EFFECTS OF AN INTERVENTION PROGRAM ON PARENTS OF YOUNG ADULTS WITH DISABILITIES

DISSERTATION

Presented in Partial Fulfillment of the Requirements for the Degree Doctor of Philosophy in the Graduate School of The Ohio State University

By

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* * * * *

The Ohio State University
2003

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ABSTRACT

The purpose of this study was to explore the effects of a 9-hour information and support program ("What’s Next") on the attitudes of parents whose children (age 16-24 years) with disabilities were in the transitioning period from school to adult life. Additionally, this study assessed the psychometric properties of the Vocational and Community Involvement Profile (VOCIP). This was accomplished by using a pretest-posttest control group experimental design.

The knowledge gained from this study will have direct implications for better understanding parents’ attitudes associated with the transition from school to adult life for their sons and daughters with disabilities. It also demonstrated the potential importance of systematic intervention aimed at improving family understanding and involvement.
Dedication

To my parents, Alvin and Beatrice Fish, for being there always.
ACKNOWLEDGMENTS

I am deeply thankful to my advisor, Dr. Bruce Growick, who encouraged me to pursue my doctorate. His belief in my abilities has made this achievement possible. My committee members, Dr. Michael Klein and Dr. Michael Scott, have been great teachers and supporters throughout the process.

To the people at the National Institute on Disability and Rehabilitation Research (NIDRR), and particularly Ellen Blassiotti, goes my sincere appreciation for their support of this research study through a Mary Switzer Merit Research Fellowship. I truly was honored to be selected in 1999 as one of five Merit Research Fellows and to receive a $45,000 stipend to assist with my research.

The Franklin County (Ohio) Board of MRDD supported “What’s Next” and cooperated to help me conduct the research. To Sue Sherwood, Sherry Brown, Jack Beatty, and Jed Morrison go my sincere thanks. Peggy Martin was the guiding spirit behind “What's Next.” Her devotion to the program has made it a huge success.

The 200 families who have been through “What’s Next” constantly inspire me because of their resilience and generosity. The stories they tell often bring tears to my eyes and astonishment to my heart.
None of this would have been possible without the love and support of my family. My children, Matt, Lauren, and Roger, have been so understanding of my time away. My mother, Bea, and brother, Larry, have cheered me on from afar and never wavered in their support. Thanks to my dear and devoted Lyna for her confidence in me. Finally, to my father, Alvin Fish, whose faith in my abilities helped me to complete this degree.
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FIELDS OF STUDY

Major Field:  Education

Studies in:  Rehabilitation Services
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abstract</td>
<td>ii</td>
</tr>
<tr>
<td>Dedication</td>
<td>iii</td>
</tr>
<tr>
<td>Acknowledgments</td>
<td>iv</td>
</tr>
<tr>
<td>Vita</td>
<td>vi</td>
</tr>
<tr>
<td>List of Tables</td>
<td>ix</td>
</tr>
<tr>
<td>List of Figures</td>
<td>xi</td>
</tr>
<tr>
<td>Chapters</td>
<td></td>
</tr>
<tr>
<td>1. INTRODUCTION</td>
<td>1</td>
</tr>
<tr>
<td>Introduction</td>
<td>1</td>
</tr>
<tr>
<td>Statement of the Problem</td>
<td>3</td>
</tr>
<tr>
<td>Significance of the Problem</td>
<td>8</td>
</tr>
<tr>
<td>Objectives of the Study</td>
<td>9</td>
</tr>
<tr>
<td>Research Hypothesis</td>
<td>9</td>
</tr>
<tr>
<td>Definition of Terms</td>
<td>10</td>
</tr>
<tr>
<td>Demographic Variables</td>
<td>10</td>
</tr>
<tr>
<td>Independent Variable</td>
<td>13</td>
</tr>
<tr>
<td>Dependent Variables</td>
<td>14</td>
</tr>
<tr>
<td>2. REVIEW OF LITERATURE</td>
<td>17</td>
</tr>
<tr>
<td>Family as a Source of Problem</td>
<td>17</td>
</tr>
<tr>
<td>The Family Life Cycle</td>
<td>23</td>
</tr>
<tr>
<td>The Launching Phase of the Life Cycle</td>
<td>26</td>
</tr>
<tr>
<td>History of Transition</td>
<td>29</td>
</tr>
<tr>
<td>Summary</td>
<td>45</td>
</tr>
<tr>
<td>Measures of Parental Perspectives of the Transition Process</td>
<td>46</td>
</tr>
<tr>
<td>3. METHODOLOGY</td>
<td>57</td>
</tr>
<tr>
<td>Research Design</td>
<td>57</td>
</tr>
<tr>
<td>Population and Sample</td>
<td>59</td>
</tr>
<tr>
<td>Program Description</td>
<td>62</td>
</tr>
</tbody>
</table>
# LIST OF TABLES

<table>
<thead>
<tr>
<th>Table</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Child Demographics</td>
<td>71</td>
</tr>
<tr>
<td>2. Family Demographics</td>
<td>73</td>
</tr>
<tr>
<td>3. Reliabilities for the Transition Experiences Questionnaire (TEQ)</td>
<td>76</td>
</tr>
<tr>
<td>4. Reliabilities for the Family Hardiness Index (FHI)</td>
<td>77</td>
</tr>
<tr>
<td>5. Factors of Vocational and Community Involvement Profile</td>
<td>78</td>
</tr>
<tr>
<td>6. Reliabilities for the Vocational and Community Involvement Profile (VOCIP)</td>
<td>81</td>
</tr>
<tr>
<td>7. Correlations Among TEQ, FHI, and VOCIP Scales (Posttests)</td>
<td>83</td>
</tr>
<tr>
<td>8. Means and Standard Deviations of the TEQ, FHI, and VOCIP Scales</td>
<td>88</td>
</tr>
<tr>
<td>9. Analysis of Variance of the Parent’s Comfort With Transition (TEQ1) Scale – Experimental &amp; Control Group Condition</td>
<td>89</td>
</tr>
<tr>
<td>10. Analysis of Variance of the Parent’s Vision for Child’s Future (TEQ2) Scale – Experimental &amp; Control Group Condition</td>
<td>90</td>
</tr>
<tr>
<td>11. Analysis of Variance of the Parent’s Response to the Schooling Process (TEQ3) Scale – Experimental &amp; Control Group Condition</td>
<td>90</td>
</tr>
<tr>
<td>12. Analysis of Variance of the Family Hardiness Index Full (TEQ3) Scale – Experimental &amp; Control Group Condition</td>
<td>91</td>
</tr>
<tr>
<td>13. Analysis of Variance of the Family Hardiness Index Commitment (FHI1) Scale – Experimental &amp; Control Group Condition</td>
<td>92</td>
</tr>
<tr>
<td>14. Analysis of Variance of the Family Hardiness Index Challenge (FHI2) Scale – Experimental &amp; Control Group Condition</td>
<td>92</td>
</tr>
<tr>
<td>15. Analysis of Variance of the Family Hardiness Index Control (FHI3) Scale – Experimental &amp; Control Group Condition</td>
<td>93</td>
</tr>
</tbody>
</table>
16. Analysis of Variance of the VOCIP Job and Independent Living (VOCIP1) Scale – Experimental & Control Group Condition ................................................................. 94

17. Analysis of Variance of the VOCIP Well Being (VOCIP2) Scale – Experimental & Control Group Condition ................................................................. 95

18. Analysis of Variance of the VOCIP Independence (VOCIP3) Scale – Experimental & Control Group Condition ................................................................. 96

19. Analysis of Variance of the VOCIP Social Acceptance (VOCIP4) Scale – Experimental & Control Group Condition ................................................................. 97
# LIST OF FIGURES

<table>
<thead>
<tr>
<th>Figure</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Design of the Study</td>
<td>58</td>
</tr>
</tbody>
</table>
CHAPTER 1
INTRODUCTION

Introduction

I just want to make sure she lives in a clean, healthy environment with nice roommates. I want to know that she has the skills to pay her share of the bills. I want to know that she has a well-balanced life with work and social activities. I’ll miss her.

Parent of a 5th-year high school student

The transition from childhood to adulthood is an important process that occurs, in some form or another, in practically every culture. In our society, successful attainment of adult status is represented by a variety of markers, completion of formal education, moving out from the family home, employment, increased independence, and marriage (Marini, 1985). Our social and educational systems are structured in such a way that graduation from high school is the most visible aspect of transition to vocational and adult status (Pallas, 1993). Emancipating to independence involves choices, decisions, and consequences for young adults. They are faced with issues such as becoming economically self-sufficient; establishing a social network apart from one’s immediate family; and contributing to one’s community through, for example, volunteer work and voting.
The purpose of the present study is to investigate how parents of youth with disabilities are influenced as a result of an information and support program. This chapter provides an overview of the research problem and the significance of the problem. The purpose of the study will be detailed, along with an explicit statement of the research questions and objectives under investigation.

This study emerged from a successful program for young adults with disabilities and their families called “What’s Next.” Peggy Martin, a parent of a 23-year-old daughter with developmental disabilities, and this author conceived the “What’s Next” program in November 1997, which began operation in February 1998. Its purpose was to support, guide, and inform families and young adults regarding the process of transition from school to work and adult life and to do so in a relaxed and comfortable setting over a period of six weeks (one and one-half hours each weekly session). The rationale behind “What’s Next” was based on the following assumptions:

a. Parent involvement in the process of planning transition is not actively fostered by the educational service system.

b. Young adults with disabilities need assistance to understand both the vocational and social ramifications of life after school.

c. Adult services vary greatly in terms of quality and availability.

d. Residential options in the community can be scary and confusing.

e. Vocational training and work experiences may have been limited.
f. Families in transition were not having their needs met nor questions answered.

   g. Youth with disabilities were experiencing limited opportunities for social connectedness and support outside their families.

After conducting the first few “What’s Next” programs, we were surprised by how little families knew about adult services, rules, and their rights. For many, it was the first time they had been afforded the opportunity to share how they felt about the future, to hear from other families, and to do so over a period of several weeks.

**Statement of the Problem**

For youth with disabilities, the transition from high school to adult life represents a time of uncertainty, complexity, and challenges. These challenges relate to the individual, the family, and the community at large, including the social service system (Blacher, 2001). Obstacles to achieving successful transition have been well documented and include lack of appropriate career, vocational, and counseling programs; limited parental involvement and exposure to work experiences; and lack of cooperative programming and collaborative planning among special and vocational education, rehabilitation, and adult service systems (Berkell & Brown, 1989; Lehmann & Roberto, 1996; Ludlow, Turnbull, & Luckasson, 1988).

Nationally, each year more than 500,000 students in special education leave their education programs, presumably to look for meaningful employment and some degree of residential independence (Whitney-Thomas, 1994). Studies in selected
states have shown that students who graduated from high school experienced poor adjustment to adult life, evidenced by low employment rates, low wages, and low rates of participation in postsecondary education and vocational training programs (Hanley-Maxwell, Whitney-Thomas, & Pogoloff, 1995; Hasazi, Gordon, & Roe, 1985). Students with disabilities dropped out of school at higher rates and were employed or were attending postsecondary programs at lower rates than were their typically developing peers. Approximately one-third of students with disabilities dropped out of school (32%), and another 4% were either expelled or suspended, compared with a 20% dropout rate for their peers without disabilities. Among out-of-school youth with disabilities, approximately 46% were reported working, a rate markedly lower than their peers (Wagner, 1989). Researchers have noted that competitive employment rates dropped as disability levels became more severe (Haring & Lovett, 1990; Renfoe, 1988).

In all areas of adult life, the evidence is compelling that young adults with disabilities did not fare as well as did their peers without disabilities (Peraino, 1993). Students typically graduate or dropped out from a system that mandated services (good, bad, or indifferent) to an adult service system that had historically been anything but forthcoming. In fact, youth with disabilities and their families frequently encountered an adult system that offered few entitlements to services, so students often were ill-prepared and unsupported in their efforts to become vocationally and socially independent and also faced the challenges of dealing with an adult service system that was fragmented and often difficult to access.
Wehman, Moon, and McCarthy (1986) defined transition 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 3-5 years; such a process must involve special educators, vocational educators, parents and/or the student, an adult service system representative, and possibly an employer. This definition stresses the importance of interdisciplinary cross-agency cooperation and parental involvement. Such cooperation is viewed as the cornerstone of effective transitional programming (Wehman et al., 1986).

The Individuals with Disabilities Education Act (IDEA) of 1990 and the Rehabilitation Act Amendments of 1992 (Wood & Test, 1997) defined transition services as a “coordinated set of activities for the student, designed with an outcome-oriented process, which promotes movement from school activities including post-secondary education, vocational and applied technology training, integrated competitive employment, continuing and adult education, adult services, independent living, or community participation” (p. 171). Such coordinated and collaborative activities were to be based on the student’s preferences and interests. Transition plans were usually initiated by school districts; educators were called upon to form relationships with students, parents, community service programs and their representatives, and advocacy organizations. First and foremost, however, transition-planning needed to consider the student’s dreams and develop a realistic approach for
making the dreams come true. The IDEA now requires that transition services be addressed in each student’s Individualized Education Plan (IEP).

The School-to-Work Opportunities Act (STWOA) of 1994 called for improving employment outcomes for all students. Congress recognized that STWOA-improved employment outcomes would require a fundamental restructuring of the educational service system (Benz & Kochhar, 1996). The relationship between schooling and the broader issue of work-force development required that states would improve the knowledge and skills of all students by integrating academic and occupational learning, integrating school-based and work-based learning, and building the connection between school environment and post-school environments, such as postsecondary education and employment. The STWOA emphasized the need to create a high-quality school-to-work transition system that enabled all students to successfully enter the workplace and participate fully in their communities (Norman & Bourexis, 1995).

Supporting parents through their children’s transitions was considered essential for successful transitions to community-based programs and services (Brotherson, Berdine, & Sartini, 1993). McNair and Rusch (1991) noted how professionals in various education and rehabilitation disciplines often commented on the importance of parents to the success of educational programs and suggested that, in the absence of special projects or funding, the single most important factor in successful transition was the parent. Successful transition from school to adulthood for young adults with disabilities must include support for parents (Benz & Halpern,
1987; Johnson, Bruininks, & Thurlow, 1987). This participation of parents was considered essential because of how their values, expectations, and experiences toward integrating and independence impacted their children. Additionally, parents represented probably the most effective advocates for their children. Parents usually were the single thread that attempted to ensure continuity between the school and the adult services. Parent involvement has been identified as a critical element in facilitating young adults with disabilities finding employment (Wehman, Kregel, & Seyfarth, 1985). The influence that parents exerted on their children’s decision-making process was all encompassing. Youth with disabilities have a history of depending on their parents for emotional, social, and educational guidance and support. Parent participation often extended well beyond the usually expected time frame of care taking, advocacy, and monitoring.

Support and understanding for parents of youth with disabilities must begin with a thorough appreciation for the concerns and attitudes they have about the transition process as well as their future expectations of the child in an adult status. According to Cowan (1991), a great deal of what happens during the transition to adult life was a renegotiation of relationships and therefore important to understand the roles that parents played in their children’s developing autonomies and decision-making skills. Much of the research that has engaged parents of youth with disabilities has been largely guided by the goal of increasing involvement of these parents in their children’s educational and transition planning processes (Stineman, Morningstar, Bishop, & Turnbull, 1993). However, despite the legal mandate for
parent participation in special education and transition planning, numerous reports suggested that parent involvement tended to be passive or submissive (Ferguson, Ferguson, & Jones, 1988; Gallivan-Fenlon, 1994; Hanley-Maxwell et al., 1995; Harry, 1992). The reality of passive involvement is both ironic and tragic in light of the significant emphasis on parent involvement during the past decade. Harry (1992) pointed to the contradictions that existed between professionally espoused values related to family involvement when interacting with families. In fact, parent intimidation and discomfort were identified as reasons for low parental involvement (Everson & McNulty, 1992).

**Significance of the Problem**

Families have had a critical impact on the successful transition from school to adult life for young adults with disabilities (Everson & Moon, 1987). For young adults with disabilities, successful transition into adulthood must include information, support, and guidance for parents (Benz & Halpern, 1987; Johnson et al., 1987). The underlying rationale for parent involvement is that parents impacted their children through their own values and expectations about such issues as integration and independence. Additionally, parents can be the single most effective advocates for their children. Recommended best practices include having families and professionals working as a team (Jamison, 1993). Therefore, it is imperative to understand and involve parents in the transition planning and implementation process for youth with disabilities. Parents who are uninformed and uninvolved may have a restricted view
toward and unresolved feelings about their children’s abilities to be vocationally and socially independent in adult life.

**Objectives of the Study**

1. Determine the impact of the “What’s Next” intervention on the attitudes and behaviors of parents of youth with disabilities who are in the transition period from school to adult life.

2. Assess the psychometric properties the Vocational and Community Involvement Profile.

**Research Hypothesis**

The primary research hypotheses described below were tested in the study using appropriate statistical procedures (e.g., ANOVA, alpha coefficients, non-parametric). All analyses were conducted using the Statistical Package for Social Sciences (SPSS/PCT version 5 1992a, SPSS for Windows). This study demonstrates the efficacy of providing systematic intervention to parents of youth with disabilities transitioning from school to work and adult life.

**Ho1:** There is a difference between the control and experimental groups on measures of Transitional Experiences after the “What’s Next” intervention.

**Ho2:** There is a difference between the control and experimental groups on measures of Family Hardiness Index after the “What’s Next” intervention.
Ho3: There is difference between control and experimental groups on measures of Vocational and Community Involvement after the “What’s Next” intervention.

**Definition of Terms**

As recommended by Ary, Jacobs, and Razavieh (1985), both the constitutive and operational definition for each variable is provided. The scale of measurement is provided following the operational definition. In educational research, most inferential statistics employed are appropriate for either interval or ratio scales of measurement; therefore, throughout this study, such variables were classified as interval. The definitions of the variables of interest are presented in three sections—demographic variables, the independent variable, and dependent variables.

**Demographic Variables**

Demographic or attribute variables cannot be manipulated and are designed to describe the participants in the study and their children with disabilities. The principal demographic variables of interest in this study for child characteristics include gender, race, level of disability, and age.

**Gender.** Constitutive definition - the classification type of sex (male, female) of a participant’s child. Operational definition - Gender was collected from the Vocational and Communication Involvement Profile demographic section. Two levels
of gender were coded—1 for males and 2 for females. The scale of measurement is nominal.

Race. Constitutive definition - a class or kind of people unified by common habits or characteristics. Operational definition - race is a nominal scale of measurement with six levels—1 for American Indian (Alaskan Native), 2 for Asian or Pacific Islander, 3 for Black, 4 for Hispanic, 5 for White not of Hispanic origin, and 6 for other. Race was collected from the Vocational and Community Involvement Profile demographic information section.

Level of Disability. Constitutive definition - functional determination of developmental disability, based on the established procedure set forth by county boards of mental retardation and developmental disabilities in Ohio. Operational definition - level of disability classifications, as rated by parents, were coded as follows—1 for mild, 2 for moderate, 3 for severe, and 4 for profound. This variable was collected from the Vocational and Community Involvement Profile. The variable “disability” is a nominal scale of measurement.

Age. Constitutive definition - the time that a person has existed since birth. Operational definition - “Age” was treated using an interval scale of measurement. This variable was collected from the Vocational and Community Involvement Profile completed by parents.

The principal demographic variables of the participants include:

Gender. Constitutive definition - the classification type of sex (male, female) of a participant’s child. Operational definition - Gender was collected from the
Vocational and Communication Involvement Profile demographic section. Two levels of gender were coded—1 for males and 2 for females. The scale of measurement is nominal.

**Marital Status.** Constitutive definition - the classification of an individual’s relationship with another person. Operational definition - Marital Status was collected from the Vocational and Community Involvement Profile. The levels of marital status were coded—1 for married, 2 for divorced, 3 for separated, 4 for widowed, and 5 for never married. The scale is nominal.

**Level of Education.** Constitutive definition - the amount of formal education received by an individual. Operational definition - Level of Education was collected from the Vocational and Community Involvement Profile. The Levels of Education were based on the participant’s report of the highest level of education received and were coded as 1 for elementary school, 2 for some high school, 3 for high school diploma or equivalent, 4 for some college, 5 for technical or trade school certification, 6 for 2-year college degree, 7 for 4-year college degree, 8 for some graduate school, and 9 for graduate degree.

**Employment Status.** Constitutive definition - the classification of the employment standing of a participant. Operational definition - Employment was collected from the Vocational and Community Involvement Profile. Employment Status was based on participant’s self report and was coded 1 for hourly wage worker, 2 for salaries, 3 for work on commission or tips, 4 for self employment, 5 for unemployment, 6 for retired, and 7 for homemaker.
Race. Constitutive definition - a class or kind of people unified by common habits or characteristics. Operational definition - Race is a nominal scale of measurement with six levels: 1 for American Indian (Alaskan Native), 2 for Asian or Pacific Islander, 3 for Black, 4 for Hispanic, 5 for White not of Hispanic origin, and 6 for other. Race was collected from the Vocational and Community Involvement Profile demographic information section.

Household Income. Constitutive definition - the classification of the total amount of money generated or received by a family unit. Operational definition - Household Income was collected from the Vocational and Community Involvement Profile. Household Income was based on gross income before taxes and coded 1 for <$9,000, 2 for $10,000-$19,000, 3 for $20,000-$29,000, 4 for $30,000-$39,000, 5 for $40,000-$49,000, and 6 for >$50,000.

Independent Variable

The independent variable for this study was associated with the delivery of transition services. Transition services as defined by the Individuals with Disabilities Education Act of 1990 means a coordinated set of activities for students, designed within an outcome-oriented process, which promotes movement from school to post-school activities, including postsecondary education, vocational training, integrated employment (including supported employment, continuing, and adult education), adult services, independent living, or community participation. The coordinated set of activities shall be based upon the individual student’s needs, taking into account the
student’s preferences and interests and shall include instruction, community experiences, the development of employment and other post-school adult living objectives, and when appropriate, acquisition of daily living skills and functional vocational evaluation.

An integral component of transition planning and implementation for youth with disabilities is the role that parents play in the process. Parent involvement was the independent variable manipulated for this study through the “What’s Next” program and intervention.

Parent Involvement. Constitutive definition - parent involvement is legally guaranteed by law and was first established under the Education for All Handicapped Children Act of 1975. It is the process by which parents contribute toward and ultimately agree to the individualized education plan for their child who is eligible to receive special education services under the law.

Dependent Variables

The following dependent variables or outcome measures were used to determine the effect of the intervention service (“What’s Next”) program.

Family Hardiness. Constitutive definition - a stress resistance and adaptation resource in families that functions as a buffer or mediating factor in mitigating the effects of stressors and demands, and a facilitation of family resiliency adjustment and adaptation over time (McCubbin, Thompson, & McCubbin, 1996). Operational
definition - the score on the Family Hardiness subscales of Commitment, Challenge, and Control.

1. Commitment - the family’s sense of internal strengths, dependability, and ability to work together.

2. Challenge - the family’s efforts to be innovative, active, to experience new things, and to learn.

3. Control - the family’s sense of being in control of family life rather than being shaped by outside events and circumstances.

Transition Experience. Constitutive definition - the events and feelings that occur for parents of youth with disabilities who are between the ages of 16-24 years. Operational definition - the score obtained on the Transition Experience Questionnaire subscales of Parent’s Comfort with Transition, Parent’s Vision for Child’s Future, and Parental Response to School Process.

1. Parent’s Comfort with Transition - how parents feel about their son’s or daughter’s associated services and supports.

2. Parent’s Vision for Child’s Future - what parents envision life will be like for themselves and their children after formal education is completed.

3. Parental Response to School Process - the response parents have as a result of the services and supports received by their child and themselves from the school system.

Vocational and Community Involvement Profile. Constitutive definition - the concerns that parents have about their children’s and their own future vocational and
social adjustment related to independence and community living. Operational definition - the score on the Vocational and Community Involvement Profile subscales of Job and Independent Living Readiness, Well-Being Concerns for the Child, Parent Child Adjustment Regarding Independence and Social Acceptance or Readiness of the Child.

1. Job and Independent Living Readiness - the extent to which a parent sees his child as having the necessary skills to work and live independently in the community.

2. Well-Being Concerns for the Child - the extent which a parent is concerned for his child’s overall safety and well-being.

3. Parent Child Adjustment Regarding Independence - how parents believe they and their children will adjust emotionally to being more independent and living in the community.

4. Social Acceptance/Readiness of Child - the extent to which a parent believes his child will be accepted by others and the child’s ability to engage others socially.
CHAPTER 2
REVIEW OF LITERATURE

Family as a Source of Problem

In the past, an exclusive emphasis has focused on problems, stresses, and inadequacies of families, has ignored the successes of families, and has directed attention away from their potential for positive adaptation. It was common practice in the 1940s and 1950s for professionals to describe parents of children and youth who are autistic or psychotic as rigid, perfectionist, emotionally impoverished, and depressed (Turnbull & Turnbull, 1990).

The eugenics movement (1880-1930) assumed parents were the underlying source of the child’s physical, emotional, and intellectual disability. A primary goal of this movement was to remove human flaws by regulating human reproduction. After studying the Kallikak family, Goddard (1912) made a strong argument that mental retardation, or “feeblemindedness,” was hereditary. National immigration quotas were set so that anyone deemed mentally impaired, based on results of early versions of intelligence tests, were prevented from entering the country and “polluting” the gene pool (Gould, 1984). Laws were passed that made marriage illegal for people thought to have mental disabilities and institutionalization increased
(Turnbull & Turnbull, 1990). More than 30 states had legalized compulsory sterilization by the 1930s (Alper, Schloss & Schloss, 1994).

The belief that parents were the root cause of the child’s disability managed to outlive the eugenics movement. According to Turnbull and Turnbull (1986), parental psychological characteristics and child-care practices often were blamed for contributing to the child’s disability. This view was particularly evident by Bettelheim (1967), who argued that children with autism withdrew from reality because their mothers were cold and rigid. Bettelheim concluded that, as part of their “therapy,” children with autism should be hospitalized with no parental contact for long periods of time (Turnbull & Turnbull, 1990).

While certain genetic factors can cause a disability, most disabilities have no known genetic basis; however, stigmatization remains one of the oppressive components of the family experience (Baxter, 1989). People with disabilities are often shunned, ridiculed, avoided, and ostracized. This sense of stigmatization is frequently sensed by other family members (Seligman & Darling, 1989). Guilt by association is not an uncommon phenomenon.

Despite increased understanding of the sources of disabilities and the complexity of factors that effect their manifestation, family-blaming continues to plague the family-professional relationship. Overtly blaming families for the difficulties that children experience has declined and changed in focus but has not disappeared in the last 20 years. For example, Ferguson, Ferguson, Jeanchild, Olson, and Lucyshyn (1993) confirmed that variations of this belief continued. In their
examination of the triadic relationship of parents, professionals, and the person with a
disability, Ferguson et al. found that professionals often viewed parents as a barrier to
developing effective working relationships with the individuals they are attempting to serve. This barrier was viewed as particularly problematic in that the professionals from the Ferguson et al. study believed that the influence of the family often diminished the adult status of the person with a disability. Families reported that they felt estranged from their loved one and were concerned that professionals had more influence in life decisions than they did.

Despite the potential challenges associated with having a child with a disability, a competence paradigm offered an alternative view that focused on the strengths and resources of families. There was empirical evidence that most families who had a member with a developmental disability were functioning at a relatively adaptive level (Dyson, 1991; Hampson, Hullgus, Beavers, & Beavers, 1988). According to Dunst, Trivette, and Deal (1988), all families had strengths and capabilities, and they responded more favorably to interventions that acknowledged these positive characteristics. Families also responded well to efforts that helped them build and display competencies through enablement and empowerment.

Clearly, mental retardation and associated developmental disabilities were a family systems phenomenon. While it is true that all families are unique, all families were also alike in being a dynamic system of interacting members. According to Jaffe-Ruiz (1984), the family system was an integral whole of interrelated components that was more than and different from the sum of its parts, and the identity of the
family reflected the common or shared identities of its constituent members. Family systems theory viewed the family as a social system with unique characteristics and needs. A basic premise was that the individual members of a family were so interrelated that any experience affecting one member would affect all (Minuchin, 1974). Members of a family unit were interlocking parts of the system. Each part of the system was connected to each other part by a continuous feedback loop. No comment or action came “out of the blue”—each had a relationship to what had gone on before. The patterns of relationships were continual and mutual. To say that one person’s actions “caused” a response in another was to miss half of the pattern, because the action in itself was already a response.

Turnbull and Turnbull (1996) quoted Satir in characterizing family life as a mobile in which “all of the pieces, no matter what size or shape, can be grouped together and balanced by shortening or lengthening the strings attached, or rearranging the distance between the pieces” (p. 195). As students with disabilities and their families went through the transition planning process, each member of the family system took on new responsibilities and roles, thus altering the delicate balance of the mobile. It was important that professionals who worked with families have a firm understanding of how family systems affect transition and vice versa, and to keep the mobile perspective in mind. “As in a mobile, you can’t arrange one without thinking about the others” (Turnbull & Turnbull, 1996, p. 195). In their seminal work to synthesize the literature on family systems theory with the literature in special
education, Turnbull, Summers, and Brotherson (1984) proposed a framework to organize family systems concepts:

1. Family resources consisted of the descriptive elements of the family, including characteristics of the exceptionality (type, level of severity), characteristics of the family (sizes and forms, cultural backgrounds, socioeconomic status, geographical locations), and personal characteristics (health, intellectual capacity and coping styles). From a systems perspective, resources could be thought of as the input of family interaction.

2. Family interaction referred to the relationships that occurred among subgroups of family members on a daily basis. These relationships—the process of interaction—were responsive to individual and collective family needs.

3. Family functions represented the different categories of needs the family was responsible for addressing. The purpose of output of family interaction was to produce responses to fulfill the needs associated with family functions.

4. Family life cycle represented the sequence of developmental and nondevelopmental changes that affected families. These changes altered family resources (e.g., a child is born) and family functions (e.g., mother stops working outside the home, which provides more time for child rearing but less family income). These changes, in turn, influenced how a family interacts.

Consider how a family system’s philosophy—which includes an understanding of family resources, interaction, functions—allowed parents and professionals opportunities to individualize their relationships, i.e., the unique circumstances of the
family were addressed over time. There should have been no preconceived notions about what the family had experienced (success or failure), what it aspired to, or how it envisioned the future.

The field of special education has traditionally focused attention on the student. Family participation (primarily the mother) has focused on development of the Individual Educational Plan (IEP) and then support of the school’s educational strategies (Wehmeyer, Morningstar, & Husted, 1999). In contrast, the family systems perspective was concerned with how to involve siblings, extended family members, and parents into the student’s transition program; how to access resources and networks of family and friends to help the student live, work, and participate in the community; and how to gauge the impact of the school to adult life transition on the entire family system (Wehmeyer et al., 1999). The difference between this perspective and the family systems approach has been summarized as, “The application of family systems theory to special education requires changes in the answer to the following question: Who is the consumer of services delivered by special education service professionals? In the past, the student has been viewed as the sole consumer. The family systems approach justifies the ‘whole family as the consumer of services’” (Turnbull & Morningstar, 1993, p. 43).

What reasons are there for actively engaging parents and family members as equal partners and reliable allies? Simply, it is the law, but also it is incumbent on the education system in this country to do everything necessary to ensure that students with disabilities make a successful transition from school to adult life. Henderson and
Berla (1995) reported the conclusions of a comprehensive review of research into parent involvement by the PTA of America:

1. When parents were involved, students achieved more, regardless of any other variable (socioeconomic status, parent’s education level, etc.).
2. The more extensive the parent involvement, the higher the achievement.
3. When parents were involved, students exhibited more positive attitudes and behaviors.
4. Students whose parents were involved had higher graduation rates and greater enrollment rates in postsecondary education.
5. Junior and senior high school students whose parents remained involved, made better transitions, maintained the quality of their work, and developed realistic plans for the future (Henderson & Berla, 1995).

According to Wehmeyer et al. (1999), there was probably no other step that educators could take as powerful and educationally effective as creating successful alliances with families. “Effective transition programs must have meaningful, active and equal family involvement” (p. 45).

**The Family Life Cycle**

The family life cycle could be considered as a series of developmental stages. These were periods of time when the family’s lifestyle was relatively stable, and each member was engaged in a series of developmental tasks related to that period of life (Duvall, 1957). Although the exact number and character of life cycle stages was
more or less arbitrary the scheme used by Duvall (1957) has been widely used. The schema was based on three sets of relatively available data—number of positions in the family, age composition of the family, and employment status of the father. The stages of the family life span were as follows:

I. Establishment (newly married, childless).

II. New parents (infants - 3 years).

III. Preschool Family (child 3 - 6 years, possibly younger siblings).

IV. School-Age family (oldest child 6 - 12 years, possibly younger siblings).

V. Family with Adolescent (oldest child 12 - 19, possibly younger siblings).

VI. Family with Late Adolescent (oldest child 16 - 20 until first child leaves home).

VII. Family is launching center (from departure of first to last child).

VIII. Postparental Family, the middle years (after children have left home until father retires).

IX. Aging family (after retirement of father).

Barnhill and Longo (1978) suggested a modification of the Duvall model for stages V and VI to the following:

V. Family with Early Adolescent (oldest age 12 - 16, possibly younger siblings).

VI. Family with Young Adult (oldest age 16 - 20 until first child leaves home).
In doing so, Barnhill and Longo (1978) attempted to delineate more clearly the various family developmental tasks, specifically to account for the increased freedom of youth 16 years and older.

In a family life cycle model, human developmental progression included two components—individual growth and developmental tasks, and family or family-network acceptance and encouragement tasks (Lantz, 1978). Using this framework, the physical, psychological, social, and spiritual development of an individual could be significantly enhanced or disrupted by an individual’s family. This depended upon the degree of a family’s readiness to accept and reinforce individual developmental progression or to move into the family’s life-cycle stage that would most encourage such individual growth for all members of the family unit (Ackerman, 1966). As all families moved through the family life cycle, they encountered periods of transition from one stage to the other. Transitions were the periods of time between stages when the family adjusted its interaction styles and roles to meet the needs of the new developmental stage (Terkelson, 1980). Transitions were usually, but not always, briefer periods than the stages they interfaced. Because these shifts might result in confusion and conflict, the transition period was almost always a time of greater stress (Neugarten, 1976). These transition periods represent potential for what Rapoport (1965) referred to as “normal family crisis.”

Within each phase of the life cycle there was a very real potential for unsuccessful resolution of conflict. However, the family must move forward. Often conflict becomes sealed over, and vulnerable points could be left behind. The
concepts of fixation and regression could come into play when the family encounters stress. With the experience of stress (internal, external, or both), it was likely that old, unresolved conflicts from partial fixation could be uncovered and reemerge (Barnhill & Longo, 1978). Families revert back or regress to old patterns of behavior and unresolved conflicts. So while a family is confronted with one difficulty, an old one is reawakened along with the old pattern of unsuccessfully coping with stress (Barnhill & Longo, 1978). An example of this, which had relevance for families of individuals with disabilities, was unresolved grief. It also might be true that the family experienced difficulty coping with a particular transition form one phase of the life cycle to another. One such example of this for families of children with disabilities was transitioning from preschool to school. Early intervention programs have made great strides in attending to and supporting families. Traditional school programs have lagged behind. It is not surprising, therefore, that families might have sensed loss and uncertainty as they ventured into the public school system with their child who had special needs. They may not have received as much unsolicited support, they probably would have to advocate more, and more than likely there would be increased attention placed on the child’s differences.

**The Launching Phase of the Life Cycle**

The launching phase of the family life cycle represented a period when children “left the nest.” Children were expected to move into increasing independence, freeing their parents to reevaluate and renegotiate their earlier
commitments and to reallocate their energy (Marsh, 1992). It was typically a time of ambivalence. Both parents and children vacillated between independence and dependence. It was a time for young adults to strike out on their own, to experiment, and to explore the world. For some, launching represented complete and total emancipation characterized by a sense of relief. For others, it was merely a time to dress rehearse for life as an adult and then return to the security and familiarity of home. When any child left home, it might not be easy for the parents, but at least it was expected and seen by society as desirable.

As part of normal development, all families struggled with what Collins and Russell (1991) referred to as “modulation of dependency” (p. 100). This was a balancing process between the need for family and the desire to break away. It was part of the continuing redefinition of the parent-child relationship. The modulation of dependency presented significant challenges when the child experienced a nonnormative sequence of events (Pallas, 1993). Poor transition outcomes for individuals with disabilities indicated that the sequence of events leading to adulthood was disrupted for these people because of their disability status (Wagner et al., 1991). Furthermore, families of students with disabilities expressed fears and concerns that these families were also affected by the transition problems experienced by young adults with disabilities (Whitney-Thomas & Hanley-Maxwell, 1996). While families of adolescents with disabilities sought to develop independence in their child (Hanley-Maxwell et al., 1995), sometimes this independence was modified by their child’s ongoing need for support and assistance. Furthermore, this assistance might be
Fear of limited services and decreased expectations for independence altered the process of “modulating dependency” (Collins & Russell, 1991, p. 100).

Like many transition stages of the family life cycle for families of individuals with disabilities, the launching phase might well be delayed or not occur at all (Turnbull & Turnbull, 1986). Such factors as severity of the disability; lack of available community, social, vocational, and residential opportunities; financial dependence of the family on the young adult’s entitlement benefits; and entrenched dependence or interdependence may have served to delay or otherwise prevent the launching process. Bob Helsel (Helsel Family, 1985) described how continued dependency became more of a problem as a child with a disability became older:

In the past [Robin] didn’t present any special problems with respect to limiting my life.... He was a member of my family. We had other children, so taking care of Robin didn’t place any special burden on us. But it seems to me as I approach retirement age and would like lots of personal freedom, he will present a problem in limiting my ability to go where I want. I am aware of the possible limitations or freedom to leave home ... [for parents of normal children] if they aren’t out of the nest, they are at least old enough so that the parents can say to them, “Take care of yourselves; I’ll see you next month!” But with Robin, we can’t do that. (p. 91)

The concerns expressed by Helsel (Helsel Family, 1985) may have reflected the views of someone who raised a child with a disability during an era where families did not have many options in terms of support and services for themselves and/or their children. In years past, families were given the choice of keeping their children at home or placing them in institutions. It was essentially a no-win situation, because if
the child remained at home, there were virtually no community services available for
the child or family. Parents became, by default, the child’s sole source of care giving,
education, and advocacy. There was an understanding that the child would become a
lifelong responsibility. It was assumed. There were no other choices or options than
institutional care.

**History of Transition**

The fields of education and rehabilitation have been concerned about the
transition of adolescents from school to work since the 1940s (Szymaski, 1984).
Much of this concern centered on individuals with mental retardation and how
sheltered employment was viewed as the primary work option. Passage of the
Education for all Handicapped Children of 1975 guaranteed free and appropriate
education for children identified as having a handicap. The law required an
Individualized Education Plan (IEP) that established specific educational goals and
objectives. Additionally, parent involvement in the planning and decision-making
process was a requirement of the statute. Cutler (1993), in describing the special
education process to parents, summarized the act as “a declaration of your child’s
educational rights and of your rights as a parent to participate in the educational
process” (p. 3).

In the early 1980s, federal emphasis was on facilitating transition from school
to work. Two outcome models were proposed by Will (1984) and Halpern (1985).
The targeted outcome in Will’s (1984) model was primarily employment, although
other aspects of adult functioning such as social interactions and leisure activity were considered important. In Halpern’s model (1985), the desired outcome of transition should have been community adjustments, employment, residential adjustment, and establishment of desirable social interpersonal networks. Halpern (1985) further proposed that community adjustment would be enhanced by developing personal factors such as self-esteem and empowering students to select their own goals and make decisions. The models introduced by Will (1984) and Halpern (1985) were both new and nontraditional in that they proposed that schools should be responsible for producing literate Americans and for producing an independent, productive, workforce (DeStefano & Wagner, 1991).

Amendments to the original Education for all Handicapped Children Act of 1975 funded transition services and mandated transition planning for students with disabilities, strongly emphasizing the importance of family involvement and collaboration with the transition process (Education of the Handicapped Children Act Amendments, 1983; Individuals with Disabilities Education Act (IDEA), 1990; Individuals with Disabilities Education Act Amendments, 1997).

Panzer, Pratt, and Wilcox (1989) conducted one of the first studies to examine transition from the perspectives of the participants. Using a statewide survey that included parents, special educators, and adult service agencies, they found that (a) transition information was not getting to parents, and they were unaware of what transition planning was, even though schools and agencies reported having provide such information; (b) transition team participants were dissatisfied with the extent of
their participation in the planning process; (c) parents had very different perceptions than did teachers and other professionals about the extent of transition planning; (d) there were significant differences between what parents wanted for their children and what they thought would be available. Results from the above study seemed congruent with the pervasive assumption that, because of their training and unique expertise, professionals “knew best.” One of the problems that arose from this type of family-professional relationship was that families, the student, and professionals might identify different needs and priorities for the individual student. Professionals still tended to view parents as passive recipients of professional knowledge, despite a decrease in this view during the past fifteen years. Educators, directly or indirectly, communicated this expectation. It built and maintained barriers to positive partnerships (Dettmer, Dyck, & Thurston, 1996).

Wood and Test (1997) conducted an important review of the special and vocational education and rehabilitation literature to determine what areas had been emphasized on the topic of transition since the passage of the 1992 Rehabilitation Act Amendments). Of the 21 articles they reviewed, 16 mentioned the RAA of 1992. Almost all of the articles concentrated on what school programs were doing or should be doing to prepare students before school exit, which preserved the “readiness” paradigm rather than “place and support.” The component receiving little attention was the policy and implementation of supporting service systems, such as agencies concerned with follow-through after school exit and those responsible for post-school outcomes. The supporting service systems included those agencies that focus more of
their attention on individuals during their adulthood (i.e., vocational rehabilitation [VR], mental health, developmental disabilities, Social Security, and others). VR, like the public education system, operated under a federal legislative mandate to collaborate with schools to improve post-school outcomes for students with disabilities. However, research indicated that school personnel, students with disabilities, and their families were not well informed on what was available through the state VR system or other adult services systems (Gallivan-Fenlon, 1994; Benz, Johnson, Mikkelsen, & Lindstrom, 1995).

What the VR system had and was mandated to offer was predicated on individual dignity, choice, self-determination, the pursuit of meaningful careers, and independent living. Additionally, the 1992 RRA supported the involvement of a parent, family member, guardian, an advocate, or an authorized representative if an individual with a disability requested, desired, or needed such support. If the family and/or friends, school personnel, advocate, or others were knowledgeable about the VR system, there was a higher likelihood that the system would work to the benefit of the individual. The Act specified that the student receive a set of activities that were coordinated and based on the individual student’s needs, preferences, and interests, including instruction, community experiences, development of employment, and other post-school adult living objectives.

Most of the rationale for federal legislation and regulations was based on the recognition that many young adults with disabilities were exiting high school unprepared for adult life. Follow-up studies conducted on former special education
students during the past two decades have consistently documented the limited outcomes obtained by young adults with disabilities as they left school and attempted to access employment, postsecondary education programs, and adult community services (DeStefano & Wagner, 1991; Halpern, 1990; Hasazi et al., 1985; Johnson, McGrew, Bloomberg, Bruininks, & Lin, 1997; Wagner, 1993). Major findings included lower than desired academic achievement levels; high drop out rates; substantial levels of unemployment and underemployment; economic instability; and dependence, social isolation, and low levels of participation in postsecondary education and training programs.

For nearly two decades, the Office of Special Education Programs (OSEP) sponsored transition research, demonstration, and training initiatives that resulted in a knowledge base of essential and promising approaches and strategies for the delivery of transition services for youth with disabilities. Examples of previous and current efforts included interagency education and training, supported employment, transition planning, student and parental involvement in school and post-school decision-making, development of adult living skills, and self-determination/self-advocacy.

DeStefano and Wagner (1991) identified the most common outcomes utilized to evaluate students while attending high schools—grades, attendance, and test scores. For youth after leaving school, it was employment, earnings, and residential status. The public school system (most notably special education) was not totally responsible for the success or lack of success of students who left school (Chadsey-Rusch, Rusch, & O’Reilly, 1991). Rather, successful transitions from school to adult life were the
responsibility of many, including educators, parents, the person with a disability, adult
service agencies, administrators, and employers.

The importance of family involvement in education extended beyond students
with disabilities. The National Parent Teacher Association had standards that (a)
promoted two-way school-home communication, (b) supported parenting skill
development, (c) recognized the integral role that parents have in assisting student
learning, (d) expected schools to welcome parents and seek their support and
assistance, (e) expected parents to be treated as full partners in the decisions that
affected their children and their families, and (f) reinforced that schools access those
community resources that would serve to strengthen schools, families, and student
learning (cited in Henderson & Berla, 1995). With so much emphasis on parent
involvement in education, educators and policy makers might have expected that
families and schools would support joint collaboration (Defur, Todd-Allen, & Getzel,
2001; Greene, 1996; Halpern, Yovanoff, Doren, & Benz, 1995; McNair & Rusch,

Families of youth with disabilities continued to report a perception of not
being valued or listened to as they participated in the special education transition
planning process and decision-making. At the same time, schools, particularly
secondary schools where transition planning took place, reported that too many
families of students with disabilities were not involved in their children’s educations,
or at best were passively involved (Davila, 1991; Greene, 1996).
McNair and Rusch (1991) suggested that parents of children with disabilities could assume three roles in the transition process—facilitator, nonparticipant, or difficult parent. In the facilitator role, the parent contributed as an integral and committed member of the transition team and was willing to be involved (e.g., receive training, attend meetings, and/or assist in finding vocational placement or living arrangements). A nonparticipant gave professional, complete control over plan development and implementation. These parents did little more than sign the transition plan and were often viewed by professionals as disinterested. The reality—the so-called nonparticipant parent might have been dealing with a variety of life circumstances that may have made them unavailable (i.e., poverty, substance abuse, and exposure to extensive violence). Families who struggled with such daily issues as feeding their children, domestic violence, and drug abuse may have been incapable of planning the future for their teen with disabilities (Turnbull & Turnbull, 1997). Additionally, cultural backgrounds might have explained why parents chose or otherwise failed to understand the reasons for and importance of being involved. Some families believed that educators and schools knew best and had little interest in assuming a “professional role” when it came to making decisions about their children’s transitions.

The “difficult parent” leaned toward outcomes other than those recommended by the transition team. This may have resulted from disagreement with a particular team member, general stress associated with the uncertainty of the transition period, or philosophical differences between the parent and other team members. Hill, Seyfarth,
Banks, Wehman, and Orelove (1987) found that parents might not have agreed with the transition team about the importance of work in the adult life of a person with a disability. While “one person’s difficult parent is another person’s advocate,” many transition programs tended to avoid or discount the difficult parent (McNair & Rusch, 1991, p. 94). According to McNair and Rusch (1991), transition programs did not necessarily embrace either of the other two types of parents but merely avoided the third type.

McNair and Rusch (1991) determined what parents said their involvement with the transition process had been, what kind of involvement they wanted, and what responsibilities they would be willing to take so as to be involved. The researchers utilized a survey sample of 200 families throughout the United States, having a son or daughter with handicaps, in the age of 14 to 25 years. The sample was identified by the Ohio Coalition of the National Parent CHAIN (Coalitions for Handicapped Awareness and Information Network). The Ohio Coalition contacted the other eight regional coalitions and asked each to identify approximately 20 families in their regions matching the criteria for inclusion in the sample. Of the 200 surveys sent, 108 were returned, and 85 were correctly completed and met the age criteria. Surveys were received from 22 states. Virtually all respondents were White (99%), and all surveys were completed by the mother. Most respondents (51%) lived in suburban areas, while 19% lived in urban and 27% in rural areas.

Results from the McNair and Rusch (1991) study yielded volumes about the discrepancies that existed between what parents aspired to in terms of involvement
during transition and what they actually received. Parents were significantly less involved in transition periods than they desired (70% wanted involvement, whereas 30% experienced involvement). Additionally, more parents desired an equal part in decision-making than were given the opportunity to do so. While 12% of the sample reported no involvement with the transition team, less than 2% desired no involvement. Parents also reported wanting to be involved finding job placements and community living arrangements more often than they had the opportunity to do so. Those parents in the study who had been or were active with their children’s transition programs reported significantly more contact from the school to enlist their involvement, compared to parents who had been less involved or not involved at all. Those parents involved with their children’s transition programs were more aware of community adult service options than were those parents who reported being unaware of their children’s transition programs. Parents who completed the transition program were significantly more likely to think that their child would be living in his or her apartment, once schooling was over, than were parents in the “currently involved” or the “unaware” group.

McNair and Rusch (1991) concluded that significantly more parents wanted to be involved with the transition team and associated equal partnership in the decision-making process than were afforded the chance to do so. They emphasized the importance of schools reaching out to parents and offering a range of involvement opportunities from which they could choose, because parents in their study aspired to
having their children live out of home, work in the community, and earn a minimum wage or better.

Wehman (1990) noted that, among the “best practices” that have been well documented in secondary special education, direct involvement of family and friends was included. Hasazi et al. (1985) interviewed 301 youths regarding employment status after high school and determined that 82% found jobs through self, family, and friends. With family support systems actively involved with the young adults with disabilities, they were more likely to be successful in finding employment.

Brotherson et al. (1993) suggested several strategies to assist families in the transition to adulthood. Special educators needed to help parents, early in their children’s lives, to have a set of expectations related to living, working, being independent, and being fully integrated in the community. Parents should have been encouraged to assign their child chores and acquire paid work experience outside of the home as a means of beginning to understand the world of work. The authors stressed the importance of special educators assisting parents and individuals with disabilities in building informal social support networks and how such networks could play a role in the transition to adulthood.

Often-missing elements in the transition planning process were the ability and willingness of parents to dream great expectations for their children with disabilities and then work to make those dreams become reality (Turnbull & Turnbull, 1988). Special educators helped parents accomplish this by encouraging them early in their children’s lives to see, read about, and experience community efforts for young adults
with disabilities to validate their own dreams of their children’s future independent successes. Transition dreams and expectations needed to begin early to increase the likelihood of transition to positive adult life outcomes (Brotherson et al., 1993).

Special educators needed to be able and willing to work with parents to assess the roles they would like to assume and the associated responsibilities they would like to undertake. This process required special educators to be sensitive and aware of the family’s needs and expectations and to address those issues within the transition planning and implementation process (Everson & Moon, 1987). When educators were willing to discern family disposition toward the future, they demonstrated respect for parent contributions. Special educators could assist parents in recognizing the importance of their contributions by affording specific ways to be involved in the transition process that might include (a) presenting information at transition planning meetings, (b) providing input to other team members regarding family strengths and needs, (c) advocating for a plan that integrated the young adult into the community and decreases dependence on the family, (d) requesting information about the service areas that might have been appropriate (residential, recreational, guardianship, financial, medical, social, behavioral, sexual), and (e) providing informal home and community skill training and behavioral intervention that complimented the secondary curricula (Everson & Moon, 1987). Other suggestions for engaging parents included (a) communicating in a manner that respected their style of communication, (b) developing a parent involvement policy that reflected a variety of options for support
and participation (Schultz, 1986), and (c) providing parents with opportunities to participate on local advocacy and inter-agency planning groups (Everson, 1990).

Some parents might find it helpful to invite an adult consumer who has already been through the transition from the school-to-adulthood process to team meetings. This consumer might be able to help team members identify community services and help the young adult who is in transition to be his/her own advocate.

The importance of family and student involvement was recognized in IDEA, yet only recently had the views of parents on transition, their preferences and choices, their familiarity with the adult service system, and their knowledge about available options been examined in any real depth. The same is true for special education teachers who played a vital role in the transition process (Goldbaum, Rebore, Siegel, & Gates-Kindred, 1994; Roessler, Brolin & Johnson, 1992; Zigmond & Miller, 1992). Research about teacher knowledge, attitudes about transition issues, or familiarity with the adult service system—a key element of transition planning—have been limited (Everson & Moon, 1987; Schmelkin & Berkell, 1989).

Goldbaum et al. (1994) studied how teachers, students, and families could become more effective participants in the transition planning process and better informed of the adult service support system. The study targeted 440 special education students age 16-21 years in the Special School District of St. Louis County. A segregated school system was selected because it was expected that a substantial majority of the population would qualify for services from the adult system serving people with developmental disabilities. Following two mailings of the surveys to
families and teachers of all students in the study population, usable responses were received from 176 (40%) families and 261 teachers who were the teachers of 60% of the students in the study population. There were 110 students about whom completed surveys were received from both parents and teachers; parental permission allowed for 32 students to be interviewed in their homes.

The family/teacher survey had two major sections. The first sought information on the transition-related services that students would need when they completed their school program, i.e., work- and living-related transportation, recreation. The parent surveys identified service needs for parents and their children that were not being met. A 33-item scaled response inventory was developed for this, which sought to identify specific need areas and the relative importance of individual needs, using a 5-point rating scale. The second part of the survey asked parents and teachers about their knowledge and experiences related to the adult service system and about their familiarity with the terms supported living, supported employment, and respite care.

In response to “which living arrangement would best meet the needs of their children” when they are ready to leave home, 41% of parents selected independent living with periodic assistance, 22% chose group homes, 16% chose supervised apartments, and 13% chose specialized facilities. Teachers’ responses to the same question was as follows: nearly half (47%) recommended independent living with periodic assistance, 23% indicated group homes, 16% indicated supervised
apartments, and 6% indicated specialized facilities. These responses contrasted somewhat by the views of students, of whom 63% preferred independent living.

Parents in this study saw supported employment as most suited to the abilities of their children, with 45% of the sample preferring this option over enclaves (17%), sheltered workshop (17%), or adult developmental training programs (14%). Parents of children with more severe disabilities were less likely to choose supported employment. Teachers saw supported employment (48%) as most suitable for their students, followed by enclaves (16%) and sheltered employment (11%). Students believed they would be ready to work when they completed their school program (69%), and they preferred to work along side nondisabled coworkers.

A factor analysis of parents responses revealed five general need areas: (1) service planning and information about services, especially services that would be needed when children were out of school; (2) stress related to caring for the child; (3) respite care; (4) health-related needs; and (5) other specific current needs for services. The higher the education level of the parents, the more likely they were to report a high need for information about future services. Sixty-seven percent of the parents reported some familiarity with the state agency responsible for providing adult services to individuals with developmental disabilities. Parents who were familiar with services (22%) tended to be those who had children with more severe disabilities. Parents’ familiarity with other state level agencies was reported to be quite low. Few teachers had a comprehensive understanding of the adult service system. An interesting finding was that teachers who were more familiar with the service system
tended to discuss a wider set of transition issues with parents. Teachers who discussed a wider set of transition issues were also more likely to be familiar with the terms “supported living” and “supported employment.”

Goldbaum et al. (1994) also found a significant correlation between teacher familiarity with the service system and the likelihood that students had transition plans. “The results of the study indicated that, while some parents had a better working knowledge of the adult service system than others, and individual parents had different information needs, most parents of students in special education required and should be provided comprehensive information on a wide range of transition related issues” (p. 34).

Whitney-Thomas and Hanley-Maxwell (1996) conducted a descriptive and ex post facto study to explore parents’ experiences as their children prepared to leave high school. They documented the differences that existed in transition experiences of parents of students with and without disabilities. Survey participants were 93 parents of students with disabilities and 111 parents of students without disabilities, all of whom were juniors or seniors in high school. This study was the first systematic investigation to compare the transition to adult life process from the perspective of parents of children with and without disabilities. Data were collected through with a questionnaire developed specifically for this investigation. Construction of the Transition Experience Questionnaire emerged from previous research (Hanley-Maxwell et al., 1995), discussed further in Chapter 3.
Factor analysis of the response data covered three major components of the parental transition experiences: (1) Parents’ comfort with the process as their children enter the adult world; (2) their vision of their children’s futures; and (3) their responses to school services. The researchers found differences between the two groups of parents in the areas of both comfort and vision. Parents of students with disabilities showed greater discomfort with the transition process from school to adult life and had less optimistic visions about their son’s or daughter’s future than did parents of students without disabilities. No significant differences were found between the groups of parents on the response to school services variable. The findings from this study document that significant others were involved and affected by the transition of the young person to adult status and that the transition to adult life can be problematic for parents of students with disabilities.

In recent years R.A. Young and his colleagues (Young, 1994; Young & Friesen, 1992; Young, Friesen, & Dillabough, 1991) examined parental influence within the context of career development. According to these researchers, the direction, guidance, encouragement, and specific actions of parents influence the child’s decision making later in life. While this body of research is specifically focused on career development, Young and Friesen (1992) maintained that the implications of this theoretical framework extended beyond merely the parents’ influence in the occupational aspirations and choices of their children. Indeed, Marini (1985) maintained that the expectations of others during both high school and the
transition years after high school mediated the process by which a young person took on adult status.

**Summary**

While others influence the decisions being made and events taking place during the transition to adulthood, this particular investigation focuses only on the perspectives of parents. From the growing body of literature that has queried parents about the transition process, it has become apparent that parental perspectives could be understood as an amalgam of at least three constructs. First, parents build hopes and dreams for their children’s futures, and their visions may in turn help shape the transition process. Second, parents involve themselves in their children’s transitions by engaging in planning and activities, which contribute to the realization of their visions. Third, parents’ expression of how comfortable they are with the transition process could provide a measure of how these individuals respond to this stressful period in their families’ lives. An investigation of the strength of parents’ visions for their children, their level of engagement with formal and informal support and planning activities, and their general level of comfort with the transition process could provide valuable information to those interested in designing smooth and successful transitions for students as they leave school and enter into adult life. The ways in which the themes of parents’ visions, engagement, and comfort have been operationalized in recent empirical and theoretical literature will be described, so as to further establish the groundwork for this study.
Measures of Parental Perspectives of the Transition Process

Vision - Critical components of parental visions for their children’s post-school lives include (a) a safe, happy residential and social life away from the family home (Hanley-Maxwell et al., 1995; Haring & Lovett, 1990; McDonnell, Wilcox, Boles, & Bellamy, 1985) and (b) increased self-definition by the young adult (Zetlin & Turner, 1985). Ferguson et al. (1988) called the change from child to adult a status transition, which is symbolized by landmark events such as graduation, turning 21, and moving into one’s own home. The transition to adult life involved more than merely the accomplishment of these events; rather it evolved over a period of time. For families of young adults with disabilities, however, parents’ visions for their children were often clouded by conflict, concern, and fear (Hanley-Maxwell, Pogoloff, & Whitney-Thomas, 1998; Zetlin & Hosseini, 1989). In addition, while young adults without disabilities envisioned increased autonomy and personal control for themselves (Moore & Hotch, 1981), parents of young adults with disabilities sensed parental control during this transition (Ferguson et al., 1988). Parents of students with disabilities may not have placed the same emphasis on self-definition as did parents of students without disabilities in their respective visions for their children. Additional research is needed, however, to better understand the complexity of the visions that parents hold for their children as they enter adult life.

Engagement - The literature that investigated the transition from school to adult life for students without disabilities emphasized increasing autonomy on the part
of the young person and a subsequent disengagement from the parents (Fleming & Anderson, 1986; Steinberg & Silverberg, 1986). This does not mean that parents were not involved in the planning of their children’s transitions or in their daily lives (Ryan & Lynch, 1989). There was, however, a paucity of empirical research that documented exactly how parents of students without disabilities were engaged in their children’s transitions into adult life.

As discussed above, the expectation of increased independence existed for young adults with disabilities. Because of individual and service limitations, parent involvement in the transition process seemed much more complex for students with disabilities. Indeed, Zetlin and Hosseini (1989) remarked that, “given the uncertainty of these young adults’ future, such support [as provided by parents] will continue to be required and then provided” (p. 411). The types of support that parents provided their children included helping them to find jobs and living arrangements (Zetlin & Hosseini, 1989), advocating for their children (Hanley-Maxwell et al., 1995), and planning for their children’s futures (Mithaug, Horiuchi, & Fanning, 1985).

Parents, however, were not alone in providing these supports to their children; therefore, parental involvement with service delivery systems was another way to measure engagement in transition planning. Indeed, parents relied heavily on the schools and adult services to help them achieve their visions and supplement their own efforts during the transition process (Hanley-Maxwell et al., 1995).

The relationship between parents and service providers was far from perfect, often parents were left with a sense of abandonment and surrender to the forces of
inadequate services and problematic working relationships (Ferguson et al., 1988; Hanley-Maxwell et al., 1995). In general, parents should have been encouraged to play central roles in the transition planning process. It was important for professionals to recognize that parents must determine the type and level of involvement that best suited their needs and that these needs may have changed over time (Hains, Fowler & Chandler, 1988). Additional research is needed to identify the services and supports that parents of students with and without disabilities currently use to better understand the roles parents play in their children’s increasing independence.

Comfort with the transition process - Reports of how parents responded to the transition process often were limited to ways parents described the stress they experienced during this time of life. Recent qualitative research, which analyzes the language of parents to understand their perspective, reported that parents expressed a great deal of uncertainty compounded by fears and frustrations (Hanley-Maxwell et al., 1995; Zetlin & Turner, 1985). Hanline and Knowlton (1988) described the dread sensed by parents as their children made the transition from preschool to elementary special education programs. These same feelings occurred for parents when their children left high school and entered an uncertain adult world (Ferguson et al., 1988). These feelings, however, may have been brought on by the complicated nature of the transition process for families of students with disabilities and might have been symptomatic of the stress inherent in the launching stage in general. Parents of graduating students without disabilities reported increased stress and
communication problems just before the time that the young adult left home (Anderson, 1990).

Available services and supports – For a person with a disability, the question of living and working independently in the community cannot be fully addressed without consideration of available services and supports. According to Irvin, Thorin, and Singer (1993), parents of young adults often were conflicted about the availability of services to meet the family’s goals. It was not uncommon to encounter long waiting lists and stringent eligibility requirements. Some communities continued to perpetuate a sheltered workshop and congregate residential care mentality. The challenge of inadequate service was not new for parents in the transition of their children to adult status, because parents also had faced these issues in schools. Most services for adults with disabilities continued to be segregated, encouraged lifelong dependency, and offered limited opportunities to participate in community life in typical adult ways (Gallivan-Fenlon, 1994). New was the erratic, nonexistent, or philosophically oppositional availability of services combined with the application of cultural norms that typically included less active parental involvement in the daily life of the child (Ferguson & Ferguson, 1987).

Another issue related to the availability of services and supports was the long-term viability of the supports and services being offered. The turnover rate among direct service personnel was very high, and funding for programs was never assumed. These factors often affected a family’s decision-making process. In a qualitative study of parents’ perspectives and needs during their children’s transition from school to
adult life, Hanley-Maxwell et al. (1995) identified five broad areas of need: (1) reliable, accessible and high quality services that addressed all aspects of adult life (e.g., transportation, adult education, recreation, residential, vocational); (2) physical separation of adult child from family through the provision of homelike residential alternatives; (3) support networks for parents, families, and adult children (e.g., respite, friendships, natural supports, and parental assistance); (4) service systems that responded to family and individual needs and goals in the time frame determined by the family and the adult with the disability (e.g., flexible service, broadening the definition of transition beyond the employment focus, increasing availability of services, providing nontraditional supports to families, refocusing the end goal to the happiness of the adult with the disability); and (5) multiple and diverse experiences for students before leaving high school.

It appeared that families who had youth with disabilities encountered very real concerns about the quality and quantity of services and supports available for their children. It is clear that these concerns may have extended well beyond the usual time construct of the launching phase of the life cycle, whether in anticipation of movement away from the family or after the individual was living away from home.

**Psychological coping** - Most parents were concerned about the safety and well being of their children in anticipation of their leaving home. While the extent of concern varied depending on cultural background, cohesion of the family system, and family values, families of children with disabilities were influenced by past experience as it related to their perspectives about the future (Ferguson et al., 1988).
According to Rainford, York, and McDonald (1992), parents had experiences that influenced their expectations for their children. Many of these experiences seemed to be reflections of their children’s personal characteristics, such as appearances and personalities. For many families of children with disabilities, the future represented giving up the familiar for something that was unknown. There often were questions about how the young adult would be able to make his or her wants known or discern who was trustworthy, and the extent to which they might have sensed loneliness or abandonment. There was also the question of how isolated the young adult might have seemed. Clearly a number of psychological factors, both on the part of the family and the young adult with the disability, were important to consider during the launching phase of the family life cycle. It is difficult to say that the psychological impact of the launching phase of the family life cycle was more challenging for families who had a member with a disability than for those who do not... so much depended on the experiences, values, and aspirations of the family system.

**Social implications** - Mothers of adolescents with disabilities mentioned the development of friendships with peers who did not have disabilities as being important (Hamre-Nietupski, 1993; Lehmann & Roberto, 1996). It was been noted that the potential for adolescents with disabilities to be lonely and viewed as “bad” or as noncontributing members of society was frightening for some parents (Lehmann & Roberto, 1996). With the advent of educational inclusion for children with disabilities came increased optimism for acceptance and understanding. According to Stainback and Stainback (1990), advocates of inclusion practices suggested that intensive
contact with people with disabilities would change society’s perspective of avoidance and fear to one of mutual respect and appreciation. The stigma associated with disabilities probably would not change much through using such approaches as public service announcements. Rather attitudes would be better changed by affording people opportunities to “sell themselves.” While considerable emphasis had been placed on teaching acceptable social and behavioral skills to people with disabilities, these efforts in some ways paled by comparison to proactive attempts to link people with disabilities to people in the community who might have been willing to accept them for who they were and what they had to offer. The following case example illustrates this point.

A community transition team was working with Harry H. to find him a job; however, he had spitting behavior, which the team felt would interfere with his ability to obtain competitive employment. Based on this assessment, the team embarked on a comprehensive and coordinated effort to get the spitting behavior under control. After several months of a strict behavioral program, Harry H. was no longer spitting. Everyone was pleased and a search was undertaken to locate a job for Harry H. in the community. Eventually, a job was found for him at a local trucking company. He was to work on the loading dock loading and unloading trucks. Curiously enough one of the favorite pastimes for men working on the loading dock was spitting. It was the socially acceptable thing to do in that particular setting. (personal communication with a supported employment training supervisor)

Prejudice in our society will not go away. Attitudes and preconceived notions do not automatically disappear. People with disabilities can make friends, provided they are afforded opportunities and supports to do so. Societal acceptance will improve as families and professional support staff increasingly allow people with
disabilities to take risks and actively promote their own participation in community. From a social perspective, the launching phase of the life cycle was as much about parents and siblings “getting a life” as it was for their family member with a disability. These families had to adjust, as all families do, to what they would do with their time, energy, and attention, once the child is no longer at home.

Financial considerations - Financial concerns among families of young adults with disabilities have been identified as a major source of stress (Thorin & Irvin, 1992). Although concern about the young adult getting a job was the single most frequently reported concern and was rated moderately stressful, the concern was reported to occur infrequently. In their study of 109 families of young adults with developmental disabilities between the ages of 15 and 25 years, Thorin and Irvin (1992) found that the responses from families concerning individual overall stress and family overall stress were dependent upon the kind of questions asked about stress. Financial and job-related concerns and associated stress ranked second only to residential concerns.

As has been mentioned, some families came to depend on the subsidy allotment for their child with a disability, thereby eligible for medical coverage. The prospect of employment brought about concerns that the individual might or might not be able to generate the same income they previously received from one or more entitlement programs. It is also well known that individuals with disabilities might be able to work only part time and/or in positions that do not offer health coverage. For these reasons, it as easy to understand why some families resisted attempts to promote
competitive employment for their sons or daughters, even though it has been well
documented that people with even the most severe disabilities can be successfully
employed and that it significantly increased their sense of self worth, improved
opportunities for community participation, and allowed them to feel as they were
making a contribution. Clearly financial concerns were a related disincentive to work.
According to Gallivan-Fenlon (1994), adult service providers, school personnel, and
families held more restrictive expectations from employment, community living, and
community participation than young adults do for themselves.

Spiritual adjustment - While much has been written about the objective burden
of having a child with a disability, there was increasing evidence of the benefits and
opportunities that also could accompany the familial experience (Marsh, 1992). Much
of the professional literature written by and for parents focused on the joys and
satisfactions of having a child with a disability (Darling, 1987). Many families
demonstrated significant resilience that Richmond and Beardslee (1988) referred to as
the family’s positive response to stress, which involved both the ideas of stressors and
the capacity to respond, to endure, or to develop and master.

The literature paid little attention to the spiritual faith of families of youth with
disabilities as they moved through the launching phase of the life cycle. Professionals
rarely mentioned the spiritual potentials for families. This was indeed unfortunate
because spirituality may well have been a driving force behind the family’s ability to
cope with and ultimately rejoice in the success of its accomplishments.
Helping families to find meaningful potentials should be a major focus of the vocational, educational, and social programs that are presumably in the business of helping youth with disabilities and their families. Rather there was a tendency to promote a system that encouraged dependence and segregated experiences. It was indeed during the launching phase that parents needed to find ways to deal with their children’s aspirations for independence and adjust to how they would redirect their time, attention, and energies. They should be supported in efforts to identify new activities and interests and encouraged to explore their spiritual worlds.

The family response - The advent of having a child with a disability presented special challenges and opportunities for the family unit. Considerable attention has been given to characterizing how families coped with and adapted to the child’s special needs (Marsh, 1992). Parents’ reactions to the birth of a child with disabilities widely varied. Factors such as religion, cultural orientation, socioeconomic status, level of education, personal goals, family support, severity of the child’s disability, how the diagnosis was conveyed, when and if the diagnosis was determined, amount of accurate information available to parents relative to the prognosis, and available resources could all effect how each family member responded (Alper et al., 1994).

There was much evidenced that family members experienced a wide range of powerful emotions in response to a diagnosis of developmental disability, including denial, shock, anger, grief, guilt, embarrassment, depression, withdrawal, ambivalence, disillusionment, and fear (Marsh, 1992). Professionals have maintained that family members underwent a process of adaptation that was similar to a mourning
process. From this perspective, it was generally assumed that family members passed through a series of stages as they mourned the loss of the normal child they anticipated. Olshansky (1962) labeled the continuing reactions to having a child with a disability as chronic sorrow. This was a useful concept because it assumed the feelings and emotions experienced by parents did not automatically get resolved and go away. The sorrow continued throughout the parent’s life. The extent to which the chronic sorrow was experienced varied over time.

In addition to ongoing emotional responses to the disability, families frequently encountered day-to-day challenges associated with the child’s disability, including increased care giving, financial demands, atypical development and behavior, discontinuity of services and support, and curtailed family activity. It was noted that raising a child with a disability involved more challenges than did raising a child without disabilities. The likelihood of long-term care, additional medical expenses, and the stigma still associated were just a few examples of the additional challenges that families face.
CHAPTER 3
METHODOLOGY

Research Design

A randomized pretest-posttest control group design was selected for this study. This particular design, by virtue of using a pretest, helped ensure that the experimental and control groups were really similar and that they were equivalent as a result of random assignment (Fraenkel & Wallen, 1992). The use of a true experimental design for this study significantly improved the probability of determining the impact of the independent variable (treatment) on the dependent variable (parent attitudes). In presenting this design, Campbell and Stanley (1963) suggested using an “X” to represent the exposure of an experimental group to treatment, experimental variables or events, and an “O” to represent a process of observation or measurement. The “R” represented random assignment to separate groups, one being experimental group and the other the control. Campbell and Stanley (1963) suggested that the pretest-posttest control group design should be diagrammed as follows:

Treatment Group: R O X O

Control Group: R O O
The pretest-posttest control group design is the most frequently used experimental design and is highly recommended for controlling the major threats to internal validity, i.e., history, maturation, testing, instrumentation, regression, selection, mortality, and interaction of selection and maturation (Campbell & Stanley, 1963).

From the standpoint of external validity, the pretest-posttest control group design raises the possibility of an interaction of testing and treatment threat. In other words, it may “alert” the members of the experimental group to do better (or more poorly) than members of the control group (Fraenkel & Wallen, 1993). The main trade-off, however, is that this design provides a means for assuring equivalence between the experimental and control group. Figure 1 provides the design used for the present study.

**Figure 1. Design of the Study**
Population and Sample

The target population for this study was parents of youth with disabilities between the ages of 16-24 years, living in Ohio, who were on the waiting list for supported living services. Each of Ohio’s counties had a designated County Board of Mental Retardation and Developmental Disabilities. These County boards were established in 1974 to serve people with moderate, severe, and profound mental retardation and developmental disabilities. County board programs were responsible for providing a full spectrum of services across the life span.

Ohio’s county boards of MRDD were required to determine eligibility through administration of the Ohio Eligibility Determination Instrument (OEDI), required for every new adult applicant. A similar document was used (the COEDI) for children. The OEDI was a 30-page document used to determine the severity of the applicant’s disability. The seven functional areas addressed in the OEDI included self-care, receptive and expressive language, mobility, self-direction, capacity for independent living, learning, and economic self-sufficiency. Each of these areas contained several items dealing with a particular aspect of that area (self-care, for example, included items dealing with eating a prepared meal, toileting, dressing and undressing, taking care of bathing and grooming needs, and taking medications). In addition, each item had several sub-items that needed to be addressed when determining whether the applicant could adequately complete each item (for example, eating a prepared meal
included sub-items that addressed cutting the food, eating the meal within an hour, eating without choking, eating without excessive spillage, lifting food and drink to mouth, and chewing and swallowing adequately). If the applicant was determined by the OEDI to have limitations in at least three of the seven areas, then they were eligible for County Board Services.

The OEDI eligibility determination process began in 1992, taking into account functional capacity based on the seven areas previously mentioned. Before 1992, individuals were eligible for services based solely on a diagnosis of mental retardation, epilepsy, cerebral palsy, autism, or severe learning disability. The change resulted in many more individuals being eligible for services—individuals often had three substantial limitations without having a specific diagnostic label.

When the present study began (September 1999), 173 individuals between the ages of 16-24 years were on the waiting list for supported living services in Franklin County OH and presumed to be living with nuclear or extended family. For those living in another arrangement, the primary caretaker was the target study participant. Supported living services referred to residential environments chosen by individuals with disabilities based on where and with whom they chose to live. Services and supports were provided based on individual need by an agency selected by the individual. In Franklin County, Supported Living options included 3-bedroom homes for up to three people and apartments for individuals or roommates. Individuals on the waiting list for supported living were not interested in group home or larger medical regulated facilities.
The researcher secured permission from the Franklin County Board of Mental Retardation/Developmental Disabilities (FCBMRDD) to randomly select and assign youth with disabilities and their families from the supported living waiting list. Based on a power analysis, a sample size of 40 parents for the experimental and 40 parents for the control group was needed for this study. Based on the required sample size, subjects were selected using a simple random selection. This procedure is one in which each member of the population has an independent and equal chance of being selected. A table of random numbers was used to select subjects. The advantage of random sampling is that it is likely to yield a representative sample (Fraenkel & Wallen, 1993)

For this study, subjects were randomly assigned to the experimental or control group. Random assignment means that every individual who is participating in the experiment has an equal chance of being assigned to the experimental or control conditions being compared (Fraenkel & Wallen, 1993). Random assignment is intended to eliminate the threat of extraneous variables that the researcher may or may not be aware of and which could well affect the outcome of the study.

Recognizing that the sample for this study would be drawn from a waiting list for supported living services presented some special considerations. The “What’s Next” program intervention (Appendix A) received significant publicity. Families became increasingly aware of the program. As a result, it was considered unethical to withhold the program from control group participants. Therefore, “What’s Next” was viewed as a springboard for ultimately participating in supported living. Control
group participants were informed that the “What’s Next” program would be made
available to them within three to five months after their involvement with the study.

**Program Description**

The “What’s Next” program was conceived and developed by this researcher and a parent of a young woman with mental retardation (Appendix A). It stemmed from lengthy discussions about the lack of opportunities for families to be involved in planning for transition. Our experience told us that meetings to discuss transitions to adult life were too often brief and did not fully provide information or emotional support that families and their young adult children needed to make decisions about the future. We wanted to provide a setting in which emotional support, information, and guidance were available over an extended period of time. The first “What’s Next” group was began in February 1998 for four weeks. As the group progressed, we received feedback from the families that they wanted to continue the meeting. Both staff and families agreed to continue the program two additional weeks.

Since the inception of “What’s Next,” more than 200 families have been served, with five groups being offered each year. Each group served between 8 to 10 families. Sessions were 1.5 hours in length and were held during 6 consecutive weeks, with the exception of holidays. The sessions were held in two adjacent houses owned by the County Board of MRDD. The living rooms in both houses provided a comfortable and relaxed setting. The only disadvantage to the houses was that they were located in a suburb outside of the city and somewhat out of the way. Despite
these limitations, the dropout rate once families entered the program has been less than 5%. Additionally, the aggregate attendance rate has consistently been approximately 80%. In other words, families seldom dropped from the program and generally attended all six sessions. Satisfaction ratings were consistently high (Appendix B). It should be noted that parents and professional staff leading “What’s Next” groups were surprised by how little children and their parents knew about services, resources, and supports in the community.

“What’s Next” was a 9-hour information and support group held over the course of six consecutive weeks. Parents attended sessions with their young adult children with disabilities. The young adults met separately from their parents except for half of the first session, during which time introductions were made and the overall program was explained. The young adults discussed self-determination, social supports, problem solving, and leisure activities. Affording the young adults a chance to build friendships and identify prospective roommates were major goals of the young adult sessions.

“What’s Next” parent sessions covered the following topics: definition of supported living and available options, entitlement benefits, explanation of the individualized service plans, separation issues, estate planning (guardianships, trusts), employment, selection of service provider, social and leisure activities, safety, and transportation. All groups were co-facilitated by parents and professional. The staff remained a constant for all groups. Staff for the parent group included a parent employed by the FCBMRDD, a social worker from the Nisonger Center UAP at The
Ohio State University, and a case manager form the FCBMRDD. They facilitated group discussion, coordinated talks by outside presenters, and presented material to the group based on their expertise, i.e., individualized service plan development, employment, and estate planning. Additionally, these individuals assisted parents with locating resources and provide emotional support on an individual basis as needed, both during and after the program. Staff for the young adult group consisted of a MSW social worker, a consumer receiving supported living services, and 2 case managers from FCBMRDD. The curriculum (Appendix A) was designed to be similar from group to group, but the focus may have differed somewhat, depending on the information and support needs of each group.

**Data Collection**

Four types of information were necessary to conduct this study: (1) demographic information on all youth and parent subjects, (2) pre- and posttest data on parents’ attitudes toward transition, (3) pre- and posttest data on family hardiness, and (4) qualitative information describing parents’ views about their children’s involvement in work and community activity. The participants completed an instrument package comprised of three components: Vocational and Community Involvement Profile (VOCIP) (Fish et al., 1997), Transition Experience Questionnaire (Whitney-Thomas & Hanley-Maxwell, 1996), and the Family Hardiness Index (FHI) (McCubbin et al, 1996). Each instrument is described below.
Vocational and Community Involvement Profile (VOCIP)

The Vocational and Community Involvement Profile (VOCIP) was created by Fish, Hayman, Martin, Moore, and Rearick (1997) (Appendix C). Its initial purpose was to have a systematic tool to better understand parental concerns about transition. As the process moved forward, the authors recognized the potential benefit of using the instrument for research purposes. The instrument contains three sections: (1) a 46-item, 7-point Likert scale where 1 equals strongly disagree and 7 equals not applicable; (2) a 12-item sociodemographic section covering items such as gender, age, race, marital status, income, severity of child’s disability, level of education, and employment status; and (3) a form containing 5 open-ended questions about parents’ views toward work and community involvement, e.g., an employer would like the following qualities about my child, I would like to see my child work as, I have the following concerns about my child’s independent living.

The VOCIP underwent review by a panel of parents of youth with disabilities, academic experts, and professionals in the field of transition to assess its content and face validity (DeVellis, 1991) (Appendix D). The feedback from the pilot test was incorporated into the final questionnaire. Items were originally generated by the authors based on a thorough review of the literature, discussions with local and national experts in the field of transition, and their own extensive personal and professional experiences. Decisions regarding retaining and/or omitting items were based on feedback received during the preliminary process of instrument validation.
**Transition Experience Questionnaire**

The Transition Experience Questionnaire, containing 60 items using a 4-point Likert scale, is designed to explore the following 4 factors: (1) parents’ visions for their children’s futures, (2) parents’ comfort with the transition process, (3) their response to the schooling process, and (4) ongoing family connection. The internal consistency estimates of the subscales are reported as follows: (a) Comfort alpha = .88; (b) Vision alpha = .83; (c) Response alpha = .85; (d) Connections alpha = .60 (Whitney-Thomas & Hanley Maxwell, 1996).

**Family Hardiness Index (FHI)**

When this study was originally proposed, the author had intended to use the Parenting Stress Index (PSI) by Abidin (1976), but it became apparent that the Family Hardiness Index (FHI) by McCubbin et al. (1996) would be better suited to measure parents’ perceptions of their families’ resilience. Additionally, the PSI would not have rendered feedback on the particular type of stressors these families experienced.

McCubbin et al. (1996) developed the Family Hardiness Index (FHI) in 1987 to measure the characteristic of hardiness as a stress resistance and adaptation resource in families that would function as a buffer or mediating factor in (a) mitigating the effects of stressors and demands and (b) facilitating family resiliency adjustment and adaptation over time. Family Hardiness referred to the internal strengths and/or ability of the family unit. The FHI consisted of 20 questions dealing with commitment (8 items), challenge (6 items), and control (6 items). Commitment was an 8-item scale
that measured the family’s sense of internal strength, dependability, and ability to work together (items #4-9, #11, #18). Challenge was a 6-item scale that measured the family’s efforts to be innovative and active, to experience new things, and to learn (items #12-17). Control was a 6-item scale that measured the family’s sense of being in control of family life rather than being shaped by outside events and circumstances (items #1-3, #10, #19-20).

The overall internal reliability for FHI was .82 (Cronbach’s alpha). For each of the subscales (commitment, challenge, and control) in the newer 3 subscales approach, the internal reliabilities were .81, .80, and .65, respectively (Cronbach’s alpha). A set of tests to validate the measure of family hardiness included the systematic examination of the association between hardiness and other criterion indices of family strengths hypothesized to be associated with hardiness. The test-retest reliability for the FHI was .86.

**Data Collection and Treatment Procedures**

A structured process for selecting a sample representative of the population was implemented by using a randomization method to select the sample (n = as per preliminary power analysis). Subjects (n = 80) were then randomly assigned to the treatment (n = 40). Pretest data were collected one week before and one week after the 6-week treatment (“What’s Next”) intervention by a mail survey for both the experimental and control groups. There was a total of five mailings, each of which corresponded to the start of a “What’s Next” group. Participants received, through a
first class mailing, survey booklets and specific instructions on completing and returning the questionnaire. The mailing, sent out two weeks before the intervention, included a cover letter explaining the information being requested, information that a follow-up survey would be sent in nine weeks, instructions about how to return the survey packet, information about financial incentive for participation, and that study results would be made available upon request (Appendix E). All parent participants were offered $25 to complete pre- and posttest survey packets in a timely manner. Reimbursement took place after the second survey packet was received.

In addition to mailing surveys, the researcher attempted to contact all participants by telephone before receiving pre- and posttest survey packets. Participants were encouraged to respond, informed about financial remuneration, and were given a number to call regarding any question regarding the process. Instructions were also provided to control group participants about future involvement in “What’s Next.”

In line with the Total Design Method (TDM) of survey research (Dillman, 2000), several steps were taken to ensure a good response rate. First was a business reply envelope, professionally printed with the address of the university and the return address of the department for the return of the completed questionnaires. Second was a cover letter stressing that respondents should be open in their responses because the data would be used in an aggregate manner and responses were anonymous. Each mailing utilized a different commemorative stamp, designed to encourage respondents
to read the mailing and to boost the return rate (Dillman, 2000). They also served as an indicator regarding the mailing to which the respondent was replying.

A total of 58 and 41 pre- and posttest packets were returned by the experimental and control group, respectively. Six subjects from each group were rejected because of omitted data. Additionally, 7 subjects from the experimental group and six subjects from the control group completed pretest packets but never completed posttest packets despite repeated mailings and telephone follow-up attempts. Actual data analyzed for the study included 45 subjects in the experimental and 29 subjects in control groups.
CHAPTER 4
ANALYSIS OF THE DATA

Results

The results section is divided into five major parts. Section #1 provides a comprehensive description of respondent characteristics and descriptive information about their children. In Section #2, assessment data are presented about the TEQ and FHI. Section #3 reports findings from an exploratory factor analysis of the VOCIP and a reliability study with the sample population. Scale correlations of the TEQ, VOCIP, and FHI are reported in Section #3. Section #4 presents a series of model testing that corresponds with the hypotheses and research questions.

Description of Respondents

At the time of the study, all of the respondents had children who were developmentally disabled based on having been deemed eligible for services from the Franklin County Board of Mental Retardation and Developmental Disabilities (FCBMRDD), Columbus OH. In addition, all of the children were on the supportive living waiting list. Table 1 describes the children whose parents participated in the study. A total of 19 males and 10 females had parents in the control group, while 23
males and 22 females had parents in the experimental group. A chi-square test of significance was used to determine if differences existed between experimental and control groups. This nonparametric test was used to analyze data that were reported in categories. The chi-square test was based on a comparison between expected frequencies and actual, obtained frequencies (Fraenkel & Wallen, 1993). A critical test value of .05 or less was used as a decision criterion. The results of this test ($\chi^2 = 1.49$, df = 1, $p = .22$) indicated that there was no significant difference between the groups.

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Control</th>
<th>Experimental</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>19 (25.7)</td>
<td>23 (31.1)</td>
<td>42 (56.8)</td>
</tr>
<tr>
<td>Female</td>
<td>10 (13.5)</td>
<td>22 (29.7)</td>
<td>32 (43.2)</td>
</tr>
<tr>
<td>Total</td>
<td>29 (39.2)</td>
<td>45 (60.8)</td>
<td>74 (100.0)</td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>28 (37.8)</td>
<td>38 (51.4)</td>
<td>66 (89.2)</td>
</tr>
<tr>
<td>Black</td>
<td>0</td>
<td>4 (5.4)</td>
<td>4 (5.4)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>1 (1.4)</td>
<td>1 (1.4)</td>
<td>2 (2.7)</td>
</tr>
<tr>
<td>Indian/Alaskan</td>
<td>0</td>
<td>1 (1.4)</td>
<td>1 (1.4)</td>
</tr>
<tr>
<td>Other</td>
<td>0</td>
<td>1 (1.4)</td>
<td>1 (1.4)</td>
</tr>
<tr>
<td>Total</td>
<td>29 (39.2)</td>
<td>45 (60.8)</td>
<td>74 (100.0)</td>
</tr>
<tr>
<td>Disability</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild</td>
<td>10 (13.5)</td>
<td>3 (4.1)</td>
<td>13 (17.6)</td>
</tr>
<tr>
<td>Moderate</td>
<td>14 (18.9)</td>
<td>19 (39.2)</td>
<td>43 (58.1)</td>
</tr>
<tr>
<td>Severe</td>
<td>5 (6.8)</td>
<td>13 (17.6)</td>
<td>18 (24.3)</td>
</tr>
<tr>
<td>Total</td>
<td>29 (39.2)</td>
<td>45 (60.8)</td>
<td>74 (100.0)</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean Age – yr</td>
<td>Mean = 19.7</td>
<td>Mean = 19.6</td>
<td>Mean = 19.7</td>
</tr>
<tr>
<td></td>
<td>SD = 2.3</td>
<td>SD = 2.0</td>
<td>SD = 2.1</td>
</tr>
</tbody>
</table>

Table 1. Child Demographics
Table 1 also compares experimental and control groups on the child’s race. No significant differences between the two groups was found ($\chi^2 = 4.25$, df = 4, $p = .37$). However, there was a significant difference between experimental and control groups on the variable of child’s disability level. Table 1 reflects that parents of the experimental group had children with more moderate (39.2%) and severe (17.6%) disabilities when compared with parents in the control group who had children with moderate (18.9%) and severe (6.8%) disabilities. Level of disability was the only child demographic for which there was a significant difference between groups; possible explanations will be discussed in Chapter 5.

The final child demographic presented in Table 1 is age of child whose parents participated in the study. The mean age for children was 19.7 years in the control group and 19.6 years in the experimental group. There was no significant difference between the two groups ($t = .16$, df = 72, $p = .875$).

Table 2 presents family demographics. For parent’s relationship to the child, the control group had 24 mothers and 5 fathers, while the experimental group had 27 mothers and 10 fathers. There were 7 additional respondents in the experimental group who were grandparents, foster parents, or stepparents. There was no significant difference between the control and experimental groups on the family demographic of parent’s relationship to child ($\chi^2 = 6.02$, df = 6, $p = .422$).
<table>
<thead>
<tr>
<th>Demographic</th>
<th>Control</th>
<th>Experimental</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Relationship</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>24 (32.4)</td>
<td>27 (36.5)</td>
<td>51 (68.9)</td>
</tr>
<tr>
<td>Father</td>
<td>5 (6.8)</td>
<td>10 (13.5)</td>
<td>15 (20.3)</td>
</tr>
<tr>
<td>Foster Parent</td>
<td>0</td>
<td>4 (5.4)</td>
<td>4 (5.4)</td>
</tr>
<tr>
<td>Step Parent</td>
<td>0</td>
<td>2 (2.7)</td>
<td>2 (2.7)</td>
</tr>
<tr>
<td>Grandparent</td>
<td>0</td>
<td>2 (2.7)</td>
<td>2 (2.7)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>29 (39.2)</td>
<td>45 (60.8)</td>
<td>74 (100.0)</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>17 (23.0)</td>
<td>28 (37.8)</td>
<td>45 (60.8)</td>
</tr>
<tr>
<td>Divorced</td>
<td>12 (16.2)</td>
<td>13 (17.6)</td>
<td>25 (33.8)</td>
</tr>
<tr>
<td>Widowed</td>
<td>0</td>
<td>3 (4.1)</td>
<td>3 (4.1)</td>
</tr>
<tr>
<td>Never Married</td>
<td>0</td>
<td>1 (1.4)</td>
<td>1 (1.4)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>29 (39.2)</td>
<td>45 (60.8)</td>
<td>74 (100.0)</td>
</tr>
<tr>
<td><strong>Employment</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hourly</td>
<td>13 (17.8)</td>
<td>20 (27.4)</td>
<td>33 (45.2)</td>
</tr>
<tr>
<td>Salaried</td>
<td>9 (12.3)</td>
<td>8 (11.0)</td>
<td>17 (23.3)</td>
</tr>
<tr>
<td>Self-Employed</td>
<td>2 (2.7)</td>
<td>5 (6.8)</td>
<td>7 (9.6)</td>
</tr>
<tr>
<td>Unemployed</td>
<td>3 (4.1)</td>
<td>1 (1.4)</td>
<td>4 (5.5)</td>
</tr>
<tr>
<td>Retired</td>
<td>1 (1.4)</td>
<td>7 (9.6)</td>
<td>8 (11.0)</td>
</tr>
<tr>
<td>Homemaker</td>
<td>1 (1.4)</td>
<td>3 (4.1)</td>
<td>4 (5.5)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>29 (39.7)</td>
<td>44 (60.3)</td>
<td>73 (100.0)</td>
</tr>
<tr>
<td><strong>Household Income</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;$9,999</td>
<td>4 (5.6)</td>
<td>0</td>
<td>4 (5.6)</td>
</tr>
<tr>
<td>$10,000 - $19,999</td>
<td>1 (1.4)</td>
<td>5 (6.9)</td>
<td>6 (8.3)</td>
</tr>
<tr>
<td>$20,000 - $29,999</td>
<td>4 (5.6)</td>
<td>7 (9.7)</td>
<td>11 (15.3)</td>
</tr>
<tr>
<td>$30,000 - $39,000</td>
<td>5 (6.9)</td>
<td>8 (11.1)</td>
<td>13 (18.2)</td>
</tr>
<tr>
<td>$40,000 - $49,999</td>
<td>4 (5.6)</td>
<td>8 (11.1)</td>
<td>12 (16.7)</td>
</tr>
<tr>
<td>$50,000+</td>
<td>11 (15.3)</td>
<td>15 (20.8)</td>
<td>26 (36.1)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>29 (40.3)</td>
<td>43 (59.7)</td>
<td>72 (100.0)</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some High School</td>
<td>3 (4.1)</td>
<td>0</td>
<td>3 (4.1)</td>
</tr>
<tr>
<td>High School</td>
<td>12 (16.4)</td>
<td>10 (13.7)</td>
<td>22 (30.1)</td>
</tr>
<tr>
<td>Some College</td>
<td>4 (5.5)</td>
<td>10 (13.7)</td>
<td>14 (19.2)</td>
</tr>
<tr>
<td>Certificate</td>
<td>0</td>
<td>4 (5.5)</td>
<td>4 (5.5)</td>
</tr>
<tr>
<td>2-year Degree</td>
<td>3 (4.1)</td>
<td>4 (5.5)</td>
<td>7 (9.6)</td>
</tr>
<tr>
<td>4-year Degree</td>
<td>2 (2.7)</td>
<td>6 (8.2)</td>
<td>8 (11.0)</td>
</tr>
<tr>
<td>Some Graduate</td>
<td>1 (1.4)</td>
<td>5 (6.8)</td>
<td>6 (8.2)</td>
</tr>
<tr>
<td>Graduate</td>
<td>4 (5.5)</td>
<td>5 (6.8)</td>
<td>9 (12.3)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>29 (39.7)</td>
<td>44 (60.3)</td>
<td>73 (100.0)</td>
</tr>
</tbody>
</table>

Table 2. Family Demographics
On the family demographic of marital status, the control group had 17 respondents who were married and 12 who were divorced. The experimental group had 28 respondents who were married, 13 divorced, 3 widowed, and 1 never married. No significant difference was found between the control and experimental groups on the characteristic of parent’s marital status ($\chi^2 = 3.43, \text{df} = 3, p = .330$).

Table 2 compares the control and experimental groups on the characteristics of employment status using the following categories: hourly, salaried, self-employed, unemployed, retired, homemaker. For both groups, hourly (45.2%) and salaried (23.3%) appeared to be the most prevalent employment status. There was 1 individual in the control group compared with 7 in the experimental group who were retired. There was no significant difference between the groups on the characteristic of employment status ($\chi^2 = 6.52, \text{df} = 5, p = 2.59$).

Control and experimental group respondents were compared on the family demographic of household income. While the control group had 4 respondents with incomes of <$9,999, the experimental group had no one in this income category. Overall, however, there was no significant difference between the two groups on the family characteristic of household income ($\chi^2 = 7.70, \text{df} = 5, p = .174$).

Table 2 reflects a somewhat higher degree of education on the part of the experimental group. This is most noticeable in the categories of some high school, some college, and some graduate. However, there was no significant difference found between the two groups on the characteristic of parent’s highest level of education ($\chi^2 = 12.10, \text{df} = 7, p = .097$).
**Measurement Assessment**

This section presents information about measures used in this study. Two of the measures, the Family Hardiness Index (FHI) and the Transition Experience Questionnaire (TEQ), were existing instruments that had undergone considerable validity and reliability testing. The Vocational and Community Involvement Profile (VCIP) was constructed for this study. Measurement reliability was assessed using Cronbach’s alpha. Alpha assesses the internal consistency of a set of items and has a potential range of values from 0 to 1. Higher scores indicate higher internal consistency. Alpha values of .70 or above are generally satisfactory for the purpose of establishing reliability. For basic research, it can be argued that increasing reliability much beyond .80 is often a waste of time and financial resources (Nunnally, 1978).

Table 3 presents coefficient alphas for the Transition Experience Questionnaire, for both the pretest and the posttest. Pretest alphas were .81 for parent’s comfort with transition, .79 for parent’s vision for their child’s future, and .85 for the parental response to the schooling process. The posttest alphas were .78 for parent’s comfort with transition, .83 for parent’s vision for their child’s future, and .89 for parental response to the schooling process. All of the TEQ scale alphas exceeded Nunnally’s (1978) .70 or above acceptability criterion, thus suggesting that the measures for the TEQ were all acceptably reliable for use in the study.
Table 3. Reliabilities for the Transition Experiences Questionnaire (TEQ)

<table>
<thead>
<tr>
<th>Scale</th>
<th>Pretest Coefficient Alpha</th>
<th>Posttest Coefficient Alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent’s Comfort with Transition</td>
<td>.81</td>
<td>.78</td>
</tr>
<tr>
<td>Parent’s Vision for Child’s Future</td>
<td>.79</td>
<td>.83</td>
</tr>
<tr>
<td>Parental Response to the Schooling Process</td>
<td>.85</td>
<td>.89</td>
</tr>
</tbody>
</table>

Both the pretest and the posttest reliability measures for the TEQ compared favorably with the internal estimates of the subscales reported by Whitney-Thomas and Hanley-Maxwell (1996), who reported a comfort alpha of .88, vision alpha of .83, and response alpha of .85. Whitney-Thomas and Hanley-Maxwell (1996) reported an alpha level of .60 for the fourth factor used in their study, the subscale connections; that factor was not compared in this study because of the relatively low internal consistency rating.

Table 4 presents coefficient alphas for the Family Hardiness Index (FHI). The full-scale coefficient alpha was .86 for the pretest and .88 for the posttest. The commitment subscale was .81 for both the pretest and posttest, and the challenge subscale was both .82 pretest and posttest. The control subscale alpha coefficient was unacceptably low (.53) at the pretest but attained a .70 alpha rating at posttest. The FHI internal consistency reliability results from this study are highly comparable with those reported by McCubbin et al. (1996). In fact, the control alpha of .60 found by McCubbin et al. (1996) is similar to the .53 pretest finding in this study.
<table>
<thead>
<tr>
<th>Scale</th>
<th>Pretest Coefficient Alpha</th>
<th>Posttest Coefficient Alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full Scale</td>
<td>.86</td>
<td>.88</td>
</tr>
<tr>
<td>Commitment</td>
<td>.81</td>
<td>.81</td>
</tr>
<tr>
<td>Challenge</td>
<td>.82</td>
<td>.82</td>
</tr>
<tr>
<td>Control</td>
<td>.53</td>
<td>.70</td>
</tr>
</tbody>
</table>

Table 4. Reliabilities for the Family Hardiness Index (FHI)

The Vocational and Community Involvement Profile (VOCIP) was specifically developed for this study. An exploratory factor analyses was done to identify a meaningful structure of the items. According to Kline (1994), the primary aim of most factor analyses was to simplify a matrix of correlations so that they could be explained in terms of a few underlying factors. The factoring approach used was a principal components analysis with a varimax rotation (Kline, 1994). The decision about how many factors to retain were supported by a Scree test, and items in which factor loading was .40 or greater were used to retain various components.

Table 5 presents the results of the principal components factor analysis for the VOCIP. The solution suggested there were four components or constructs that defined the underlying structure of the initial item pool: (1) job and independent living readiness, (2) well-being concerns for the child, (3) parent/child adjustment regarding independence, and (4) social acceptance or readiness of child. The various items that defined these scales and their factor loading are shown in Table 5.
<table>
<thead>
<tr>
<th>Questionnaire Item</th>
<th>Factor Loading**</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Job and Independent Living Readiness</strong></td>
<td></td>
</tr>
<tr>
<td>Q2 My child has skills he/she can use to earn a living.</td>
<td>.514</td>
</tr>
<tr>
<td>Q4 My child is mature enough to work in the community.</td>
<td>.552</td>
</tr>
<tr>
<td>Q6 My child would be safe living in his/her own apartment.</td>
<td>.666</td>
</tr>
<tr>
<td>Q7 My child would be safe riding the bus by him/herself.</td>
<td>.737</td>
</tr>
<tr>
<td>Q10 My child can be left alone on a job site for a full workday.</td>
<td>.707</td>
</tr>
<tr>
<td>Q12 My child will succeed on his/her own.</td>
<td>.737</td>
</tr>
<tr>
<td>Q13 My child can arrange for supports needed to get to work.</td>
<td>.650</td>
</tr>
<tr>
<td>Q15 I am confident my child will make good choices for safety.</td>
<td>.707</td>
</tr>
<tr>
<td>Q16 My child will be able to work in the community.</td>
<td>.717</td>
</tr>
<tr>
<td>Q18 My child will secure a job paying more than minimum wage.</td>
<td>.716</td>
</tr>
<tr>
<td>Q19 My child will receive adequate insurance benefits.</td>
<td>.616</td>
</tr>
<tr>
<td>Q21 My child would handle unwanted sexual advances.</td>
<td>.617</td>
</tr>
<tr>
<td>Q22 I want final say in the choice of a job for my child.</td>
<td>.656</td>
</tr>
<tr>
<td>Q24 My child should make enough money to support self.</td>
<td>.579</td>
</tr>
<tr>
<td>Q29 My child would be able to understand directions.</td>
<td>.401</td>
</tr>
<tr>
<td>Q30 It is important I be involved in finding a job for my child.</td>
<td>.480</td>
</tr>
<tr>
<td>Q37 My child can use the telephone independently.</td>
<td>.443</td>
</tr>
<tr>
<td>Q40 My child would be able to travel independently.</td>
<td>.645</td>
</tr>
<tr>
<td>Q42 My child would be able to stand up for his/her rights.</td>
<td>.543</td>
</tr>
<tr>
<td><strong>Well-Being Concerns for the Child</strong></td>
<td></td>
</tr>
<tr>
<td>Q1 Having my child live outside of our home would be difficult.</td>
<td>.411</td>
</tr>
<tr>
<td>Q3 My child will have difficulty emotionally if he/she moves out.</td>
<td>.428</td>
</tr>
<tr>
<td>Q5 I am concerned what will happen to my child as I get older.</td>
<td>.611</td>
</tr>
<tr>
<td>Q11 My child would be taken advantage of in the community.</td>
<td>.588</td>
</tr>
<tr>
<td>Q17 I worry that health concerns will affect my child on the job.</td>
<td>.599</td>
</tr>
<tr>
<td>Q23 My child needs support to maintain long-term employment.</td>
<td>.457</td>
</tr>
<tr>
<td>Q29 My child would be able to understand directions.</td>
<td>.503</td>
</tr>
<tr>
<td>Q33 My child would be able to express his/her needs.</td>
<td>.537</td>
</tr>
<tr>
<td>Q34 My child’s health needs will be met if he/she moves out.</td>
<td>.497</td>
</tr>
<tr>
<td>Q36 My child’s safety in a job situation is a concern.</td>
<td>.561</td>
</tr>
<tr>
<td>Q38 I feel that others will accept my child.</td>
<td>.467</td>
</tr>
<tr>
<td>Q40 My child will be able to travel independently.</td>
<td>.408</td>
</tr>
<tr>
<td>Q41 My child will do activities like people without disabilities.</td>
<td>.464</td>
</tr>
<tr>
<td>Q42 My child would be able to stand up for his/her rights.</td>
<td>.412</td>
</tr>
<tr>
<td>Q45 I will always be responsible for my child financial needs.</td>
<td>.631</td>
</tr>
</tbody>
</table>

Table 5. Factors of Vocational and Community Involvement Profile
Table 5 continued

<table>
<thead>
<tr>
<th>Questionnaire Item</th>
<th>Factor Loading**</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Parent/Child Adjustment Regarding Independence</strong></td>
<td></td>
</tr>
<tr>
<td>Q3 My child will have difficulty emotionally if he/she moved out.</td>
<td>.525</td>
</tr>
<tr>
<td>Q17 I worry that health concerns will affect my child on the job.</td>
<td>.433</td>
</tr>
<tr>
<td>Q20 I am concerned income will reduce if my child moves out.</td>
<td>.741</td>
</tr>
<tr>
<td>Q25 Nothing will be able to replace school upon graduation.</td>
<td>.683</td>
</tr>
<tr>
<td>Q26 My child needs long-term training in a sheltered workshop.</td>
<td>.555</td>
</tr>
<tr>
<td>Q27 My child’s independent standard of living will be acceptable.</td>
<td>.442</td>
</tr>
<tr>
<td>Q28 I am afraid my child would lose benefits with a job.</td>
<td>.580</td>
</tr>
<tr>
<td>Q35 My child would be bored living on his/her own.</td>
<td>.825</td>
</tr>
<tr>
<td>Q43 Without supervision, my child would be involved with crime.</td>
<td>.415</td>
</tr>
</tbody>
</table>

| **Social Acceptance and Readiness of Child**                                      |                  |
| Q8 Friends my child meets will treat him/her with respect.                         | .479             |
| Q9 I am worried my child will be taken advantage of sexually.                      | .576             |
| Q21 My child would be able to handle sexual advances.                              | .582             |
| Q31 Providers will be able to care for my child as well as I do.                   | .537             |
| Q32 Support is available to help my child be successful.                           | .721             |
| Q38 I feel that others will accept my child.                                      | .447             |
| Q43 Without supervision my child would be involved in crime.                      | .472             |

* Extraction Method: Principal Components Analysis  
  Rotation Method: Orthogonal – Varimax  
  Number of Factors Decision: Scree Test  
** Items with Factor Loading of .40 or greater were retained.

A factor is a dimension or construct that is a condensed statement of the relationships between a set of variables. Even more simply stated, a factor is a construct operationally defined by its factor loading (Kline, 1994). Questions #7, #12, #16, and #18 on the VOCIP were the highest loaded variables produced in factor #1—my child would be safe riding the bus by him/herself, my child will succeed on his/her own, my child will be able to work in the community, and my child will be able to secure a job that pays more than minimum wage. Clearly these questions were
indicative of issues related to independence and job readiness and thus guided the
decision to define factor #1 as job and independent living readiness.

Factor #2 of the VOCIP has been defined as well-being concerns for the child
and was influenced by highly loaded variables, such as questions #5, #11, #17, and
#45—I am concerned about what will happen to my child as I grow older, my child
would be taken advantage of if out in the community alone, my child has health
concerns that I worry will affect him/her on the job, and I will always be responsible
to provide for some of my child’s financial needs.

Factor #3 of the VOCIP was defined as parent/child adjustment regarding
independence. Questions #20, #25, #28, and #35 were the highest rated—I am
concerned that our family budget will be reduced if my child moves out, there will not
be anything to replace school when my child graduates, I am afraid my child would
lose his/her benefits in a community job, and my child would be bored living on
his/her own.

Factor #4 of the VOCIP was defined as social acceptance or readiness of child.
Questions #9, #21, #31, and #32 were the highest rated—I am worried my child will
be taken advantage of sexually, my child would be able to handle unwanted sexual
advances of others, support providers will be able to care for my child’s needs as well
as I do, and adequate support is available to help my child be successful.

Table 6 presents pretest and posttest VOCIP reliabilities. The pretest alphas
for job and independent living readiness, well being concerns for the child,
parent/child adjustment regarding independence, and social acceptance or readiness of
the child were .92, .83, .74, and .63, respectively. Posttest alphas were .92, .85, .68, and .75, respectively. The pretest reliability for the social acceptance or readiness of child was slightly below Nunnally’s (1978) .70 acceptability criterion.

<table>
<thead>
<tr>
<th>Scale</th>
<th>Pretest Coefficient Alpha</th>
<th>Posttest Coefficient Alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>Job &amp; independent living readiness</td>
<td>.92</td>
<td>.92</td>
</tr>
<tr>
<td>Well being concerns for child</td>
<td>.83</td>
<td>.85</td>
</tr>
<tr>
<td>Parent/child adjustment regarding independent</td>
<td>.74</td>
<td>.68</td>
</tr>
<tr>
<td>Social acceptance or readiness of child</td>
<td>.63</td>
<td>.75</td>
</tr>
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</table>

Table 6. Reliabilities for the Vocational and Community Involvement Profile (VOCIP)

In summary, the measures used in this study were, for the most part, reliable. All of the TEQ scales had acceptable alphas. Three of the four FHI scales (excluding control) had acceptable alphas, and the VOCIP had three of four scales with acceptable alphas.

**Scale Correlations**

Table 7 presents a matrix of correlations for all the scales used in the study. These correlations reflect both within instrument relationships (e.g., correlations between the VOCIP scales) and between instrument correlations (e.g., correlations between the VOCIP scales and FHI scales). These correlations express the extent to which scales measured similar concepts. For the purpose of this discussion, a series of conventions for describing correlation coefficient values will be used. According to
Pine (1977), it is helpful to have verbal combinations that describe a particular range of correlation coefficient values. For example +1.00 represents a prefect positive relationship, +0.66 to +0.99 a very large positive relationship, +0.36 to +0.65 a large positive relationship, and +0.16 to +0.35 a medium positive relationship. This process continues to 0.00, which is described as no relationship. Similar wording is used to describe negative correlation coefficients that range from 0.00 to –1.00, a perfect negative relationship.
** Correlation is significant at the .01 level (two-tailed)

Table 7. Correlations Among TEQ, FHI, and VOCIP Scales (Posttests)

<table>
<thead>
<tr>
<th></th>
<th>TEQ Parent’s Comfort w/ Transition</th>
<th>TEQ Parent’s Vision TEQ1</th>
<th>TEQ Parent’s Response to the Schooling Process TEQ2</th>
<th>TEQ Parent’s Response to the Schooling Process TEQ3</th>
<th>FHI Commitment FHI1</th>
<th>FHI Challenge FHI2</th>
<th>FHI Control FHI3</th>
<th>VOCIP Independent Living VOCIP1</th>
<th>VOCIP Well-Being VOCIP2</th>
<th>VOCIP Independence VOCIP3</th>
<th>VOCIP Social Acceptance VOCIP4</th>
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<tr>
<td>TEQ1</td>
<td>--</td>
<td>-.471**</td>
<td>-.335**</td>
<td>-.155</td>
<td>-.229</td>
<td>-.095</td>
<td>-.067</td>
<td>-.399**</td>
<td>-.589**</td>
<td>-.611**</td>
<td>-.491**</td>
</tr>
<tr>
<td>TEQ2</td>
<td>--</td>
<td>--</td>
<td>.294**</td>
<td>.102</td>
<td>.147</td>
<td>.123</td>
<td>-.046</td>
<td>.610**</td>
<td>.705**</td>
<td>.588**</td>
<td>.397**</td>
</tr>
<tr>
<td>TEQ3</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>.0195</td>
<td>.102</td>
<td>.000</td>
<td>.139</td>
<td>.155</td>
<td>.212</td>
<td>.368**</td>
<td>.326**</td>
</tr>
<tr>
<td>FHI</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>.891**</td>
<td>.874**</td>
<td>.701**</td>
<td>-.126</td>
<td>-.001</td>
<td>.154</td>
<td>-.186</td>
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<tr>
<td>FHI1</td>
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<td>--</td>
<td>--</td>
<td>--</td>
<td>.733**</td>
<td>.464**</td>
<td>.362**</td>
<td>-.107</td>
<td>-.018</td>
<td>.116</td>
<td>-.176</td>
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<td>FHI2</td>
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<td>--</td>
<td>--</td>
<td>--</td>
<td>.362**</td>
<td>--</td>
<td>-.139</td>
<td>.015</td>
<td>.060</td>
<td>-.156</td>
</tr>
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<td>FHI3</td>
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<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>-.078</td>
<td>.009</td>
<td>.231</td>
<td>-.119</td>
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<tr>
<td>VOCIP1</td>
<td>--</td>
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<td>--</td>
<td>--</td>
<td>.779**</td>
<td>.528**</td>
<td>--</td>
<td>--</td>
<td>.604**</td>
<td>--</td>
</tr>
<tr>
<td>VOCIP2</td>
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<td>--</td>
<td>--</td>
<td>--</td>
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<td>--</td>
</tr>
<tr>
<td>VOCIP3</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
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<td>--</td>
</tr>
<tr>
<td>VOCIP4</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
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<td>--</td>
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</tr>
</tbody>
</table>
The within instrument correlations indicated that the various scales measure similar constructs with some being more similar than others. For example, the TEQ scales had large to medium correlations of -.471, -.335, and .294. These correlations showed an inverse relationship between parent’s comfort with transition and parent’s vision for the child’s future and parent’s response to the schooling process. There is a significant but only positive relationship between parent’s vision for the child’s future and parent’s response to the schooling process. On the other hand, the family hardiness scale showed a pattern of positive relationships. As seen in Table 7, the full scale had a high correlation with all of the subscales. This was to be expected because the full scale was composed of each subscale. The subscale correlations for the FHI also showed large to very large correlations, suggesting they measured similar things, although this was less so with the control subscale (.362).

Finally, the four VOCIP scales appeared to have a large to very large correlation between one another. This suggests that the scales were not independent and that they had a positive relationship. Table 7 shows a very positive relationship between VOCIP #1 (job and independent living readiness) and VOCIP #3 (parent/child adjustment regarding independence). Table 7 also shows large positive (.604) relationship between VOCIP #1 (job and independent living readiness) and VOCIP #4 (social acceptance readiness of child). Additionally, Table 7 reflects a very large positive relationship (.690) between VOCIP #2 (well being concerns for the child) and VOCIP #3 (parent/child adjustment regarding independence). There was a large positive relationship (.537) between VOCIP #2 (well being concerns for the
child) and VOCIP #4 (social acceptance or readiness of child). Table 7 also shows a large positive and also significant relationship at the .01 level of significance between VOCIP #3 (parent/child adjustment regarding independence) and VOCIP #4 (social acceptance or readiness of child).

The between instrument correlations, shown in Table 7, indicate that the FHI and VOCIP instruments did not measure similar things. All of the correlations are very low and not significant. The correlations between the TEQ and VOCIP scales, however, do suggest that relationships existed between these scales. Specifically, the TEQ #1 (parent’s comfort with the transition process) had a significant inverse relationship with VOCIP #1 (job and independent living readiness) and VOCIP #2 (well being concerns for the child), but does have a significant positive relationship with VOCIP #3 parent/child adjustment regarding independence and VOCIP #4 (social acceptance or readiness of child).

According to Fraenkel and Wallen (1993), validity referred to the appropriateness, meaningfulness, and usefulness of inferences that researchers made based on the data they collected. They also suggested that the validation of an instrument was the process of collecting evidence to support such inferences. Validity could be defined as the extent to which any measuring instrument measured what it was supposed to measure. Cronbach (1971) suggested that the purpose of validation was not just to validate a test but to interpret data arising from a specific procedure. In this study, the VOCIP was developed for the purpose of measuring certain criteria that were represented in the form of VOCIP scales. There were two forms of criterion-
related validity—predictive and concurrent. Predictive validity occurred when there was a time interval between administration of the instrument and obtaining the criteria scores. When instrument data and criterion data were gathered at merely the same time and the results compared, this was referred to as an attempt to obtain concurrent validity (Fraenkel & Wallen, 1993). Based on the findings of significant correlations between most of the VOCIP scales and the TEQ scales, it appeared that there was indeed concurrent validity between the two instruments. This substantiates that the VOCIP seemed to be measuring the criteria it was designed to address.

**Model Testing**

The primary purpose of the study was to examine the impact of the “What’s Next” program on the various TEQ, FHI, and VOCIP scales. The statistical method that matched the experimental-control pretest-posttest designs used in the study was the one-within, one-between analysis of variance (Kennedy, 1978). The design had two components—a between-subject component that represented the randomly selected and assigned subjects to either the control or experimental groups, and a within subject component that represented the pretest and posttest measurement process. A series of one-within, one-between ANOVAs was conducted for each measurement scale. The means that were tested and standard deviations are shown in Table 8. An overall mean and standard deviation and control and experimental mean and standard deviation are shown for each scale, yielding few examples of large differences between the control and experimental groups.
Because a series of one within and one between analyses of variance were conducted, a Bonferroni adjustment (Kennedy, 1978) was made to alpha. For the TEQ and FHI scales, the actual alpha used was .0167 (.05 ÷ 3). For the VOCIP scales, the adjusted alpha was .0125 (.05 ÷ 4).
<table>
<thead>
<tr>
<th>Scale</th>
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<th>Control</th>
<th>Experimental</th>
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<tbody>
<tr>
<td><strong>Transition Experience Questionnaire</strong></td>
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<tr>
<td>Parent’s Comfort with Transition</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pretest</td>
<td>36.03 (7.81)</td>
<td>37.75 (7.22)</td>
<td>34.93 (8.05)</td>
</tr>
<tr>
<td>Posttest</td>
<td>35.24 (7.52)</td>
<td>36.04 (7.33)</td>
<td>34.75 (7.68)</td>
</tr>
<tr>
<td>Parent’s Vision for Child’s Future</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pretest</td>
<td>28.30 (6.93)</td>
<td>29.04 (5.81)</td>
<td>27.84 (7.56)</td>
</tr>
<tr>
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<td>29.39 (7.73)</td>
<td>28.72 (6.89)</td>
<td>29.79 (8.24)</td>
</tr>
<tr>
<td>Parental Response to Schooling Process</td>
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<td></td>
<td></td>
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<tr>
<td>Pretest</td>
<td>20.18 (6.28)</td>
<td>20.86 (6.52)</td>
<td>19.74 (6.15)</td>
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<tr>
<td>Posttest</td>
<td>19.80 (6.83)</td>
<td>20.31 (7.37)</td>
<td>19.51 (6.56)</td>
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<td><strong>Family Hardiness Index</strong></td>
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<tr>
<td>Full Scale</td>
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<tr>
<td>Pretest</td>
<td>47.44 (7.83)</td>
<td>47.97 (5.72)</td>
<td>47.09 (9.03)</td>
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<td>Posttest</td>
<td>46.73 (8.38)</td>
<td>45.93 (9.50)</td>
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<td>Commitment</td>
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<td></td>
<td></td>
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<tr>
<td>Pretest</td>
<td>19.92 (3.70)</td>
<td>20.10 (2.91)</td>
<td>19.80 (4.17)</td>
</tr>
<tr>
<td>Posttest</td>
<td>19.82 (3.82)</td>
<td>19.83 (4.10)</td>
<td>19.82 (3.68)</td>
</tr>
<tr>
<td>Challenge</td>
<td></td>
<td></td>
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<tr>
<td>Pretest</td>
<td>15.33 (3.73)</td>
<td>15.66 (3.27)</td>
<td>15.11 (4.04)</td>
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<tr>
<td>Posttest</td>
<td>14.93 (4.06)</td>
<td>14.72 (4.62)</td>
<td>15.07 (3.71)</td>
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<td>Control</td>
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<tr>
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<td>14.56 (2.30)</td>
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<td>14.53 (2.52)</td>
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<tr>
<td>Posttest</td>
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<td>13.69 (3.38)</td>
<td>14.78 (2.41)</td>
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<td>Job and Independent Living Readiness</td>
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<tr>
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<tr>
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<td>46.85 (11.03)</td>
<td>48.15 (11.03)</td>
<td>46.02 (11.08)</td>
</tr>
<tr>
<td>Posttest</td>
<td>48.06 (11.16)</td>
<td>47.21 (12.20)</td>
<td>48.53 (10.65)</td>
</tr>
<tr>
<td>Parent/Child Adjustment Regarding Independence</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pretest</td>
<td>33.12 (7.10)</td>
<td>31.17 (8.11)</td>
<td>34.26 (6.31)</td>
</tr>
<tr>
<td>Posttest</td>
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<td>33.24 (7.76)</td>
<td>32.00 (5.55)</td>
</tr>
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<td>Social Acceptance or Readiness</td>
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</tr>
<tr>
<td>Pretest</td>
<td>21.93 (5.05)</td>
<td>22.10 (6.05)</td>
<td>21.82 (4.34)</td>
</tr>
<tr>
<td>Posttest</td>
<td>21.90 (5.70)</td>
<td>22.00 (7.04)</td>
<td>21.79 (4.72)</td>
</tr>
</tbody>
</table>

Table 8. Means and Standard Deviations of the TEQ, FHI, and VOCIP Scales
Table 9 presents the ANOVA for the TEQ scale parent’s comfort with transition. The means that are tested are shown in Table 8—pretest control mean = 36.04, posttest control mean = 36.04, and pretest experimental mean = 34.75. None of the effects tested was found to be significant at the $p \leq 0.0167$ level.

<table>
<thead>
<tr>
<th>Source</th>
<th>ss</th>
<th>df</th>
<th>ms</th>
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<td>Between Subjects</td>
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</tr>
<tr>
<td>Group</td>
<td>179.801</td>
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<td>179.801</td>
<td>1.0803</td>
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<td>Within Subjects</td>
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<td></td>
<td></td>
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</tr>
<tr>
<td>Pre/Post</td>
<td>33.976</td>
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<td>2.017</td>
<td>.160</td>
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<td>Error</td>
<td>1145.595</td>
<td>68</td>
<td>16.847</td>
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</table>

Table 9. Analysis of Variance of the Parent’s Comfort With Transition (TEQ1) Scale – Experimental & Control Group Condition

Table 10 presents the ANOVA for the TEQ scale, parent’s vision for the child’s future. The means are shown in Table 8—pretest control mean = 29.04, posttest control mean = 28.72, pretest experimental mean = 27.84, and posttest experimental mean = 29.79. Although none of the effects tested was found to be statistically significant at the $p \leq 0.0167$ level, the experimental group experienced nearly a 2-point rise in the mean score between pretest and posttest, while the control group mean score decreased slightly between pretesting and posttesting.
Table 10. Analysis of Variance of the Parent’s Vision for Child’s Future (TEQ2) Scale – Experimental & Control Group Condition

Table 11 presents the ANOVA for the TEQ scale, parental response to the schooling process. The means that were tested are shown in Table 8—pretest control means = 20.86, posttest control mean = 20.31, pretest experimental mean = 19.74, and posttest experimental mean = 19.51. None of the effects tested was found to be significant at the $p \leq .0167$ level.

Table 11. Analysis of Variance of the Parent’s Response to the Schooling Process (TEQ3) Scale – Experimental & Control Group Condition
Table 12 presents the ANOVA for the FHI full scale. The means that were tested are shown on Table 8—pretest control mean = 47.97, posttest control mean = 45.93, pretest experimental mean = 47.09, and posttest experimental mean = 47.24. While none of the effects tested were found to be significant at the $p \leq .0167$ level, there was a slight decrease in mean scores within the control group between pretesting and posttesting, while the experimental group essentially remained the same.

<table>
<thead>
<tr>
<th>Source</th>
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<th>df</th>
<th>ms</th>
<th>F</th>
<th>p</th>
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<tr>
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<td><strong>Within Subjects</strong></td>
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<td>Pre/Post</td>
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<td>Pre/Post Group</td>
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<td>Error</td>
<td>1652.366</td>
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<td>23.605</td>
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Table 12. Analysis of Variance of the Family Hardiness Index Full (TEQ3) Scale – Experimental & Control Group Condition

Table 13 presents the ANOVA for the FHI scale, commitment. The means that were tested are shown in Table 8—pretest control mean = 20.10, posttest control mean = 19.83, pretest experimental mean = 19.80, and posttest experimental mean = 19.82. None of the effects tested was found to be significant at the $p \leq .0167$ level, but a slight decrease in the mean score was detected in the control group between pretesting and posttesting, while the experimental group remained the same.
Table 13. Analysis of Variance of the Family Hardiness Index Commitment (FHI1) Scale – Experimental & Control Group Condition

Table 14 presents the ANOVA for the FHI scale, challenge. The means that were tested are shown in Table 8—pretest control mean = 15.66, posttest control mean = 14.72, pretest experimental mean = 15.11, and posttest experimental mean = 15.07. None of the effects tested was found to be significant at the $p \leq .0167$ level; however, there again was a slight decrease in mean score for the control group between pretesting and posttesting, while the experimental group remained essentially the same.

Table 14. Analysis of Variance of the Family Hardiness Index Challenge (FHI2) Scale – Experimental & Control Group Condition
Table 15 presents the ANOVA for the FHI scale, control. The means that were tested are shown in Table 8—pretest control mean = 14.59, posttest control mean = 13.69, pretest experimental mean = 14.53, and posttest experimental mean = 14.78. While there was no statistically significant interaction for this scale at the protected .0167 level, this finding seems to suggest that the experimental group had a sense of being more in control than did the control group as a result of a mean score decrease for the control group between pretesting and posttesting and a mean score increase for the experimental group between pretesting and posttesting.

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<tr>
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Table 15. Analysis of Variance of the Family Hardiness Index Control (FHI3) Scale – Experimental & Control Group Condition

Table 16 presents the ANOVA for the VOCIP scale, job and independent living readiness. The means that were tested are shown on Table 8—pretest control mean = 75.00, posttest control mean = 73.04, pretest experimental mean = 62.46, and posttest experimental mean = 60.98. The between-subject effects were found to be significant at the p < .0125 level. It should be noted that there was a decrease in mean
scores between pretest and posttest for both the control and experimental groups. Additionally, there was a considerably higher mean score for the control group both at pretesting and posttesting. One possible explanation for decreased posttest means for both groups might be the effects of testing and intervention. In other words, as parents consider the realities of adult life for their children and learn more about the lack of community services and supports, they may have second thoughts about how well their children would fare in the community. The higher mean score for the control group, both at pretesting and posttesting, might be explained by the experimental group being comprised of a greater percentage of individuals with more severe disabilities.

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Table 16. Analysis of Variance of the VOCIP Job and Independent Living (VOCIP1) Scale – Experimental & Control Group Condition

Table 17 presents the ANOVA for the VOCIP scale, well being concerns for child. The means that were tested are shown in Table 8—pretest control mean = 48.15, posttest control mean = 47.21, pretest experimental mean = 46.02, and
posttest experimental mean = 48.53. While there was no statistically significant interaction effect at the projected $p = .0125$ level, there was a pronounced interaction at the .0167 level. This seemed to suggest that the subjects in the experimental group had less concern for the well-being of their child as a result of the “What’s Next” intervention.

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Table 17. Analysis of Variance of the VOCIP Well Being (VOCIP2) Scale – Experimental & Control Group Condition

Table 18 presents the ANOVA for the VOCIP scale, parent/child adjustment regarding independence. The means that were tested are shown in Table 8—pretest control mean = 31.17, posttest control mean = 33.24, pretest experimental mean = 34.26, and posttest experimental mean = 32.00. While there were no statistically significant effects for this scale at the protected $p = .0125$ level, there was a pronounced interaction at the .014 level. This finding of a crossed or disordinal interaction is one in which the control group mean went up while the experimental group mean went down. According to Kennedy (1978), a disordinal interaction
tended to negate serious interest in the main effects of the methods of instruction or other intervention variable. One possible explanation for this interaction would be that parents who gained information about transition, in an in-depth manner, may have had a variety of questions and uneasiness about their ability to cope with greater independence.

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<td>Pre/Post</td>
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Table 18. Analysis of Variance of the VOCIP Independence (VOCIP3) Scale – Experimental & Control Group Condition

Table 19 presents the ANOVA for VOCIP scale, social acceptance or readiness of child. The means that were tested are shown in Table 8—pretest control mean = 22.10, posttest control mean = 22.00, pretest experimental mean = 21.82, and posttest experimental = 21.79. None of the effects tested was found to be significant at the p < .0125 level.
In summary, interaction effects were statistically significant in 1 of 11 subscales tested. One of the 3 scales that indicated significant interaction was VOCIP scale—job and independent living readiness. There was a pronounced interaction effect for VOCIP subscales, well-being for the child and adjustment regarding independence.
CHAPTER 5
SUMMARY, CONCLUSIONS, AND RECOMMENDATIONS

This study was based on the premise that (a) parents and family members of youth with disabilities represented a critical component of the transition from school to adult life process, (b) parents needed a variety of opportunities in which to be involved, and (c) parent concerns about the future for their children with disabilities needed to be understood and supported over an extended period of time. Failure to engage parents’ worries and concerns may have been a barrier to successful transition planning (Wehmeyer et al., 1999). This chapter presents a summary of the findings from the current study with (a) review of the results and conclusions, (b) limitations of the study, (c) implications for practice, and (d) suggestions for future research.

Summary of the Results

It was anticipated, as a result of random assignment, that no difference would exist between the control and experimental groups on the child demographic variables—gender, race, disability level, and age. There was no significant difference between the two groups, at the point of pretesting, except on the variable of disability level. Parents in the experimental group tended to have children with more moderate
and severe disabilities, based on self report. Several explanations may account for this finding. Parents who were assigned to the experimental group were not all available to participate because of such factors as time constraints, availability, and interest. So, in effect, there was some degree of self selection that came into play as a result of the time and transportation requirements over a 6-week period. A point could be made that those parents of children with more severe disabilities had a greater long-term vested interest in participating. Specifically, the child’s pressing need for long-term services necessitated a need to know and be informed. These also would tend to be families eligible for and knowledgeable about how to maximize services and support.

Ho1 was that no difference existed between the experimental and control group on family characteristics—parent’s relationship to the child, marital status, employment status, household income, and level of education. No significant differences were found on the family demographic variables. It should be noted, however, that the experimental group tended to be slightly better educated and was comprised of far more individuals other than natural parents (grandparents, foster parents, and step-parents).

In summary, the first two hypotheses seem to suggest that the experimental and control groups did match up as a result of random assignment of subjects.

The reliability of all three measures used in this study was explored. Internal consistency of each of the subscales was estimated using a Cronbach’s alpha coefficient. Reliability estimates for each instrument and related subscales suggested overall satisfactory or above reliability. The only exceptions were a low result of .53
on the family hardiness index pretest subscale of control and a pretest alpha of .63 on
the vocational and community involvement profile subscale of social acceptance or
readiness of the child. As mentioned in Chapter 4, the low alpha on the FHI control
subscale was consistent with findings previously reported by McCubbin et al. (1996).
The low alpha coefficient of .63 on the VOCIP subscale of social acceptance or
readiness of the child may be explained by a relatively low number of items (n = 7)
within this particular subscale.

An important component of this study was the development and validation of
the Vocational and Community Involvement Profile. Factor analysis of the data
uncovered four major components of parental concern about the transition
experience—(a) parents’ perceptions of children’s readiness to work and live
independently, (b) parents’ concern for the well-being of their children, (c) parents’
concerns about how both they and their children would adjust to increased
independence for the children, and (d) parents’ perceptions of how accepted their
children would be and how ready they were socially as it related to increased
independence. Items in the job and independent readiness factor addressed
components such as vocational maturity, ability to handle functional skills of daily
living, and social/safety awareness issues. Items that comprised well-being concerns
for the child dealt with how safe the child would be, supervision that would be needed,
and emotional attachment for both parent and child. The parent-child adjustment
regarding independence factor addressed the anticipated adaptations that would be
experienced by both parent and child as a result of increased independence, i.e., the
impact that child moving out would have on family finance and child. The social acceptance or readiness of the child factor consisted of items that asked parents if they thought their children would be able to meet new friends, ward off sexual and other unwanted advances, and be well cared for and supported by support staff.

These four factors emerged as the most definable interpretation of the questionnaire items. This exploratory factor analysis was attempted as a first step in validating the VOCIP. However, these preliminary results need to be viewed with caution. The sample size for this study (n = 74) is less than Kline (1994) considered “quite sufficient” (p. 73). According to Kline (1994), factor analyses that were conducted with samples smaller than 100 needed replication in other samples, and his general rule of thumb was—the more subjects, the better.

A series of correlation analyses was conducted both within and among the three instrument measures used in this study. The results indicated that all three instruments experienced significant correlations between their respective subscales. It would appear that the VOCIP subscales all had large to very large positive correlations, suggesting they were measuring similar things. Of interest was the finding of a very large positive correlation of .779 between the VOCIP subscales of job and independent living readiness and well-being concerns for the child. This finding essentially suggested that the child’s overall readiness to assume independence was not without considerable concern, on the part of the parent, for the child’s well-being. In other words, the child’s competence should be considered in tandem with a natural concern that any parent would have for their child’s well-being and safety.
Between-scale correlations revealed no relationship between either the VOCIP or TEQ with the FHI. This finding was understandable, given that the FHI was intended to measure resiliency and stress, while the other two instruments were designed to measure parent concerns and experiences related to transition. Of particular interest, however, was the apparent concurrent validity that seemed to have been established between the VOCIP and the TEQ. For the most part, these two instruments seemed to be measuring similar constructs. The only subscales for which a significant correlation was not found was between TEQ3 (parents’ response to the school process) and VOCIP1 and VOCIP2 (job and independent living readiness and well-being concerns for the child, respectively). While both of these instruments had certain limitations, it was encouraging that they both attempted to quantify parent concerns and experiences regarding the transition process from school to adult life for youth with disabilities. This finding established some promising opportunities for future inquiry, using one or both of these instruments.

The model testing portion of this study was designed to examine the impact of the “What’s Next” program. The assumption was that “What’s Next” had a positive impact on the lives of youth with disabilities and their parents and that, as a result of participation in the program, parents would have fewer concerns about the transition process. Two of the 11 subscales did indicate a significant interaction at the protected alpha level. Most notable was the finding that subjects in the experimental group had significantly fewer concerns about the well-being of their children than did subjects in the control group. This would support the notion that parents who received
information and support regarding the various aspects of transition tended to be more at ease as a result of the experience. This finding was encouraging, given what McNair and Rusch (1991) found in their study that asked parents of youth with disabilities what they would be willing to do to be involved in transition programs. The greatest percentage of subjects in their study responded most frequently to the two following statements: (a) take transition training and (b) participate in a parent support group.

The other significant finding from the model testing was the VOCIP subscale parent child adjustment regarding independence. The control group scores improved, while mean scores for the experimental group went down between pretesting and posttesting. A possible explanation was that, as a result of the “What’s Next” experience, parents in the experimental group may have experienced a certain degree of anxiety when considering their child’s impending independence. For the control group, an increased score may have resulted simply from considering this issue but not having to confront it consistently over a 6-week period.

Limitations

There are inherent limitations in any empirical study. Such limitations may result from characteristics of the research design and rival hypotheses that are either not considered or controlled for in the investigation. As a result, the extent to which conclusions could be made about a single piece of research is limited by the validity of the particular study. Fraenkel and Wallen (1993) defined validity as “the
appropriateness, meaningfulness, and usefulness of the specific inferences researchers make based on the data they collect” (p. 139).

One of the limitations, in terms of the external validity of this study, was the relatively small sample size. Generalizations about findings could be made only for the parents whose sons or daughters were on the waiting list for supported living services from the Board of Mental Retardation and Developmental Disabilities in Franklin County OH. Additionally, the age range of the selected subjects may have been too broad. Issues experienced by parents of children 16-20 years may be far different than those experienced by parents with children 21-24 years. The wide age range may also have influenced parents response to certain VOCIP and TEQ questions that addressed the high school experience in the past tense.

The “What’s Next” program, although it had a set curriculum, did vary somewhat because of the needs of a particular group of parents. As a result, there was no way of ensuring that parents in the experimental group all received the same amount and/or emphasis of information and support. In addition, the parents who participated in “What’s Next” did have the necessary time, transportation, and support resources to do so. It should also be cautioned that the “What’s Next” program may have had an inverted effect. In other words, participating in the program may have heightened anxiety, ambivalence, and confusion about the future. While information was presented about services and supports that were available, it also implied what was missing. Additionally, testing participants just two weeks after the last session
may have been too soon for them to have a chance to integrate what they had learned and felt.

The “What’s Next” program had no program effect. This could mean that the program was not right for the target audience. However, this appears to contradict what more than 200 parents who completed evaluations of the program have reported (Appendix B). Rather, it was more plausible that there was one or more errors of measurement. An additional question was, “Do the VOCIP and TEQ actually measure major components of the ‘What’s Next’ program?” Further investigation will be required to answer this question.

The VOCIP showed promising signs of measuring what it was designed to measure. However, more rigorous development of the instrument is required with a larger sample. As a threat to internal validity, the threat of testing should be mentioned as a possible limitation of this study. A posttest-only design might warrant further inquiry.

Conclusions and Implications

Transition from school to adult life for young adults with disabilities and their families was not a static period in time. Rather, it was a process. This process often occurred over an extended period of time and involved adjustment and accommodation. Transition meant leaving familiar territory and entering a world of uncertainty and risks.
There were several benefits resulting from family involvement in the education of students with disabilities. Involvement led to better school attendance, reduced dropout rates, higher educational assessment scores, and improvement in student attitudes such as self-esteem and confidence (Flaxman & Inger, 1991). Parent involvement served as the overarching bridge between a child’s life at home and school. Parent and family involvement and advocacy has been noted to result in better educational programs in schools and better resources in the community for students with disabilities (Sinclair & Christenson, 1992).

Parents experienced many concerns about the transition from school to adult life for their children with disabilities, including economic, safety, self-sufficiency, social isolation, quality and quantity of adult services, availability of residential options, and related support services (Chadsey-Rusch et al., 1991; Whitney-Thomas & Haley-Maxwell, 1994; Turnbull & Turnbull, 1997).

In many ways, parents have the most to gain or lose from the transition process. That is why it is so important for them to be equal partners in decision making. Sitlington, Frank, and Carson (1991) found that, after three years out of high school, 46% of youths with mental retardation lived with family members, while 31% relied primarily on parents for financial assistance and support. Holden (1996) reported that, of the 31,041 adults receiving county board services in Ohio, 13,938 or 45% (by far the largest group) of the total were living with parents, a legal guardian, or another relative. It is unfortunate that a prevalent image of families, among
professionals, is that the family represented a barrier to a youth with disability experiencing increased independence.

Although parent involvement in the decision-making and transition planning process was essential to adult success, in many instances parents and other family members were not active partners. Rather, based on findings from McNair and Rusch (1991), parents reported being less involved in transition programming than they wished and wanted to have an equal part in decision-making but did not have the opportunity. Parents who were involved in transition programming were more likely to have formulated a post-school plan for their son or daughter.

Parents who participated in the “What’s Next” program appeared to be more in control of their family situation as a result of their experience. Additionally, parents in the experimental group had fewer concerns about the well being of their child based on the information and support they received. This finding was interesting in light of safety being the single most frequent pretest category response to the VOCIP open-ended question, “I have the following concerns about my son/daughter’s independent living.” This study established concurrent validity between the VOCIP and the TEQ. In other words, the two instruments appeared to measure similar constructs. While clearly further development of both instruments is necessary, initial steps have been taken to compare different groups of parents vis-à-vis the transition process from school to adult life and to do so in a quantitative manner. Only through further investigation and replication of these instruments with other samples can their applicability be fully determined.
The present findings represent parents’ overall assessments of the transition process as their sons and daughters transition to adult life. Measures of successful outcomes and definitions of what comprises a successful transition to adult life remain virtually untapped. Additionally, the study utilized such measures within the context of a parent involvement intervention/program.

In conclusion, there appeared to be promise for programs that systematically support and inform parents about the transition process. Clearly every parent is different, and their propensity for involvement will vary. However, optimal outcomes for youth with disabilities will occur once parent involvement is more fully embraced by educational and adult service systems. One of the principal contentions of this study was that parent involvement did not simply happen because it was legally mandated. Simply signing an educational plan did not in turn translate to full and equal participation with the planning and decision-making process. Parents are not going away. They will remain parents, and they deserve to be treated with dignity and respect. Whether parents are part of the problem or not, they need to be a part of the long-term solution for their sons and daughters.

**Recommendations**

This study was based on the premise that families of youth with disabilities benefit significantly from a systematic program of information and support during the transition period between school and adult life. While parent involvement was mandated by law, there were rarely checks and balances to ensure that it took place.
Several curricula have been developed that clearly delineated key components to successful parent involvement and collaboration, but these actions ultimately were left up to educators and other professionals to operationalize and implement.

The following recommendations are made as a result of what has been learned from this study and from the empirical and theoretical findings during the 10 to 15 years preceding this study.

1. Develop a means of measuring what both parents and their young adult children learned as a result of the “What’s Next” program. Specific content components would need to be developed and then prioritized in terms of importance. By documenting improved knowledge on the part of the participants, efficiency of the “What’s Next” program could be more clearly defined and identified.

2. Determine specific actions that define parent involvement. Such actions would extend beyond school and might also include helping a child find and maintain employment, linking a child to social activities, and advocating on the child’s behalf. Once parent involvement is better defined, it can then be more directly linked to such post-school outcomes as employment and independent living readiness.

3. Itemize in the student’s IEP and transition plan the intent of “What’s Next” and/or other parent involvement activities are supposed to accomplish. This way, parents and teachers have a much clearer understanding of their respective roles and responsibilities. What parents learn from programs like “What’s Next” can be channeled back and used in the formalized transition planning process.
4. Conduct longitudinal follow-up of consumer participation in the “What’s Next” program. Such follow-up would include how the knowledge learned from the program translates to concrete outcomes such as employment status, wages, degree of independence, and extent of social connections.

5. Compare the perceptions of parents and teachers regarding the extent of parent involvement before and after the “What’s Next” program. Not only would this information help document the efficacy of the program, it would serve as a means for keeping communication open between parents and teachers regarding respective expectations.

6. In future programs to support, involve, inform, and study parents and young adults with disabilities, control for factors such as degree of disability and stage of the youth with disability in the transition process. Experience from this study suggested that parents of children with more severe disabilities had different concerns and might require slightly different information than would parents of children with less severe disabilities. Likewise, families with children still in high school were likely to have slightly different information needs and concerns regarding the future than those with sons and daughters who had left the formal education system.

7. Continually remind professionals about the importance of parents in the lives of youth with disabilities. The concern of a parent for their child’s well being must be taken into consideration for transition planning. It might be well to consider requiring educators and adult service providers to administer an instrument such as the VOCIP or TEQ as part of the required plan development process, so that parent and
family needs and concerns can be better understood. Wehmeyer et al. (1999) cautioned that an instrument alone should not be the sole means of determining family involvement, interests, or needs. Rather, these authors ascribed to the use of such tools as steps toward greater parent and professional communication. All too often, however, steps that should or need to be taken do not happen. Unless and until more specific mandates and expectations are placed on professionals to truly engage parents in the transition process, it probably will not occur.

8. Allow professionals additional time to interact and learn from families. Parent involvement has to be fostered by school systems and individual teachers. According to Wehmeyer et al. (1999), “the professional who really wants to help a student will try to understand the family dynamics and draw family members into the decision making process” (p. 10). The parent professional partnership is not something that emerges once a year at the IEP meeting. While some teachers and other professionals value parents for what they have to contribute to the process, others do not know how to interact with parents. Additionally, there are many professionals who simply do not see it as part of their role—it takes time away from their “real” job. What they fail to recognize is that collaboration with parents is their job, their responsibility, and an essential component to maximizing the potential of the students with disabilities they are supposed to be serving. Teachers need to have release time, possibly tied into continuing education or professional development. This would be time they could use to actually interact and plan with parents. It could also be time for teachers to receive supervision regarding how to engage or otherwise
problem-solve with families. Such supervision would need to be the responsibility of
the school but might be done in conjunction with a disability, social service, or mental
health agency.

9. Encourage participation of and contributions from siblings and extended
family members. Parents are only one source of information about the student. What
they know and how they view the future may be very different from other family
members. Efforts should be made to actively elicit the views, concerns, and
suggestions of siblings and extended family members and encourage their
participation in transition planning meetings. Siblings may have long-term
responsibility for the care and coordination of services for their brother/sister. This is
particularly true as their parents age (Seltzer, Krauss, & Janicki, 1994). Involvement
as early as possible would help them be both better informed and more empowered.

10. Meet with families in a relaxed environment. Whenever possible, efforts
should be made to meet with families in relaxed and nonthreatening environments. A
school classroom or conference room often is not conducive to a free flow of
information and ideas regarding someone’s future. Parents and their children are apt
to be less threatened, more a part of the team, and far more respected if the transition
planning process takes place in comfortable settings, preferably outside the school.

11. Provide parent-to-parent contact during transition. Early intervention and
early school age education programs tend to foster parent involvement and parent-to-
parent support. However, as children grow older and advance through the education
system, two things typically happen—(1) the education system is less forthcoming and
available, and (2) parents become tired of constantly having to fight with and monitor the system. The end result is that parents often end up being less involved at a time—the transition period—during which their participation is critical. The transition period is also an important time in which to interact with other parents for the purpose of exchanging information, sharing experiences and concerns, and receiving support.

12. Strengthen efforts for parents to receive ongoing information and support. Participants in the experimental group never had an opportunity to receive information and gain support regarding the transition process over an extended period of time. Many of them lacked information and did not know what they thought about the future, reinforcing the need for ongoing opportunities for parents to share, learn, and be supported. Having a structured format for addressing the future can help make the transition process seem real and more understandable. When parents do not have opportunities to acquire information, express concerns, and share what they know and think, optimal transition outcomes for youth with disabilities are not realized.

Need for Future Research

This study concluded that parents seem more in control and have fewer concerns about the future well-being of their children with disabilities as a result of being involved in a transition planning program. While these findings are encouraging, they clearly fail to substantiate the full benefit of such a program. More empirical research is needed that controls the type of parent involvement provided and then measures the effects of those services on employment and independent living.
outcomes for youth with disabilities. The following research studies are proposed to explore these relationships.

1. Conduct a study to better understand parent involvement during transition. This study would require a large and representative sample of parents who have children representing differing disability types, severities, and ages. A more detailed understanding of how parents want to be involved should suggest and ultimately translate to improved and increased opportunities for parent involvement.

2. Investigate the relationship between parent involvement with employment and independent living outcomes. A study is needed that would measure the long-term impact of parent involvement on such variables as employment status, level of income, social involvement, and level of independence of youth with disabilities. Such a study would also need to examine differences between people with mild disabilities (such as learning disabilities) and those people with more significant disabilities (such as cognitive and physical disabilities).

3. Explore better methods to measure parent concern about transition. One of the limitations of this study was that both instruments used to measure parent concerns about transition lacked comprehensive psychometric standardization. Additional studies to further develop these instruments will help professionals better understand specific concerns being experienced by parents. In addition, a large quantitative study to establish the most prevalent concerns encountered by parents would assist policy makers and parent advocates in their efforts to improve services and supports for parents.
4. Investigate the importance of involving siblings in the transition process. An exploratory study is needed to understand what siblings think about their brother or sister transitioning from school to adult life. This could be determined through initial focus groups and subsequent development of a survey instrument. Better understanding of the sibling perspective would open the door for improved involvement of siblings in the transition planning and implementation process. Future studies to explore the impact of sibling involvement on post-school outcomes for youths with disabilities would also be very useful. Another interesting line of inquiry might be whether students with disabilities would likely have improved outcomes as a result of both siblings and parents being actively involved in the transition planning and implementation process.

5. Investigate the role of teachers in parent involvement. A study is needed that would identify those characteristics and experiences which predispose certain teachers to actively promote parent involvement (personal or family experience with disability, years of teaching experience, racial or cultural background, gender). Subsequent studies that might link positive teacher attitudes toward parent involvement with student outcomes would also be of interest.

6. Explore attitudes and practices of administrators toward parent involvement. More information is needed about how education and adult service administrators view and promote parent involvement during transition. Such a study would provide valuable information for policy makers and parent advocates.
Appendix A

“What’s Next” Program
“What’s Next” Program

I. Overview of “What’s Next”

II. Problem Statement

III. Project Outline

IV. Session One: Introduction to the Program

V. Session Two: Supported Living

VI. Session Three: The Individualized Service Plan

VII. Session Four: Choosing a Provider

VIII. Session Five: Creative Housing

IX. Session Six: Supported Employment, Social Security/Medicaid, or Guardianship
Overview

The “What’s Next” project will help individuals with developmental disabilities and their families improve their social networks, improve consumer choice in selecting housemates, and smooth the transition process by providing emotional supports and education regarding resources. The program will work to provide more consistency in the process of assisting consumers to find potential housemates for the Creative Housing Program.

Goals

- Facilitate roommate matches for consumers who are on the waiting list for Creative Housing and offer socialization opportunities.
- Provide resource information and linkages to consumers and families.
- Improve the consumer’s choice in choosing housemates while increasing the social contacts that can lead.
- Provide support to families who have a member going through the transition process.

The program will achieve these goals by holding group sessions with approximately eight families over a 6-week period. Consumers will increase their socialization skills by participating in recreational activities with peers. Family members will have the opportunity to meet one another and participate in facilitated group discussion regarding the transition experience. Resource material will be provided and linkages with services and supports facilitated.
Problem Statement

The “What’s Next” project is designed to address two divergent needs. The first is for a program to support families that are going through the process of transitioning a member from the home into alternative housing and from school to work. The second need is to increase the opportunities for consumers to meet peers and choose potential future roommates.

Families in Transition

The transition of a child from high school into the “real world” is difficult and emotional for all families. The parent has spent almost 20 years in the role of an “active parent” and now moves into the more ambivalent role of the parent of an adult. Similarly, the child slowly sorts out what being an adult means to them and takes on this new role. The period is fraught with the struggle of both the parents and the child of wanting to stay in the “nest,” safe and protected, while also wanting independence.

While the transition period is difficult for any family, it is at least expected and considered socially desirable. Families with a child with a disability must often make choices where all of the options have an element of undesirability – socially and personally. The expectations themselves are changed as well. The child will likely not be able to live and sustain himself dependently and will have to rely on a service system to provide for their needs. The expectations must also be moderated by the availability of services. The most significant transition – moving away from home – is much more complicated and for many families is delayed indefinitely because of unavailability and unreliability of services.

The significance of the transition for the family should not be underrated. One author argued that this transition occurs on three different levels. First, it is a “bureaucratic” transition from the required system of family involvement and school services to the unstable, frequently unavailable, and unmandated system of adult services. Second, it is a transition in family functioning. Each member of the family unit has their roles, and this transition process is a renegotiation of these roles. Last, it is also a status transition as the individual moves from childhood to adulthood. This change in status also affects the status of the other family members.

Transition is a very difficult time for families emotionally. This emotional need, however, is frequently left unapprised. The “What’s Next” project includes a component of emotional support, particularly for the parents of people with developmental disabilities. Families will be able to meet with professionals and other parents and will discuss their concerns and feelings regarding the transitioning process. This component is important for reducing the stress of the family and assisting the transition process in proceeding smoothly.

Consumer Social Networks

People with developmental disabilities frequently have difficulty developing adequate social skills. Opportunities to further develop those skills also are lacking in the community.
The “What’s Next” program will provide young adults with developmental disabilities a clubhouse environment in which to develop their social skills and social networks with their peers. Volunteer staff will be available to facilitate relationships between then participants and provide assistance with skill development and conflict resolution.

The Franklin County Mental Retardation and Developmental Disabilities (FCMRDD) system has an extensive list of people who are eligible for Creative Housing services but do not have housemates. This list is constantly growing as more individuals become eligible. Currently, there is no formal method for assisting people with developmental disabilities to locate potential housemates. Often people with developmental disabilities are expected to agree to move in with someone after just a few meetings. Frequently, these matches subsequently dissolve. The “What’s Next” project is a method for individuals to develop social networks that can potentially lead to a living arrangement that the individuals choose.

Additionally, family members will be able to meet one another and develop positive relationships. Successful placements can depend upon the family members being comfortable with one another as much as the individuals being comfortable with one another. We believe that the project will increase the number of successful creative housing placements by increasing the opportunity for individuals with developmental disabilities to develop natural relationships with peers while also increasing family involvement in the transition project.

The “What’s Next” project will also provide information regarding community resources for the various aspects of transition that the individual and family are going through (i.e., supported work programs, guardianship information, and benefit eligibility). Most parents indicate that they would like to be more involved in their child’s transition team. We believe that providing resource information in a usable format, in addition to the group process, will assist in empowering families to take a more active role in the transition team.
Session One

Goals

• Make participants feel comfortable in the group setting.
• Familiarize participants with the parent and young adult components of the program.
• Give parents an opportunity to share their families’ journey with the group.

New Vocabulary

None.

Materials Needed

• Nametags
• Nametag covers
• Markers
• Various stickers

Activities

• Name Tags
• Ice Breaker
• Discussion
• Breakaway
• Discussion

Session One Outline

Parents and their children arrive and meet together.

1. Name Tags - Staff will discover the participant’s favorite color before the first session. Each person’s nametag is printed in his or her favorite color. Being printed in each participant’s favorite color individualizes the nametags.

2. Ice Breaker - Each participant arrives and is shown to a table with nametag supplies on it. They are instructed to choose stickers to put onto their nametags that represent their personality. Once everyone has arrived and constructed their nametag, each participant tells the group why they chose the stickers they did and how they represent them.

3. Discussion - This is the only session that the parents and young adults will be participating together. The facilitator of the young adult group explains how the program will run in the following weeks. The young adults will arrive at the cottage in following weeks, while the parents will be meeting in the main house. The facilitator explains the objectives of both groups to the young adults and their parents.
The homework assignments for the young adults are discussed as well. This is an opportunity for all participants to ask questions about the groups.

4. Breakaway - At this point the young adults and their families separate. The young adults move down to the cottage where they will begin a separate curriculum. This is where they will meet for the remainder of the program.

5. Discussion - Those parents who feel comfortable are encouraged to share their family’s story with the other members of the group. This can often be an emotional time for the group as families share their personal struggles with virtual strangers. The other group members offer natural emotional support to those families choosing to share their struggles. Finally, each family shares their hopes and dreams for where they see their son or daughter in the future.

Session Two

Goals

- Parents will become aware of what supported living is, and who is eligible.
- Parents will learn the options available through supported living.
- Parents will learn about the funding and structure of supported living.

New Vocabulary

Supported Living - Service that provides people with Mental Retardation and Developmental Disabilities the supports they need to live as independently as possible.

Materials

Residential Resource Guide prepared by the Franklin County Board of MRDD.

Activities

- Discussion

Session Two Outline

Parents and young adults split into two groups.

Discussion

What is supported living? - Many families choose to keep their children with mental retardation and developmental disabilities at home with them. This is often a choice made out of fear. Families are afraid their son or daughter will not be safe and able to make important decisions if they live on their own. Parents are also fearful that their son or daughter will have difficulty solving problems that arise. Supported living offers these families a way of alleviating some of their fears. Supported living is an approach used to help individuals with
mental retardation and developmental disabilities live as independently as possible within their community, either with their family or on their own. It provides the supports that are necessary for an individual to live where they choose. Supported living is not simply the act of finding someone a place to live—it is providing the person with the necessary supports to live on their own. Supported living helps individuals with mental retardation and developmental disabilities in all life areas that they feel they need help with.

**Topics**

What are the options? - Supported living offers a number of options for individuals to choose. There are many housing options available through supported living. One choice is Creative Housing. Individuals who choose this option living in Creative Housing homes with roommates and receive support from providers. Another option is the Rent Subsidy Program. In this option, the individual chooses to live in an apartment, alone, or with roommates. The Franklin County Board of MRDD helps the individual with paying for the rent and Creative Housing can help the individual locate an apartment. Those individuals who live in apartments may also use providers from a provider agency to support them. Individuals may also choose to live with their families and receive supports from a provider agency.

What is the funding source? - Supported living funding is issued through the Ohio Department of MRDD, Franklin County, The Individual Options Waiver (IO waiver), Residential Facility Waiver (RFW Waiver), and from ICF/MR funding.

What is the structure? - Those individuals who choose supported living will receive a service coordinator. The service coordinator helps the family access services and supports they need. The service coordinator helps develop the individualized service plan (ISP) for the individual. This is a plan for the supports that the person will need while they are in supported living. There is an entire session devoted to the ISP. A Family Support Specialist helps families with roommate selection, provider selection, and housing selection.

What is the eligibility/criteria? - All individuals eligible for county board services should be placed on the residential waiting list. Once their name falls within the range of those people being served, the Case Manager will talk with them about their residential options. If the individual chooses the supported living option, the Case Manager takes the individual’s request to the Placement Committee. If the placement committee determines the individual is eligible for supported living, Residential Planning and Support will begin the supported living process with the individual.
Session Three

Goals

- Parents will learn about the Individualized Service Plan (ISP).
- Parents will become familiar with all seven sections of the ISP.
- Parents will learn how to construct an effective ISP.

New Vocabulary

Individualized Service Plan - A plan developed for individuals living in supported living. The plan lists all the needed services and supports for the individual.

Materials

Individualized Service Plan handout.

Activities

Discussion.

Session Three Outline

Parents and young adults split into two groups.

Discussion

What is an individualized service plan (ISP)? - The individualized service plan (ISP) is a plan that is developed for individuals needing support through supported living. It is developed by the Service Coordinator and is reviewed at least annually. The individual and their family is very involved in developing the ISP, it includes their choices, hopes, dreams, and needs. It is the guide for the service providers and outlines all of the services and supports they have agreed to provide for the individual.

Topic One: The facilitator will explain all seven sections of the ISP.

Choices and Options - Under this section of the ISP are supports the individual may need with regards to decision-making, meal planning, self-advocacy, shopping, time management, and vacation.

Personal Income - Under this section of the ISP are banking, benefits, checkbook maintenance, renters insurance, taxes, and writing checks.

Housing - Under this section of the ISP are home modifications and housekeeping.
Community Membership - Under this section of the ISP are community access, dating, family and friends, making appointments, providing transportation, public transportation, recreation assistance, and socialization and telephone skills.

Personal Satisfaction - Under this section of the ISP are agency awareness and job satisfaction.

Health - Under this section of the ISP are adaptive equipment, behavioral interventions, child counseling, laundry, meal preparation, medical assistance, medication assistance, personal care, nutrition and diet.

Safety - Under this section of the ISP are emergency procedures and first aid.

Topic Two: Constructing an ISP - The process of ISP construction is explained to parents. The focus of the discussion is mainly on the importance of being specific in the wording used in the ISP. It is emphasized to parents that the ISP is the contract between their provider and the County Board of Mental Retardation and Developmental Disabilities.

Session Four

Goals

- Parents will learn the services a provider can offer their son or daughter.
- Parents will learn how to hire a provider agency.
- Parents will also learn about staff training, staff recruitment, staff retention, and accountability regarding provider agencies.

New Vocabulary

Provider: An agency that provides necessary supports to individuals with mental retardation and developmental disabilities in the setting in which they choose to live.

Materials

None

Activities

Discussion

Session Four Outline

Parents and young adults split into two groups.
**Discussion**

Choosing a provider. - Larry Milam from ADD will come and speak to the group on the roles and responsibilities of the provider and how the family can help to write an ISP that will work for their son or daughter. This discussion offers assurance to families who have heard horror stories about provider agencies and are apprehensive about becoming involved with a provider.

**Topics**

What is a provider? - This is an agency chosen by the individual and the family who will provide supports to the individual in the setting in which they choose to live. The provider assists the individual with the supports that are written in the individual’s ISP.

How do you hire an agency? - The individual and their family interview the provider agencies to decide which agency they would like to choose.

What training does an agency’s staff receive?

How is staff recruited for the agency?

How can you find out about staff retention at an agency?

Are provider agencies held accountable for their actions?

**Session Five**

**Goals**

- Parents will learn what Creative Housing is able to offer to their son or daughter.
- Parents will learn what home modifications are and how to receive modifications that are needed.
- Parents will learn the provider’s role in a Creative Housing home.
- Parents will learn how the program is funded.
- Parents will learn about Creative Housing’s Rent Subsidy Program.
- Parents will be made aware of past neighborhood reactions to Creative Housing.

**New Vocabulary**

Creative Housing - Program that makes neighborhood housing affordable and accessible to people with disabilities.

**Materials**

Creative Housing Brochure
Activities

Discussion

Session Five Outline

Parents and young adults split into two groups.

Discussion

Creative Housing - Pat Rafter, Director of Creative Housing, speaks on the subject as well as gives a slide presentation.

Topic One

How does creative housing work? - The goal of creative housing is to make neighborhood housing affordable and accessible to people with disabilities. Creative housing leases properties that the tenants choose, and then lease the property to the tenant at below market rates. The tenants and their families have control over where they live, what type of housing they live in, and with whom they live.

What are housing modifications and how can a family get them? - Housing modifications are renovations to homes that make them more accessible to people with disabilities. Tenants and their families help creative housing come up with modifications that are practical and economical. Some examples of home modifications are wheelchair ramps, accessible showers, and strobe-light-equipped smoke alarms.

How is creative housing funded? - Creative housing is funded through both public and private funding sources.

What is the role of the provider in a creative housing home? - The tenant interviews and chooses whom they would like as their support service providers. The Franklin County Board of MRDD helps the tenant develop their individualized service plan (ISP), and then shares that information with the providers. The providers may need to be there 24 hours a day or as little as a week. It is up to the client to help define the service provider’s role.

What is the rent subsidy apartment program? - Creative housing subsidizes the difference between 30% of a tenant’s income and fair market rental rates as established by HUD. Creative Housing also inspects the apartments annually to ensure they are being maintained satisfactorily.

How could a family get modifications to the family home? - Creative Housing does provide modifications to family homes to provide more accessibility and better health care to people with disabilities. This is done as part of the Medicaid Home and Community Based Waiver Program.
What in the past have been neighborhood reactions in the community to creative housing? - Creative housing has seen positive reactions from neighbors. They work with any neighbors who are interested in learning more about developmental disabilities.

**Topic Two**

The families are asked what they have not learned that they would like more information about. These topics are what will be discussed in Session #6.

**Session Six**

The format of this session differs depending on what the participants would like to talk about. It is often about supported employment, Social Security/Medicaid, or Guardianship. This week is devoted to topics the families would still like to learn more about. Families are also asked to share what they feel their future will hold according to their son or daughter’s transition.

**Supported Employment - Goals**

- Parents become familiar with the concept of support employment.
- Parents learn about the funding sources for supported employment.
- Parents learn how supported employment effects their son or daughter’s social security and health insurance benefits.
- Parents learn about some different types of jobs available through supported employment.

**New Vocabulary**

Supported Employment: Provides support to individuals with disabilities in the workplace that need to ensure their success on the job.

**Materials**

Spotlight on Supported Employment Booklet.

**Activities**

Discussion

**Supported Employment Outline**

Parents and young adults split into two groups.

**Discussion**

What is supported employment? - Supported employment is paid work performed by people with disabilities who need ongoing support to ensure they are successful on the job.
Supported employment seeks to create the ideal job by matching job tasks, job training, and ongoing supports to the employee.

Who helps a person find a job through supported employment? - A supported employment planning team helps an individual through the planning process. The planning process is based on the individual’s abilities, career interests, and support needs. The information obtained during planning is helpful to identify jobs, accommodations, and services that will help the person to obtain a job within the community. The individual’s planning team should include the individual, their family, friends, agency representatives and anyone that provides services to the individual.

What agencies fund supported employment?
   1. County Boards of Mental Retardation and Developmental Disabilities (MRDD)
   2. County Alcohol, Drug and Mental Health Boards
   3. Rehabilitation Services Commission
   4. Local School District

How will working effect the individual social security and health insurance benefits? - The individual needs to request a benefit analysis to see if their employment will affect their social security benefit. The planning team can also help to set up a work incentives program that can help the individual make the transition from benefits to earned income. Not all jobs will offer medical insurance. An individual may be eligible for Medicare or Medicaid while they are pursuing employment. The team will help the individual with issues regarding health insurance.

What types of jobs are available through supported employment? - With job accommodations the variety of jobs people with disabilities can perform is expanding greatly. Through job restructuring, rehabilitation technology, and assistive devices an individual with disabilities is able to do a wide variety of jobs. The planning team will help to identify funding for assistive devices that may be needed for the individual.

**Social Security/Medicaid Goals**

- Parents will learn about SSDI and SSI.
- Parents will learn about Medicare benefits.
- Parents will learn how to file for SDDI, SSI, and Medicare.
- Parents will learn how to discover if a paying job will affect their child’s benefits.

**New Vocabulary**

Social Security Disability Insurance (SSDI): This is an earned benefit that is acquired through medical disability and earnings which are below $700 monthly which is the current substantial gainful activity (SGA) level. A claim will be denied if the applicant earns at or above SGA.

Supplemental Security Income (SSI): Recipients can include those 65 or older, 18 or older with a physical or mental impairment, disabled children, or an adult or child who is blind. The purpose is to ensure a minimum level of income to those individuals.
Work incentives: Set up to enable the individual with an impairment to achieve gainful employment, increase their independence and autonomy, effect empowerment, and move towards self-support through meaningful employment. There are different types of work incentives offered depending on the individual benefits.

Medicare: An insurance program serving people 65 or older and individuals with disabilities regardless of their income.

Medicaid: Health care program serving eligible low-income people of any age who do not have the resources needed to pay for medical expenses.

**Materials**


**Activities**

Discussion

**Social Security/Medicaid Outline**

Parents and young adults split into two groups.

**Discussion**

What is Social Security Disability Insurance (SSDI)? - An earned benefit that is acquired through medical disability and earnings that are below the substantial gainful activity level (SGA). To be eligible the applicant must have paid in for enough years to be eligible for the coverage, be medically disabled, and not be working or earn less than the SGA level.

What is Supplemental Security Income (SSI)? - Benefit that is based on need. The purpose is to secure a minimum level of income for the eligible recipients. It requires that the applicant have a medical disability, have earnings below the SGA, and a limited amount of financial resources. Recipients can be those 65 or older, 18 or older with a physical or mental impairment, disabled children, or an adult or child who is blind.

How does a person file for SSDI or SSI? - Applications can be filed in person or by telephone with the local Social Security Office.

What are Work Incentives? - They are intended to help the people with an impairment to achieve employment, increase their independence, empower themselves, and move toward self-support through their employment. Work incentives make it possible for people receiving SSDI and SSI to work and still maintain their SSDI and SSI eligibility, keep their monthly cash payments, and still receive Medicare or Medicaid. The work incentives for both SSI and SSDI are explained in this portion of the presentation.
What is Medicare? - An insurance program that serves people 65 or older and individuals with disabilities regardless of their income. To become eligible the person must apply at the local Social Security office.

What is Medicaid? - A health care program serving eligible low-income people of any age who do not have the resources needed to pay for medical expenses. To establish eligibility the person must contact the county department of human services. In this portion of the presentation Medicare and Medicaid will be compared.

What information do you need to have when applying for SSDI or SSI? - You will need the social security number for you and any dependents who are applying for benefits, a document that shows proof of age for each person applying for benefits, information about your income and assets, information about the home in which you live, proof of your disability and how it effects your life.

How will a paying job affect my son or daughter’s disability benefits? - Mr. Swain will show the parents how a consultant can evaluate a person’s work income and use the work incentives to figure an adjusted benefit for the person with a disability. Just because a person with a disability has gained paid employment does not mean that they will automatically lose their benefits.

**Guardianship - Goals**

- Parents learn about what guardianship is.
- Parents learn about how to obtain guardianship.
- Parents learn about the types of guardianship available.

**New Vocabulary**

Guardianship - When a person is declared incompetent, a guardianship can be court ordered. A Guardianship acts on behalf of the person who is declared incompetent.

**Materials**

- Guardianship Brochure from the Probate Court of Franklin County.
- An overview of the Guardianship Statutes and Procedure in Ohio Probate Courts.

**Activities**

Discussion

**Guardianship Outline**

Parents and young adults split into two groups.
**Discussion**

What is Guardianship? - A Guardianship is a court ordered relationship in which the guardian acts on behalf of the ward. A guardian can be an adult person or corporation appointed by the Probate Court. Any interested person can apply to be a guardian. A ward is a person who is unable to care for themselves or their property. An incompetent adult or a minor child is able to have a court appointed guardian. A person is defined incompetent as “any person who is so mentally impaired as a result of a mental or physical illness or disability, or mental retardation, or as a result of chronic substance abuse, that he is incapable of taking proper care of himself or his property or fails to provide for his family or other people for whom he is charged to provide.”

How is Guardianship started? - The guardianship process is started by filing an application on court-approved forms in the probate courts of the county where the ward resides. A hearing will be held before the Probate Judge or a Magistrate, at which time a determination will be made as to the necessity for the guardianship and the suitability of the applicant.

What types of Guardianship are available?

1. Person and/or estate – A guardian of the person controls and protects the personal needs of the ward. A guardian of the estate controls and protects the assets of the ward.
2. Limited – The authority of the guardian is limited to specific purposes.
3. Interim – When a guardian is no longer able to serve or is removed, an interim guardian may be appointed for a short period of time, until a hearing can be held to appoint a new guardian.
4. Emergency – Upon emergency, the court may appoint a guardian without notice of the ward or their family. The emergency guardian serves for a short time to protect against significant injury to the person or estate of the ward.
Dear What’s Next Participant,

We were delighted that you participated in What’s Next and appreciated your cooperation. Enclosed please find a questionnaire packet that we would like you to complete and return in the self-addressed stamped envelope. This information is a follow-up of the survey packet you completed before the What’s Next group.

Upon receiving this packet from you I will be forwarding a check for $25.00 to each person filling out the packet. Thank you for all your ongoing support! Also, remember to complete all questions on the survey. Please call me if you have any questions at (614) 292-7550. Take care.

Sincerely,

Tom Fish
Appendix B

Results of “What’s Next” Feedback Forms
Results of “What’s Next” Feedback Forms

Respondents used the following scale ...
SA = Strongly Agree
A = Agree
N = Neutral
D = Disagree
SD = Strongly Disagree
NR = No Response

<table>
<thead>
<tr>
<th>Response</th>
<th>#</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I know more about supported living options than I did before the program. (n=55)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SA</td>
<td>36</td>
<td>65.45%</td>
</tr>
<tr>
<td>A</td>
<td>16</td>
<td>29.09%</td>
</tr>
<tr>
<td>N</td>
<td>1</td>
<td>1.81%</td>
</tr>
<tr>
<td>D</td>
<td>1</td>
<td>1.81%</td>
</tr>
<tr>
<td>SD</td>
<td>1</td>
<td>1.81%</td>
</tr>
<tr>
<td>2. I think I know and understand the housing options for my child. (n=55)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SA</td>
<td>20</td>
<td>36.36%</td>
</tr>
<tr>
<td>A</td>
<td>32</td>
<td>58.18%</td>
</tr>
<tr>
<td>N</td>
<td>3</td>
<td>5.45%</td>
</tr>
<tr>
<td>D</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>SD</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>3. I think the sessions were helpful for me and my child. (n=55)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SA</td>
<td>35</td>
<td>63.63%</td>
</tr>
<tr>
<td>A</td>
<td>17</td>
<td>30.90%</td>
</tr>
<tr>
<td>N</td>
<td>3</td>
<td>5.45%</td>
</tr>
<tr>
<td>D</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>SD</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>4. I enjoyed the sessions. (n=55)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SA</td>
<td>36</td>
<td>65.45%</td>
</tr>
<tr>
<td>A</td>
<td>17</td>
<td>30.90%</td>
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<td>N</td>
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<tr>
<td>SD</td>
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<tr>
<td>5. I believe my child enjoyed the sessions. (n=55)</td>
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<tr>
<td>SA</td>
<td>32</td>
<td>58.18%</td>
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<td>SD</td>
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<tr>
<td>NR</td>
<td>2</td>
<td>3.63%</td>
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<tr>
<td>6. I feel better about my child’s future. (n=55)</td>
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<tr>
<td>SA</td>
<td>17</td>
<td>30.90%</td>
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<td>7. I found the handouts helpful. (n=55)</td>
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<td>SA</td>
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<tr>
<td>NR</td>
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<td>1.81%</td>
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</table>
10. What topics or information did you find most useful?

- All – presented very well.
- I found all the information most helpful. What steps to take, how supported living works, etc.
- I thought all were helpful. There were many that I didn’t know about.
- The creative living information.
- Steps to go through before placement actually occurs.
- We appreciated hearing about other parents’ and children’s situations.
- Agency as speaker. Creative Housing – Pat Rafter as speaker.
- Each topic was useful, but it was the reinforcement of information that was most useful. The information wasn’t just put out and moved past. The information was reexplained and reinforced. I got a real sense that what we heard was, in reality, the way it is.
- I enjoyed hearing Larry Milam. The provider part of this whole supported living process is to me the most important issue.
- SSI and Social Security disability. Housing options. Also, this was very convenient time wise for working families. The time frame of one and a half hours is about right, too.
- The service provider piece was quite good. Having been involved in the process for a while, some of the topics were redundant, yet appropriate. I appreciated the piece on SSI/Medicare, etc.
- SSI and Medicaid, placement issues.
- Much of this information needed to be out to people long before the children turn 18 or become eligible for housing.
- Turnover of the providers and the things that go on in the homes.
- The overview of all that is available and explanation of details regarding the housing choices.
- Understanding the options available through supported living.
- ISP planning, housing options, process in general.
- I particularly enjoyed the discussion by the head of Creative Housing.
- Care provider information.
- Most sessions had useful information. Handouts were great. Bringing experts in to talk and answer our questions was excellent.
- Housing and service options. Social network & contacts. Talking with other parents and grandparents. Social contacts for my nephew.
• The many options that are available. The opportunities available to the children (young adults). The red tape route and the need for perseverance. Sharing with other parents or caregivers.
• Choosing a provider and what their role is.
• I thought it was a good idea having someone come and talk with us about the agency and provider (very helpful), because we don’t know unless we’re told about what is going on.
• The steps on how to look for a house, then provider, etc. How the “case manager” is involved in overseeing any problems.
• Creative housing, provider services, how to interview.
• Selecting & interviewing providers.
• Agency person – ISP information.
• The topic about creative housing, but all were helpful.
• All topics were useful to me. I really learned a lot and appreciate the opportunity to attend.
• All sessions.
• Creative housing information.
• Creative housing.
• Handouts.
• Creative housing and assisted living. More than I thought it could be. Did not know anything about care providers. Found this info and everything related to them very useful.
• The more you know, the less you know. I found topics on employment, agencies to help, and networking important.
• Creative housing, TSPs, provider, benefits.
• Creative housing, SSI.
• Info on how to interview, log & access, guardianship, trust funds.
• Benefits. We did not understand how that worked before the classes.
• Understanding creative housing, learning about the ISP, finding out the process to access creative housing, social opportunities for my child, SSI information.
• All! The creative housing session was great and so uplifting. What a comfort seeing the photos, knowing our child could be part of that! We feel a lot better!
• The speaker of the last evening, April 27. [Ron Swain]
• Different options. Things we need to do to get ready for Nicole’s moving.
• Supported living options, SSI info, how to prepare for creative housing – furniture, etc., choosing roommates. My child enjoyed learning about options for his future – exciting for him.

11. What information was not discussed that you think should be covered in future training sessions?
• None.
• None.
• Expose us to different social events we can get our kids involved in so they can choose (or we help) with roommates.
• SSI, food stamps, financial topics.
• Roommate selection process – how to arrive at a compatible group.
• Thought you did a very nice job.
• Estate planning, guardianship.
• Can’t think of anything right now.
• Nice job!
• How families can go about finding a match or matches for their child. It would have been great to have visited 1 or 2 or several supported living options, i.e., creative housing, group home.
• Estate planning, legislative updates, SSI process, qualifications.
• Job placement and testing for the handicapped.
• When you know nothing about a subject, you can’t say what was missing.
• Perhaps some more info on sequence of events or possible scenarios of sequence of events. Little more info on transportation issues.
• I think caregivers and parents need to understand that they can choose one option and change if circumstances permit and staying in contact with support people and not be afraid to ask or be afraid of change. It’s a scary lonely world without support.
• Legal guardianship was only touched on slightly, and it would be helpful to hear more on that in relation to supported living.
• There was so much information dispersed in the last session, I don’t know how much more could be addressed. We ran out of time as it was.
• What happens when mistakes or failures are made?
• More about guardianship
• Discuss all options or programs available regarding employment and/or nonemployment options. I think when graduation nears, someone should be in charge to assist parents on “all” available options. Take a look at student and look at “creative” options for their future, along with the parents.
• Opportunities to meet other families to form relationships that could be roommates.
• People without caseworkers or those who have just gotten one need a pre-session of sorts to talk about benefits, assistance programs, and terminology used (very important). I walked into all of this cold and could not ask questions because I didn’t understand enough to even form them in my mind.
• Guardianships. Also, future care. How clients are taken care of after parents are not around.
• Guardianships.
• More than I even considered was covered. I thought a very well rounded program was put together.
• Finding roommates.
• Social activities or programs that are available for those whom have graduated.
• N/A – I just wish the classes could continue. We know there is so much to learn. We will miss all our “new friends.” Thanks for a wonderful 6 weeks!

12. Other comments or suggestions?
• Thank you. I really enjoyed myself. Very informative.
• Possibly invite parents to speak who have been in supported living program for a few years (tips, do’s & don’ts, etc.). Enclose return envelope.
• Very good program. Have a 1-night follow-up 6 months later.
• A list of families in our “What’s Next” section completed with first names, children, and phone numbers, so we can keep in touch. An agenda of what we will cover and what our children are covering.
• All of you were fantastic. Thanks for the time and understanding. I enjoyed each and every session. We went home with a lot on our minds to think about.
• The first week, when everyone talked about their story, was very heart-wrenching for me. I am sorry we were not able to attend the last meeting so we could talk to more people who had been all the way through the process. Attending this class has had a lasting effect on my daughter, who now seems to be more open to the social aspect of life. I am so happy for her. If nothing else, this is a remarkable change. I appreciated the promptness of starting and ending times (I have to get up early!). It would be great if you had your supported living caseworker assigned by the meetings, or maybe a liaison to answer questions. I started out feeling a bit overwhelmed, but as we went on, things became clearer. I am not sure where to go from here, but we are at the “locating a roommate” stage, and I am at a loss. My daughter is an important concern to me, and I do feel better about the supported living program. I am so good to know people who have done this already and see that it works. I’m also glad you were honest with your problems with it. I think I’ll be better able to cope when they come my way. Thank you for starting this group. At first I didn’t know enough to even ask questions, and then they came from everywhere, but at least you could answer them. My daughter enjoyed having separate meetings, and it was good for me, too. I can see that this will be a long process, but it has its good points, too.
• It was great to hear and participate with such enthusiastic and dedicated people. Despite the many obstacles, they did and search to be as helpful as possible. It has been such a relief to know that these options are available and that people do care.
• A better way of matching roommates is needed. Unless participants have roommates already picked out themselves, the establishment falls way short in this area. MRDD should spend some of the taxpayers’ money to establish a faster and more updated method to find roommate matches! A computer database system with privacy act information eliminated should be available to caseworkers.
• I thought the whole agenda was good and interesting. I enjoyed meeting other parents and their experiences.
• Very informative and worthwhile. We enjoyed the sessions.
• A monthly newsletter geared specifically to support living information and changes – perhaps including a list of families looking for matches. Periodic social functions with other families at the transition phase. I’d like to take this time, also, to express my gratitude to Peggy Martin and staff for the time and effort taken to initiate the “What’s Next” program. As the mother of an 18-year-old multi-handicapped son, I was totally in the dark as to the options that were available for him regarding community placement. If it weren’t for my fortunate involvement in the “What’s Next” program, I fear I would have remained uninformed of the options available. The “What’s Next” program is a most valuable resource for parents of youth who are in the transitioning stage. I do hope it will take hold, perhaps expand, and continue to be an integral part of the transition phase from home to community.
• It would be helpful to include one visit to a current housing site. I would have like to have heard from one of the service providers on one of the sessions.
• I would recommend 6 weeks. I think 6 weeks is the amount of time needed to answer all
the questions and get the information needed.
• When a child is identified at an early age, the parents should be made aware of all the
options and available support out there, rather than allowing them to struggle along in the
dark.
• I would like to see more parent support groups created. I would be interested. People that
have special children sometimes feel lonely and disconnected. It would help to talk with
someone who is expressing the same feelings. Also, we can share some important
information concerning programs, etc.
• The social interaction for the kid was excellent! They really enjoyed it, and it made it feel
good and right. The time spent at the sessions was valuable for all of us. Thanks for your
time and effort. Good job.
• Thanks for these sessions. It was good to meet other families, to hear the worries,
concerns, and hopes. This is an excellent program that is a must for families. Thanks to
all staff who participated, who shared their knowledge and support.
• After all the evenings, I still don’t have a real feeling as to how long the process will take.
Is it short-term, e.g., within the next year, or will it be 5 or 7 years? Thank you for the
time, effort, and openness you showed us all.
• Very well put together, organized, friendly. We felt welcomed and free to share our
deepest thoughts and concerns. Four stars for Peggy Martin and her assistants.
• I enjoyed the meetings very much. Everyone at MRDD seems to work very hard.
• I found this class to be most helpful, and questions were answered. I left feeling so much
better about my child’s future.
• Very helpful and comforting to know I’m not alone in this and there are successful
networking systems in place. Thank you. Feedback about how the kids are responding
would be nice. My daughter had some fears come up, and I had a hard time figuring what
triggered them.
• I think you need to contact parents sooner than 20 or 21 years of age. The survey part was
way too long. Good job, Peggy & Tom.
• Have parents rotate bringing snacks.
• Get this program to people with children who are younger, middle school perhaps. We let
our child travel through the system, letting the school do what they thought best, which
turned out to be pretty good. If I had been involved in a program like yours earlier, my son
(and I) might be farther along and better prepared for transitions, options, new goals, etc.
• The system needs to change so that families get into this kind of program during high
school rather than after they leave.
• I enjoyed and was educated with all of the sessions. I’m glad I was prodded to start
attending. Keep up the good work.
• Enjoyed and appreciated very much. The education to the program was evident, and my
child loved it, too! It’s nice having a parent do this. They understand.
• Wonder program and very informative. Thank you!
• Thank you for providing information that was sorely needed. Also for providing an
interpreter for Bill and Regina. Also, we appreciate all your personal concern for our
problems. We believe that all of the speakers understood where the parents stood and
why we had so many fears. Keep up the good work.
• Enjoyed meeting other families. Social contacts for my child were great. Thank you.
• Thank you for a great learning experience! We have really found comfort in coming here for the past six weeks. The classes have been so informative. We really appreciate you “sharing” with us. We feel a lot better about the “future.” It doesn’t seem so unattainable at this time for our child/family.
• Peggy Martin and Tom Fish are very kid and interesting individuals.
• There needs to be more communication between the schools and MRDD about different living options. This should start when the children are in junior high school.
Appendix C

Instrument
Vocational and Community Involvement Profile

Purpose – The purpose of this instrument is to identify the concerns and apprehensions parents might have as their sons and daughters transition to vocational and community life. The instrument is intended to help parents and professionals communicate effectively and understand one another so as to maximize the student’s social and vocational potential.

For the purpose of this questionnaire, “child” will be used the same as youth, student, adolescent, etc. The questionnaire should take about 15 minutes to complete. Try to answer each question and remember that your initial response is probably the most accurate. All information provided by you will be held in the strictest confidence.

Date: __________________________

Name of Individual Completing this Questionnaire __________________________

Relationship of Person Completing this Questionnaire to Child __________________________

Child’s Name __________________________

Child’s Age __________________________

Child’s Gender M ______ F ______

Thomas Fish, Jodi Hayman, Peggy Martin, Cathy Moore and David Rearick
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A. Parental Concerns

Directions: Please indicate the extent to which you agree or disagree with each of these statements.

- If you **Strongly Disagree** with the statement, circle 1.
- If you **Disagree** with the statement, circle 2.
- If you **Slightly Disagree** with the statement, circle 3.
- If you **Slightly Agree** with the statement, circle 4.
- If you **Agree** with the statement, circle 5.
- If you **Strongly Agree** with the statement, circle 6.

Read each statement carefully and circle your responses as shown in the example.

**Example:** I enjoy participating in research projects. 1 2 3 4 5 6

The respondent **Agrees** with the statement.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Slightly Disagree</th>
<th>Slightly Agree</th>
<th>Agree</th>
<th>Strongly Agree</th>
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</thead>
<tbody>
<tr>
<td>1. Adjusting to my child living outside of our home would be difficult.</td>
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<td>2. My child has skills he/she can use to earn a living.</td>
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<td>3. My child would have a difficult time emotionally if he/she moved out to live independently or with others.</td>
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<td>4. My child is mature enough to work in the community.</td>
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<td>5. I am concerned about what will happen to my child as I get older.</td>
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<td>6. My child would be safe living in his/her own apartment.</td>
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<td>7. My child would be safe riding the bus by him/herself</td>
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<td>8. Friends my child meets in the community will treat him/her with respect.</td>
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<td>9. I am worried my child will be taken advantage of sexually.</td>
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### A. Parental Concerns

<table>
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<tr>
<th></th>
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<th>Strongly Disagree</th>
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<th>Slightly Agree</th>
<th>Agree</th>
<th>Strongly Agree</th>
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<tbody>
<tr>
<td>10. My child can be left alone on a job site for a full work day once he/she knows the duties of the job.</td>
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<td>11. My child would be taken advantage of if out in the community alone.</td>
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<td>12. My child will succeed on his/her own.</td>
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<td>13. My child can arrange for the supports needed to get to work.</td>
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<td>14. I am worried that my child will engage in inappropriate sexual advances towards others.</td>
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<td>15. I am confident that my child will make good choices for his/her safety.</td>
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<td>16. My child will be able to work in the community.</td>
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<td>17. My child has health concerns that I worry will affect him/her on the job.</td>
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<td>18. My child will be able to secure a job that pays more than minimum wage.</td>
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<td>19. My child will be able to receive adequate insurance benefits from his/her place of employment.</td>
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<td>20. I am concerned that our family budget will be reduced if my child moves out.</td>
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<tr>
<td>21. My child would be able to handle unwanted sexual advances of others.</td>
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<td>22. I want to have the final say in the choice of a job for my child.</td>
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<td>23. My child will need support to maintain long-term employment.</td>
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<tr>
<td>24. It is important that my child makes enough money to support him/herself.</td>
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<td>25. There will not be anything to replace school when my child graduates.</td>
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<td>26. My child needs long-term training in a vocational center/sheltered workshop.</td>
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<td>27. If my child moves out, he/she will have an acceptable standard of living.</td>
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<td>28. I am afraid that my child would lose his/her benefits in a community job.</td>
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<td>29. My child would be able to understand directions.</td>
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</table>
### Parental Concerns

<table>
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<tr>
<th></th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Slightly Disagree</th>
<th>Slightly Agree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>30. It is important that I be involved in finding a job for my child.</td>
<td>1</td>
<td>2</td>
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<tr>
<td>31. Support providers will be able to care for my child's needs as well as I do.</td>
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<tr>
<td>32. Adequate support is available to help my child be successful.</td>
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<td>2</td>
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<td>33. My child would be able to express his/her needs.</td>
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<td>5</td>
<td>6</td>
</tr>
<tr>
<td>34. My child's health care needs will be met if he/she moves out of my house.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>35. My child would be bored living on his/her own.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>36. My child's safety in a job situation is a concern.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>37. My child can use the telephone independently.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>38. I feel that others will accept my child.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>39. Co-workers will treat my child the same as they do others.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>40. My child will be able to travel independently in the community.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>41. My child will engage in the same activities that people without disabilities do.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>42. My child would be able to stand up for his/her rights.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>43. Without supervision my child would be involved in criminal activity.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>44. My child will be able to manage his/her money successfully.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>45. I will always be responsible to provide for some of my child's financial needs.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>46. My child would be better off having only friends who also have special needs.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>
B. Demographic Information

Instructions: Circle the appropriate response about yourself in numbers 1-7, complete numbers 8-9.

1. What is your gender?
   1 Male
   2 Female

2. What is your marital status?
   1 Married
   2 Divorced
   3 Separated
   4 Widowed
   5 Never Married

3. What is your highest level of education completed?
   1 Elementary School
   2 Some High School
   3 High School Diploma or Equivalent
   4 Some College
   5 Technical or Trade School Certification
   6 2-Year College Degree
   7 4-Year College Degree
   8 Some Graduate Work
   9 Graduate Degree

4. Which of the following describes your employment status?
   1 Hourly Wage Worker
   2 Salaried
   3 Work on Commission or Tips
   4 Self-Employed
   5 Unemployed
   6 Retired
   7 Homemaker

5. What is your race/ethnic background?
   1 American Indian/Alaskan Native
   2 Asian or Pacific Islander
   3 Black
   4 Hispanic
   5 White, Not of Hispanic Origin
   6 Other, Please Specify __________

6. What is your total household gross income (before taxes)?
   1 less than $9,999
   2 $10,000 - $19,999
   3 $20,000 - $29,999
   4 $30,000 - $39,999
   5 $40,000 - $49,999
   6 more than $50,000

7. How would you rate your child’s level of disability?
   1 Mild
   2 Moderate
   3 Severe
   4 Profound

8. In what year were you born? __________

9. How many people live in your household? (Be sure to count yourself.)
   ________ Children
   ________ Adults
C. Views about your child's involvement in the community and on the job.

Please complete the following items.

1. I have the following concerns about my son/daughter's independent living: 
   
   
   
   
   
   
   
   
   
   
   
   

2. An employer would like the following qualities that my child has 
   
   
   
   
   
   
   
   
   
   
   
   

3. My child would like to work as a ___________________________ when he/she is out of school.

4. I would like to see my child work as a ___________________________ when he/she is out of school.

5. Any other concerns not addressed in this questionnaire? 
   
   
   
   
   
   
   
   
   
   
   
   

Thank you for your time and cooperation.
Appendix D

Vocational and Community Involvement Profile -
History of Development
Vocational and Community Involvement Profile -
History of Development

2-95 Members of the LISW supervision team identified a need to better understand parental concerns regarding their son’s or daughter’s transitioning into the community or vocational life. The way in which these concerns were dealt with played a critical role in the level of success of the transition.

2-95 to 5-95 We conducted a review of current literature regarding instruments that could gather this information. One instrument, by Dr. Jeff McNair, was determined to lack the depth of focus we were looking for. We were unable to find an instrument that would meet the need.

5-10-95 We started developing a questionnaire, based on categories of concern that parents had expressed to us.

6-14-95 The initial title for the instrument was “Work and Emancipation Scale.”

10-95 Met with Jan Henderson, OSU Agriculture research professor, and discussed our draft of the instrument. She offered suggestions that clarified the categories, question balance, and specific wording.

12-21-95 After making needed changes, we sent a draft of the profile to 5 parents and later made a follow-up call to collect feedback. Parents were selected from caseloads and contacts of the members of the supervision team. Fourteen parents participated.

1-8-96 We sent the draft to 19 professionals throughout the nation, who were interested in and knowledgeable about transition. Eight responses were returned.

1-96 to 6-96 We digested the feedback and honed the profile.

5-3-96 Tom Fish, Cathy Moore, and Peggy Martin presented the profile to the Ohio Transition Conference in Columbus OH.

6-25-96 We sent Draft #4 to 6 parents.

7-24-96 We sent Draft #4 to Jan Henderson and Mark Tase for feedback.

11-8-96 Tom Fish and David Rearick presented Draft #5 to the Pathways Conference at Salt Fork State Park Lodge, Cambridge OH.

11-13-96 Based on feedback, we completed Draft #5.

11-19-96 Tom Fish and two graduate students entered data for 22 parents who had responded to Draft #4.
Being a parent of a 19 year old dual diagnosed daughter that suffers from obsessive compulsive disorder and mental retardation, I felt comfortable calling parents and asking them their thoughts on the Vocational and Community Involvement Profile. I spoke with parents that children were either multi-handicap, developmentally handicap, or had a severe behavioral handicap. Their ages ranged from 13 to 20 and depending on their disability and age the concerns varied.

Some parents were confused by some of the questions if they did not apply to them. If a parent isn’t receiving any money for their child they didn’t understand the question of concern if their child moved out that they would lose funds. On Page 5 they were not sure who the question was directed to the parent or the child. Most parents felt the questionnaire was too long and could have addressed more important points. Several parents had concerns on sex and communication skills and felt were needed to address them. They were also confused with the cluster sheets, as to what they were to do with them. Two parents were depressed after filling this questionnaire out because they said it made them think about issues they were not ready to deal with. Most of the parents said they like to take one day at a time and it was difficult for them to answer because they really don’t know what their future plans are. One mother took offense to the question about her child being involved in crime and about feeling empty if their child moved out. She said it made her sound neurotic. Parents felt the survey gave them insight in to some areas that they had not thought about. Transportation, insurance benefits and transitional counseling were what they considered to be good hard questions of concern. One parent said if she had filled out this survey a year ago her answers would have been totally different because now that they are involved in Option 4 they are having things become a reality that they would of thought to be impossible. It was in agreement that if these questions were given in middle school and again in high school that there would be a large difference in how they would be answered. Parents did like the idea of it being administered in middle school because it gave them plenty of time to prepare for the future. By learning what was ahead of them they could start accessing services and become a stronger advocate. One parent whose daughter is on the high end of the developmentally handicap class felt some of the questions to be ridiculous.

My recommendation would be to shorten the survey and to take out any areas that seem offensive and add others that were omitted. I would be more specific on who is to answer on page 5 and would not attach the cluster sheets. I would make sure all questions apply to any student in special education and that all parents would understand the subject matter.

Peggy Martin
123 Walcreek Dr. E.
Gahanna, Ohio 43230
614-476-2047
September 27, 1996

Dear Parent,

Enclosed please find a questionnaire which is being developed to increase understanding between parents and professionals regarding transition from school to work for youth with disabilities. I would appreciate your help in filling out the questionnaire so that we can determine if it properly constructed and accomplishes what it is supposed to.

If you agree to participate, simply complete the instrument and return it to me by October 18, 1996. It should take approximately 15 minutes to complete. There are no right or wrong answers and all responses will be kept confidential. Please fill free to make any comments or suggestions about the questionnaire, after you have completed it. If you participate and would like more feedback on the results, let us know and we should have some findings by the first of the year.

Thanks in advance for your willingness to help with this project.

Sincerely,

[Signature]

Thomas Fish
Associate Director
August 21, 1998

Dear Parent or Guardian,

Enclosed please find a questionnaire which is being developed to increase understanding between parents and professionals regarding transition from school to work for youth with disabilities. I would appreciate your help in filling out the questionnaire so that we can determine if it properly accomplishes what it is supposed to.

If you agree to participate, simply complete the instrument and return it to me as soon as possible. It should take approximately 15 minutes to complete. If there are two questionnaires in your packet, then both parents should fill them out separately. Please feel free to make any comments or suggestions about the questionnaire, after you have completed it. If you participate and would like more feedback on the results, let us know.

Thanks in advance for you willingness to help with this project.

Sincerely,

[Signature]

Thomas Fish
Appendix E

Correspondence & Documentation
Correspondence & Documentation

July 21, 1999

Dear Parent,

I am writing to request your participation in a study designed to identify concerns that parents have about the transition of their sons and daughters from high school to adult life. Results from the study will help us understand more about what parent's want and need during the transition process for their son and daughters. This study is a joint effort between The Ohio State University Nisonger Center and the Franklin County Board of MR/DD specifically through the What's Next program. We are excited to hear that you will be participating in the What's Next program, which is a six-week (9-hour) information and support group program for parents and youth with disabilities. The What's Next program has been in existence for two years. The research study is a very small part of What's Next.

Enclosed please find a survey packet that will take approximately 25 minutes to complete. Additionally there is a self addressed stamped envelope for you to return the packet. If you choose to participate, you will receive a second packet to complete in approximately 2 months. You will be able to participate in the What's Next program even if you choose not to complete this survey packet. Each parent is requested to complete a survey packet independently and not to influence one another responses.

Your participation is greatly valued and upon successful completion of both survey packets each parent will receive $25.00. In addition to conducting this study, I was a developer of the What's Next program and will be one of the leaders of the weekly group sessions. Your responses will be kept confidential and we will be happy to provide you with a copy of the results of the study. If you decide to complete the questionnaire, please answer every question asked with only one answer by going with your "gut" response. Please feel free to contact me at 614-292-7550 if you have any questions.

I want to thank you in advance for your willingness to help make this a meaningful and worthwhile study, which will ultimately help to better support youth with disabilities.

Sincerely,

Thomas Fish
Director of Employment Services
July 21, 1999

Dear Parent,

The attached questionnaire is called “The Vocational and Community Involvement Profile.” It was recently developed by a group of parents and professionals in order to help identify concerns parents have about their teenage sons and daughters with disabilities living and working in the community. This questionnaire is intended to promote dialogue and understanding between parents and professionals.

At this point we are still in the process of refining the questionnaire and would like to ask your assistance. I am writing to see if you would be willing to complete the questionnaire and return it to me in the enclosed self-addressed envelope. It should take approximately 15 minute to complete. Your responses will be kept confidential and we will be happy to provide you with a copy of the final version of the questionnaire. If you decide to complete the questionnaire, please answer every question asked with only one answer by going with your “gut” response. Please feel free to contact me at 614-292-7550 if you have any questions.

I want to thank you in advance for your willingness to help make “The Vocational and Community Involvement Profile” a meaningful and worthwhile instrument which will ultimately help to better support youth with disabilities.

Sincerely,

[Signature]

Thomas Fish
Director of Employment Services

TF/pbs
Oral Solicitation Script

Hello Mr./Mrs. __________________. My name is __________________ and I am calling about a study being conducted by the Ohio State University Nisonger Center in conjunction with the Franklin County Board of MR/DD to learn more about how parents of young adults with disabilities feel about the transition process from school to work. It is my understanding that your son/daughter is on the waiting list for supported living through the county board. I also know that your family will be participating in the upcoming *What’s Next* group. By now you have probably already received a survey packet from us. I am basically calling to find out if you have any questions about the survey packet [PAUSE]. I also want to clarify that not completing the packet will in no way jeopardize your participation in What’s Next. But I also want to remind you that the information you provide will help us learn more about parent perspectives during the transition process. Additionally, I want to let you know that by completing the survey packet before and after What’s Next, you will receive $25.00 with our thanks and appreciation.

So at this point are there any questions? [PAUSE]. I want to thank you for being involved.
Control Group Letter

Dear Parent,

I am writing to request your participation in a study designed to identify concerns that parents have about the transition of their sons and daughters from high school to adult life. This study is a joint effort between The Ohio State University Nisonger Center and the Franklin County Board of MR/DD. As part of this study you will have the opportunity to participate at a later date in the What's Next program. What's Next is a six week (9 hour) information and support group program for parents and youth with disabilities.

Enclosed please find a survey packet that will take approximately 25 minutes to complete. Additionally there is a self addressed stamped envelope for you to return the packet. If you choose to participate, you will receive a second packet to complete in approximately 2 months. Each parent is requested to complete a survey packet independently and not to influence one another responses.

Your participation is greatly valued and upon successful completion of both survey packets each parent will receive $25.00. Your responses will be kept confidential and we will be happy to provide you with a copy of the results of the study. If you decide to complete the questionnaire, please answer every question asked with only one answer by going with your “gut” response. Please feel free to contact me at 614-292-7550 if you have any questions.

I want to thank you in advance for your willingness to help make this a meaningful and worthwhile study which will ultimately help to better support youth with disabilities.

Sincerely,

[Signature]

Thomas Fish
Director of Employment Services
Experimental Group Letter

Dear Parent,

I am writing to request your participation in a study designed to identify concerns that parents have about the transition of their sons and daughters from high school to adult life. Results from the study will help us understand more about what parent's want and need during the transition process for their son and daughters. This study is a joint effort between The Ohio State University Nisonger Center and the Franklin County Board of MR/DD specifically through the What's Next program. We are excited to hear that you will be participating in the What's Next program, which is a six-week (9-hour) information and support group program for parents and youth with disabilities. The What's Next program has been in existence for two years. The research study is a very small part of What's Next.

Enclosed please find a survey packet that will take approximately 25 minutes to complete. Please complete this survey and bring it with you to What's Next on Thursday May 25, 2000. If you choose to participate, you will receive a second packet to complete in approximately 2 months. You will be able to participate in the What's Next program even if you choose not to complete this survey packet. Each parent is requested to complete a survey packet independently and not to influence one another responses.

Your participation is greatly valued and upon successful completion of both survey packets each parent will receive $25.00. In addition to conducting this study, I was a developer of the What's Next program and will be one of the leaders of the weekly group sessions. Your responses will be kept confidential and we will be happy to provide you with a copy of the results of the study. If you decide to complete the questionnaire, please try to answer every question asked with only one answer by going with your “gut” response. You certainly may feel free to not answer a particular question. Please contact me at 614-292-7550 if you have any questions.

I want to thank you in advance for your willingness to help make this a meaningful and worthwhile study, which will ultimately help to better support youth with disabilities.

Sincerely,

[Signature]

Thomas Fish
Director of Employment Services
Dear Participants,

I was delighted to have your participation in this study. I appreciate your time and efforts in filling out all the questionnaires. Enclosed please find a check for $25 for each person who completed the study. It is my hope that you found this study beneficial to you.

Again, thank you for your participation and ongoing support. If there is anything I can further assist you with please don’t hesitate to call me at 292-7550. Thank you and take care.

Sincerely,

Tom Fish
BEHAVIORAL AND SOCIAL SCIENCE
HUMAN SUBJECTS INSTITUTIONAL REVIEW BOARD (IRB)  MEETING DATE: January 14, 2000
THE OHIO STATE UNIVERSITY

RESEARCH PROTOCOL:

00B007  IMPROVING PARENT INVOLVEMENT ASSOCIATED WITH SCHOOL TO WORK TRANSITION FOR YOUTH WITH DISABILITIES, Bruce S. Growich, Thomas R. Fish,
Physical Activity & Educational Services

was presented for review by the Behavioral and Social Sciences IRB to ensure proper protection of the rights and
welfare of the individuals involved with consideration of the methods used to obtain informed consent and the
justification of risks in terms of potential benefits to be gained, the IRB action was:

_____ APPROVED  _____ DEFERRED*

X  _____ APPROVED WITH CONDITIONS*  _____ DISAPPROVED

_____ NO REVIEW NECESSARY

* Research cannot begin until conditions have been met.

*CONDITIONS/COMMENTS:

Subjects were deemed NOT AT RISK, and the protocol was unanimously APPROVED WITH THE FOLLOWING
CONDITIONS:

1. Revise both of the parent letters of solicitation as follows, and provide copies to the IRB.
   • Describe more clearly what portion of the project is research, and what is part of the "What-If" program.
   • Indicate that parents can participate in the "What-If" program even if they choose not to complete the questionnaire.
   • If the researcher is also the person conducting the "What-If" program, please inform the parents.
   • Include information about the benefits of the research and the risks to participants (if any).
   • Remove the instruction about completing every question. Tell parents that you would like for them to answer every
     question, but they may choose not to answer questions that they do not want to answer.

2. Will the researcher be using an oral solicitation script? If so, please submit a copy of the script.

If you agree to the above conditions, PLEASE SIGN THIS FORM IN THE SPACE PROVIDED BELOW AND
RETURN WITH ANY ADDITIONAL INFORMATION REQUESTED TO THE HUMAN SUBJECTS REVIEW DESK,
300 Research Foundation, 1960 Kenny Road, Campus, within one week. Upon such compliance, the approval form
will be mailed to you. (In case of a deferred protocol, please submit the requested information at your earliest
convenience. The next meeting of the IRB will be two weeks from the meeting date indicated above.)

Date:______________________________

__________________________________________
signatures of principal investigator and all
co-investigators

HS-025A
Rev. 2/92
(Conditions/Comments)
REFERENCES


Holden, L. (1996). Observations that were taken from removing the mask data that has been collected. Report from the Ohio Department of Mental Retardation/Developmental Disability.


