization] and see what practical courses they have to fit her abilities to."

"With jobs so scarce and cutbacks in funding for workshops or grants to businesses that employ special people, I really hope there is something out there for them to do."

One of the parents stated specific concerns:

"One of my concerns is that an unethical employer may take advantage of a naive and trusting person such as [child]."

Parents who indicated they were not at all concerned made the following comments:

"As we just can't see him doing any job we just want him to enjoy his life doing what he enjoys (music and TV)."

"[A supported employment agency] is looking after this for him and so far I am very happy with the way things are going for him."

Parents were asked to indicate the extent they were satisfied that schools are doing, or have done, a good job

preparing their child for the transition to work and adult life. In terms of satisfaction, the responses varied widely but, generally, were almost divided. Thirteen parents (33.1%) were on the "not satisfied" end of the scale. Fourteen parents (37%) were found to be on the "satisfied" end of the scale. Ten parents (27%) were found to be in the middle of the scale.

A number of parents made comments on this component of the questionnaire to elaborate on their selection. Parents who indicated a satisfaction with the schools in preparing their child for the world of work and adult life made the following comments:

"[Child's] teacher has truly tried her best...

"We are satisfied with the school program and they show very much interest in her transition. We are very pleased with the program."

"Attempts are made to balance academic/vocational preparation/lifeskills in the mainstream and segregated setting - social interaction with mainstream is limited so that peer relationships with 'regular' students have little opportunity to develop - relationships with other special ed. students are encouraged/developing."

"[School] staff have been very dedicated."

"[School] has tried hard to accommodate my daughter's disabilities."

Parents who indicated a lack of satisfaction with the degree the school prepared their child for work and adult life made the following comments:

"Schools do not appear to understand the transition required. The focus is more on #04 programs and our children have to conform. Graduation from school appears to be the focus, not transition."

"Work experience programs did not show employment conditions as they truly are. Because she was not on payroll, expectations were too high. Free labour to do tasks nobody else would do. Integration in school did not work. She spent school life being baby sat."

"I am disappointed in the amount of work experience [child] has had. Most experience that he has had has been group experience and he has done a lot of collating."

"The schools have a very limited amount of time or required facility made available to give the appropriate training for each individual students' needs and give them the hands on experience."

"In the last three years [child] has attended high school there has been very little progress. There is no structure, total disorganization. It is almost like administration and staff of the school have no idea how to run a special education class."

"Our child is always placed in regressive programs

because he is not deemed high functioning enough to cope in the more progressive programs. The regressive programmers do not generally have a vision of what might be possible so, therefore, transition to work and adult life is not thought through."

"...They had her doing work far below [her] level. They had her doing work far below her ability many years ago. She liked it. She learned 'helplessness.' Now she thinks she can't learn."

Parents who indicated a middle score on the range of satisfaction with the schools made the following comments:

"His school programs with [teacher] at [school] was very good and directed towards preparing him for general life skills. The move to [different school] was a disaster and now efforts are being made to regain momentum."

"I always felt I had to be assertive and found high school the most stressful."

Table 14 shows the degree parents indicated a satisfaction with their involvement in their child's school-to-work transition planning. Three (8.4%) parents indicated a lack of satisfaction, twenty-two parents (61.8%) indicated satisfaction and eleven parents (30.6%) were in the middle on the scale with no clear indication of how much they were satisfied with their involvement. The comments made by parents provide a measure of insight into how or why they

Table 8

School Placement Best Describing Child's Current Program

Placement	Number of Responses	
	n	(%)
Regular class	3	(7.9%)
Special class	15	(39.5%)
Combination regular/special class	13	(34.2%)
Special school	4	(10.5%)
Other	3	(8.1%)
Total	38	

Table 9

Type of Work Expected For Child After Graduation

Type of Work	Number of Responses	
	n	(%)
Competitive employment	7	(18.4%)
Supported employment	20	(52.6%)
Sheltered employment	5	(13.2%)
Not working	3	(7.9%)
Other	3	(7.9%)
Total	38	

Table 10

Type of Work Preferred For the Child After Graduation

<u>Type of Work</u>	<u>Number of Responses</u>
	<u>n (%)</u>
Competitive employment	10 (26.3%)
Supported employment	22 (57.9%)
Sheltered employment	2 (2.6%)
Not working	1 (5.3%)
Other	3 (7.9%)
<hr/>	
Total	38
<hr/>	

Table 11

Importance of Work For The Child After Graduation

<u>Level of Importance</u>		<u>Number of Responses</u>
		<u>n (%)</u>
Not important	1	5 (13.2%)
	2	1 (2.6%)
	3	2 (5.3%)
	4	3 (7.9%)
Very important	5	27 (71.1%)
<hr/>		
Total		38
<hr/>		

Table 12

Extent of Concern of Employment Situation After Graduation

<u>Level of Concern</u>		<u>Number of Responses</u>
		<u>n (%)</u>
Not at all concerned	1	5 (13.2%)
	2	0 ((0%))
	3	2 (5.3%)
	4	5 (7.9%)
Very concerned	5	26 (68.4%)
Total		38

Table 13

Extent of Satisfaction With Schools in Preparing the Child
for Work and Adult Life

<u>Level of Satisfaction</u>		<u>Number of Responses</u>
		<u>n (%)</u>
not at all satisfied	1	3 (8.1%)
	2	10 (27.0%)
	3	10 (27.0%)
	4	4 (10.8%)
very satisfied	5	10 (27.0%)
Total		37

rated this component of the questionnaire as they did. Some of the comments suggest that, while parents may be satisfied with their involvement, it does not mean they are satisfied with the outcomes of their involvement.

A number of parents who indicated a lack of satisfaction with their involvement made the following comments:

" I have a daily log that keeps me posted, plus, the teacher phones if necessary."

"We help her every possible way with her school work, also we always present ourselves for teachers' meetings and transition committee meetings."

"With the school I always tried very hard to be very involved. Twice (for reasons of being told I was overprotective) I backed off - Gr. 3 and Gr. 10. Within two months his self-esteem was 'zero' and the program had fallen apart. Schools do not understand the needs of these children."

"I always felt I should have stepped in sooner (grade 10 was a waste as far as work experience goes)."

"I feel that I am directing and implementing my child's school-to-work transition with very little help from the school."

Only one parent who indicated a lack of satisfaction with his/her involvement in the transition process for the

child made a comment:

"We have drawn her abilities to their attention. They acknowledge she does have the abilities we say she has, yet have really done nothing about it. But it could be that many opportunities are not available."

However, some parents who scored in the middle of the scale with no clear leanings either way made the following comments:

"Have had input with school and job placement services. Unfortunately input sometimes ignored. We insisted placement and [supported employment agency] in order to create employment skills."

"[Child] seems to do well only in theory work. Had been sheltered by special education teachers. He relied on them."

"[Supported employment agency] are the first getting to know [child] and vice versa. The staff is excellent but we have concerns about what role the school should play in programming, etc."

"I would like to be more involved in transition planning."

"When we have gone for meetings, everything looks great on paper, but unless you are like a police person nothing seems to get done and we have seen very little progress in the three years of high school."

"I do get together with [child's] teachers, etc., to plan her individual education plan. However, I want to know more about what is happening in between I.E.P.'s. I get the strong feeling [school] considers me an overconcerned manipulative parent - no so! I am concerned and informed. However, I don't like involving myself where I'm seen as opposition."

Parents were asked to indicate the extent of involvement they would like to have in their child's school-to-work transition planning (see Table 15). Predictably, the majority of parents (73.7%) indicated a preference to be involved. Some of these parents added comments to complement their responses:

"It is extremely important for parents to be involved so that they can help plan and work towards independence."

"I will never back off again. [Child] needs to be advocated for and I will do that for him! Keep up the good work. We need it."

"I want to be involved in planning."

"I have been involved and believe [child] would not be having the work experience he has had without my pushing."

"Involved and taken seriously in terms of what I believe [child] is capable of... Somehow, [school's] teaching style (especially in the integrated classes) don't seem to fit [child's] learning style. Their methods of

dealing with her problems haven't proven effective. For years, I have considered having [child] transferred to another high school, but changes are very difficult for [child]. She hasn't wanted it."

"As much as possible and consistent with the programs available."

Only one parent preferred not to be actively involved. Nine parents (23.7%) scored in the middle with no clear indication of the degree they want or do not want to be involved in their child's school-to-work transition planning. However, in some cases the comments made suggested more than the rating they gave. Some of these comments are as follows:

"I would definitely want to know what she would be doing but [child] tends to work better if I'm not involved."

"We work on her social skills at home. Job marketable skills we are not trained to teach. We will be her support for as long as we can but we will not be here forever. She will need someone she trusts in a support capacity."

Parents were asked to indicate the extent they believed their views and wishes were taken into account with regards to their child's school-to-work transition planning (see Table 16). The majority of parents (64.8%) shared a belief that their views and wishes were taken into account. Some of the comments parents added to elaborate

on their rating suggests that, while parents may believe their wishes are taken into account, it does not necessarily mean they are satisfied with the outcomes, nor do they believe their views and wishes were always taken into account. Some of the parents who indicated they believed their views and wishes were taken into account made the following comments on the questionnaire:

"We are satisfied that our views and wishes are very much respected."

" I believe we are 'heard' - perhaps because I am involved through my work in similar planning, I would not accept a situation where my husband/myself were not here."

"The school does very well but home life, personal decision-making is very hard for our boy. He likes school."

"We have been and continue to be involved. But as parents we always feel that more could be done (perhaps). We have to be aware of [child's] ability at this time to do things."

"School knows my views and has decided not to oppose them."

Five parents (13.5%) indicated a lack of belief that their views and wishes were taken in account with regards to their child's school-to-work transition planning. Two of these parents made the following comments:

"From the school side - none. From [supported

employment agency] - very supportive and full regards are taken to our needs and wishes."

" They listen at the I.E.P. meetings, but believe that I have unrealistic expectations where [child] was concerned. They seem to take what I say with a grain of salt."

Eight parents (21.6%) rated this item in the middle. Some of the comments these parents made are as follows:

"School [is] looking to push her out of system as soon as possible. Easiest route is best. Once she is twenty-one she will be someone else's problem. We resent this and feel unable to change this approach..."

"My wishes and ideas are listened to but I don't think they are always acted on. Staffing seems a problem."

"It seems to have taken a lot of visits/meetings to make sure my views and wishes are taken into account. Without repeat visits I feel nothing would be done."

The final item on the questionnaire was designed to probe whether parents have ever been involved in the advocacy or training of students with disabilities (see Table 17). Nineteen parents (51.4%) indicated no previous involvement. Eight parents (21.6%) indicated very much involvement. Ten parents (26.6%) fell between the two extremes on the scale.

Thirteen parents made comments on the questionnaire. Based on these comments, the range and depth of involvement in advocacy or training was wide. Those who indicated an involvement did so in the capacity of teachers, foster

Table 14

Extent of Parent's Satisfaction With Their Involvement in
the Child's School-To-Work Transition Planning

<u>Level of Satisfaction</u>	<u>Number of Responses</u>
	<u>n (%)</u>
Not at all satisfied 1	1 (2.8%)
2	2 (5.6%)
3	11 (30.6%)
4	12 (33.3%)
Very satisfied 5	10 (27.8%)
<hr/>	
Total	36
<hr/>	

Table 15

Extent of Involvement the Parent Would Like to Have in the
Child's School-to-Work Transition Planning

<u>Level of Preference</u>	<u>Responses</u> n (%)
<u>Not to be actively involved</u>	1 1(2.6%)
	2 0(0%)
	3 9(23.7%)
	4 6(15.8%)
<u>To be actively involved</u>	5 22 (57.9%)
<u>Total</u>	38

Table 16

Extent Parents Believe Their Views and Wishes Are Taken Into Account with Regards to Their Child's School-to-Work Transition Planning

<u>Level of Accounting</u>	<u>Number of Responses</u>	
		<u>n (%)</u>
Not at all taken into account	1	2 (5.4%)
	2	3 (8.1%)
	3	8 (21.6%)
	4	10 (27.0%)
Very much taken into account	5	14 (37.8%)
<hr/>		
Total		37

Table 17

Extent Parents Have Been Involved in the Advocacy or
Training of Students with Disabilities

		Number of Responses
<u>Level of Involvement</u>		<u>n (%)</u>
Not at all involved	1	19 (51.4%)
	2	4 (10.8%)
	3	4 (10.8%)
	4	2 (5.4%)
Very much involved	5	8 (21.6%)
<hr/>		
Total		37
<hr/>		

parents, advocacy groups, or supported employment agencies, and in support groups.

One parent who was involved in the school system as a teacher commented "...I know a fair amount about the 'systems', but that really didn't help me because to try alone to change attitudes is impossible. I feel this is a very valuable program and I will support you in any way I can."

Interview and Discussion Groups Data Analysis: What the Parents Said

As previously indicated, two discussion groups were conducted in my home. Five parents were interviewed over the telephone. Nine individuals or couples were interviewed in person. In all 26 parents participated in some form in the second phase of this study, that is, in either an interview or in a discussion group. The 26 parents were drawn from 20 separate families.

All parents participating in the interviews or discussion groups received a set of 12 discussion issues. These issues formed the basis of the interviews or discussion groups. However, parents often digressed from the issues and wanted to share information not directly related to any particular issue. The comments parents made were probed for elaboration. In addition to the interviews, four parents provided written responses to the discussion

issues. This was not at any time requested, however parents told me they wanted to add their written responses.

During these interviews and discussion groups, parents disclosed information which was personal and important to them. The extent parents shared information and confided in me is much appreciated. Together, the information provided forms a basis for what parents' perceptions and views are, as well as the basis for these perceptions.

There are a number of issues which surfaced in the interviews and discussion groups. The content was analyzed and the variety of issues or points made were categorized. Many of these issues were disclosed by different parents. Parents shared a number of perceptions. On some issues parents revealed differences in opinion. It is assumed that these perceptions were based, at least in part, on the experiences parents have had.

There was a gap of time between the completion of the questionnaires and the commencement of interviews and discussion groups. During that time some of the children of these parents had exited the school system. Other parents had children still within the school system. The delay from the completion of the questionnaire and interviews and discussion groups often provided parents with more insight. Their children had been part of the world of adult life and their graduation from school was an event of one or two, or

three years ago in some cases. Parents shared their perceptions at the time their children were in school as well as their perceptions, in some cases, years after graduation. It was felt by me that parents genuinely wanted to share their perceptions, their experiences and their thoughts. I believe that parents considered that what they had to share was relevant and needed to be known.

Category Identification

Categorizing the information was a daunting task. There was overlap between issues which the parents raised or spoke about. Some areas could not be so clearly defined that they could only be referred to in isolation. Often parents would mention two or more issues with a few words. Also, some issues were not specifically referred to, yet the issues they represented could be construed or interpreted as such. Finally, some of the comments parents made could be relevant to more than one category.

The following categories were points that parents made, or issues that arose during the interviews or discussion groups. As already mentioned, there is overlap between issues and parents did not always use a specific word to describe an issue or an experience. However, the essence of what was said was often clear by virtue of the intent, of what was said, and the emotions and feelings in which they were expressed. The essence of parents' perceptions is best

captured by their own words.

Work experience. Parents have indicated the value they place on work experiences. They have also shared some positive and negative work experiences their children have had. A few parents offered suggestions for potential work experiences which would suit their child and offer a measure of success and satisfaction. One parent said that work experience was the best part of her child's transition but she emphasized that she had to push for that. She further added that work experience in the community was necessary as opposed to acquiring work experience in a school.

Several parents referred to the need for employment for their children as being essential for a sense of self-worth and dignity and a feeling of belonging in the community. Parents compared the work experiences their children have had during the transition from school as well as after graduation. They applauded certain work experiences and job sites while conceding that other work experiences were unsuccessful for one reason or another. Some parents liked variety in work experiences as well as exposures to a number of them. Some parents indicated inappropriateness of work experiences. One mother wrote that, while her daughter very much enjoyed the work experience, the work she was doing "doesn't require that she develops herself as a person."

Other parents spoke about a variety of work

experiences, some of which were better than others.

Parent Involvement. Parents overwhelmingly expressed the importance of parent involvement in the education and school-to-work transition of their children. Some parents also felt their involvement was not particularly welcomed. One parent wrote, "Sometimes it is not welcomed to be involved."

One mother, in a written expression of the importance of parental involvement, wrote:

Parents are the individuals who have cared for and supported their special needs child around the clock for 20 or 21 years. It is obvious that it is they who know and understand their young adult child's spoken and unspoken yearnings and heart-felt desires. They and their young person, together, need to be involved in this next most important phase of his (her) life.

Positive experiences. A number of parents expressed satisfaction with some experiences their children have had. Some of the satisfaction was due to one or more factors, such as specific individuals involved in their child's transition from school, special programs, activities, degree of cooperation and collaboration, or successful outcomes as perceived by them. Several parents related positive experiences or a feeling of satisfaction with the school their child presently attends, or attended. One parent who

expressed positive feelings about the school division also recognized that, despite all the school tried to do, there were shortcomings:

I'm very grateful for everything the school system has done for [daughter]. I certainly can't really find fault with it. There are areas that certainly could be made more available to the parent...but I honestly think they are doing their best with the amount of money they have for funding and for staffing. And to cut back on that staffing was an awful thing to do [referring to provincial cutbacks to Education]. I don't know just how those teachers cope with that.

Another parent was very pleased with the efforts of her son's school, "...they look at everything...they're doing as much as they can...really on the ball."

Parents have frequently said that the work experiences their children have had were positive and they were considered by many parents to be one of the highlights of the transition process.

While some parents were very pleased with the school programs, others were not. Several parents were highly satisfied with the supported employment agencies and personnel with whom their children were involved. One parent indicated, "the [supported employment agency] was

fantastic. The counsellors and job coaches, or whatever you want to call them, would go with him and they'd do a good job in the workplace."

Negative experiences. Parents have offered personal anecdotes relating to negative experiences they or their children have had. These anecdotes had a common thread of insensitivity or lack of tact by people, and the parents were sensitive to that. One parent related an anecdote about a bus driver who shouted out the door "We're in the parking lot, come and get her!" The parent felt that the directness and lack of discretion was insensitive and it very much annoyed her. She added that her daughter has good receptive language and understood.

Another parent remembered that when she got involved with her child's transition and expressed concerns she was told by school personnel that she was an "overprotective parent".

One parent wrote at length about the inappropriateness and inadequacy of her daughter's program or placement at school:

Up until this year [daughter] was treated like a person who was incapable of learning. She was 'babysat for'. She was given lower elementary levels of tasks in an institutional-level environment, forced to work and play with low

functional students, some with serious behavioural problems.

The father of one young adult with severe, multiple disabilities bitterly related an incident years ago when his child was young. Although the incident he related occurred almost twenty years ago and obviously did not involve any transition from school, the feelings and the bitterness remained strong when he spoke of it. It was triggered by the discussion of his daughter's transition. It is relevant, however, to parents' perceptions because it still reflects the need for options and collaboration which was not present in his example. He related the following:

You know the advice we got from doctors. Put her in [an institution] and forget she was ever born. That was their greatest statement.... you can't take care of her at home because she's retarded, she'll be too much trouble. It's my kid! Not like yours or the neighbour's. She's mine. What do you mean put her somewhere and forget her? That's the advice we got from all the doctors.

The parents of one young man who graduated three years earlier related a lack of satisfaction with their son's high school experience. They elected to have him leave school at the appropriate age rather than stay in school longer. They explained why:

Some things academic didn't get worked out properly...there was a sense that it was kind of filling in time somewhat...why put in another few years doing a repeat of work experience and fooling around with elective classes which aren't that beneficial anyway.

They add that their son has had several work experiences working with a supported employment agency but, "he has had four long periods of doing nothing...so he's had very long periods of having no work and being at home." The father was assuming the lack of work success had something to do with a poor job market but summed up by stating "it's been a disappointing experience, I would think." He did give the school credit, however, for doing "a very good job in doing the transition". He is not sure why the period after the transition seemed so unsuccessful.

Another parent was quite disappointed with the transition process. He spoke with some bitterness about his son's school-to-work transition experience:

There was something missing in the transition because he still could have stayed in school for three years and we were kind of hoping... and of course the resource teachers and things like that again, with all due respect, they have the right buzz words but what they actually get done is very little.

Some parents were not completely satisfied with their child's school experience, or work training or transition but they did not have the feeling that it was a negative experience. Unequivocal or ambivalent feelings were shared:

Of course as a parent you always think, hey, my son can do anything. It's just a matter of training him right...but you have also to know that your child cannot do everything...so there is always that doubt. Maybe the school division is doing the best it can but [son] just didn't benefit from it because of the way he is.

Support groups and networks. Parents indicated that social networks and support groups are invaluable. One parent related, "The only parents who are given anything are those involved with other associations, other parents, other sources."

Another parent said that her main sources of support came from those outside schools and community service agencies. Her sources of support came from herself, family and friends.

Frustration. A number of parents have shared a sense of frustration with the school system or community service agencies. Some of this frustration was disclosed directly. Other times the frustration could be read between the lines. Schools conduct major meetings for students in the

transition years. Depending on the school, these meetings have been referred to either individual education plan (IEP) meetings, individual program plan (IPP) or PATH meetings. In these meetings, the focus is on the goals and how to reach them. A level of frustration by parents was felt during or following these meetings. One parent shared her frustration with personnel at a meeting for her child. She stated, "no matter how hard they try not to, the facilitators gear it toward where they want to go". She offered a recommendation for her perceived difficulty at these meeting. "I think it's better if they get some outside facilitators - an agency or whatever - but some outside facilitator because they'll be much more objective."

Another parent spoke specifically about her frustration on the emphasis on academics for her child as opposed to life skills training. She related an incident when she finally went to an administrator of her child's school and directly said, "You're not listening to what my husband and I are trying to tell you."

One parent exhibited a sense of frustration in a lack of school-to-work success despite efforts from the school. She describes her expectations for her daughter's work education who was 21 years of age and was just about to exit the school system:

...I suppose, to be ready for the job market, but

which is not really a realistic expectation because where the school finishes there is a heck of a big gap before the marketable skills of a handicapped person are available. But if you were to ask me, "What can your daughter do?" I'd have to say, "I don't know."

One parent related anecdote after anecdote about transitional objectives not met, plans not followed through, parents' suggestions not heeded, and then summed up his feelings. He remarked, "I used to get very frustrated. That's why I'd come home and say I've lost all faith in the teaching profession."

Another parent referred to her frustration specifically in recounting some of her experiences involved in the transition of her child:

You are going from a system where you have taken total responsibility for your young person into a system where you have to play a game. And you have to know who to connect with in order to make this happen six months down the road. So you have to figure out this game and in the mean time there is a lot of time getting frustrated, trying to sort out what really needs to happen, and to do that advocating and to be a strong person to believe what you believe should be happening, or could happen.

The frustration in another parent's words could be sensed but it was a frustration borne from attitudes of government, and society in general, in the face of parents simply trying to help their children with disabilities find work:

Parents are tired of, I guess, kicking down doors. They've been doing it all their lives and they are saying, 'Well, we want our young adult to get up and get a job and have a little independence, a little bit of life, and [to give] some measure of dignity to themselves.

Transportation and mobility. Transportation concerns were not referred to except in one case. The parent spoke about the difficulty in procuring transportation for her child. She commented, "the transportation rules are not flexible. You have to book 48 hours in advance and know where you are going and when [you are] returning."

Integration. Parents have expressed widely divergent views on the integration of their child. Some parents were advocates of it; others were opposed to it. One parent whose child was not ever integrated wanted very much for that to happen. When asked if the school personnel were aware of her wishes she replied "oh, yeah, oh yeah. [School personnel] is philosophically the person for integration over anything, but it never happened."

Another parent wrote to me about her experiences in trying to ensure her daughter was integrated in school and

her failure to achieve this:

"...I have been ...doing my best to have her fully integrated and working up to her full potential. All of my labours were totally fruitless. The school system made up all kinds of excuses to keep her in Special Ed. when I knew right along [daughter] does not belong there."

Other parents were opposed to integration or, in hindsight, felt that integration was a failure. One parent whose son had graduated three years earlier and who had been integrated had this to say:

He just sat there in some classes and [it was] useless. There's no way you're going to be sitting in a grade 12 English class and absorbing tests...I don't care. He just doesn't have the capacity to do that, so I think some of the classes were a waste of his time.

Another parent compared a positive, non-integrated setting for her daughter in a small country school to the integrated program she was in when they moved to Winnipeg:

And it took her a long time to get used to the idea that she had to sit in a classroom full of other people and she'd come home and say, "I don't know what they are talking about, Mommy?" You know, like, "Why do I have to go there? Why can't I go back to the way it was?" And I said, "Well, this is the way life is in Winnipeg." I understand where some parents want their

children to be integrated because they feel they are missing out on a lot of things. But I'm afraid I'm not one of those parents that believes that.

Quality of life. Some parents referred to the quality of life as being the utmost of importance. The parents who did, suggested that work is a key factor in the quality of one's life. It provided a sense of self-worth and meaning. However, it was not the only factor. Friendships, community involvement, and physical well being were components of the quality of life. The overriding goal and overwhelming priority of some parents was for their child to be happy.

One parent of a daughter with multiple disabilities investigated different program options for his daughter following graduation. Several were ruled out because of his perceptions of the lack of quality of life they would provide his daughter. Based on the programs he saw, he and his wife pursued a supported employment option. He said:

When we were searching what to do with [child] after graduation at 21, or whatever age it was, and so she went to various programs in the city and I want to to tell you, some of them are so depressing it's unreal. It's just like you're retarded, you sit in that chair or wheelchair and that's it...we went to a couple of them and I just about cried when I was in there. It's so depressing.

Several parents have alluded to aspects of a transition from school to work and adult life that are important components, but do not only represent work. A successful transition encompasses many components and to focus only on work is to diminish the importance and desire for the others. A parent commented:

But it's not even just work. It's got to be work, [but] it's got to be socialization and leisure [activities]...it's very difficult when they graduate because it's all these significant factors - sociability, recreation, jobs, money...For a young lady to think about buying clothing and to look prettier, for a guy to be able to do things that you see other people doing, and to have someone to do it with.

Another parent said:

As a child gets older you get more and more of these perceived problems stacking up. It's not only education and not only a job, but it's sociability, independent living, recreation, you might say life skills, continuing education, on and on. And I guess the question to ask is, 'What is the role of the school here?'

Residential concerns and opportunities. A few parents had concerns about the future residential arrangements of her child. One parent said, "That is one thing social workers will tell you. [Children with disabilities] have

got to leave home before they are 18, otherwise they'll be home until they are 30 something." The same parent also commented about a concern that her child will have to live at home forever.

Other parents have also indicated difficulties in procuring alternate residential arrangements. A few parents have investigated group homes and have been told that there are no openings in group homes. One parent spoke about other people who were aging and found themselves in a situation where they had to seek alternate living arrangements for their child.

Community involvement. While work was, in most cases a priority for parents it was by no means the only component of the transition to adult life. Recreational opportunities in the community and leisure options were shared as being of great importance as well. This aspect of one's life was frequently recognized by parents as providing an added measure of quality to the life of their child.

Friendships. One aspect of adult life which a number of parents indicated as being very important was friendship and having a social network. Parents recognized that, while work was a priority, the importance of friendships cannot be diminished. Some parents suggested introducing a "Circle of Friends" concept into schools to promote friendships and social networks for youth and young adults with

disabilities. However, one parent said that the Circle of Friends his son was involved with was of a superficial nature and eventually fizzled out.

Another parent remarked:

Social skills are far more important than the [vocational] tasks. We all need a friend and we've got to teach our kids to be friends and interact with them and be role models. This is really depressing isn't it [laughs]? But that's how I feel...I want [son] to have a friend and I want him to be happy.

Other parents also expressed a need for their children to acquire social skills, a social network and friends. One parent said, unequivocally, that friends and peers was what was needed more than anything else. He stated, "That's what he has missed. If you and I growing up, didn't have a good buddy or friend of some sort, just think about what life would be like."

Another parent also attributed fundamental importance to friendships:

It's so important to have that friend. We think back, when we were teens, how devastated we would have been if we had to sit home with mom and dad...I think if they had a friendship it gives them focus to their lives. I think that gives them stability and commitment to function at a higher level...and knowing

that there is more completeness to their life...My son, he's 21 and you're looking at his best friend. I think that's a pity. I'm not going to be around forever, either.

Another parent had some similar sentiments:

We were able to provide him with some social activities, but that's very much lacking. I mean he's a young man. He needs to be with young people. And he's always with his parents. I wouldn't want to be with my parents all the time.

One parent said about the importance of friendship:

The school tries to fill it through integration kinds of purposes, but to me it seems rather superficial in some ways. It's not a true friendship kind of building thing in many cases and in order to be successful in the adult world you have to develop the friendships.

Expectations. Some parents have indicated that the expectations schools and agencies had for their children were too low. One parent said:

That's the other thing. I found nobody has enough expectations. I found nobody has any expectations....Their expectations were always for failure so they always got it. They achieved their expectations. You know, we can't go into the

community because...I can't do this because...unless we have this and this and this - no, they are not risk takers.

Another parent suggested that her disappointment with the transition outcome for her child may have been due to her expectations for her child being too high.

One parent related a story about how the expectations of professionals for his child were too low because they failed to understand his daughter. He related the story to reflect a cynicism or doubt about the competence of whom he referred to as the "experts".

I mean these people and the guys who run these departments...I think they go to the books and say 'The child's this, this is as far as they are expected to go and that's all they look at. They don't say maybe she'll walk. She's got such and such a disease [and] she's never going to walk. That's it. They told us she'd never stand. It took us thirty days.

Several parents of young adults with severe multiple disabilities had no expectations for a work situation. One of the young adults who graduated two years previously was involved with a supported employment organization. Work was not an expectation, nor was it rated as important. Their priorities were to improve or maintain physical functioning

and to take part in physical activities in the communities with one to one assistance.

One parent, when asked about her expectations, replied, "I don't know, we don't want to expect too much out of him and it was kind of hard because, of course, you feel that we want to have the best potential out of him..."

Concerns. Parents have shared a number of concerns they harbour and some concerns surfaced more frequently than others. Parents have expressed a worry about the future.

One parent commented:

As a parent you say to yourself, O.K., you coast all through public school and you start to get a little antsy in high school. A few more years of schooling and then what? And that's where you start. If you're really that complacent, if you get agitated you say, well come on now, I'm not asking something for nothing. I want to know what's out there, you know. You hear of cutbacks all the time and you think, I wonder if it's going to affect [daughter] in a couple of years. And it worries you. Who do you ask?

Another questioned, "What good is it going to do thinking about six years from now when I'm not sure whether certain things may not fall into place tomorrow." Several parents worried about the unavailability of employment in any form. Some parents were concerned that the work

available would not be suitable for their child. One parent, whose daughter was still in school, was very much concerned that there would be few residential or work options upon graduation. These were her two main concerns. Several parents' concerns were generally that their children would not be prepared for work, or adult life in general.

One parent of a young adult with severe multiple disabilities spoke about the vulnerability of her son due to his limitations.

Parents spoke about job concerns and a lack of companies, businesses and employers who may be leery of hiring a young adult with a disability.

Matching. Several parents referred to the need for proper matching of the job or work with the youth or young adult. One parent wrote "proper matching seems to be the biggest factor." Another parent shared a similar view on the need for better matching: "Look at the skills an individual has and the needs of that individual, and then find the job."

Importance of work. The majority of parents indicated that work was an important aspect of adult life and they had hoped for meaningful, satisfying employment for their children. One mother spoke about the meaning work has for her son:

...he feels a lot of self-worth by going to work and

to be rewarded with a cheque, I mean, when it's pay-day, he's done it. Even though he's killed himself all week and he's got blisters, that cheque makes it worthwhile, and he feels good about it.

Other parents spoke of the dignity and independence a job gives young people with disabilities.

However, work was less important for parents who had a child with severe or multiple disabilities. For them, the concept of work or employment was idealistic and not realistic for their child. Other things were more important. As one parent stated when asked about work as a goal for her daughter:

No, I don't think it's realistic for her. There are people who can do these kind of things. For [daughter], I mean, it would just be a case of an aide putting [daughter] hand over hand and doing the work so what would be the point?

One parent spoke about the importance of work from a different perspective: "As parents we had really wanted him to just give something in return to the community that has helped us so much." She went on to say that the work education program her son was involved in was worthwhile. She states "I can surely say...this work education really gave him an opening."

Lack of follow-through, commitment or continuum. A familiar theme which surfaced time and time again was a lack of follow through or commitment from schools or agencies to effectively implement a transition plan and to follow it through. One parent said:

There also has to be somebody...to take ownership or take responsibility to make sure that what people say actually happens...[the] plan looks good at meetings but in between times, when things are supposed to be happening at school, you think this is what the plan was and this is what is supposed to be happening, somehow it doesn't happen...there was no consistency, there was not anything so of course [work experience] was never successful...it was just kind of hit and miss. Today we do it, tomorrow we don't...

The same parent offered some advice to other parents. She suggested, "You have to go out and you shouldn't sit there and hope things happen. They have to keep out there and say this is what's happening; this is where we're at."

Another parent expressed a disappointment that the plans for her son did not meet her expectations "...it never took off...At that time you are really keen because you think it might make a difference, but it hasn't. It never did take off."

Another parent stated, "I got the impression from the school that they would look after her as long as she was

there. Once she was gone, good-bye!. You know, one less to worry about."

Related to a lack of follow-up was a sense by parents that there was not enough collaboration between individuals or agencies which are vital to transition. One parent commented:

...so this was one of the concerns as a parent. We had to get our kids ready to leave and be able to get into the community and I, personally, feel there has never been enough communication between educators, the parents, and the students. The ball gets lost in the shuffle. And everybody has really good intentions but nothing is ever done after.

Some parents indicated that programs and plans they were promised never materialized. One parent regretted the lack of socialization in school for her daughter despite initial plans to enhance the process. She commented, "There was supposed to have been a Circle of Friends. It never materialized. They were supposed to have like a buddy system and it never materialized."

Another parent said:

You can sit in a [meeting] with them and they get all, 'Oh, it sounds great' and the whole nine yards, but once that's over, to actually get things going and implement the program that they talked about,

and the things they wanted to accomplish...I'm very disappointed with that in high school.

Some parents have related differences between schools. The perceptions of one school may have been positive while their perceptions of another school were negative. Several parents indicated substantial differences in the service delivery and transitional programs between schools.

A difficult and trying period often occurred after graduation. Some parents have said that the continuum from school into adult life failed for some reason and there was a void, or periods of inactivity, in the months or years following graduation. One parent suggested that schools need to be realistic with what really happens after school.

One parent believed a lack of follow-through was due to a failure to develop and promote linkages with different key groups:

They look at this in a very short term finite view and they don't do linkages very well. Their concept is, 'Well, we have so-and-so until 21, that's when our commitment ends'...and instead of looking and figuring out how they can correct it, they tend to want to work alone...and so as a result, the schools work in isolation and they don't want the agencies and there is also a bit of competition, perhaps, over turf."

A perceived failure to follow-through or succeed with plans was also recognized as not being the fault of school personnel. There was acknowledgement that the best of intentions may fail to be productive for other reasons. A parent reflected on this:

...teachers probably don't get the training they need to do that - to learn about the job market, and so on. If you know one or two (teachers), and you get to know them, you know that they are just overwhelmed with a variety of other tasks that they have to do and to find the time, to find the opportunities to get training, and to do what they'd like to do...the time just isn't there.

One parent thought that school-to-work transition planning may be hampered by a lack of commitment by personnel involved in the transition process, as well as schools in general:

Another concern I have is that sometimes I think if any sort of establishment or group wants something to fly, to get off the ground and be successful, they have to give it an appropriate priority within their list of overall tasks and duties...and I'm not convinced, sometimes, that the teachers assigned to some of these responsibilities in the special education area really feel that what they are doing is

viewed by their peers and, perhaps by trustees, and other businesses as being as important as all other aspects....[there is a need] to let teachers know that what they are doing in special education is appreciated, is essential, and is deemed by the principals and the superintendents and the trustees, whomever, as being a very essential and integral part of the educational process, and maybe even more important because they are dealing with special needs.

A few parents spoke about a void following high school where there was vocational inactivity for a period of time. Some parents spoke of inactivity for intervals of time between working at job sites. Some parents had the sense that once their child graduated, the school was no longer involved and they were beginning all over again in a quest for a suitable and successful work experience.

Lack of cooperation between key groups. A few parents expressed a view that there was a lack of cooperation or collaboration by schools and adult service agencies, not with parents, but with each other. Some parents felt that one group or agency, whether it was the school or social worker or business, did not know what the other group was doing. Parents referred to endless work experiences but with no success rate. One parent spoke of his views:

"...I just wonder if people in the government and school boards take this seriously because they seem to work in a disjointed fashion. You've got parents going to the schools and schools saying, 'What sort of jobs do you feel your young son or daughter might be best suited for? O.K., we'll try to find something.' But then this depends on other supports beyond the school. And the schools, at least our experience has been, seem not to be working in conjunction with these other agencies which are a very integral part of the overall picture of training, support and job creation.

Another parent spoke about a lack of understanding by schools that others need to be involved:

...what we have just actually found is that the school just really doesn't understand the job market and they're under the impression, as all of these training programs are, that all you have to do is provide training. They don't understand the concept of support...training isn't the issue. The issue is support. And how do you support a person on the job? First you have to find the job, then you have to train, and then you have to support. The schools have a hard time finding the job, they don't do too bad a job training, but they don't understand

support, and long term support. And that's where all of this falls apart.

A parent provided an analogy suggestive of schools working in isolation, "Someone said that one of the problems with schools are they are almost an island in society....and they don't necessarily have any idea what's happening in the world."

Sense of not being listened to. Several parents directly expressed feelings that their views, suggestions, or recommendations were not respected or valued, let alone adhered to. Parents who alluded to this did so with a sense of bitterness. One parent wrote:

...I have been strongly encouraging the school to try and develop a "Circle of Friends' for [child]. More than once, I have offered to volunteer my time at [the school] to facilitate such a program. I was totally ignored in this sincere attempt to help secure some caring, supportive friends to help [child] overcome her timidity."

Another parent said she wanted to see certain changes in her child's program at school. When asked whether she made her views known she replied:

All the time, but the school had it's own agenda and it doesn't matter who was at these meetings. They were going to stick to their own agendas. And it

actually got to the point where I would bring people in that would support [me], and I think parents sometimes feel that they are not listened to seriously. You bring your own advocates with you and I brought teachers with me, really supportive people, but it's really hard to change someone's day plan if that's what they are going to do....this is going to sound really negative, but when I look back at being subjected to a school setting all these many years and I ask myself, 'What have we done to prepare [son] for the real world - it doesn't look very good.

One parent also, in hindsight, talked about her daughter's education and recognized that the school erred in not heeding their suggestions. She reflectively said:

I think they did a lot of things right. But I think, had they listened to us about the type of child she was and what we felt was best for [child] that, if they had taken our input and used it along with their expertise, I think [child] would have had a much better program than what she did through the school system.

Advocacy and parental input. The roles parents play as advocates has surfaced several times during the interviews or discussion groups. Parents see themselves as their

child's foremost and strongest advocate, which they are. They recognize that they need to advocate in order to serve the needs of their children. In addition to participating in a telephone interview, one parent wrote, "I have had to push and fight for everything insofar as [child's] academic and social life is concerned. I made inquiries and got [child] involved in [various organizations, school clubs and activities]."

Many parents indicated they had sufficient input into their child's transition with respect to being informed about the transition plans. However, input and participation were gray areas for parents. They were invited to participate but they did not know how. It was uncharted waters for many parents and they relied on the expertise and guidance of personnel involved in the transition process. One parent commented:

The [multidisciplinary meeting] was well done. What I'm saying is it was all mapped out beautifully and the buzz words were all there by those people that ran the resource world out there. But the implementation was not there.

One parent spoke of parents' constant struggle to see that their children's needs are met. What they are striving for is what is taken for granted by the rest of society. He stated:

So we are not asking for anything that isn't out there in other segments of the population...a chance and a little bit of training, integration of services, where the right hand knows what the left hand is doing. But don't lose focus of what people are doing. It's for that individual. It's not to protect this departments's turf or that department's budget."

One parent had advice for other parents with regards to advocating for their child in the transition process:

You have to start looking early enough so you need to get that information as well as trying to find that out early. You need to have the confidence to deal with the system...and you need to feel comfortable doing that.

Funding The area of funding was an issue raised by some parents. Not one parent suggested that the funding provided was adequate. Several parents conveyed a need for increased funding. One parent said, "The point is put the money behind the person and you'll get him off the system, but the system is that it's easier to keep [person with a disability] on the welfare system.

Another parent in criticizing the funding to education by the current provincial government said, "The government is very foolish because it's so expensive to keep these people in institutions. And I think...a lot of parents

would choose to look after [child] if they got the [financial] help."

Another parent criticized the lack of commitment by the government:

Government has not made a commitment to the individual who will not be leaving school, so the transition planning and all the knowledge and all of the time is for nought because our current provincial government is saying we don't have the money to support people with needs...right now the issue is funding. If post-secondary funding is not in place then I think we'll all be in a terrible [dilemma]. And there is every indication they are going to allow this to happen.

Information wanted. A recurring theme in the interviews and discussion groups was a sense that parents did not receive enough information from the personnel involved with their child's transition.

Frequently, parents did not know what to ask. Some parents, only after meetings or after the child's graduation from school, realized what information they would have liked to have. The following comments by different parents emphasized the need for more information:

It's never given to parents, even if you ask for it. You have to know what to ask for... You have to be

involved...parent to parent, whatever you can get involved in. You have to know exactly what is there and what to - not even what to ask for - but what to say you want...You have to know that if you want something you have to use the word 'crisis'. Nothing is there... I would have liked to see that social workers actually come and tell parents what the options are.

One parent said, "It seems to be that once you leave school you realize what you needed to know." It appeared that parents who had children who already exited the system were more aware of information they were not given or did not know but, after the fact, regretted not having received it.

Another parent said:

But I was not that happy with the program and more unhappy, I think, at the end than I was at the beginning because at the beginning I really didn't know what I should be asking and what I should be expecting. Then you'd hear other parents talk and I'd think, "Oh!"

She suggested:

They should discuss those things about the future and let them know some of the money implications. ...but nobody ever told me any of those things.

Nobody even told me. Those are things they should be discussing.

When asked why she thought she didn't receive the information she wanted she said, "I honestly don't think they have that information. They really don't have all that information. They're wonderful at what they do, but they don't have all the answers."

Another parent repeated the sentiments of others in not knowing what to ask, "We really didn't know what we should be looking for, or what we should be doing, or whatever."

One parent wished she had known more about what options were available after her child had graduated from high school. She gave an example of knowing, after the fact, that her daughter was eligible for a disability pension for Special Olympics. She stumbled across this information by chance. She also stated that she believed that the reason the information she needed was not forthcoming was due to teachers not being informed, not that they did not care. She further wanted to know, and questioned why she didn't know, other pieces of information. She asked "What is L1 funding? What is happening with that money? Where is the funding going to? Parents don't know where that money is allocated."

Another parent related the lack of planning for the transition for her daughter, "We had one meeting that I

remember - one meeting that we did some discussing about [transition] and that was it. But I understood there should have been more."

Another parent said, "I mean I think it's tough enough out there for those kids and for their parents. At least if you can get some information, anything will help. You have to be well armed to face the world out there."

One parent said:

I don't think the school had enough information and, if they did, I don't think we got enough of that information...about the options down the road and the kinds of things to do to get him ready. Our biggest fear was what happens after he leaves school?

Another parent spoke about a multidisciplinary meeting to discuss transition which was initiated with the best of intentions but, in the end, she walked away without the information she needed. She related, "It was fun to do. But I felt it was very philosophical...and at the end of it you say to yourself, 'What did I get from that?' She did, however, concede that the different personnel she met in that meeting was helpful to her.

A few parents believed that they were given a lot of options and were given information on a lot of programs. Some of the information was shared by schools, whereas other sources of information were social workers or supported

employment personnel. A number of parents made specific reference by name to individuals whom they have encountered in the transition process and who made a huge difference in terms of the information provided, or the assistance given.

Some parents were very pleased with the amount of information they were given during the transition process.

One said:

Yes, I was very pleased because it was left to us and we were given a lot of options. There were a lot of programs out there...in fact we must have had about five or six meetings in the last two years...they were very good, very good meetings.

Most of the time they took anywhere from an hour to two hours...and of course the first thing they asked was probably the most important thing which was, "What did we want for [child] when she graduated, you know, what did we expect?"

Another concurred:

Not only was the information given over the phone but in person and through notes. They did a really good job in giving information out and making us knowledgeable about whatever was out there. They were really good because they gave us support agencies. They gave us everything about the tax deductions [and] the government. They gave us the

whole spiel.... Everything was coordinated through the school. That special education teacher was very, very well put together.

Cooperation and collaboration with parents. Parents recognized the need for their input, but at the same time they emphasized an equal need for parents and personnel involved in the transition process to work cooperatively and collaboratively to meet the needs of their children. Several parents suggested this was easier said than done. One parent commented "You...come in and you really try to work together as a team, but if parents don't really see eye to eye I felt that you, basically, just got ignored."

Human element. Several parents suggested the human element, that is the empathy and compassion, was lacking by people involved in the transition process of their children. One parent said, "The transition-to-work has a large component that is neglected. It is very systematic but not humanized".

Both parents of a young adult with severe, multiple disabilities which greatly minimized independence emotionally related stories of a lack of sensitivity and compassion demonstrated by the medical community years ago when the parents sought a diagnoses, information, and help. While the anecdotes shared are not directly related to the school-to-work transition it emphasizes some parents'

associations with a lack of sensitivity in the system. One of these, at the end of the interview, recommended that personnel - whether the medical community, education or community service agencies - demonstrate more tact and compassion. The mother also recognized individuals who were very helpful.

One parent wrote, "[Child] needs to have opportunities to associate with a group of warm, supportive, caring, accepting, Christian-like people who speak to her in the same way that they'd speak to their own much-loved high school age children."

Specific individuals involved in a youth or young adult's transition process were mentioned often. Parents mentioned specific individuals - teachers, guidance counsellors, administrators, social workers, supported employment personnel, instructional assistants, etc. - as being key people who offered them the advice, guidance or needed help given them or their child. Some parents had no kind words for other personnel involved in the transition of their son or daughter.

Feelings of stress. Most parents did not specifically refer to feelings of stress they may have felt. There were stories and anecdotes, and parents shared their thoughts. From facial expressions, the tone of voice, and the substance of the dialogue it appeared that parents felt

feelings of stress, frustration, or bitterness. One parent related:

Being involved in so many things and going out and getting extra jobs because it cost you more money to have [children with disabilities] at home. Like you are supposed to take care of [children with disabilities], bring in the extra money and be involved [with organizations for people with disabilities], to know what is out there and what is happening...there should be stronger support for parents...There are still parents out there who think [children with disabilities] are going to be in something. It gets worse and worse and worse. It's not better.

Another parent spoke of his energy being zapped dealing with day to day problems:

To me, I think a good way to describe the average life of a family of special needs is pressure scheduling. You deal with problems as they occur and there are always problems occurring. And they can, like a cancer, just eat away at your time and your energy.

Intimidation. Two different parents spoke about feeling intimidated by the whole transition process. While parents did not believe there was any explicit intention by

professionals to try to be intimidating, the parents found these meetings and interaction with transition personnel somewhat frightening and unnerving. One parent was not pleased with some of the approaches or transition plans but she felt reluctant to make her views known. As she stated, she "didn't want to ruffle any feathers."

Contact. The extent parents are contacted by school personnel is important to them. Parents want to be kept informed about their child's transition and progress on a regular basis. One parent stated she feels very much a part of the team when she is contacted for information or for input. She expressed a wish for having been contacted on an ongoing basis and not only when problems arise. She referred to instances when she thought things were fine and then she was contacted about crisis situations which escalated without her knowledge.

The "system". Some parents have referred to schools and community service agencies, the bureaucracy, government programs, rules, regulations, and so on, generally and collectively as the "system". The system was not viewed favourably when reference was made to it. One parent summed up her view quite simply as "a system that isn't really."

One parent also referred to "the system" and flatly stated that she let go of the system "because the system didn't work". She bluntly added, "The whole system sucks".

What the parents want. Several of the wishes or desires parents have were shared. Parents of young adults who have already graduated from school have, in hindsight, also made their wants known. Some of these have already been alluded to, such as friendships, more academics, more life skills training, more integration, less integration, more information on funding, work and residential options, more contact with the schools, more empathetic personnel involved in the transition process, and more social skills training. One parent believed there was too much support at the school which led to helplessness by the child.

The majority of parents who participated in the interviews and discussion groups make specific reference to the importance of meaningful work and the hope that it will be achieved.

While the number of hours worked or the amount of money earned was not usually referred by parents, one parent did express a wish that her daughter receive full time employment in a paid position.

Some parents had preferences and goals for specific job sites after graduation, whereas other parents knew that work was important and desirable but had no specific preferences. Parents did want the jobs to be meaningful for their children and to be a source of pride and satisfaction. Several parents said that what was most important was for their children to be happy.

While parents reiterated the importance of employment, some parents viewed the type of employment as important as well. One parent had higher preferences for the employment of her child than she had expectations. She commented, "I think it's sad that my son can only be a dishwasher or a grocery helper or something like that. I'm sure that if certain companies could be charitable and maybe pick one individual and try to really train him to do something..." One parent was disillusioned with the work experience opportunities given her daughter:

I got the impression that it might have been the same person that was looking for job experiences for the other regular students and they were getting all the good ones and our kids were getting what was left over. That's the impression I got...and granted, our skills are a little bit more limited and there were some we couldn't take I suppose, but certainly they were capable of a lot more than they were given.

On the same note, several parents want to see, or would have liked to have seen, more work options in terms of work sites, work experiences, and work opportunities. In essence, they wanted variety because they believed the greater the options the greater chance their child would find the optimum work school-to-work approach and most

suitable work option.

One parent echoed this view:

The work experience program at the time was awful...in a sense that there was no variety. It was the same thing over and over again that the kids were offered to do. The same experiences; the same placements.

Parents' recommendations and solutions. Parents offered several recommendations to improve the school-to-work transition process. One parent suggested, "Let's put someone in the school division that oversees transitioning - someone outside of the school division."

Other parents recommended increased exposure to a variety of job sites and work situations. Several parents recommended that the transition process begin early, such as age 16, or even while the child is in junior high school. There was a consensus that this process is fundamentally important to the outcome after graduation. Most parents indicated that the process for their child began at about 16 years of age. Other parents criticised the fact that the transition process did not start early enough.

Several parents indicated a need for consistency in approaches and cooperation and collaboration between key groups, such as schools, supported employment agencies, social workers, businesses and, government. There was a feeling that groups work in isolation and this leads to a

breakdown in the transition process and a void following graduation where there is inactivity. A parent emphasized that personnel within the entire system needs to understand the job market.

A restructuring of the individual education plan or the individual program plan was recommended. Some parents felt that, just prior to graduation, the format and emphasis of this major meeting should reflect the impending graduation and transition from school. A parent commented, "The [individual program plan] doesn't deal with the transition into the community...I think the whole [individual program plan] should change as the children get older. [Child's individual program plan] hasn't changed since he was nine." She also reflected on her annoyance with the limited time allowed her for the meeting, "...one hour is not enough time...everyone is watching their watches. You are discussing this whole kid's future for a whole year!"

Another suggestion was for parents to meet more often with school personnel and not necessarily in large multi-disciplinary meetings. As one parent recommended, "...parents should be welcomed to sit down much earlier and more frequently with the school, even every two months to say 'O.K., this worked, this didn't work', and do it jointly."

Another parent recommended that schools:

...articulate information and pass it on to families because they don't do it soon enough and often enough. It would give parents more time to deal with the issues. It would also give parents more confidence in the overall programming to them.

Some parents' recommendations were directed at the provincial government. One parent recommended that, "...the government should do something in taking the initiative of inviting the big corporations to open their doors to the handicapped in training."

Another parent recommended that:

...there needs to be a liaison person in the school or in the community that you can go to and you can sit down with and you can say, "Help me...There should be a little handbook given to you when you get to be a parent of a handicapped kid who gets to be a certain age. This is the system. This is how you access the system. This is what's in the system. But of course there is nothing like that.

One parent whose son had a variety of work experiences during high school which lead to no real job recommended that there be more emphasis on job permanence.

Another recommendation was for a genuine multidisciplinary, multi-agency approach to meet the needs of the individual:

...I think in educational and long term best interests of the young people there should be some sort of comprehensive plan - government, school divisions, teachers, resource people - so that there is sort of a work plan where school leaves off, another agency is picking up. They know the background of the individual, the supports, the training, the job selection...

This parent also suggested that schools "have not figured out how to enroll employers, how to make them understand their obligation and their commitment to students."

It was suggested that schools often do not understand the real working world and they need to find the means to do so:

...but to actually go out and watch a student with a job and to understand where that employer's focus is coming from and whether or not that will lead to a permanent paying job, they have a great difficulty on a consistent basis of doing that.

One parent suggested that school divisions hire or establish a "job person" who establishes contacts in the community with businesses and employers, who establishes and promotes interagency networks and who can share the necessary information with the necessary people involved.

Another parent suggested, "There needs to be, I think, more emphasis in the school system, something that encourages parents to get involved and not try to shut them out, but rather to bring them into the process."

Chapter Five

CONCLUSIONS AND RECOMMENDATIONS

The purpose of this study was to examine the perceptions of parents of youth and young adults with cognitive disabilities with respect to the school-to-work transition of their children. Data was accumulated through mail-in questionnaires, interviews, and discussion groups. The conclusions, based on the findings will be presented in this final chapter. Recommendations to enhance the school-to-work transition process and to better meet the needs of youth and young adults, as well as their parents, will also be made.

Conclusions and Implications

The parents who participated in this study were, in some ways, a diverse group. The disabilities of their children varied in nature and severity. Their children attended schools in five different school divisions and the program delivery varied from student to student depending on the school they attended and their individual disabilities. Consequently, the experiences the parents had with the transition process and the influences on their perceptions varied. The one main commonality these parents had with each other was that their sons and daughters were transitioning or had transitioned from school to the adult world. In the vast majority of cases, the world of work

following graduation and the pursuit of it was a major objective.

While so much of the focus in research on the transition of young people from school is on the individual, there has been a recent recognition that families as entire units or systems also experience transitions (Mallory, 1996).

Several issues emerged from this study. While there were differences of opinion from parents on various points, such as integration versus non-integration and on the amount of emphasis on academics versus life skills and work experience, there were several themes. Many parents shared similar perceptions and similar needs.

The majority of parents are concerned about employment for their children after graduation. It is an area which they view seriously and one which is the source of deep emotions. That parents should have concerns about the employment prospects of their children is not without justification. There are indications that the prospects for individuals with disabilities in the job market have not been very good. It has been said that "joblessness, rather than employment, is the norm among persons with disabilities" (Will, 1984a, p. 15). There is other evidence that the employment prospects among special needs students who graduated from high school were somewhat dismal

(Mithaug, Horiuchi & Fanning, 1985; Agran, 1987; Edgar, 1987; Pilley, 1988; Chadsey-Rusch, Rusch & O'Reilly, 1991).

There are indications that the rate and type of vocational placement in open employment for individuals with severe/profound mental impairments is not encouraging, with most placements being in sheltered workshops (Haring and Lovett, 1990a; Horrocks, 1991; Richardson, Koller & Katz, 1988). There is a growing trend, however, for individuals with disabilities to find work in community-based employment (supported or competitive employment) as opposed to sheltered employment (Frank & Sitlington, 1993). These results suggest that individuals with disabilities can and do succeed in a competitive job market. However, a successful transition is very much dependent on sound transition planning, follow-along, and follow-up practices from school staff and adult service agencies, as Frank and Sitlington (1993) also noted.

For a minority of parents, employment was not an issue, however. For them employment was not a priority because of the severity of the disabilities of their children. For these parents, employment was, generally, not considered a reasonable expectation. For them the priorities were to promote, enhance and ensure other areas of significance in the lives of their children, such as physical well being and comfort, residential opportunities, and participation in

community leisure, and recreational activities.

The majority of parents (71%) expected their children to be working in supported or competitive employment situations after graduation. Supported employment in recent years has become an increasingly viable and valued option (Hagner & Dileo, 1993). Only 21% of parents expected their children to be working in sheltered employment situations or not to be working.

The preferences parents had were similar but slightly higher in terms of aspirations. The majority of parents (84%) preferred their children to be working in competitive or supported employment situations. A few parents (8%) preferred sheltered employment or "not working" situations for their children.

The data suggests that sheltered employment situations are not preferred and not expected. Work situations in the community is the goal of most parents for their children.

The importance of work was rated highly. On a 5-point scale, 71% of the parents rated work for their child after graduation as very important. The reasons given for the lack of importance attributed to work were almost identical to the ones provided for the lack of concern for employment. Namely, the severity of the disabilities presented different priorities for parents and work situations were not high priorities, if they were perceived as options at all.

Parents were almost evenly split on the degree of satisfaction they had with schools in preparing their children for the transition to work and adult life. Thirty-seven per cent of the parents were in the satisfied end of the rating scale and 35% were found to be in the unsatisfied end of the rating scale.

Despite this even split, the majority of the parents (64.8%) believed their views were taken into account more than they were not taken into account. The implication appears to be that parents may feel that they are being heard but that does not equate to being satisfied with transitional outcomes.

Parents provided reasons in the form of stories, anecdotes and related experiences for being less than satisfied with the transition process. They included a perceived lack of follow-through and commitment by personnel, not being listened to, and unsatisfactory work experience outcomes, as well as needs which were not met. A sense that schools work too much in isolation and that they failed to provide information on options and the availability of opportunities within the community was a view that was shared by a number of parents.

Johnson, Bruininks and Thurlow (1987) have argued that the effectiveness of cooperative service planning and the availability of needed adult services strongly influence the

extent to which youth with disabilities reached their desired employment goals. Some parents also referred to inter-agency collaboration which was beneficial for their children.

During the interviews and discussion groups, in addition to being asked what their experiences were and whether their child's needs were being met, parents were asked to provide solutions. Parents were asked to provide insight on what was helpful, on what they would like to see take place to prepare their children for the transition to work and adult life, and how best to meet their needs. Parents offered suggestions and made some recommendations. These included:

- better matching between jobs and students,
- the promotion of friendships,
- more community involvement,
- the provision of more information on options, funding, opportunities,
- more involvement with parents by schools,
- a greater understanding by school personnel of the intricacies of the transition process,
- more cooperation and collaboration between key groups,
- greater commitment by schools and more emphasis on outcomes,
- greater sensitivity to the needs of parents, and
- a greater commitment from government in terms of meeting the needs, including increased funding.

Some of the suggestions parents made were consistent with the findings from a study conducted in Winnipeg by Penner, Douglas and Van Lieshout (1992). In that study, it was suggested that there should be a greater emphasis on practical work experience, greater access to community-based work experiences, and that the transition to work should begin before the student leaves school.

Parents have had a mixture of positive and negative experiences regarding the transition of their students. For some, the negative outweighed the positive and vice versa. For some parents, the transition years had similarities with earlier education experiences; for others, they were different. Parents spoke about the frustrations they felt in their interactions with the "system", namely schools and adult service delivery systems.

Recommendations

The transition from school to adult life for youth with disabilities has been a priority for families, schools, and rehabilitation services for well over a decade (Wehman, 1992). The transition from school to employment is a part of the broader transition to adult life. Karan, Lambour, and Greenspan (1990) contend that the transition is a lifelong concept and it should not be viewed as applying to any specific point in time. Educators need to examine their priorities, and the procedures and components of the

education process to determine what is most important in transition planning (Morgan, Moore, & Salzberg, 1992). The solutions to enhancing a smooth transition from school to adult life has been investigated in previous research. A common concern revolved around the provisions of linkages from school to various community agencies (Knox and Parmentier, 1990). What also emerged from Knox and Parmentier's study is the view that those involved in the transition process should be concerned with all aspects of the life of someone with a disability, such as recreation and friendship, and not just employment. These are consistent with what parents have said in this study.

Parents have indicated that work alone is not enough. In transition planning for students with cognitive disabilities, it is imperative that a heightened awareness be placed on identifying the aspects of life which provide a further dimension of quality, in essence the overall quality of life. Similar sentiments have been echoed in the form of career education (Kanchier, 1990; Meers, 1992) for students with disabilities. Kanchier notes that the primary goal of career education is to help individuals to meaningful and productive lives in the occupational, interpersonal, domestic, and recreational contexts. Parents recognize this. Several have made it clear that friendships and social networks for their children are priorities. Chadsey-

Rusch, Rusch and O'Reilly (1991) noted targeted outcomes of school-to-work transitioning of two models. In one model, the goal was primarily employment, although other aspects of adulthood, such as social and leisure activities were also deemed important. In the other model, community adjustment was the desired outcome of transition services of which employment was only one of three components. The other two components were residential adjustment and establishing a social and interpersonal network.

While a successful transition to work should incorporate a quality of life perspective, it depends on what success means for the person measuring it. The success of a school-to-work transition should not be based solely on productivity and job retention. In addition to job-task performance, the success of an employment outcome should be measured from an ecological perspective, such as integration, satisfaction with job, and economic benefits (Gaylord-Ross & Chadsy-Rusch, 1991).

It should be remembered that the transition from school to work is but one aspect of the transition to adult life for youths with cognitive disabilities. The transition to adult life should not be evaluated entirely from the employment perspective (Halpern, 1985; Steere, Wood, Pancsofar & Butterworth, 1990; Wisniewski, Alper & Schloss, 1991).

There should be increased interagency collaboration and cooperation in the transitions of young people with cognitive disabilities. This should include planning, instruction, placement, as well as ongoing supports for the individual. Parents have suggested that schools, at least to some degree, work in isolation to the detriment of successful and meaningful transition outcomes. Along the same lines, schools, particularly school personnel who are involved in the transition process, should have more access to community resources.

Parents have criticized the lack of implementation of transition practices. They have frequently said that the transition plan looks good on paper but they often were not followed through. Schools need to define the transition approaches or practices that are used, they need to identify a means of ensuring the implementation of the plans, and, finally, they need to develop a means to identify and measure the outcomes of the transition plan. In essence, there needs to be an assessment of transition-related outcomes. This would require follow-up practices of graduates during the year following their graduation, in addition to follow-along practices.

The sharing of information has been an issue frequently cited by parents. Schools need to share a wide array of information with parents. These would include employment options such as supported employment agencies, community

recreation and leisure options. The parents should be made aware of the availability of support groups and organizations for individuals with disabilities. Government programs, policies and procedures should be made available, including the funding procedures and practices. Parents have a right to know that. Access to such information may alleviate some of the stress experienced by parents. Recent research suggests that some parents of individuals with disabilities experience added stress during periods of transition (Baxter, Cummins & Polak, 1995). That research also identifies a lack of consultation and a lack of information as being a source of the stress.

With such an overwhelming amount of useful information, schools and transitional personnel should have a database or a written synopsis of these options. A pamphlet or booklet on these options and services should be made available to parents during the transition years. The development of such a transition booklet would be a worthwhile endeavour for schools or school division to pursue. Some parents have been given much information, but some parents have been given very little.

Schools or school divisions should consider hiring or appointing someone to the role of an employment specialist who would have the knowledge and expertise to develop linkages with the communities, is well-versed

on the options and supports available, and who can be a liason between parents, the business sector and community adult service personnel. In addition, this employment specialist should have the means and knowledge to access all of these sources. They must be skilled in marketing the services of their students, of matching students to work situations, and addressing the concerns of parents and business personnel.

With the necessity of cooperation and collaboration of key groups it is necessary to have a coordinator. Schools are ideally suited to coordinate the transitional efforts and they should assume that responsibility.

Parents have questioned the effectiveness of teachers involved in the transition process or delivery. That does not necessarily mean that teachers are incompetent, nor does it mean they are ineffective. It does suggest, however, that the expectations of parents are often not met. Parents also harbour views that their input is not acted upon. There seems to be a need for better communication between schools and parents. The expectations, preferences, and priorities of parents need to be understood. Conversely, parents need to be made aware of the role, objectives, and perhaps limitations of the school in terms of funding and manpower.

Parents should be contacted on a more regular and

informal basis and not necessarily only at times of large multi-disciplinary meetings. Parents need to be kept informed and they need to know that the schools want them to be informed and want their input.

Repetto and Correa (1996), in their assessment of critical transition practices, have suggested many of the components which the parents of this study suggested. These include long-term and short term goals, special education and related service needs, projected dates for initiation and duration of services, and objective evaluation procedures. Further, the components must be outcome oriented, there must be consideration given to community and adult living experiences, and there must be participating agency responsibilities and linkages.

There should be early transition planning, beginning at age 16 at the latest. The age of 14 has been suggested as a starting age for transition planning (Johnson, Thompson, Sinclair, Krantz, Evelo, Stolte & Thompson, 1993).

Considerations for Future Research

There is little information on the extent and nature of employment retention in supported employment programs. There is wide agreement on the benefits of supported employment programs to youth and young adults with disabilities. A premise of supported employment is that it should be available for individuals regardless of the

severity of their disabilities. The low expectations of some parents and the belief that their children at work is not a feasible option raises some questions about the universal application of supported employment for all individuals with disabilities.

Parents have said that friendships and social networks are important for the well being of their children. Those components in the transition to work and adult life improve the quality of life. There is a need for more research that not only measures the outcomes, but also defines the quality of social lives experienced by transitioning youth (Chadsey-Rusch & Heal, 1995).

While this study has dealt with the perceptions of parents, there is a need to ascertain the perceptions of youth and young adults with disabilities in terms of the school-to-work transition. Also, there is a need to determine the perceptions of teachers who are involved in the transition process.

Summary

The parents in this study, through their perceptions of the school-to-work transition process, have provided some needed input into the transitional practices in use today. Their experiences and suggestions have been transformed into the following recommendations, some of which were adapted from Johnson, et al. (1993) and Smith, Edelson-Smith, and

Stodden (1995):

- provide information to families on school and community services, adult services and employment options,
- increase parent participation levels in transition planning,
- provide for early transition, at 16 years at least,
- emphasize friendships, social networks, and leisure and recreational activities in the transition,
- address all transition areas and seek clarification on parents' expectations, preferences and priorities,
- ensure parents know what role the school plays in the transition process,
- conduct follow-up and follow-along studies,
- anticipate students' needs for adult services and support,
- provide leadership and coordinate the efforts in the transition process,
- assist parents in recognizing the importance of their input and contributions,
- address parents' concerns regarding future employment,
- develop a transition handbook and develop expertise in the area of transition, and
- increase commitment and funding by the government.

References

- Agran, M. (1987). Teaching self-control procedures to individuals who are mentally retarded. Career Development of Exceptional Individuals, 10 (2), 107-115
- Allan, D. A., & Affleck, G. (1985). Are we stereotyping parents? A postscript to Blacher. Mental Retardation, 23, 200-202
- Amado, A. W., Lakin, K. C., & Menke, J. M. (1990). Chartbook of services for people with developmental disabilities. Minneapolis: University of Minnesota, Center for Residential Services.
- Anderegg, M. L., Vergason, G. A., & Smith, M. C. (1992). A visual representation of the grief cycle for use by teachers with families of children with disabilities. Remedial and Special Education, 13 (2), 17-23
- Antonucci, T. C. (1985). Personal characteristics, social support and social behavior. In R. H. Binstock & E. Shana (Eds.), Handbook of aging and social sciences, (2nd ed., pp. 94-128). New York: Von Nostrand Reinhold.
- Bailey, D. B., Jr., Blasco, P. M., & Simeonsson, R. J. (1992). Needs expressed by mothers and fathers of young children. American Journal on Mental Retardation, 97 (1), 1-10

- Bailey, D. B., Jr., & Wolery, M. (1989). Assessing Infants and Preschoolers with Handicaps. New York: MacMillan Publishing Co.
- Baumgart, D., Filler, J., & Askvig, B. A. (1991). Perceived importance of social skills: A survey of teachers, parents and other professionals. The Journal of Special Education, 25 (2), 236-251
- Baxter, C. (1989). Investigating stigma on stress in social interactions of parents. Journal of Mental Deficiency Research, 33, 455-466
- Baxter, C., Cummins, R., & Polak, S. (1995). A longitudinal study of parental stress and support: From diagnosis of disability to leaving school. International Journal of Disability, Development and Education, 42 (2), 125-236
- Beckman, P. (1983). Influences of selected child characteristics on stress in families of handicapped infants. American Journal of Mental Deficiency, 80, 150-156
- Benz, M. R., & Halpern, A. S. (1986). Vocational preparation for high school students with mild disabilities: A statewide study of administrator, teacher and parent perceptions. Career Development for Exceptional Individuals, 9 (1), 3-15
- Biklen, S. K., & Moseley, C. R. (1988). "Are you retarded?"

- "No, I'm catholic": Qualitative methods in the study of people with severe handicaps. Journal of the Association for Persons with Severe Handicaps, 13 (3), 155-162
- Blacher, H. (1984). Sequential stages of parental adjustment to the birth of a child with handicaps: Fact or artifact? Mental Retardation, 27 (2), 55-68
- Blacher, J. (1990). Assessing placement tendency in families with children with severe handicaps. Research in Development Disorders, 11 (4), 349-359
- Blacher, J., & Baker, B. L. (1992). Toward meaningful family involvement in out-of-home placement settings. Mental Retardation 30 (1), 35-43
- Blacher, J., Nihira, K., & Meyers, C. E. (1987). Characteristics of home environment of families with mentally retarded children: Comparison across levels of mental retardation. American Journal of Mental Retardation, 91, 313-320
- Black, M. M., Molaison, V. A. & Smull, M. W. (1990). Families caring for a young adult with mental retardation: Service needs and urgency of community living requests. American Journal on Mental Retardation, 95 (1), 32-39
- Botuck, S., & Winsberg, B. G. (1991). Effects of respite on mothers of school-age and adult children with severe

- disabilities. Mental Retardation, 29 (1), 43-47
- Brantlinger, E. (1991). Home-school partnerships that benefit children with special needs. The Elementary School Journal, 91 (3), 249-259
- Brickey, M. P., Campbell, K. M., & Browning, L. J. (1985). A five-year follow-up of sheltered workshop employees placed in competitive jobs. Mental Retardation, 23 (2), 67-73
- Bromley, B., & Blacher, J. (1989). Factors delaying out-of-home placement of children with severe handicaps. American Journal on Mental Retardation, 94, 284-291
- Brotherson, M. J., Turnbull, A. P., & Bronicki, G. J. (1988). Transition into adulthood: Parental planning for sons and daughters with disabilities. Education and Training in Mental Retardation, 23 (3), 165-74
- Brown, F. (1987). Meaningful assessment of people with severe and profound handicaps. In M. E. Snell (Ed.), Systematic instruction of persons with severe handicaps, (3rd ed., pp. 39-63). Columbus, Ohio: Merrill Publishing Company.
- Bullis, M. & Egelston-Doss, J. (1990). Priorities in the school-to-community transition of adolescents who are deaf. Career Development for Exceptional Individuals, 13 (1), 71-82
- Chadsey-Rusch, J. (1990). Social interactions of secondary-

- aged students with severe handicaps: Implications for facilitating the transition from school to work. Journal of the Association for Persons with Severe Handicaps, 15 (2), 69-78
- Chadsey-Rusch, J., Rusch, F. R., & O'Reilly, M. (1991). Transition from school to integrated communities. Remedial and Special Education, 12 (6), 23-33
- Chadsey-Rusch, J., & Heal, L. W. (1995). Building consensus from transition experts on social integration outcomes and interventions. Exceptional Children, 62 (2), 165-186
- Chang, M. K. (1988). Follow-up Studies of Graduates with Mental Retardation: A Review. Illinois Schools Journal, 67 (2), 26-30
- Chinn, P. C., Drew, C. J., & Logan, D. R. (1979). Mental retardation: A life cycle approach. St. Louis, Missouri: The C. V. Mosby Company.
- Cohen, S., Agosta, J., Cohen, J., & Warren, R. (1989). Supporting families of children with severe disabilities. Journal of the Association for Persons with Severe Handicaps, 14 (2), 155-162
- Cole, D. A., & Meyer, L. H. (1989). Impact of needs and resources on family plans to seek out-of-home placement. American Journal on Mental Retardation, 93 (4), 380-387

- Crnic, K. A., Friedrich, W. N., & Greenberg, M. T. (1983).
Adaptation of families with mentally retarded children:
A model of stress, coping and family ecology. American
Journal of Mental Deficiency, 88 (2), 125-138
- Davis, S. (1988). Transition from school to work: A
parent's perspective. Career Development for
Exceptional Individuals, 11 (1), 51-56
- Davis, C., & Bullis, M. (1990). The school-to-community
transition of hearing-impaired persons with
developmental disabilities - A review of the
literature. American Annals of the Deaf, 135 (5),
352-363
- Dawson, R., & Kierney, J. (1988). A survey of parent's
views. British Journal of Special Education, 15 (3),
123-125
- Dyson, L. L. (1991). Families of young children with
handicaps: Parental stress. American Journal on Mental
Retardation, 95 (6), 623-629
- Dyson, L., & Fewell, R. F. (1986). Stress and adaptation in
parents of young handicapped and nonhandicapped
children: A comparative study. Journal of the Division
for Early Childhood, 10, 25-35
- Edgar, E. (1987). Secondary programs in special education:
Are many of them justifiable? Exceptional Children,
53 (1), 556-561

- Elksnin, L.K., & Elksnin N. (1990). Using collaborative consultation with parents to promote effective vocational programming. Career Development for Exceptional Individuals, 13 (2), 135-142
- Epps, S., & Myers, C. L. (1989). Priority domains for instruction, satisfaction with school teaching, and postschool living and employment: An analysis of perceptions of parents of students with severe and profound disabilities. Education and Training of the Mentally Retarded, 24 (2), 157-167
- Erickson, M., & Upshur, C. C. (1989). Caretaking burden and social support: Comparison of mothers of infants with and without disabilities. American Journal on Mental Retardation, 94, 250-258
- Everson, J. M., & LaCourt, T. (1990). A follow-up of former special education students: A model for program evaluation. Remedial and Special Education, 12 (1), 30-37
- Falvey, M. A. (1986). Community-based curriculum: Instructional strategies for students with severe handicaps. Baltimore, Maryland: Paul H. Brookes Publishing Company
- Ferguson, P. M., Ferguson, D. L., & Jones, D. (1988). Generations of Hope: Parental Perspectives on the transitions of their children with severe retardation

- from school to adult life. Journal of the Association for Persons with Severe Handicaps, 13 3, 177-187
- Flagg-Williams, J. B. (1991). Perspectives on working with parents of handicapped children. Psychology in the Schools, 28 (3), 238-246
- Flynt, S. W., & Wood, T. A. (1989). Stress and coping of mothers of children with mental retardation. American Journal on Mental Retardation, 94, 278-283
- Flynt, S. W., Wood, T. A., & Scott, R. L. (1992). Social support of mothers of children with mental retardation. Mental Retardation, 30 (4), 233-236
- Foley, K. (1988). School/community based programs for students with moderate to profound mental retardation. The Pointer, 32 (2), 22-26
- Fourqurean, J. M., & LaCourt, T. (1990). A follow-up of former special education students: A model for program evaluation. Remedial and Special Education, 12 (1), 16-23
- Frank, A. R., & Sitlington, P. L. (1993). Graduates with mental disabilities: The story three years later. Education and Training in Mental Retardation, 28 (1), 30-37
- Frey, K. S., Greenberg, M. T., & Fewell, R. R. (1989). Stress and coping among handicapped children: A multidimensional approach. American Journal on Mental

Retardation, 94 (3), 240-249

Foley, K. (1988). School/community based programs for students with moderate to profound mental retardation.

The Pointer, 32 (2), 22-26

Frey, K. S., Fewell, R. R., & Vadasy, P. F. (1989).

Parental Adjustment and changes in child outcome among families of young handicapped children. Topics in

Early Childhood Special Education, 8 (4), 38-57

Friedrich, W. N., & Friedrich, W. L. (1981). Psychosocial assets of parents of handicapped and nonhandicapped

children. American Journal of Mental Deficiency, 88, 41-48

Gallimore, R., Weisner, T. S., Kaufman, S. Z., & Bernheimer,

L. P. (1989). The social construction of ecocultural niches: Family accommodation of developmentally delayed

children. American Journal on Mental Retardation, 94, 216-230

Gargiulo, R. M., & Graves, S. B. (1991). Parental

feelings: The forgotten component when working with parents of handicapped preschool children. Childhood

Education, 63 (7), 176-178

Gaylord-Ross, R., & Chadsey-Rusch, J. (1991). Measurement of work-related outcomes for students with severe

disabilities. The Journal of Special Education, 25 (3), 291-303

- Gaylord-Ross, R., Gaylord-Ross, C., Hagie, C., Musante, P., Lee, L., Siegel, S., & Jameson, D. (1988). Considerations and outcomes in traditional supported employment. Career Development of Exceptional Individuals, 11 (1), 43-50
- Gill, D. H. (1988). Vocational and special education: Cultivating the relationship. B.C. Journal of Special Education, 12 (3), 245-252
- Glidden, L. M. (1993). What we don't know about families with children who have developmental disabilities: Questionnaire on resources and stress as a case study. American Journal on Mental Retardation, 97 (5), 481-495
- Goodall, P., & Bruder, M. B. (1986). Parents and the transition process. The Exceptional Parent, 16 (2), 22-28
- Griffin, S. L., & Lowry, J. (1989). Supported employment for persons with deaf-blindness and mental retardation. Journal of Visual Impairment and Blindness, 83 (10), 495-499
- Hagner, D., & Dileo (1993). Working together: Workplace culture, supported employment, and persons with disabilities. Brookline Books: Cambridge, MA
- Halpern, A. S. (1985). Transition: A look at the foundations. Exceptional Children, 51, 479-486

- Halvorsen, A. T., Doering, K., Farron-Davis, F., Usilton, R., & Sailor, W. (1989). The role of parents and family members in planning severely disabled students' transitions from schools. In G. H. S. Singer & L. K. Irvin (Ed.), Support for caregiving families: Enabling positive adaptation to disability, (253-267). Baltimore, Maryland: Paul H. Brookes Publishing Company.
- Hanline, M. F. (1991). Transitions and critical events in the family life cycle: Implications for providing support to families of children with disabilities. Psychology in the Schools, 28 (1), 53-59
- Hanline, M. F., & Halvorsen, A. (1989). Parent perceptions of the integration process: Overcoming artificial barriers. Exceptional Children, 55 (6), 487-492
- Hardman, M. L., Drew, C. J., Egan, W., & Wolf, B. (1991). Human exceptionality (3rd ed.). Boston: Allyn & Bacon
- Haring, K., & Lovett, D. L. (1990a). A follow-up of special education graduates. The Journal of Special Education, 23 (4), 463-476
- Haring, K., & Lovett, D. (1990b). A study of the social and vocational adjustment of young adults with mental retardation. Education and Training in Mental Retardation, 25 (1), 52-61

- Haring, K. A., Lovett, D., & Saren, D. (1991). Parent perceptions of their adult offspring with disabilities. Teaching Exceptional Children, 23 (2), 6-10
- Harper, D. C. (1984). Child behavior toward their parent: A factor analysis of mother's reports of disabled children. Journal of Autism and Developmental Disorders, 14 (2), 165-180
- Harris, S. L. (1984). Interventional planning for the family of the autistic child: A multidimensional assessment of the family system. Journal of Marital and Family Therapy, 10 (2), 157-166
- Harris, V., & McHale, S. M. (1989). Family life problems, daily caregiving activities, and the psychological well-being of mothers of mentally retarded children. American Journal on Mental Retardation, 94 (3), 231-239
- Harvey, D. H. P. (1984). The self concept of physically disabled siblings: An empirical investigation. Journal of Child Psychology and Psychiatry, 215 (2), 273-284
- Hasazi, S. & Clark, G. M. (1988). Vocational preparation for high school students labelled mentally retarded: Employment as a graduation goal. Mental Retardation, 26 (6), 343-349
- Hasazi, S. B., Gordon, L. R., Roe, C. A., Hull, M. Finck, K. & Salembier, G. (1985). A statewide follow-up on post high school employment and residential status

- students labelled "mentally retarded". Education and Training of the Mentally Retarded, 20, 222-234
- Heal, L., Copher, J. I., De Stefano, L., & Rusch, F. (1989). A comparison of successful and unsuccessful placements of secondary students with mental handicaps into competitive employment. Career Development for Exceptional Individuals, 12 (2), 167-177
- Heller, T., & Factor, A. (1991). Permanency Planning for adults with mental retardation living with family caregivers. American Journal on Mental Retardation, 96 (2), 163-176
- Hill, J. W., Seyfarth, J., Banks, P. D., Wehman, P., & Orelove, F. (1987). Parent attitudes about working conditions of their adult mentally retarded sons and daughters. Exceptional Children, 54 (1), 9-23
- Hoisch, S. A., Karen, R. L., & Franzini, L. R. (1992). Two-Year Follow-up of the Competitive Employment Status of Graduates with Developmental Disabilities. Career Development for Exceptional Individuals, 15 (2), 149-155
- Horrocks, C. (1991). Isolation and security: Transition process and outcomes for graduates with mental handicaps. B.C. Journal of Special Education, 15 (2), 177-198
- Houser, R., & Seligman, M. (1991). A Comparison of stress

and coping by fathers of adolescents with mental retardation and fathers of adolescents without mental retardation. Research in Developmental Disabilities, 12 (3), 251-260

Janssen, D, Isles, T., O'Keefe, S, & Sabatino, D. A.

(1988). The intent of secondary education. Illinois Schools Journal, 67 (2), 17-25

Johnson, D. R., Bruininks, R. H., & Thurlow, M. L. (1987).

Meeting the challenge of transition planning through improved interagency cooperation. Exceptional Children, 53 (6), 522-530

Johnson, D. R., Thompson, S. J., Sinclair, M. F., Krantz, G.

C., Evelo, S., Stolte, K., & Thompson, J. R. (1993). Considerations in the design of follow-up and follow-along systems for improving transition programs and services. Career Development for Exceptional Individuals, 16 (2), 225-238

Kanchier, C. (1990). Career education for mentally

handicapped adolescents. Journal of Career Development, 16 (4), 269-281

Karan, O. C., Lambour, G., & Greenspan, S. (1990). Persons

in transition. In R. L. Schalock (Ed.), Quality of life: Perspectives and issues, (pp.85-92). Washington,

D. C.: American Association on Mental Retardation.

Kaufman, A. V., Adams, J. P., Jr., & Campbell, V. A.

- (1991). Permanency planning by older parents who care for adult children with mental retardation. Mental Retardation, 29 (5), 293-300
- Kazak, A., & Marvin, R. (1984). Differences, difficulties and adaptation: Stress and social networks in families with a handicapped child. Family Relations, 33, 66-67
- Kiernan, W. E., McGaughey, M. J., & Schalock, R. L. (1988). Employment Environments and Outcomes for Adults With Developmental Disabilities. Mental Retardation, 26 (5), 279-288
- Kirk, S. A., & Gallagher, J. J. (1985). Educating Exceptional Children (4th ed.). Scarborough, Ontario: Nelson Canada.
- Knowlton, H. E., & Clark, G. M. (1987). Transition issues for the 1990's. Exceptional Children, 53 (6), 562-563
- Knox, M., & Parmentier, T. R. (1990). Transition from school to adult life: Views of school leavers with disabilities. International Journal of Disability, Development, and Education, 37 (1), 45-55
- Konanc, J. T., & Warren, N. J. (1984). Graduation: Transitional crisis for mildly developmentally disabled adolescents and their families. Family Relations, 33, 135-142
- Kornblatt, E. S., & Heinrich, J. (1985). Needs and coping abilities in families of children with developmental

- disabilities. Mental Retardation, 23 (1), 13-19
- Krauss, M. W. (1993). Child-related and parenting stress: Similarities and differences between mothers and fathers of children with disabilities. American Journal on Mental Retardation, 97 (4), 393-404
- Krauss, M. W., & Erickson, M. E. (1988). Informal support networks among aging mentally retarded persons: Results from a pilot study. Mental Retardation, 26, 197-201
- Krauss, M. W., Seltzer, M. M., & Goodman, S. J. (1992). Social support networks of adults with mental retardation who live at home. American Journal on Mental Retardation, 96 (4), 432-441
- Kregel, J., & Wehman, P. (1989). Supported employment: Promises deferred for persons with severe disabilities. Journal of the Association for Persons with Severe Handicaps, 14 (4) 293-303
- Kubler-Ross, E. (1969). On death and dying. New York: MacMillan.
- Landesman-Dwyer, S., Berkson, G., & Romer, D. (1989). Affiliation and friendship of mentally retarded residents in group homes. American Journal of Mental Deficiency, 83, 571-580
- Larson, S. A., & Lakin, K. C. (1991). Parent attitudes about residential placement before and after deinstitutionalization: A research synthesis. Journal

of the Association for Persons with Severe Handicaps,
16 (1), 25-38

- MacMillan, D. L., & Turnbull, A. P. (1983). Parental involvement with special education: Respecting individual preferences. Education and Training of the Mentally Retarded, 18 (1), 4-9
- Mahoney, G., O'Sullivan, P., & Robinson, C. (1992). The family environments of children with disabilities: Diverse, but not so different. Topics in Early Childhood Special Education, 12 (3), 386-402
- Mallory, Bruce., L. (1996). The role of social policy in life-cycle transitions. Exceptional Children, 62 (3), 213-233
- Martin, S. S., Brady, M. P., & Kotarba, J. A. (1992). Families with chronically ill young children: The unsinkable family. Remedial and Special Education, 13 (2), 6-15
- McDonnell, J. (1987). The integration of students with severe handicaps into regular public schools: An analysis of parents' perceptions of outcomes. Education and Training in Mental Retardation, 22 (2), 98-111
- McDonnell, J., Hardman, M. M. L., & Hightower, J. (1989). Employment preparation for high school students with severe handicaps. Mental Retardation, 27 (6), 396-

405

- McDonnell, J., Nofs, D., Hardman, M., & Chambless, C. (1989). An analysis of the procedural components of supported employment programs associated with employment outcomes. Journal of Applied Behavior Analysis, 22 (4), 417-428
- McNair, J. & Rusch, F. R. (1991). Parental involvement in transition programs. Mental Retardation, 29 (2), 93-101
- Meers, G. D. (1992). Getting ready for the next century: Vocational preparation of students with disabilities. Teaching Exceptional Children, 24 (4), 36-39
- Meyers, C. E., & Blacher, J. (1987). Parents' perceptions of schooling for severely handicapped children: Home and family variables. Exceptional Children, 53 (5), 441-449
- Miller, R. J., La Follette, M., & Green, K. (1990). Development and field test of a transition planning procedure - 1985-1988. Career Development for Exceptional Individuals, 13 (1), 45-55
- Minnes, P. M. (1988). Family resources and stress associated with having a mentally retarded child. American Journal on Mental Retardation, 93 (2), 184-192
- Mithaug, D. E., Horiuchi, C., & Fanning, P. N. (1985). A

- report on the Colorado statewide follow-up survey of special education students. Exceptional Children, 51, 397-404
- Moon, M. S., & Beale, A. (1985). Vocational training and employment: Guidelines for parents. Exceptional Parent, 14 (8), 35-38
- Morgan, R. L., Moore, S. C., & Salzberg, C. L. (1992). Transition from school to work: Views of secondary special educators. Education and Training in Mental Retardation, 27 (4), 315-323
- Morgan-Redshaw, M., Wilgosh, L., & Bibby, M. A. (1990). The parental experiences of adolescents with hearing impairments. American Annals of the Deaf, 135 (4), 293-298
- Neubert, D. A., Tilson, G. P., Jr., & Ianacone, R. N.. (1989). Postsecondary transition needs and employment patterns of individuals with mild disabilities. Exceptional Children, 55 (6), 494-500
- Nisbet, J., & Hagner, D. (1988). Natural supports in the workplace: A reexamination of supported employment. Journal of the Association for Persons with Severe Handicaps, 13 (3), 260-267
- Noble, J. H., & Conley, R. W. (1987). Accumulating evidence on the benefits and cost of supported and transition employment for persons with severe disabilities.

Journal of the Association for Persons with Severe Handicaps, 12, 162-174

- Noh, S., Dumas, J. E., Wolf, L. C., & Fisman, S. N. (1989). Delineating sources of stress in parents of exceptional children. Family Relations, 38, 456-461
- Odom, S. L., & Shuster, S. K. (1988). Naturalistic inquiry and the assessment of young handicapped children and their families. Teaching Exceptional Children in Special Education, 6 (12), 68-82
- Olshansky, S. (1962). Chronic sorrow: A response to having a mentally defective child. Social Work, 43, 190-193
- Olshansky, S. S. (1966). Parent responses to a mentally defective child. Mental Retardation, 4, 21-23
- Ormerod, J. J., & Huebner, S. E. (1988). Crisis intervention: Facilitating parental acceptance of a child's handicap. Psychology in the Schools, 25 (4), 422-428
- Orr, R. R., Cameron, S. J., Dobson, L. A., & Day, D. M. (1993). Age-related changes in stress experienced by families with a child who has developmental delays. Mental Retardation, 31 (3), 171-176
- Peck, C. & Hong, C. (1988). Living Skills for Mentally Handicapped People: Therapy in Practice. Croom Helm, Australia: Croom Helm Ltd.

- Penner, C., Douglas, C., & Van Lieshout, R. (1992). School transition to work: An assessment of employment issues and opportunities affecting people with disabilities. Manitoba Employment Development Incorporated. (pp. 1-24)
- Peterson, N. L. (1987). Early Intervention for Handicapped and At-Risk Children: An Introduction to Early Childhood-Special Education. Denver, Colorado: Love Publishing Company.
- Pilley, J. (1988). Plans & outcomes: A study of the transition of the Vancouver School Board's 1987 mentally handicapped graduates. B.C. Journal of Special Education, 12 (3), 201-213
- Repetto, J. B., & Correa, V. I. (1996). Expanding views on transition. Exceptional Children, 62 (6), 551-563
- Richardson, S. A., Koller, H., & Katz, M. (1988). Job histories in open employment of a population of young adults with mental retardation. American Journal on Mental Retardation, 92 (6), 483-491
- Roessler, R. T., Brolin, D. E., & Johnson, J. M. (1990). Factors Affecting Employment Success and Quality of Life: A One Year Follow-up of Students in Special Education. Career Development for Exceptional Individuals, 13 (2), 95-107

- Rousey, A., Best, S., & Blacher, J. (1992). Mothers' and fathers' perceptions of stress and coping with children who have disabilities. American Journal on Mental Retardation, 97 (1), 99-109
- Rusch, F. R., Chadsey-Rusch, J., & Lagomarcino, T. (1987). Preparing students for employment. In M. E. Snell (Ed.), Systematic Instruction of persons with severe handicaps (3rd ed., pp. 471-490). Columbus OH: Merrill.
- Schalock, R. L., McGaughey, M. J., & Kiernan, W. E. (1989). Placement into nonsheltered employment: Findings from national employment surveys. American Journal on Mental Retardation, 94 (1), 80-87
- Seiter, M. (Ed.), (1992). Mental Retardation: Definition, Classification, and Systems of Supports - Workbook. Washington, D.C.: American Association on Mental Retardation.
- Seltzer, G. B., Begun, A., Seltzer, M. M., & Krauss, M. W. (1991). Adults with mental retardation and their aging mothers: Impacts of siblings. Family Relations, 40 (3), 310-317
- Seyfarth, J., Hill, J. W., Orellove, F., McMillan, J., & Wehman, P. (1987). Factors influencing parents' vocational aspirations for their children with mental retardation. Mental Retardation, 25 (6), 357-362

- Smith, G. J., Edelson-Smith, P. J., Stodden, R.A. (1995).
How to avoid the seven pitfalls of systematic planning.
Teaching Exceptional Children, 27, (4), 42-47
- Sowers, J. (1989). Critical parent roles in supported
employment. In G. H. S. Singer & L. K. Irvin (eds.),
Support for caregiving families: Enabling positive
adaptation to disability (pp. 103-119). Baltimore,
Maryland: Paul H. Brookes Publishing Company.
- Sowers, J., & Powers, L. (1989). Preparing students with
cerebral palsy and mental retardation for the
transition from school to community-based employment.
Career Development for Exceptional Individuals, 12 (1),
25-35
- Spreat, S., Telles, J., Conroy, J. W., & Feinstein, C.
Colombatto, J. J. (1987). Attitudes toward
institutionalization: A national survey of families of
institutionalized persons with mental retardation.
Mental Retardation, 25 (5), 267-274
- Stainback, W., & Stainback, S. (1989). Using qualitative
data collection procedures to investigate supported
education issues. Journal of the Association for
Persons with Severe Handicaps, 14 (4), 271-277
- Stark, J., & Goldsbury, T. (1988). Analysis of labour and
economics: Needs for the next decade. Mental
Retardation, 26 (6), 363-368
- Steere, D. E., Wood, R., Pancsofar, E. L., & Butterworth,
J., Jr. (1990). Outcome-based school-to-work
transition planning for students with disabilities.

Career Development for Exceptional Individuals, 13 (1),
57-69

Stewart, L. (1974). We have met the enemy and he is us.

American Annals of the Deaf, 119, 706-715

Summers, J. A., Dell'Oliver, C. Turnbull, A. P., Benson, H.
A., Santelli, E., Campbell, M., & Siegel-Causey, E.

(1990). Examining the individualized family service
process: What are family and practitioner preferences?
Teaching Exceptional Children in Special Education, 10
(1), 78-99

Todis, B., & Singer, G. (1991). Stress and stress
management in families with adopted children who have
severe disabilities. Journal of the Association for
Persons with Severe Disabilities, 16 (1), 3-13

Turnbull, A. P., Summers, S. A., & Brotherson, M. J. (1986).
In J. J. Gallagher & P. M. Vietze (Eds.), Families of
handicapped persons: Research, programs, and policy
issues, (pp.45-63). Baltimore, Maryland: Paul H.
Brookes.

Turnbull, A. P. & Turnbull III, H. R. (1988). Toward great
expectations for vocational opportunities: Family-
professional partnerships. Mental Retardation, 26
(6), 337-342

Unger, D., & Powell, D. (1991). Supporting families under
stress: The role of social networks. Family

Relations, 29, 566-574

Waggoner, K., & Wilgosh, L. (1990). Concerns of families of children with learning disabilities. Journal of Learning Disabilities, 23 (2), 97-113

Waisbren, S. E. (1980). Parents' reactions after the birth of a developmentally disabled child. American Journal of Mental Deficiency, 84, 345-351

Warren, F., & Warren, S. H. (1989). The role of parents in creating and maintaining quality family services. In G. H. S. Singer & L. K. Irvin (Eds.), Support for caregiving families: Enabling positive adaptation to disability, (pp. 55-68). Baltimore, Maryland: Paul H. Brookes Publishing Company.

Wehman, P. (1984). Transition for handicapped youth from school to work. In J. Chadsey-Rusch (Ed.), Conference proceeding document: Enhancing transition from school to workplace for handicapped youth (pp. 22-39). Champaign, Illinois: University of Illinois, Office of Career and Development for Special Populations.

Wehman, P. (1988). Supported employment: Toward equal employment opportunity for persons with severe disabilities. Mental Retardation, 26 (6), 357-361

Wehman, P. (1990). School-to-work: Elements of successful programs. Teaching Exceptional Children, 23 (1), 40-

- Wehman, P. (1992). Life Beyond the Classroom: Transition Strategies for Young People with Disabilities. Baltimore, Maryland: Paul H. Brookes Publishing Co.
- Wehman, P., Sale, P., & Parent, W. (1992). Supported employment strategies for integration of workers with disabilities. Stoneham, MA: Andover Medical Publishers.
- Weisenstein, G. R., Stowitschek, J. J., & Affleck, J. Q. (1991). Integrating students enroled in special education into vocational education. Career Development for Exceptional Individual, 14 (2), 131-144
- White, S., Smith, H., Meers, G., & Callahan, J. (1985). The key to transition - The merging of vocational and special education. Journal of Vocational Special Needs Education, 8 (1), 11-16
- Wikler, L. (1986a). Chronic stresses in families of mentally retarded children. Family Relations, 30, 281-288
- Wikler, L. (1986b). Periodic stresses in families of children with mental retardation. American Journal of Mental Deficiency, 90, 703-706
- Wilgosh, L. (1990). Issues in education and daily living for families of children with disabilities. The Alberta Journal of Educational Research, 21 (4), 229-

309

- Will, M. (1984a). Let us pause and reflect - but not too long. Exceptional Children, 51, 11-16
- Will, M. (1984b). OSERS programming for the transition of youth with disabilities: Bridges from school to working life. Washington, D.C.: U.S. Department of Education.
- Wisniewski, L. A., Alper, S., & Schloss, P. (1991). Work-experience and work-study programs for students with special needs: Quality indicators of transition services. Career Development for Exceptional Individuals, 14 (2), 43-56
- Witcher, A. E. (1989). The grief process as experienced by parents of handicapped children. Principal, 68 (4), 30-32
- Ysseldyke, J. E., & Algozzine, B. (1982). Critical issues in special education and remedial education. Boston: Houghton Mifflin.

Appendix A

April 7th, 1994

Dear Parent:

I am writing to tell you about a research study designed to examine the perceptions of parents of children with disabilities with respect to the school-to-work transition. The results of this study will be used to complete my master's thesis in education at the University of Manitoba, Faculty of Education. The purpose of this letter is to tell you a little about the research study and to invite you to become a part of it.

The role of parents in the transition process is an important one. Parents can offer valuable insights into the positive or negative aspects of the school-to-work transition. Knowledge of the perspectives, concerns, needs, expectations and priorities of parents may lead to a better understanding by school personnel and community service workers and enhance the transition process.

This study is a part of the "Manitoba Transition Project: From School to Work and Adult Life" research project in which you are already participating. Parents agreeing to participate will be sent a questionnaire in order to gather some background information as well as to learn about parents' perceptions. Completing the questionnaire should take approximately 15 to 30 minutes of your time. It will be understood that non-return of the questionnaire will constitute non-participation in the study.

Of course, your participation in this aspect of the project is entirely voluntary. You may refuse to participate or you may withdraw from the study at any time. Your decision to withdraw would not, in any way, penalize you or your child. Your names will not be used when the study is written up and your identities and the information you provide will not be divulged to anyone other than the research team of the Manitoba Transition Project.

In addition, a number of parents or sets of parents, who agree to complete the questionnaire might be invited to participate in one of two or three in-depth discussion groups with several other parents. The discussion groups will be a means for parents to comment or elaborate on issues emerging from the questionnaire.

Only parents who have previously agreed to participate in

the discussion group phase of the study might be approached for this. The time and location of the discussion group would be agreeable to all. Participating in the parent discussion group could take from one to two hours of your time. Parents will receive a list of issues we would like you to think about before the scheduled discussion group. With parents' permission, I would like to video tape the discussion group. The video will remain a confidential source of information within the Manitoba Transition Project. Once the research is completed, however, the video tape will be destroyed.

It might be necessary to conduct individual interviews with some parents to discuss their views on the school-to-work transition of their child. However, as with the discussion group participants, only parents who have previously agreed to participate in an interview might be approached. The interview may take one to two hours of your time.

The topic of the questionnaire and the discussion group, in general, is school-to-work transition experiences surrounding your child, as well as your perceptions of the transition process.

After the information has been analyzed, all participants will be provided with general information pertaining to the study's findings.

For more information please contact:

Harold Hoffmann
74 Pirson Cres.
Winnipeg, Manitoba
R3V 1R4
Tel. 261-6320

Thank you for considering this opportunity to participate.

Sincerely yours,

Harold Hoffmann

Appendix B

Harold Hoffmann
74 Pirson Crescent
Winnipeg, Manitoba
R3V 1R4

April 27th, 1994

Dear Parent,

Earlier in April you were sent information about a research study designed to examine the perceptions of parents of children with disabilities with respect to the school-to-work transition and to invite you to become a part of it. Included with the information package sent to you was a questionnaire, a consent form, and a stamped, self-addressed envelope. The purpose of this letter is draw your attention once again to the information package.

If you would like to participate in the questionnaire phase of this study, please sign the consent form and return it to me along with the completed questionnaire. If you prefer not to take part in the study, please indicate that preference in the appropriate place on the consent form. Either way, regardless of whether you wish to take part in the study, returning the consent form would be much appreciated.

In the event that the original information package was not received by you, please contact me and I will send out another one to you immediately.

If you have already responded, please disregard this letter. Also, if you have any questions, do not hesitate to contact me.

Thank you for your cooperation.

Sincerely yours,

Harold Hoffmann

TELEPHONE 261-6320

Please indicate your willingness to participate in the questionnaire phase of the study on this consent form and return it to me.

(Please check)

Yes, I would like to participate in the questionnaire phase of this study. ___

Signature of consent

OR

No, I would prefer not to participate in this study. ___

Regardless of whether or not you have consented to participate in this study, please return this page to me in the enclosed self-addressed and stamped envelope.

Thank you for your cooperation.

Harold Hoffmann

Appendix C

PARENT QUESTIONNAIRE

Please answer every question and circle or check off only one choice for every question. Feel free to elaborate or to add any additional comments in the spaces provided.

Please consult the Glossary of Terms if you are unsure about what is meant by some of the terms used.

When you have completed the questionnaire please mail it with the accompanying self-addressed, stamped envelope.

Background Information:

1.0 Full Name of Parent _____ Date: _____

1.1 Gender M ___ F ___

1.2 Relationship to Child: _____ Parent
 _____ Guardian
 _____ Foster Parent
 _____ Other (Please specify) _____

1.3 Age of Parent: _____ under 41 years
 _____ 41 - 50
 _____ 51 - 60
 _____ 61 - 70
 _____ over 70

1.4 Please describe the nature of your child's disability.

1.5 Please indicate the degree to which your child's independence is limited by his or her disability?

not limited 1 2 3 4 5 very limited

Comments: _____

1.6 Which school placement best describes your child's current program?

Regular class _____
Special class _____
Combination regular class/special class _____
Special school _____
Other (please describe) _____

Parent Perceptions:

2.0 Please indicate the type of work you expect your child to be engaged in soon after graduation.

- ___ work in competitive employment
- ___ work in supported employment
- ___ work in sheltered employment (example: sheltered workshop)
- ___ not working
- ___ other (please comment)

Comments: _____

3.0 Please indicate the type of work you prefer your child to be engaged in after graduation.

- work in competitive employment
- work in supported employment
- work in sheltered employment (example: sheltered workshop)
- not working
- other (please comment)

Comments: _____

4.0 Please indicate how important is it for your child to be working after he or she graduates from school.

not important 1 2 3 4 5 very important

Comments: _____

5.0 Please indicate the extent you are concerned about your child's employment situation after he or she graduates from high school?

not at all concerned 1 2 3 4 5 very concerned

Comments: _____

6.0 Please indicate the extent you are satisfied that schools are doing, or have done, a good job preparing your child for the transition to work and adult life.

not at all satisfied 1 2 3 4 5 very satisfied

Comments: _____

7.0 Please indicate the extent you are satisfied with your involvement in your child's school-to-work transition planning.

not at all satisfied 1 2 3 4 5 very satisfied

Comments: _____

8.0 Please indicate the extent of involvement you would like to have in your child's school-to-work transition planning.

I would prefer not to be actively involved 1 2 3 4 5 I would prefer to be actively involved

Comments: _____

9.0 Please indicate to what extent you think your views and wishes are taken into account with regards to your child's school-to-work transition planning.

not at all taken into account 1 2 3 4 5 very much taken into account

Comments: _____

10.0 Have you ever played a role or been involved in the advocacy or training of students with disabilities?

not at all involved 1 2 3 4 5 very much involved

Comments: _____

For clarification on any items in this questionnaire please contact:

Harold Hoffmann
74 Pirson Crescent
Winnipeg, Manitoba
R3V 1R4

TELEPHONE 261-6320 (HOME)

Appendix D

GLOSSARY OF TERMS

ASPIRATIONS: refers to a goal or position which is strived for; idealized expectations of potential and prospects; what you wish to see happen.

AUTONOMY: refers to being able to decide how or when to perform the work; essentially a form of independence at work.

COMMUNITY-BASED WORK SITE: refers to an actual work site in the community where individuals acquire work experience.

DISABILITY: refers to a limitation of function that results from an impairment of a specific organ or body system.

EMPLOYMENT OPTIONS:

SHELTERED EMPLOYMENT: refers to employment in a controlled environment where payment is typically less than minimum wage and there is minimal integration. Co-workers are usually individuals with disabilities.

SHELTERED WORKSHOP: refers to a non-profit, charitable organization or institution conducted for the purpose of carrying out a recognized rehabilitation program for workers with disabilities. Wages are typically low and the environments are segregated from workers without disabilities.

SUPPORTED EMPLOYMENT: refers to paid work that occurs in normal, integrated business environments for persons with disabilities. It provides long-term permanent support throughout the duration of employment in case problems occur and retraining is needed.

COMPETITIVE EMPLOYMENT: refers to unsubsidized employment where payment is at or above the minimum wage and work is generally performed in an integrated work site.

EXPECTATIONS: refers to what you think will realistically happen; the likelihood of something happening.

INTEGRATION: refers to individuals with disabilities being with individuals who do not have a disability (such as at school or work).

INTEGRATED WORK SITE: refers to working in a location where workers without a disability work. It is the opposite of a segregated setting catering to a special population.

PREFERENCES: basically refers to one's first choice; what one selects, favours or wants.

QUALITY OF LIFE: refers to the concept of viewing an individual's total life situation as opposed to narrowly focusing on one aspect at one point of time. Dimensions of quality of life may include:

- 1) physical well being including health and fitness
- 2) cognitive well-being including personal satisfaction, material well being including adequate income, a home and transportation
- 3) social well being including membership in a community, choice, respect, competence and valued relationships
- 4) recreational opportunities
- 5) employment
- 6) residential opportunities.

SOCIAL SUPPORTS: Interpersonal transactions involving support or assistance in some form (this may include help, support or input from community services, agencies, school personnel, and family).

VOCATIONAL EDUCATION/VOCATIONAL TRAINING: refers to specific coursework or training which assists students to acquire, to some extent, interpersonal skills, communication skills, adequate work habits, specific vocational skills and general employability skills.

Thank you for your participation!

Appendix E

Harold Hoffmann
114 Smuggler's Cove
Winnipeg, Manitoba
R3X 1R7

April 19th, 1996

Dear Parent,

In April, 1994 you became involved in a research study designed to examine the perceptions of parents of children with disabilities with respect to the school-to-work transition. The results of the study will be used to complete my master's degree at the Faculty of Education, University of Manitoba. The purpose of this letter is to give you an update on the progress of this study and to invite your participation in the next phase of the study. Despite the delay in the research of this project due to personal reasons, for which I apologize, I assure you I am keen to proceed. The research is continuing as planned with the full support of Dr. Richard Freeze of the "Manitoba Transition Project: From School To Work and Adult Life" in which you participated.

In the first phase of the study, parents who consented to participate were sent a questionnaire designed to illicit some demographic information as well as information about their perceptions on the school-to-work transition of their child. Thank you for your responses. The results of those questionnaires have been tabulated and analyzed.

The next phase of the study is to invite your participation in one of two or three in-depth discussion groups with several other parents. The discussion groups will be a means for parents to comment or elaborate on issues which emerged from the questionnaire. Parents who can not or prefer not to participate in a discussion group are invited to participate in an individual interview with myself, also to elaborate on issues which emerged from the questionnaires. The discussion group or the interview could take from one to two hours of your time.

Only parents who have previously agreed to participate in the discussion group phase of the study will be approached or contacted for this. The day and time of the discussion group would be agreeable to all. The location, if agreeable to participants, will be my home. Parents will receive a list of issues to think about before the scheduled discussion group (or interview).

The topic of the discussion group (or interview), in general, is school-to-work transition experiences surrounding your child, as well as your perceptions of the transition process, at the time the questionnaire was completed - and since. General issues which had arisen from the questionnaires will also be shared with you.

The information from the discussion groups or interviews will be analyzed as well as compiled with the information previously provided through questionnaires. By the end of the summer all participants of this research project will be provided with general information pertaining to the study's findings.

I would like to facilitate the discussion groups or meet individually with parents for the interview from the middle to the end of May on days and at times convenient to the parents. Therefore, as soon as you can, please complete the form on the following page indicating your willingness to participate in the discussion group, or the interview, and return it to me in the enclosed envelope.

Of course, your participation in this aspect of my study is entirely voluntary. You may refuse to participate further and you may withdraw at any time. Your decision to withdraw would not, in any way, penalize you or your child. Please note that the information was and will be confidential. Your names will not be used when the study is written up and your identities and the information you previously provided, or will provide, will not be divulged to anyone other than the research team of the "Manitoba Transition Project: From School to Work and Adult Life" in which you participated.

This study is conducted with the belief that the insights and experiences parents can offer about the positive and negative aspects of the transition from school to work and adult life are valuable. A knowledge and awareness of the perspectives, concerns, needs, and priorities of parents may lead to a better understanding by school personnel and community service workers of the school-to-work process from the parents' perspective. It is hoped that the information can enhance the school-to-work transition process.

Again, I thank you for your earlier participation in the questionnaire, for considering to participate in the discussion or interview phase of the study, and for your patience during the previous delay of progress.

Please do not hesitate to call me for more information or if you have any questions.

Sincerely yours,

Harold Hoffmann
TELEPHONE 253-1681

Please indicate your willingness to participate in the discussion group phase of the study on the consent form and return it to me.

(Please check)

.....

_____ Yes, I would like to participate in the discussion group phase of this study.

Signature of Consent

.....

(AND/OR)

_____ Yes, I would like to participate in the interview.

Signature of Consent

.....

(OR)

_____ No, I prefer not to participate further.

Regardless of whether or not you have consented to participate in the discussion group or the interview, please tear off and return this page to me in the enclosed self-addressed and stamped envelope.

Thank you for your cooperation.

Harold Hoffmann

Appendix F

Harold Hoffmann
114 Smuggler's Cove
Winnipeg, MB R3X 1R7

May 20th, 1996

Dear Parent,

Thank you for agreeing to participate in a parent discussion group. If you haven't already been contacted regarding the day and time of the meeting you will be shortly.

As I indicated in the previous letter to you, the topic of the discussion group, in general, is school-to-work transition experiences surrounding your child, as well as your perceptions of the transition process. As parents, your insights and perceptions of your child's transition from school to work or adult life are valuable. Therefore, the emphasis of the discussion group will be for you to elaborate on questionnaire findings and anything relevant to the issue.

Hopefully one of the following days and times will be convenient for you.

Wednesday, May 29th at 7:00 p.m.

(or)

Thursday, May 30th at 7:00 p.m.

(or)

Saturday, June 1st at 7:00 pm.

You will be contacted, if you have not been already, to confirm a date.

Enclosed you will find a map to my house. If you aren't sure about the directions or the location don't hesitate to call me.

You will also find some general questions or "discussion issues" which are meant to provide a focus for participants. They were found to be of relevance to the school to work transition from on the findings of the questionnaire as well as from some of the comments made. They are there for you to think about.

If you have any questions or concerns, or if you would like some more information, please call. If no one is home the answering machine will be on and I will get back to you as soon as I can.

I look forward to meeting you.

Sincerely yours,

TELEPHONE 253-1681

Appendix G

DISCUSSION ISSUES

How do you think parents want to be involved in the school-to-work transition process?

What is the best way to enlist your support and meet your needs?

How beneficial is (or has been) the high school program in preparing your child for the transition from school to work?

How beneficial have work experience or work preparation programs been?

Have your child's needs been met?

What has been helpful or effective and what hasn't?

Do you think parents are adequately informed about their child's school program, vocational options, community linkages and supports?

What information would you, as parents, like to have (regarding options for school and options for after graduation?)

What would you like to see take place in school and during transition planning in order to prepare your child for life after graduation?

What are the concerns you have over your child's transition from school to work and adult life?

What challenges does your child encounter in the transition process?

Are there any solutions?



Faculty of Education
ETHICS APPROVAL FORM

To be completed by the applicant:

Title of Study:

Families in Transition: An Exploratory Study of Parents' Perceptions of the School-to-Work Transition of their Children With Disabilities

Name of Principal Investigator(s) (please print):
Harold Hoffmann

Name of Thesis/Dissertation Advisor or Course Instructor (if Principal Investigator is a student) (please print):

Dr. D. Richard Freeze

I/We, the undersigned, agree to abide by the University of Manitoba's ethical standards and guidelines for research involving human subjects, and agree to carry out the study named above as described in the Ethics Review Application.

Richard Freeze

Signature of Thesis/Dissertation Advisor or Course Instructor (if required)

Harold Hoffmann
Signature(s) of Principal Investigator(s)

Area for committee review and signature, containing faint text and a grid pattern.