A Qualitative Study of the Effects of Transition Services on the Quality of Life for Post-High School (0 - 2 years) Students with Down's Syndrome who are Educable Mentally Retarded

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A QUALITATIVE STUDY OF THE EFFECTS OF TRANSITION SERVICES ON THE QUALITY OF LIFE FOR POST-HIGH SCHOOL (0 - 2 YEARS) STUDENTS WITH DOWN’S SYNDROME WHO ARE EDUCABLE MENTALLY RETARDED

JOSEPH A. FINLEY, JR.
A Qualitative Study of the Effects of Transition Services on the Quality of Life for Post-High School (0 - 2 years) Students with Down’s Syndrome who are Educable Mentally Retarded

By

Joseph A. Finley, Jr.

A Dissertation Submitted to the Faculty of College of Education In Partial Fulfillment of the Requirements for the Degree of Doctor of Philosophy

Lynn University
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I would like to thank the wonderful parents, special students, and school district administrators, who were so generous with their time and who work so hard for the good of the special children in their care.

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Finally, my wife’s good humor, patience, and love brought me through many emotionally low moments. I would never have been able to have completed my journey without her. All my eternal thanks and endless love to you.
This qualitative study examined the effects of Transition Services on the quality of life of special needs students. Selected parents, students, and district school employees were interviewed, observed, and presented with questionnaires in an investigation into the effects of Transition Services on the quality of life for post-high school special needs students. Data was transcribed, coded, triangulated, and analyzed to understand what effect Transition Services actually had on quality of life of these students. The study resulted in fifteen major findings:

a) district personnel distill Transition Services down to positive adult outcomes for success, b) selection criteria for district level Transition Services personnel varied between districts, c) past perception of Transition Services by district personnel shaped the current program(s), d) current vision of Transition Services by district level personnel varies by district, e) accomplishments of Transition Services at the district level shared concurrency, f) needed areas of improvement
in Transition Services at the district level varied by district(s), g) the effect of Transition Services in all three districts was perceived as positive, h) the reason(s) for the positive effect of Transition Services varied by district(s), i) the perceived qualifications of a district level Transition Services person varied by district, j) parents had little or no understanding of what Transition Services constitutes, k) the majority of the parent participants felt Transition Services was a failure, l) all parent participants wanted categorizing/labeling of students at this level, m) unemployment of student participants was a major issue, n) all student participants lived with their families, o) the majority of student participants perceived their overall quality of life as good, regardless of employment status.

The study concludes that Transition Services had little or no effect on the quality of life of these students, and that there are a variety of major issues that arose in regard to district level employees’ perception, parents not understanding their rights under IDEA, and to the perceived quality of life expressed by the student participants.
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Introduction
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CHAPTER 1: INTRODUCTION

Every day in the United States, one out of approximately eight hundred children is born with Down’s Syndrome. Down’s Syndrome, or Down Syndrome, is a human disorder caused by chromosome abnormalities that develop during germ-cell formation. The normal human chromosome number is forty-six; each somatic cell has twenty-two pairs of autosomes and one pair of sex chromosomes. If the sex cell receives an extra chromosome 21 when formed, the child will have three chromosome 21 in each cell—accounting for 96 percent of the Down Syndrome cases (Donegan & Potts, 1988).

Prior to World War II, children with the syndrome rarely grew to adult age, but with improved medical practices and home care, their life expectancy is now about fifty to sixty years. With this expected life span, the quality of life (QOL) has recently become an important national and international issue in the field of mental retardation and developmental disabilities (Goode, 1988; Anonymous, 2002). There are a number of reasons for this interest, including concern, that many feel, about the quality of life of disabled persons, the demonstration that social environments have considerable impact on an individual’s lifestyle, the fact that complex programs require complex outcome measures, the re-emergence of the holistic health perspective, and the concern that many people have about how others find satisfaction and life quality in a rapidly changing world (Schalock, 1990).
Significance of Problem

It is virtually impossible to state precisely the number of exceptional children for many reasons: (1) the different criteria used by states and local school systems to identify exceptional children; (2) the relative resources and abilities of different school systems to provide preventive services, so that an at-risk student does not become a special education student; (3) the imprecise nature of assessment and the large part that subjective judgment plays in interpretation of assessment data; and (4) the fact that a child may be identified as eligible for special education at one time in his/her school career and not eligible (or included in a different disability category) at another time (Heward, 2000).

The most complete and accurate information on how many exceptional children live in the United States is derived from the child count data in the U.S. Department of Education’s Annual Report to Congress on the education of the country’s children with disabilities (Ibid). More than 5.7 million children and youth with disabilities, or 7.7 percent of the resident population ages three to twenty-one, received special education services during the 1996 - 1997 school year (U.S. Department of Education, 1998). Specifically, in the disability category of mental retardation, there were 447,426, or 11.4 percent, of the total special education population (Ibid). This 11.4 percent represents a significant amount in regard to the overall population, and deserves further attention as to quality of life issues (Heward, 2000).
Overview

There are numerous studies that have been conducted on the two main educational programs currently in use - inclusion (Zionts, Smith, & Wisnewski, 1995; Shinn & Yasutake, 1997) and self-containment (Hilton, 1983; Bower, 1991; Diamond, 1994; McLeskey, 1990). The majority of the studies on inclusion provided positive feedback in relation to academic gain. Results revealed that students with disabilities, in the inclusive school program, made significantly more progress in reading and comparable programs in math, when compared to the students who were provided services in resource classes (Waldron, 1990). There are also those that relate inclusive programs to social and environmental issues for projected success (Waldron, 1990). The findings and their implications exemplify the potential significance of research examining the interplay of individual student characteristics and contextual environmental factors.

There is no clear consensus in the field about the meaning of inclusion (Kaufman & Hallahan, 1994). Virtually all special educators support the responsible inclusion of students with disabilities in regular classrooms, and the development and evaluation of new models for working more cooperatively with general educators to serve all students (Smith & Hilton, 1997; Vaughn, Schumm & Brick, 1998).

Many parents of children with disabilities strongly support the placement of their children in regular classes; others have resisted it just as strongly, thinking that the regular classroom does not offer the intense, individualized education their children need (Heward, 2000). The self-contained/resource classroom setting, specifically, any classroom that brings
together children with similar disabilities under the direction of specially trained teachers so that
the child's total educational needs are provided in the class by the teacher, is both a self-
contained classroom and a special class (Suran & Rizzo, 1979), which is addressed in a variety
of studies (Bower, 1991; Diamond, 1994; McLeskey, 1990; Waldron, 1990; Cook, 1999; Espin,
1997) and tends to have a varying opinion as to the actual value of the inclusive setting. Deno
(1996) noted that the teacher made few attempts to adjust instruction for students who were
having difficulties and were not progressing (Espin, 1998).

However, Baker and Zigmond reported in 1995 that, although they felt that special
education students were receiving a very good “general” education in these inclusive
programs, students seemed to get very little “special” education. They concluded that
“special” education in inclusive programs is, by design, no longer special (Baker & Zigmond,
1995). All of the studies reviewed had measured outcomes that were performance-based in
nature.

The common denominator that links both programs together, in regard to quality of life
issues, is Transition Services as mandated by the Individuals with Disabilities Education Act of
1990 (IDEA) (IDEA; P.L. 101-476). Recognition of the importance of Transition Services, and
the importance of student involvement in transition-related planning and decision making, were
formally articulated in IDEA (Ibid, 1990). This policy initiative stemmed, in part, from
considerable debate and discussion over the previous decade about effective means of
ameliorating disappointing post-school outcomes for students with disabilities. The basic
purpose of the Transition Service requirement in IDEA was to better prepare students with disabilities to enter the work place, go on for further training, become as independent as possible, and contribute to society (Storm, DeStefano, & O’Leary, 1996). The assumption and intent of the law were that a formalized process that focused on Individualized Educational Program (IEP) development, planning, educational programs, services and supports toward post-school outcomes could improve the quality of life of young adults with disabilities (Ibid, 1996).

IDEA defines Transition Services as a coordinated set of activities between public schools and post-secondary agencies that promote movement from school to post-school activities (Wright & Wright, 1999). IDEA also requires that each student’s IEP include a statement of interagency responsibilities for providing these activities and of any needed linkages to services, such as vocational rehabilitation or independent living arrangements. These linkages to post-school services have been identified in the literature as critical to positive, ongoing, post-school success (Collet-Klingenberg, 1998; Koller, 1994; Rusch, Enchelmaier, & Kohler, 1994).

The Individuals with Disabilities Education Act (IDEA) Amendments of 1997 (Public Law 105-17) mandate that the IEPs of students with disabilities include a statement of transition needs related to students’ courses of study beginning at age fourteen, and a Transition Service component for students with disabilities age sixteen and older. The initial passage of the federal mandate for transition planning occurred in the context of at least a decade of attention to the
need to develop transition policies, programs and services for youths with disabilities that would allow them to make successful transitions from school to adult life (DeStefano & Wermuth, 1992; Wehman, 1992; Heward, 2000).

Much of the research occurring prior and subsequent to the legislative mandate for transition planning has focused on identifying promising practices related to achievement of positive adult life outcomes such as employment, independent living and participation in post-secondary education and community life (Stowitschek & Kelso, 1992). These promising practices include utilizing the transition planning process and related instruction as vehicles for fostering self-determination and self-advocacy skills among students with disabilities (Field, 1996; Field, Martin, Miller, Ward, & Marshall, 1996; Martin, Marshal, & Maxson, 1993; Ward, 1996; Wehmeyer, 1996; Wehmeyer & Schwartz, 1997; Wehmeyer & Ward, 1995), incorporating diverse family and cultural perspectives in transition planning (Boone, 1992; Harry, 1992; Sontag & Schacht, 1994; Turnbull & Turnbull, 1996), and using person-centered planning processes to create a more responsive and family centered meeting context (Forest & Pearpoint, 1992; Salembier & Furney, 1994; Salembier & Furney, 1997; Turnbull et al., 1996).

The Florida Department of Education, Division of Public Schools and Community Education, Bureau of Instructional Support and Community Services, publishes information designed to assist school districts, state agencies which support educational programs, and parents in the provision of special programs (Greenwood, 1997). In Florida, boys and girls who
have special learning needs are called exceptional students, and the special help they are given at
school is called Exceptional Student Education (ESE) (Greenwood, 1997).

IDEA says that Transition Services must be put into the IEPs of students with disabilities
who are age fourteen or older. Transition Services may also be put into the IEPs of younger
students (Storms, et al., 1996). Transition Services are a set of activities that help a student
move from school to post-school activities. A transition team, made up of the student, parents,
teachers, and representatives of other agencies, plans the activities that help a student make the
transition (Greenwood, 1997). Under Florida law, Transition Services means a coordinated set
of activities for a student with a disability, designed within an outcome-oriented process, that
promotes movement from school to post-school activities, which may include post-secondary
education, vocational training, integrated employment (including supported employment),
continuing and adult education, adult services, independent living, or community participation
(FAC, 1997). These linkages to post-school services have been identified in the literature as
critical to positive, ongoing, post-school success (Collet-Klingenberg, 1998; Koller, 1994;
Rusch, Enchelmaier, & Kohler, 1994). However, even though IDEA requires that post-school
transition activities be available to all students with disabilities, they are included most
frequently in transition plans for students with more severe disabilities and only infrequently, if
at all, in plans for students with learning disabilities (Defer, Getzel, & Kregel, 1994; Grigal et
al., 1997; Levinson & Ohler, 1998).

As the life expectancy of children and youth with chronic illnesses and disabilities
continues to improve, Transition Services will play a larger role in the post-secondary arena
(Heward, 2000). The national statistics for adults with disabilities show poor adult outcomes associated with this group of individuals. United States estimates indicate that there are approximately 24 million people over the age of fifteen who are considered to have a severe disability, representing about 20 percent of the United States population (U.S. Department of Commerce, 1994). Rates of unemployment for people with disabilities range from 60 to 75 percent. Less than one-half of one percent (one in five hundred) of individuals receiving Supplemental Security Insurance (SSI) ever permanently leave the rolls (U.S. General Accounting Office (GAO), 1998). Federal expenditures are estimated to be between nearly $200 billion to over $300 billion annually. More than 95 percent of these funds are appropriated for health care costs and income assistance, attesting to the negative impact on this particular group (Coelho, 1998; U.S. GAO, 1998).

When special education is judged by its ultimate product, the youth who leave secondary school programs, it becomes clear how much further the field must progress. Too many young adults with disabilities are unsuccessful and unhappy in their post-school adjustment (Heward, 2000). Although useful, isolated statistics do not provide a complete picture of the overall adjustment to adult life experienced by young people with disabilities. Being a successful adult involves much more than holding a job; it is achieving status as an independent member of society, the ability to participate in society, to work, have a home, raise a family, and share the joys and responsibilities of community life (Fisher, 1999).
Research Questions

The 1990's have seen the life expectancy of individuals with Down's Syndrome reach to about fifty to sixty years old (Goode, 1988; Anonymous, 2002). With this extended life span, the quality of life has recently become an important national and international issue (Ibid). The problem suggests the need to investigate the correlation, at the post-high school stage (0 - 2 years), of the effects of Transition Services on the quality of life for Down's Syndrome students that are classified as Educable Mentally Retarded (EMR). The purpose of this study is to examine what effects Transition Services have on the quality of life for Down's Syndrome students (EMR) in the post-high school stage (0 - 2 years). The primary research question of this study is: What effects do Transition Services have on the quality of life (QOL) for post-high school (0 - 2 years) students with Down's Syndrome (EMR)? More specifically,

- What is the QOL for students in the State of Florida, in three county public school systems, who are Down's Syndrome (EMR), post-high school (0 - 2 years) and received Transition Services?

- What is the QOL for students, in a cross-county comparison (three county public school systems), who are Down's Syndrome (EMR), post-high school (0 - 2 years) and received Transition Services?

Definitions

Potentially vague concepts and their acronyms related to this study are defined accordingly. Individuals with Disabilities Education Act (IDEA): Public Law 94-142 was named the Education of All Handicapped Children Act when it was enacted; later, it was renamed the Education of the Handicapped Act; now it is known as the Individuals with
Disabilities Education Act (IDEA), which is how it is referred to under its various titles (Fischer, et al., 1998). These federal laws overshadow all other federal legislation related to educating the disabled. IDEA makes certain federal funds available to schools that comply with its requirements. Additionally, Section 504 of the Rehabilitation Act of 1973, would cut off any and all federal funds from schools that discriminate against the disabled (Fischer, et al, 1998).

**Down’s Syndrome:** Down’s Syndrome, or Down Syndrome, is a human disorder caused by chromosome abnormalities that develop during germ-cell formation. The normal human chromosome number is 46; each somatic cell has 22 pairs of autosomes and one pair of sex chromosomes. If the sex cell receives an extra chromosome 21 when formed, the child will have three chromosome 21 in each cell - the most common cause of the syndrome (96 percent) (Donegan & Potts, 1988).

**Exceptional Student Education (ESE):** ESE, or special education, has accomplished a great deal during the past thirty years. At one level, special education is an important part of society’s response to the needs of exceptional children and the rights of individuals with disabilities - a response brought about by parental advocacy, litigation, legislation and, increasingly, self-advocacy by disabled persons themselves. At another level, special education is a profession with its own history, cultural practices, tools and research base, focused on the learning needs of exceptional children and adults. But at the level where exceptional children most meaningfully and frequently contact it, special education is individually planned, specialized, intensive, goal-directed instruction (Heward, 2000). When practiced most
effectively and ethically, special education is also characterized by the use of research-based teaching methods, the application of which is guided by direct and frequent measures of student performance (Bushell & Baer, 1994; Greenwood & Maheady, 1997).

**Educable Mentally Retarded (EMR):** Intellectual functioning is most often measured by a standardized intelligence (IQ) test. Of the two most widely used intelligence tests, the Stanford-Binet Intelligence Scale (Thorndike, Hagen, & Sattler, 1986) and the Wechsler Intelligence Scale for Children - Revised (WISC-R) (Wechsler, 1974), the norm and average score is 100 (Heward, 2000). Educators use different terms for the various levels of mental retardation. For many years, students with mental retardation were classified as either educable mentally retarded (EMR) or trainable mentally retarded (TMR), which refer to mild and moderate levels of retardation, respectively (Heward, 2000). The American Association on Mental Retardation (AAMR) published a definition, in 1983, of mental retardation referring to significantly sub-average general intellectual functioning, resulting in, or associated with, deficits in adaptive behavior and manifested during the developmental period (Grossman, 1983). Adaptive behavior is the effectiveness or degree with which the individual meets the standards of personal independence and social responsibility expected of his age and social group (Ibid). Many professionals support the AAMR’s shift to a more conservative definition of mental retardation requiring an IQ score of at least two standard deviations below the mean (eighty-five to seventy or less) of an IQ test (Heward, 2000). With a level of mild retardation, the intelligence test score will range from fifty to fifty-five to approximately seventy (Grossman, 1983; American Psychiatric Association, 1994).
**Transition Services:** The most significant provision of IDEA was the mandate for transition planning for students age fourteen and older. It placed the initial responsibility for transition planning on state and local education agencies. IDEA used the term "Transition Services" in the language of the law and the regulations for the first time (Clark & Kolstoe, 1995). Under the law, Transition Services are defined as:

> a coordinated set of activities for a student, designed within an outcome-oriented process, which promotes movement from school to post-secondary education, vocational training, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation ... 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 evaluation. (20 U.S.C. 1401[a][19].

**Quality of Life (QOL):** The QOL model used in this study is based on the seminal studies of the quality of American life by Campbell, Converse, and Rogers (1976). The model views a person's perceived quality of life as a result of three levels of life experience including:

1. personal characteristics and objective life conditions in various life domains;
2. the perceptions or mind sets of significant persons and services about persons with disabilities;
3. one's personal beliefs about what is important and how the world works. The measurement of QOL falls within three large areas, including psychological well-being, personal satisfaction, and social indicators. Psychological well-being relates to relations with other people, social/community and civic activities, personal development and fulfillment, and
recreation. Personal satisfaction relates to marriage, family life, health, neighborhood, friendships, job/work, housing, usefulness of education, standard of living, amount of education, and savings. Social indications relate to health, social welfare/stability, friendship, standard of living, education, public safety, housing, neighborhood, and leisure.

**Limitations**

Since the study will focus on three county public school systems in the State of Florida, the study is limited in application to the Florida public school systems and may not apply equally well to experiences in other states. Furthermore, since a phenomenological design was used, the in-depth effectiveness of this research method may be compromised in the effort to make cross-county analysis.

However, the collection of thick, rich description of interviews, observations, and documents, combined with the use of the multiple site design, also helped increase generalizability (Merriam, 1998). Thick description is a term borrowed from anthropology meaning the complete, literal description of the incident or entity being investigated, through the collection from many sources (Merriam, 1998). Thick description produces in readers the feeling that they have experienced, or could experience, the events described (Caeswell, 1998). Then the reader may decide for themselves if the findings are generalizable (Lincoln & Guba, 1985).
CHAPTER 2: REVIEW OF RELATED LITERATURE

IDEA (P.L. 101-476, 105-17) contained language that made the delivery of Transition Services to students with disabilities more than just a good idea or a best practice, but the law. In addition to requiring that Transition Services be provided to students fourteen and older, IDEA mandated student involvement (Martin, Marshall, & Maxson, 1993; Wehmeyer & Ward, 1995). Despite a sustained emphasis in policy statements and the literature regarding the importance of student support, the outcomes facing many adolescents with disabilities as they leave high school are unemployment, economic dependence, and segregation (Hasazi, Hoch, & Cravedi-Cheng, 1992; Sitlington, Frank, & Carson, 1993; Harris & Associates, 1994; U.S. Department of Education, 1995; Blackorby & Wagner, 1996). Work is a highly valued activity in the American society. In fact, not only does it provide economic support, but it also has a major impact on one’s social status and self-image (Szyrnanski & Hershenson, 1998).

Unfortunately, people with disabilities often encounter obstacles to participation in the work force (Flexer, et al., 2001). Three to five years after exiting school, less than 8 percent of young persons with disabilities are reported to be fully employed or receiving post-secondary training, active socially, and living independently in the community (Wagner, 1995). Furthermore, less than 10 percent of special education graduates are estimated to be living above the poverty level three years after graduation (Affleck, et al., 1990).

Analysis of post-secondary outcome studies corroborate the findings that few students with disabilities are living independently, working full or part-time, or enrolled in post-
secondary education (Hasazi, et al., 1992). Findings such as these have focused attention on what has become a dominant issue in special education today, that is, the transition from school to adult life in the community (Heward, 2000).

The purpose of this review of related literature is to outline the results of studies and literature on quality of life (QOL) for students with Down’s Syndrome (EMR), post-high school (0 - 2 years) in regard to Transition Services. The review will: (a) discuss various aspects of Transition Services, (b) describe the roots and current uses of Transition Services, (c) discuss QOL, and (d) present the results of research into factors that influence QOL.

**Transition Services**

Transition Services are a coordinated set of activities that help a student move from school to post-school activities. Transition activities developed for the student are a guide to successful post-secondary living, based on the individual student needs, account for the student’s likes and interests, and needed activities in the areas of instruction, community experience, and development of daily living skills and functional vocational evaluation, if appropriate (Florida Department of Education, 2000). Furthermore, it promotes movement from school to post-school activities, including post-secondary education, vocational training, integrated employment (including support employment), continuing and adult education, adult services, independent living, or community participation (Heward, 2000). Recognition of the importance of Transition Services and the importance of student involvement in transition-related planning and decision-making were formally articulated in the Individuals with Disabilities Education Act
of 1990 (IDEA; P.L. 101-476). The basic purpose of the Transition Service requirement in IDEA was to better prepare students with disabilities to enter the work place, go on for further training, become as independent as possible, and contribute to society (Storm, DeStefano, & O’Leary, 1996).

The IDEA of 1997 (P.L. 105-17) extended the notion of Transition Services to include the transition into a high school course of study related to students’ individual career interests. It mandated that, by no later than age fourteen, a student’s IEPs (Individualized Education Programs) must specify Transition Services that are necessary for them to participate in their desired course of study (Flexer, et al., 2001).

In writing IDEA of 1997, the Congressional committee noted:

“the IEP provisions added by P.L. 105-17, are intended to provide greater access by children with disabilities to the general curriculum and to educational reforms such as school-to-work programs (IDEA, 1997).”

Roots and Current Use of Transition Services

The importance of providing support for students as they make the transition from school to adult life has been advocated for over ten years (Will, 1984; Halpern, 1985, 1992; Rusch & Mithaug, 1985; Rusch & Phelps, 1987). Support models that have received considerable attention include Will’s (1984) bridges model of school to employment, proposed by the Office of Special Education and Rehabilitative Services (OSERS), Halpern’s (1985) model of school to
community adjustment, the 1990 Individuals with Disabilities Education Act (IDEA), which mandated support for the transition from school to a range of post-school adult outcomes, and the 1994 School-to-Work Opportunities Act, which addressed employment among all youth. This approach has the added advantage of providing students with the opportunity to learn and practice the role of worker (Taylor, 1997). These models are based on the assumption that students require varying degrees and duration of support to experience full community participation, as they make the transition from school to adult life (Will, 1984; Halpern, 1985; Rusch, et al., 1992).

Unfortunately, little consensus exists on the most effective practices to support the transition from school to adult life (Halpern, 1992; Rusch, 1992; Johnson & Rusch, 1993; Kohler, 1993; Green & Albright, 1995). Review articles have questioned what we knew about what works in school-to-work transition, even after a decade of research, development, and demonstration (Stowitschek, 1992). Review of best practices in transition suggested that, although there is some social validation to support a relationship between current transition practices and post-school outcomes, there is limited empirical evidence identifying critical components of the transition process (Kohler, 1993). Without knowledge of how practice relates to outcomes, the field cannot expect that schooling systematically will improve the adult outcomes of secondary special education students (Rusch, 1992). Applied research offers some insight into critical factors that have been demonstrated empirically as supporting successful student outcomes, particularly, paid work experiences during high school (Hasazi, Gorden, &
Rol, 1985; Scuccimara & Specce, 1990); a network of family and friends (Hasazi, et al., 1985); community-based instruction (McDonnell, et al., 1993); parent involvement (Schalock, 1986; Heal, et al., 1990); social skills training (Mithaug, Horiuchi, & Fanning, 1985; Heal, et al., 1990); employment skills training (Hasazi, et al., 1985; Mithaug et al., 1985; Schalock, 1986); and follow-up supportive services (McDonnell et al., 1989; Wacker et al., 1989; Heal et al., 1990).

Policy makers and state directors of special education, who participated in focus groups, agreed that a transition model should support broad-based student outcomes such as personal and social adjustment, physical health, and citizenship (Yaseldyke, Thurlow, & Bruininks, 1992; National Center for Educational Outcomes, 1993). Directors of federally-funded model demonstration transition programs were reported to concur that support models should address multiple outcomes of social participation, perceived and actual social support, and personal, peer, and co-worker acceptance (Chadsey-Rusch & Heal, 1995), as well as social integration, functional life skills, employment, and post-secondary education (Rusch, Kohler, & Hughes, 1992; Rusch, Enchelmaier, & Kohler, 1994). Further, parents and practitioners who were surveyed agreed that parental involvement, community-based instruction, and social and employment skills training were critical support model components (Halpern, 1985; Benz & Halpern, 1987). Kohler (1998), conceptualized transition activities as falling into five categories: (1) student-focused planning; (2) student development; (3) family involvement; (4) collaboration; and (5) development of program structure and attributes. Persons with
disabilities, parents, and teachers who responded to questionnaires advocated a broad-based model of support that targets employment, social, community, and independent living skills (Lovett & Harris, 1987; Epps & Myers, 1989; Morgan et al., 1992). However, we cannot ignore findings that indicate that secondary education has not resulted in successful adulthood for many special education students. It is particularly critical to identify valid models of support for special education students that may improve these outcomes (Council for Exceptional Children, 1995). The ultimate measure of educational effectiveness is the extent to which the school system contributes to the quality of life of its graduates (Flexer, et al., 2001).

Quality of Life

There has been a long history of interest in the concept of, and quest for, a life of quality. Ever since the ancient Greeks, people have tried to find out how to implement the conditions of the “good life.” Plato’s Republic reflects the age-old quests for the means of insuring a high quality of life, not only for a few chosen individuals, but for society as a whole (Schalock, 1990).

There are a number of reasons for the concept of quality of life (QOL) becoming an important issue, including concern that many feel about the QOL of community-placed disabled persons (Baker & Intagliata, 1982; Bradley & Clarke, 1976; Emerson, 1985; Landesman, 1986; Schalock, Keith, Hoffman & Karan, 1989; Schalock & Lilley, 1986; Schalock & Thornton, 1988; Zautra, 1983); the demonstration that social environments have considerable impact on an
individual’s way of life (Schalock, 1990); the fact that complex programs require complex outcome measures, the re-emergence of the holistic health perspective, and the concern that people have about how others find satisfaction and life quality in a rapidly changing world (Donegan & Potts, 1988; Goode, 1988; Schalock, 1990). It is important to build a career path that will be motivating and engaging for many years into adulthood, and lead to what the student considers an optimal quality of life (Flexer, 2001).

Throughout the professional community, authors use and define the concept of QOL quite differently. Despite their differences, the following four premises regarding QOL apply (Goode, 1988):

1. QOL is essentially the same for persons with disabilities and without disabilities. Persons with and without disabilities want the same things in their lives, have the same needs, and want to fulfill responsibilities in the same way other persons in society do.

2. QOL is basically a social phenomenon and a product primarily of interactions with others. This requires a social ecological definition of QOL for the individual that also incorporates the QOL of significant others in the setting.

3. QOL is the outcome of individuals meeting basic needs and fulfilling basic responsibilities in community settings (family, recreational, school, and work). Individuals who are able to meet needs and fulfill responsibilities in ways satisfactory to themselves and to significant others in community settings, experience a high QOL in those settings.

4. QOL is a matter of consumer rather than professional definition. QOL issues should be defined by consumers and other citizens, rather than by professionals in the field. Ultimately, it is how the individual perceives and evaluates his own situation, rather than how others see him, that determines the QOL he or she experiences.
The concept of quality of life will probably replace de-institutionalization, normalization, and community adjustment issues (Schalock, et al., 1989). Many advocates and professionals now realize that the physical presence of individuals with disabilities in integrated residential, work, and community settings is an important step, but the only true meaningful outcome must be an improved quality of life (Heward, 2000).

Attempts to conceptualize and measure a person’s QOL does not have a long history and, in reference to persons with mental retardation and closely related disabilities, the history is even shorter (Schalock, et al., 1989). Despite the short history, efforts to conceptualize and measure QOL are multiplying because of three types of interests in life quality research that are much more evident now (Andrews, 1986):

- Increased attention devoted to describing the life quality of particular national subgroups and comparing them with more general national populations (Andrews & Whithey, 1976; Campbell, Converse & Rodgers, 1976).

- Increased interests in how time-related phenomena link to life quality, and specifically, the use of time and the effects of age, period, and cohort (Schalock, 1990).

- Increased concern for the social and psychological dynamics of perceived well-being, including factors related to social support, social integration, interpersonal trust, internal control, autonomy/independence, self-confidence, aspirations/expectations, and values having to do with family, job, and life in general (Schalock, 1990).

The pioneering work by Robert Edgerton (1967; 1975) on issues relating to quality of life among mentally retarded individuals is well known to most readers and represents a significant
milestone in the history of QOL research (Schalock, 1990). Since Edgerton’s original work, numerous individuals involved with the disabilities field have focused on a number of outcome variables that have been associated with successful community adaptation, that is, quality of life (Bell, et al, 1981; Bruininks, 1986; Halpern, et al, 1986; Intagliata, et al, 1981; Schalock, et al, 1989; Schalock & Thornton, 1988). There are a number of commonalities to these models:

- Community integration and involvement in recreation, clubs, events, and community activities.
- Social and interpersonal relations, including family members, friends, neighbors, and acquaintances.
- Living environment, including some degrees of control, developmental services, safety and normalization of settings.
- Meaningful work with its financial and status byproducts.

Developing any reliable and valid quality-of-life measure requires considerable effort, effort that promises to result in a fuller understanding of the lives of developmentally disabled individuals (Schalock, 1990). The decade of the 1990's has truly been the decade of quality of life. Inherent in this evolution and change has been the concept of quality of life - a concept that speaks of equity, value, growth, potential, and good (Schalock, 1997).

**THE LAW**

On June 4, 1997, President Clinton signed into law amendments to the Individuals with Disabilities in Education Act (IDEA) (Flexer, 2001). A sibling of the Americans with Disabilities Act of 1990 (ADA), initially, IDEA was intended to provide children with
disabilities a "free and appropriate public education" (Riley, 1995a). The term "disability" can refer to a broad range of physical conditions, and consequently, IDEA identifies several characteristics contributing to students being labeled "learning disabled." In the definition section of the act, special education students are identified as those students (i) with mental retardation, hearing impairments (including deafness), speech or language impairments, visual impairments (including blindness), serious emotional disturbance (hereafter referred to as 'emotional disturbance'), orthopedic impairments, autism, traumatic brain injury, other health impairments, or specific learning disabilities; and (ii) who, by reason thereof, need special education and related services (U.S. Department of Education, 1997).

IDEA is a federal special education statute that does not cover post-secondary educational institutions. However, because it is the primary statute governing students' rights and responsibilities in higher education, the educational programming of elementary and high school students with disabilities, parents, school officials, guidance counselors, and students alike have many mis-conceptions of students' rights and responsibilities in higher education.

IDEA establishes specific procedural safeguards and the right to a Free Appropriate Public Education in the Least Restrictive Environment. Section 504 and the ADA provide that qualified persons with disabilities cannot be excluded from participation in, denied the benefits of, or be subjected to discrimination by any service, program, or activity of a post-secondary institution, and further provides that services must be provided in the most integrated setting (Coleman v. Zatcheka, 1993; Olmstead v. Zimring, 1999). IDEA requires that special educational services ensure a meaningful benefit from education. Section 504
and the ADA are designed to provide only equivalent access to educational and extra-curricular programs and opportunities, not specialized education, such as individualized tutoring.

IDEA protects children whose impairments meet the criteria listed in the thirteen classifications set out in the federal regulations, and who require special educational services in order to benefit from an education. A recent IDEA reauthorization allows schools to avoid a "label" and service students based on "disability." Nevertheless, the classifications are generally used by schools and are commonly understood (Simon, 2001).

IDEA calls for the provision of various supplemental aids and services without charge, including diagnostic testing and evaluation, occupational and physical therapy, speech and language therapy, specialized tutoring and resource room services, books on tape, counseling, para-professional aides, as well as note taking, testing modifications and adaptive equipment. Thus, IDEA is quite broad in the scope of services it provides to students with disabilities, but narrow in its criteria as to who is a student with a disability (Simon, 2001). Post-secondary students are entitled only to reasonable accommodations in the form of academic adjustments or auxiliary aids, and services such as readers, interpreters, real-time captioning, note takers, testing modifications, alternate text, priority registration, audio taping of lectures, etc. Post-secondary students are not entitled to specialized tutoring, specialized counseling, occupational, physical, or speech and language therapies, etc. For many post-secondary students with disabilities, the unavailability of specialized tutoring without an additional fee is particularly problematic (Simon, 2001).
In addition, under IDEA, the public school is responsible for identifying students with disabilities and for evaluating them for possible special educational services. Post-secondary institutions have no such obligations - either to identify students with disabilities or to assess and document their disabilities. Thus, Section 504 and the ADA put the legal and financial burden on the student with a disability to seek appropriate assessment.

However, the IDEA Amendments of 1997 (Public Law 105-17) mandate that the Individualized Education Programs of students with disabilities include a statement of transition needs related to student's courses of study beginning at age fourteen, and a Transition Services component for students with disabilities age sixteen and older (Heward, 2000). The initial passage of the federal mandate for transition planning occurred in the context of at least a decade of attention to the need to develop transition policies, programs, and services for youth with disabilities that would allow them to make successful transitions from school to adult life (DeStefano & Wermuth, 1992; Wehman, 1992). IDEA emphasizes the importance of including students and parents as active participants in Individualized Education Program and transition planning, and using collaborative and interagency approaches to developing outcome-oriented plans based on students' needs, taking into account their preferences and interests.

Much of the research occurring prior and subsequent to the legislative mandate for transition planning has focused on identifying promising practices related to achievement of positive adult life outcomes, such as employment, independent living, and participation in post-secondary education and community life (Stowitschek & Kelso, 1992). These promising
practices include utilizing the transition planning process and related instruction vehicles for fostering self-determination and self-advocacy skills among students with disabilities (Field, 1996; Field, Martin, Miller, Ward & Wehmeyer, 1998; Martin & Marshall, 1996; Martin, Marshall & Maxson, 1993; Ward, 1996; Wehmeyer, 1996; Wehmeyer & Schwartz, 1997; Wehmeyer & Ward, 1995), incorporating diverse family and cultural perspectives in transition planning (Boone, 1992; Harry, 1992; Sontag & Schacht, 1994; Turnbull & Turnbull, 1996), and using person-centered planning processes to create a more responsive and family centered meeting context (Forest & Pearpoint, 1992; Salembier & Furney, 1994; Salembier & Furney, 1997; Turnbull et al., 1996).

**Summation**

The complexity of the transition process is such that appropriate systematic implementation of IDEA's requirements is quite difficult (Everson & McNulty, 1992). As a result, when individuals with disabilities exit special education programs and enter society, they often encounter low levels of employment, substandard living, isolation from the community, and difficulties developing and maintaining relationships (Bergen, 1993; Peraino, 1992; Powell & Hecimovic, 1985; Schleien, 1993). The National Organization on Disability (2000) found that individuals with disabilities are more likely to be unemployed, lonely, and unhappy with their lives than individuals without disabilities. Other studies of youths graduating from special education programs revealed that, in comparison to students without disabilities, students with disabilities participate in post-secondary education less, are less likely to be employed, and lack social and interpersonal skills (Peraino, 1992), and that many of them are lonely and dissatisfied
with their free-time experiences (Malian & Love, 1998). These findings indicate that, as a whole, individuals with disabilities do not fare as well as their non-disabled peers in any aspect of adult life.

Throughout the literature on individuals with disabilities, community integration and social relationships have been cited as primary indicators of quality of life (Evans, Burns, Robinson, & Garrett, 1985; Halpern, Nave, Close, & Nelson, 1986; Harner & Heal, 1993; Hughes, et al., 1997; Keith & Schalock, 1994; Schalock, Keith, Hoffman, & Karan, 1989). Frank and Sitlington (1990) classified graduates from a special education program as “successful” if they had adjusted to post-school life by obtaining employment, living independently, paying part of their living expenses, and becoming involved in more than one community leisure activity. Leisure participation is a critical component of community integration (Rynders & Schleien, 1988). Demchak (1994) concluded that, when individuals with disabilities engage in appropriate recreation and leisure activities, they increase their chances for success in the community.

Learning how to adjust oneself to community life and participation in recreation and leisure activities are thus a significant part of the post-school transition process (Halpern, 1990, 1993; Thoma, 1999). Enhancing the social networks (e.g., number and variety of friends, community supports) of individuals with disabilities has also been identified as a key factor that would contribute to a better transition and increased quality of life (Block & Vogler, 1994; Demchak, 1994; Heyne, Schleien, & McAvoy, 1994; Heyne, 1995; Schleien, 1993).
Research in the last decade has clearly shown that, if provided adequate training and support, individuals with moderate to severe disabilities can be productively employed (Rusch, Chadsey-Rusch, & Johnson, 1991).

Although useful, isolated statistics do not provide a complete picture of the overall adjustment to adult life experienced by young people with disabilities. When assessed at a period of less than two years out of school, only 6.4 percent of all youth with disabilities met employment, residential arrangements, and social activities domain criteria (Heward, 2000). When the same measures are assessed after individuals have been out of school for three to five years, 20 percent were judged to be independent in all three domains (Wagner, et al., 1993).

CHAPTER 3: METHODOLOGY

In order to better understand Transition Services, as they relate to quality of life for Down’s Syndrome students (EMR) in the post-high school stage (0 - 2 years), a phenomenological study of three county public school systems in Florida was conducted. The use of a phenomenological study adds confidence to the findings and strengthens the study’s precision, validity, and stability by addressing the “four R’s”: representativeness, reactivity, reliability, and replicability (Miles & Huberman, 1994). This section contains: (a) the basis for the choice of interviews; (b) observation and document analysis as data collection process and analysis; (c) the method selection of subjects to be involved; (d) the data collection process and analysis; (e) the generalizability, reliability, and validity of the study; and (f) options for interpretation of the data collected.
Perspective

The choice of the qualitative approach for the study of this question was appropriate, because the perspective on events and actions held by the people involved in them is not simply their account of these events and actions to be assessed in terms of its truth or falsity; it is part of the reality that you are trying to understand (Maxwell, 1992; Menzel, 1978).

In a qualitative study, you are interested not only in the physical events and behavior that is taking place, but also in how the participants in the study make sense of this and how their understanding influences their behavior (Maxwell, 1996). Qualitative research is based on the view that reality is constructed by individuals’ interaction with their social worlds (Merriman, 1998). In order to understand the meaning people make of their experiences, the researcher must collect data that will give a rich description of the phenomenon under investigation (Glesne & Peshkin, 1992; Creswell, 1998). The focus on meaning is central to what is known as the interpretive approach to social science (Brendo & Feinberg, 1982; Geetz, 1973; Rainbow & Sullivan, 1979). Further, qualitative data, with its emphasis on people’s lived experiences, is fundamentally well suited for locating the meaning people place on the events, processes and structures of their lives (Miles & Huberman, 1994).

This researcher’s background will help his choice of methodology. He has been involved with special education students for the past seventeen years, the last six of which have been in Florida. As a parent of a child with Down’s Syndrome and a member of the National Down Syndrome Society (NDSS), he was selected to attend the Educational Leadership Summit of the NDSS Institute for Special Education Leadership. This summit was held in Orlando, Florida, on December 2 - 3, 2000, with the sole purpose of drafting a strategic plan to improve special
education in Florida. Transition Services and quality of life were just two of the many areas that were addressed. The purpose of the methodological choice will allow the researcher to observe how Transition Services function at the district and area levels, as well as what, if any, effect they have on the quality of life of the particular student population.

Interviewing, observation, and document analysis are accepted parts of a qualitative study and are integral in order to triangulate data, so that the truth of the experience can be discovered as completely as possible (Creswell, 1998; Merriam, 1998; Glesne & Peshkin, 1992). A qualitative interview is an interaction between an interviewer and a respondent in which the interviewer has a general plan of inquiry, but not a specific set of questions that must be asked in particular words and a particular order (Babbie, 1998). It is generally a conversation in a general direction and pursues specific topics raised by the interviewee. Observation allows the researcher to make meaningful, careful, deliberate measurement of the real world for the purpose of describing objects and events (Babbie, 1998). It further allows the researcher to see the phenomenon in action. Document analysis or manifest content refers directly to the visible, objectively identifiable characteristics of a communication, such as the specific words in a book, the specific colors used in a painting, and so forth (Babbie, 1998). It gives insight into the background and products of the phenomenon in question. Thus, by triangulating, the researcher can draw conclusions that are well-grounded (Creswell, 1998; Merriam, 1998; Glesne & Peshkin, 1992).

A central element in research is the standardized questionnaire. In regard to the fundamental issue of measurement, the questionnaire ensures that exactly the same observation technique is used with each and every respondent in the study (Babbie, 1998). The linking of
qualitative and quantitative or standardized data has been a topic of great controversy over the years. However, all research data ultimately are basically qualitatively grounded to a raw experience, we may attach either words or numbers (Berg, 1989; Campbell, 1974). The issue is one of knowing when it is useful to count, and when it is difficult or inappropriate to count at all, when data are non-standardized, and there are no clear rules for saying what is variation and what is error (Gherardi & Turner, 1987).

This study will be one of qualitative exploration, linked with the findings of a standardized questionnaire, leading to deeper qualitative test findings (Miles & Huberman, 1994).

**Research Design**

The design of the study is a qualitative, phenomenological design that seeks to gain a view of reality, as constructed by the participants themselves (Merriam, 1998). Qualitative research attempts to recreate the lived experiences of participants in context (Miles & Huberman, 1994). Three public school systems from Florida were selected in a tri-county area, allowing for a maximum variation in the choice of sites and the sample of participants.

**Sample**

A stratified, purposeful sample of key members of each county's public school system was utilized, that is: the Transition Services coordinator at the three district levels, and nine students from post-high school (0 - 2 years) who had received Transition Services,
as well as, nine parents/care givers of the students. An attempt was made to balance the numbers of members of representative groups so that no one group provided the majority of input.

**Data Collection**

The methods used to collect data was in-depth, formal interviews, observations of meetings, and questionnaire use, all of which are accepted methods of qualitative research (Creswell, 1998; Merriam, 1998; Glesne & Peshkin, 1992).

Twenty-one participants were formally interviewed. Each interview lasted approximately one to two hours. Interviewees were informed of the nature of the research and the interview materials in advance, and their written permission was secured (see Appendix A: Written Consent Form). The student participation consent form was written in language approximating the fifth grade level and read to the participants. All interviews were audio-taped and transcribed. The public school employees were asked open ended questions about Transition Services, and the implementation of Transition Services, and what role they play (see Appendix B: Interview Guide; see Appendix C: Interview Questions). The students were given a Quality of Life questionnaire and, if unable to answer individually, a parent or care giver was asked to assist (see Appendix D: Quality of Life Questionnaire). Additional questions were developed based upon the participants’ response. Confidentiality of all participants and schools was strictly guarded, according to county, district and university policy.

Reliability and validity are concerns for qualitative researchers. In order to assure a reliable and valid study, accepted qualitative techniques, such as rich description, member-
checking, and triangulation of the data, was used (Creswell, 1998; Glesne & Peshkin, 1992; Merriam, 1998; Miles & Huberman, 1994). The phenomenological design is reinforced in the idea that there is no single reality to get right but, in fact, reasonable conclusions are out there somewhere (Miles & Huberman, 1994).

Sample Population

This section presents descriptive information concerning the participants, counties, and schools that will be selected. A description of each county’s educational population, socio-economic status of students and per-pupil expenditures is presented for comparative purposes. Participant sample was selected based upon cognitive ability, as defined in the definition section, residence in the specific counties, and the ability on the researcher’s part to locate the participants. The high schools were selected based upon student membership in the desired sample population.

Participants

The participant sample is a stratified, purposeful sample, that is, a sample of people that represent a role such as district level administrator, parent and graduated student. A purposeful sample allows the researcher to select a sample from which the most could be learned (Merriam, 1998). Further, in purposeful sampling, the researcher is led to seek out subjects who have experienced the types of experiences the researcher seeks to understand (Denzin, 1989). Additionally, a stratified sample allows the researcher to more clearly delineate sub-groups and facilitates comparisons between groups and between cases (Miles & Huberman, 1994). The participant sample was selected based upon cognitive ability, as defined in the
Definition Section, residence in the specific counties, and the ability on the researcher’s part to locate the participants. The participants were located with the assistance of private Down’s Syndrome associations located in the particular counties. However, there are no rules for a sample size in a qualitative study (Patton, 1990). Since the study will be concerned with Transition Services in regard to QOL, representatives from each of the three counties were included, specifically, a district level transition services administrator.

Although the percentage of EMR students who have graduated from the particular high schools, and were selected in the study, is not reflected in the statistical data by high schools, a re-selection did not have to occur to insure that appropriate percentages of EMR students are available to make a purposeful sample justifiable. In purposeful sampling, also referred to as judgment sampling, the researcher selects a sample based on his or her experience or knowledge of the group to be sampled. Within the domain of purposive sampling are a number of specific approaches that are useful in qualitative research; specifically, homogenous sampling, which is the selecting of participants who are very similar in experience, perspective, or outlook; this produces a narrow, homogenous sample that makes data collection and analysis simpler (Gay & Airasian, 2000).

The sample in this study was composed of twenty-one participants involved at the district, graduated student levels, and parent/care givers: three district level Transition Services administrators, nine graduated students with Down’s Syndrome (EMR), and nine groups of parents. The sample offered a view of the perceptions of people of different groups and roles as to what are Transition Services and what effects they have on QOL of the specific graduated student group.
Descriptions of the schools and their students are presented in the following sections. Each school has been given a letter designation to protect its identity, and participants are identified only by their role.

With the student population being selected, the appropriate high school(s) are described as far as age, enrollment, class sizes, disabled student population, and limited English proficiency as a percentage of total population, thereby giving a generalized comparable overview from school to school and county to county.
Elementary School students receiving reduced/free lunch.
Middle School students receiving reduced/free lunch.
Elementary School student mobility rate.
Middle School student mobility rate.
High School student mobility rate.
County 1

The public school district in this county, designated as county 1, is located in Florida. As of 1999 - 2000, the student population was 146,492. The elementary school student population was 72,102; middle school student population was 33,790; and the high school student population was 40,602 (Florida School Indicators Report, 2000).

Two indicators of the socio-economic status of students are the percentage of students who qualify for free and reduced lunch and the percentage of children who move during the year. In 1999 - 2000, county 1 had 49.4 percent of the elementary school students, and 40.1 percent of the middle school students, qualify for the lunch program. No statistics for the lunch are kept for high schools in the state. Mobility rates for this county were 27 percent elementary school; 25.5 percent middle school; and 28.7 percent high school. These rates reflect students who leave the school system, other than drop-out percentages (Florida School Indicators Report, 2000). The financial, per-pupil expenditures for exceptional students at the elementary, middle, and high school levels were $7,690.00 (Ibid).

County 2

The public school district in this county designated as county 2 is located in Florida. As of 1999 - 2000, the student population was 235,249. The elementary school student population was 119,728; middle school student population was 54,002; and the high school student population was 61,519 (Florida School Indicators Report, 2000).
Two indicators of the socio-economic status of the students are the same as mentioned in county 1. In 1999 - 2000, county 2 had 43.7 percent of the elementary school students, and 38.5 percent of the middle school students qualify for the lunch program. Once again, no statistics are kept for high schools in the state. Mobility rates for this county were 27.1 percent elementary school; 25.3 percent middle school; and 26 percent for high school. These rates reflect students who leave the school system, other than drop-out percentages (Florida School Indicators Reports, 2000). The financial, per-pupil expenditures for exceptional students at the elementary, middle and high school level were $5,425.00 (Ibid).

County 3

The public school district in this county designated as county 3 is located in Florida. As of 1999 - 2000, the student population was 351,028. The elementary school student population was 176,705; middle school student population was 79,407; and the high school population was 94,916 (Florida School Indicators Report, 2000).

Two indicators of the socio-economic status of the students are the same as mentioned in county 1. In 1999 - 2000, county 3 had 70.1 percent of the elementary school students, and 66.1 percent of the middle school students qualify for the lunch program. Once again, no statistics are kept for high schools in the state. Mobility rates for this county were 34.5 percent elementary school; 33.9 percent middle school; and 38.3 percent for high school. These rates reflect students who leave the school system, other than drop-out percentages (Florida School Indicators Report, 2000). The financial, per-pupil expenditures for exceptional students at the elementary, middle, and high school level were $8,051.00 (Ibid).
Selection of Schools

The counties (1, 2, 3) were selected via purposeful sampling, as well as the school(s) in the particular county from which the EMR student(s) graduated.

The schools were selected based upon student membership, in the desired sample population. Purposeful sampling is the best way to obtain the desired representative sample. Although no technique, not even random sampling, guarantees a representative sample, the probability of achieving one is higher for this procedure than for any other (Gay & Airasian, 2000). All of the high schools in each of the three counties, in each student membership group, were listed and assigned an identifying code number. The number of schools was dependent upon the availability of the specific student membership population at each school.

The high schools that were selected have varying percentages of disabled students. A high school, for example, with less than 2,000 students will have a total disabled student population of approximately 12 percent; a high school, for example, with less than 3,000 students will have a total disabled student population of approximately 5.7 percent; and a high school, for example, with less than 4,000 students will have a total disabled student population of 17.7 percent (Florida School Indicators Report, 2000). Six of the student participants were from schools with less than 2000 students and three of the student participants were from schools with less than 3000 students with the disabled student population percentages reflected in the aforementioned information.
Data Collection Procedures

**Interviews**

In-depth, formal interviews, using an interview guide, were conducted in order to understand the experience of other people and the meaning they make of that experience (Seidman, 1998). The interview guide insured continuity of questioning to insure that each participant at each site was asked the same questions.

Potential interviewees were contacted initially by telephone to ascertain their willingness to participate in this study. Convenient interview dates and times were established, and a second contact confirmed the pre-established date and time of the interview. During the initial contact, the purpose and methods of the research, and a brief outline of the interview topic, was explained. At the actual interview, participants were asked to complete a brief information form (see Appendix B: Interview Guide) and provided an addressed, stamped envelope with which to return the completed form to the researcher. Additionally, the participants were given time to read and sign the consent form required by the university (see Appendix A: Written Consent Form).

Each professional educator was interviewed once in an in-depth, formal interview, using open-ended questions (see Appendix C: Interview Questions) and the interview guide (see Appendix B: Interview Guide). Each interview lasted approximately one hour for the three education professionals. These interviews were audio-taped and transcribed, and transcripts of the interviews were provided to the participants for any clarification or additional
information. Participants’ identities were protected by the use of pseudonyms, and the interview audio tapes are kept in a secure location. Informal interviews were conducted as data was being collected, and as themes emerge, additional questions precluded any follow-up process.

Each student graduate was interviewed once in an in-depth, formal interview, using the QOL Questionnaire (see Appendix D: Quality of Life Questionnaire) and the interview guide (See Appendix B: Interview Guide). The parent or care provider was present during the entire interview process to assist, if necessary, with explanations of problem questions or interpretation of participant responses. Each interview lasted approximately one to two hours for the nine student graduates, and the interviews were audio taped and transcribed, and transcripts of the interviews were provided to the participants for any clarification or additional information. Participants’ identities were protected by the use of pseudonyms, and the interview audio tapes are kept in a secure location. Informal interviews were conducted as data was being collected, and as themes emerge, additional questions precluded any follow-up process.

Extreme precautions were taken to protect participants’ identities. Information was reported in such a manner to avoid identifying the source of the offered information. Any opinions or statements that may endanger the participants’ anonymity were carefully considered and, if used, the permission of the participant was obtained.
Observations

Observations were used to maximize the inquirer's ability to grasp motives, beliefs, concerns, interests, unconscious behaviors, customs, and the like; observation allows the inquirer to see the world as his subjects see it, to live in their time frames, to capture the phenomenon in and on its own terms, and to grasp the culture in its own natural, ongoing environment; observation provides the inquirer with access to the emotional reactions of the group introspectively; that is, in a real sense, it permits the observer to use himself as a data source; and observation allows the observer to build on tacit knowledge, both his own and that of members of the group (Guba & Lincoln, 1981).

During all interviews, the researcher followed the plan developed by Merriam (1988), which consists of the following five observational elements: the setting, the participants, activities and interactions, frequency and duration, and subtle factors.

When looking at the setting, what is the physical environment like? What is the context and what kinds of behavior does the setting promote or prevent? In regard to the participants, describe who is in the scene, how many people and their roles. What brings these people together and who is allowed here? Activities and interaction are important to explain what is going on. Is there a definable sequence of activities? How do the people interact with the activity and with one another? How are the people and activities connected or interrelated? Frequency and duration are essentially when the situation began and how long it lasted. Is it a recurring type of situation, or is it unique? If it recurs, how frequently and how typical of such
situation is the one being observed? Subtle factors are less obvious, but perhaps as important, to the observation. Some of these factors include informal or unplanned activities, symbolic and connotative meanings of words, non-verbal communication such as dress and physical space, unobtrusive measures such as physical clues and what does not happen, especially if it should have happened (Erlandson, et al., 1993). An observation guide (see Appendix E: Observation Guide) was used to provide structure and continuity in the recording of observations with all participants.

**Questionnaire**

The 1990 version of the QOL Questionnaire (Schalock, Keith, & Hoffman, 1990) represents the instrument from which the actual survey was derived. (See Appendix D.) The QOL Questionnaire is scored by totaling the Likert scale value for each question and deriving mean and standard deviation value for each student sample and population. However, the QOL Questionnaire was utilized solely as a qualitative guide for insuring that the same questions were asked to the participants. The QOL Questionnaire addresses four areas: satisfaction, competency/productivity, empowerment/independence, and social belonging/community integration. The aforementioned areas are considered significant; that is, in early adulthood, satisfaction with family, standard of living, work and education are significant predictors; in mid-adulthood, satisfaction with family and work remain salient, but housing and community replace education and standard of living as priorities; in late adulthood, satisfaction with family, work, community, standard of living and spare time
activities remain significant predictors, but health becomes increasingly important, and among the elderly, satisfaction with health, spare time activities, spiritual matters, family life, and financial concerns are predictive of life satisfaction (Lehman, et al., 1995). The QOL Questionnaire is based on the results of considerable research and the following four principles of the conceptualization of QOL for persons with disabilities. These four principles are the basis for determining the questions contained in the QOL Questionnaire:

- QOL is essentially the same for persons with or without disabilities. Persons with or without disabilities want the same things in their lives and have the same needs for decision making and choices as other persons in society.

- QOL is basically a social phenomenon and a product primarily of interactions with others.

- QOL is the outcome of individuals meeting basic needs and fulfilling basic responsibilities in community settings.

- QOL is primarily a subjective phenomenon. Ultimately, it is how the individual perceives and evaluates his own situation, rather than how others see him or her, that determines the QOL he or she experiences (Andrews & Whitney, 1976).

The QOL Questionnaire (see Appendix D: Quality of Life Questionnaire) is a forty-item rating scale designed to measure the overall quality of life of a person with mental retardation. The QOL Questionnaire will not be used in a quantitative approach; that is, it will not be rated or
scored according to its design. Rather, it was a qualitative guide to ensure continuity and replication of questions asked to participants. Their responses were recorded and coded for cross-case analysis, member checking, and triangulation of the data. For individuals with sufficient language skills, the instrument was administered in an interview format. For people who lack the necessary language skills, the instrument was completed by parents, who know the individual well, and who are familiar with the individual’s current activities and living environment. The QOL Questionnaire is based on more than a decade of work and is among the most extensively researched instrument currently available for assessing the quality of life of people with mental retardation (Schalock & Keith, 1993).

There is a long tradition of scholarly work in the quality of life beginning with Thorndike (1939) and continuing with the seminal studies on quality of American life by Campbell, Converse and Rogers (1976) and by Andrews (1986). Attempts to measure a person’s quality of life have used one of two approaches: objective and subjective. The objective approach assesses external objective indicators such as standard of living, health, education, safety, and neighborhood (Andrews & Whitney, 1976; Campbell, et al., 1976). The subjective approach stresses the person’s perception and evaluation of one’s life experiences, focusing on factors such as physical and material well-being, relations with other people, community activities, personal development, and recreation (Flanagan, 1978, 1982). Within the mental retardation/developmental disabilities (MR/DD) field, the subjective measurement approach has been used most extensively (Edgerton, 1975; Heal & Chadsey-

The QOL Questionnaire was designed to meet the need for an instrument to assess the quality of life of persons with mental retardation and developmental disabilities (Schaloch & Keith, 1993). The QOL Questionnaire was read to the participants and discussed with the parents/caregivers. This ensured a modicum of understanding and comprehension by the student participant(s). Students’ oral answers were recorded by the interviewer on the QOL Questionnaire.

**DATA ANALYSIS**

Data analysis is probably the aspect of qualitative research that most clearly distinguishes it from experimental and survey research, and the one that is least familiar to researchers coming to qualitative research from other traditions (Maxwell, 1996). The initial step in qualitative analysis is reading the interview transcripts, observational notes, or documents that are to be analyzed (Dey, 1993; Smith, 1979; Tesch, 1990).

A purpose of this study was to add a rich description of the participants’ experiences and their perceptions of the truth of their experiences for, in the general, lies the particular (Merriam, 1998), based on the principles of a qualitative study and its findings.

Data analysis focused on discovering themes that may emerge from the data collected, in relation to participants’ perceptions of their roles in and goals, as related to Transition Services and quality of life issues. Commonalities of beliefs about roles across participants was sought to
gain insight into the problems encountered or processes regarding Transition Services and quality of life issues. Differences of themes was sought to offer insights into ways that each county district administrator viewed their role in regard to Transition Services. Data collected from the district levels of the three counties was analyzed separately to create a context for the cross-case analysis of data. Likewise, the data collected from the students was analyzed in the same fashion.

Data analysis began with interviews and observations. Field notes, in which impressions or important notes were recorded, were done so during, and immediately following, observations and interviews. Additionally, all interviews were audio recorded of all educational professionals, transcribed and annotated. Interviews of the students were audio recorded for a rich, full observational record of events. Analytic memos were written by the researcher during the course of the data analysis, in order to assist in organizing the data and capturing any evolving themes. A researcher's journal was also kept throughout, in which the researcher captured personal thoughts, questions, or observations during the course of the analysis. During transcription and following the completion, a careful editing process of the transcripts was conducted to reveal any emerging themes arising out of common terms or statements offered by the participants. These categories were reexamined during the entire scope of the study, as is normal in qualitative research (Miles & Huberman, 1994).

When the data collection and preliminary data analysis was completed, data was coded according to predominant themes. Each case was analyzed separately, and then a
cross-site analysis was conducted. The researcher was cognizant as to themes that were revealed, both within each group and site, as well as common across each group and site. Verification of common themes was sought by cross-checking all sources of data for corroboration of statements made by participants or specific site observations to determine if the same theme(s) arise in all three school districts, thereby insuring increased reliability and validity of the data analysis through triangulation (Creswell, 1998; Glesne & Peshkin, 1992).

Differences between various interviewees, observations and questionnaire reviews were also noted. Qualitative data analysis attends to ferreting out the essence of the basic structure of a phenomenon, that is, to see the object of study from several different angles or perspectives, so researchers may better understand the underlying factors that may be affecting or shaping what is being examined (Merriam, 1998).

The collection of thick, rich description of interviews, observations, and documents, combined with the use of the multiple site design, also helped increase generalizability (Merriam, 1998). Thick description is a term borrowed from anthropology meaning the complete, literal description of the incident or entity being investigated, through the collection from many sources (Merriam, 1998). Thick description produces in readers the feeling that they have experienced, or could experience, the events described (Creswell, 1998). Then the reader may decide for themselves if the findings are generalizable (Lincoln & Guba, 1985).
Finally, through member checking, that is, by asking participants to review the transcripts of their interviews and the plausibility of the findings, the validity of the qualitative research design was enhanced, and researcher bias minimized (Merriam, 1998). Additionally, a clear audit trail of data collection in the form of researcher logs was maintained and should allow another researcher to replicate the study, if desired (Miles & Huberman, 1994).

**LEGAL ISSUES**

When dealing with issues of consent and competency for persons with developmental disabilities, specifically mental retardation, one must look to the Florida Statutes. Under the Florida Statutes, Volume 14A, Part 1, Title XXIX, Public Health Section 393, Developmental Disabilities Subsection .063.43, the following definition sets the groundwork for a baseline definition:

"'Retardation' means significant sub-average general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the period from conception to age eighteen. ‘Significantly sub-average general intellectual functioning,’ for the purpose of this definition, means performance which is two or more standard deviations from the mean score on a standardized intelligence test specified in the rules of the department. ‘Adaptive behavior,’ for the purpose of this definition, means the effectiveness or degree with which an individual meets the standards of personal independence and social responsibility expected of his or her age, culture group, and community.” (Developmental Disabilities, FS 393.063.43, 1998)

According to Mr. Terry Ketera, (personal communication, November 16, 2001), Program Director, State of Florida, Division of Developmental Services, District 10, the State considers
all individuals with developmental disabilities as defined in Florida Statutes, Section 393.00, to have competency, capacity, and consenting ability, unless otherwise determined in a separate proceeding, according to the procedures and requirements of Florida Statutes, Chapter 744 and the Florida Probate Rules.

The following sections in the Florida Statutes reflect the same:

"The issue of competency of a person with mental retardation shall be determined in a separate proceeding according to the procedures and requirements of Chapter 744 and the Florida Probate Rules." (Developmental Disabilities, FS 393.11.10(b), 1998).

"The issue of capacity of a person with developmental disabilities shall be determined in a separate proceeding according to the procedures and requirements of Chapter 744 and the Florida Probate Rules." (Developmental Disabilities, FS 393.12..1(b), 1998).

"Persons who are developmentally disabled shall have a right to consent to or refuse treatment, subject to the provisions of S.393.12(2)(a) or chapter 744." (Developmental Disabilities, FS 393.13.3(h), 1998).

ASSUMPTIONS AND LIMITATIONS

In view of the fact that the study focused on three school districts in Florida, the study was limited in application to the particular school districts in Florida and, as such, may not be applicable in other states. Further, the generalizability of the findings was limited to those participants, and perhaps to participants of similar composition and situation. The fact that multiple sites were used, the in-depth effectiveness of the phenomenological study may be reduced in order to effect a broader context of cross-district and participant analysis.
CHAPTER 4: DATA ANALYSIS AND FINDINGS

This chapter presents the analysis of the data collected in the formal interviews, observations, and the review of demographics collected during the course of the study. Because the data was collected during the Fall and Spring semester of 2001 school year, and from participants who represent various groups that have been associated with Transition Services, the scope of these findings is limited to that time period and this group of participants.

The purpose of the study was to determine what effects Transition Services have on the quality of life (QOL) for Down's Syndrome students that are classified as Educable Mentally Retarded (EMR) in the post-high school stage (0 - 2 years). More specifically, what is the QOL for students in the State of Florida, in three county public school systems, and in a cross-county comparison of the three county public school systems, who are Down's Syndrome (EMR), post-high school (0 - 2 years) and received Transition Services. Fifteen major findings were discovered as the data was analyzed:

- District personnel distill Transition Services down to positive adult outcomes for success.
- Selection criteria for district level Transition Services personnel varied between districts.
- Past perceptions of Transition Services by district personnel shaped the current program(s).
- Current vision of Transition Services by district level personnel varies by district.
Accomplishments of Transition Services at the district level shared concurrency.

Needed areas of improvement in Transition Services at the district level vary by districts.

The effect of Transition Services in all three districts was perceived as positive by district personnel.

The reason(s) for the perceived positive effect of Transition Services varied by district(s).

The qualifications of a district level Transition Services person varied by district.

Parents had little or no understanding of what Transition Services constitutes.

The majority of the parent participants felt Transition Services was a failure.

All parent participants wanted categorizing/labeling of students at this level.

Unemployment of student participants was a major issue.

All student participants lived with their families.

The majority of student participants perceived their overall quality of life as good.

This chapter will be divided into three sections, presenting these findings in more detail. The first will present information gathered from district level sources on understanding Transition Services, past and present perceptions, and the impact on students for the three selected county school systems. The second section will present data gathered from parent participants as to their understanding of Transition Services, effectiveness of Transition Services
and categorizing of post-secondary school students. The third section will examine the data collected from the post-secondary student participants, as to their QOL after graduation from high school. Chapter 5 will discuss the implications of the findings presented in this chapter in greater depth.

Section One: District Level: Understanding Transition Services; past and present perceptions, roles and accomplishments and impact on students from the three selected county school systems.

The following is the coding breakdown for the summation of district employees’ comments: DC1, district employee (D) for County (C) 1; DC2, district employee (D) for County (C) 2; DC3, district employee (D) for County (C) 3.

The clear delineation provided as a backdrop by IDEA influenced the formulation of nine questions presented to the participants at the district level. The district level participants from the three county school systems presented varying explanations and philosophic views as to what Transition Services are, as far as their understanding of IDEA. County 1, district level participant (DC1) was a male, over the age of fifty-five, who graduated in the late 1960’s with a graduate degree and major field of study in special education. His current function is as a director in the hierarchy of the school system, with sixteen years of experience at the district level in Transition Services. Previously, he was a teacher for eight years and has been in the County 1 school system (C1) for sixteen years.

The setting for the interview was the district office, which was a very small room that had volumes of books and resource information stacked conspicuously in every corner. The phone was constantly ringing and being placed on hold, so as to limit the amount of
interruptions, thereby, limiting the length of each answer to approximately twelve minutes. He was extremely willing to answer all questions, but had to be probed constantly to stay on track. The appearance of someone who was over-worked with extreme multi-tasking was present, but this did not interfere with his sincerity and strong feelings for this type of work and special students. The interview lasted approximately one hour and thirty minutes.

When questioned as to what specifically Transition Services are, he felt that, primarily, they are services of any type that help the student plan and eventually achieve positive adult outcomes. It was imperative to identify what the adult outcomes were, i.e., employment, independent living, etc., and then provide the services that were needed to help the student achieve these outcomes. Community participation, employment and independent living were felt to be very important as a means of measuring positive adult outcomes. It is apparent that his main focus, in regard to Transition Services, is in the area of positive adult outcomes, ensuring that they are achieved through the use of all available program services. He related some comments to the federal terminology areas of outcomes, i.e., employment, community integration, etc., as being important areas to focus upon.

When asked how he became involved with Transition Services at the district level, he explained that, when he was first hired by the district, it was as the Mental Handicapped (MH) Program supervisor, which was the predecessor of Transition Services. Then, in the early 90's, when transition became a pointed issue, the district created the Transition Services coordinator position and, with his concentration in MH, he was appointed to the focus position and shifted to transition.
When looking at the participant at the district level, County 1, a question of perception as to the understanding of the role of Transition Services, pre-district level employment, and currently in his position at the district level, arose. He described his past perceptions as being focused on vocational preparation, that is, making sure that the students with disabilities were receiving the vocational training, especially the special diploma students. Previously, there was a strong concentration on the special diploma students, so as to ensure they had the skills and that they were actually job placed, while they were still in school. He explained that they tried to ensure they had a number of work experiences, but that the last one was an individual competitive job, so when vocational rehabilitation got the student, they already have part-time employment. His current, or changed perception, of Transition Services occurred with the advent of IDEA. This radically changed the focus with specific emphasis on specific areas of transition, and this started to define the actions of today. It tended to broaden those four areas of experience, and it started a need to examine what could be done for students getting standard diplomas who have a disability.

In view of these changed perceptions, the important accomplishments of Transition Services during his tenure at the district level were in the areas of the creation of new services and relationships with outside agencies. The services have been expanded, and more students and families are reached. Contracts with agencies for services are being arranged while the students are still in school, and the rapport with these agencies is very good.

As a follow-up question, he was asked what areas need improvement, and he expressed that it is not felt that there is sufficient or quality Transition Services for students with disabilities seeking a standard diploma. There is a great need for this population of students
(ESE) to have the standard diploma option. Further, in regard to placement of qualified individuals in to the various Transition Services positions, initially, these individuals were vocational rehabilitation type people, and they did not quite understand the different populations’ needs.

One of the major issues, that is continually at the forefront of all those involved in Transition Services, is the effect that Transition Services has on the student population. The effect that the district employee, County 1, described was awareness, at an early age, that started the needed planning. Further, it made the students and families more aware of the agencies and services that are available, and what the possibilities are for all those involved. It provided students and parents alike a needed blueprint, as far as, who to contact, how to contact them, and where other sources of help may be located.

In regard to advice to perspective Transition Services employees, the best advice is that you are going to have to learn many new things, specifically, the agencies, and realize you are not going to be in the classroom. You will have to deal with families on a different level and deal with these families in their homes. You must know and understand persons with disabilities in order to provide them the necessary services they need for positive adult outcomes. In closing, DC1 felt strongly that the need exists for the appropriate number of personnel to provide the services at the district level and, if adequately staffed, success will be inevitable. It is very important to market Transition Services as they relate to the district. People have to be made aware of the need/value of transition, because anything that is not contributing directly to academic skill or being attributable to passing the Florida competency tests (FCAT), is questionable as far as value.
County 2, district level participant (DC2) was a male, over the age of fifty years, who graduated in the late 60's with a graduate degree in exceptional student education (ESE). His role at the district level is as a program specialist for Transition Services, with thirty-two years of experience in this area. The main function that he performs in Transition Services is training of school system personnel for twenty-five county high schools. He has been at the district level for twelve years and taught for twenty years, previously. His total time in the county school system is thirty-two years.

The setting for the interview was at the district office, in a 10 x 10 foot cubicle. The space was a repository for volumes of transition information, with file cabinets in the corners containing large amounts of Transition Services material. It was a very busy office with constant interruptions from other personnel, phone calls and e-mails; however, the participant was very easy to speak to and made every effort to answer the questions of all who entered his space. He seemed to present a reassuring demeanor, and never lost focus as to his strong feelings towards the special needs population that he served. The interview lasted one hour and twenty minutes giving approximately eight minutes per answer.

The district employee explained that he was previously a program specialist for high school and, through that particular job, he was involved with training and other specifics that related to transition. He continued by explaining he also was involved with the high school Exceptional Student Education (ESE) program, and the ESE specialist would always take the student through transition, as part of their duties, and hand them off to an appropriate agency. When he arrived at the district, there was not a transition specialist, so when the position was created in County 2, he was given the position and told to exclusively work on transition matters.
His pre-district employment gave rise to some past perceptions as common themes in education in general, that is, curriculum. He explained that there is a whole scope and sequence for preparing the students, and that he “could not divorce” himself away from the high school curriculum. If they have a good foundation through the curriculum, they will be prepared to become successful adults. The curriculum will give them the necessary social skills and employment skills and the functional academics they need to become successful adults. He continued that, in his mind, there is no difference today in regard to his perception of Transition Services. He only felt that some systemic developments may have changed, but not, per se, his perception.

As far as accomplishments in the Transition Services area, he expressed that, year to date, the biggest accomplishment was the revitalization of the interagency council. That being said, all the appropriate agencies have been united under the one council, and this allows for a positive flow of information, information that is vital for the success of our students and needed by the parents to make educated decisions. This has been identified as a problem area, and the district is trying to create a parent-friendly booklet or brochure that can go to schools and parents. This would be based on the similar brochure that is utilized on the interagency council, and thus, helping to eliminate mis-information.

One very important area of needed improvement, in County 2, is in the community service program. Trying to get the community service providers (CSP) to understand that students with some moderate to severe disabilities, who are included in high school, have been placed out in the community through supportive employment, and perform admirably. The CSP’s are going to have to look at their program(s) differently. A student with some mild
cognitive issues, going into a sheltered workshop, is not going to be acceptable anymore, because he or she has already been out in the community through community based instruction. Everyone involved must communicate to the community agencies, particularly the parents, that they have to change the way they do business. In relationship to the effect of Transition Services on the students, the district employee felt that it was a positive effect, referring to the hundreds of seniors who were sent to vocational rehabilitation, as well as to the appropriate agencies where additional training has been paid for through vocational rehabilitation.

The County 2 district employee explained that, for someone new wanting to get involved with Transition Services at the district level, they have to know the community, as well as, the nature of adults with disabilities; in particular, what services are out there and which ones are appropriate for specific groups of students. They are going to have to be flexible and accept that there are different ways to approach any problem. In conclusion, DC2's closing comments related to time to do your job well, funding to provide services needed and, most importantly, follow-up to see what is working. The student exits the school system and is placed in an appropriate agency and, at this point, the school has done its job. However, there must be a way of tracking the student from this point forward to ensure that the student is actually gainfully employed and not home doing nothing.

The district employee from County 2, when queried as to his understanding of what Transition Services are, expressed, in general terms, that they prepare the student to be a successful adult, that is, to the best of his or her ability. The federal terminology of the Transition Services areas of instruction, community experience, post-school adult living,
employment, independent living skills, etc., all relate to preparing the students with disabilities to be successful adults, to the best of their abilities. He relates Transition Services to adult outcomes and incorporates some of the federally mandated areas as examples. However, his main thrust is preparation of the students to be successful adults.

County 3, district level participant (DC3) was a female over the age of thirty-five, who graduated in the late 1980's with a Master's Degree in reading and learning disabilities. Her role in Transition Services, at the district level, is that of a coordinator. She has been involved with Transition Services for fourteen years and describes her function in Transition Services as that of a facilitator. She has been at the district level for three years and previously taught for eleven years. Her entire time in the County 3 school system is fourteen years.

The interview occurred at the district office in a 12 x 6 foot office. The actual space was filled with volumes of Transition Services information and appeared to be relatively organized into specific categories. There was a constant flow of people asking questions, and phone calls interrupting the interview. She was extremely busy and multi-tasked to capacity. However, she took great care to answer all questions and presented a very cordial, good-natured attitude at all times. She presented an almost contagious zeal for exceptional student education, which surfaced continually throughout the interview, and explained that she loved to teach and still keeps in touch with "her kids." The interview lasted one hour and ten minutes, with the average time per answer of approximately seven to eight minutes.

The district employee from County 3 expressed her understanding of Transition Services in a very philosophical manner. Essentially, Transition Services basically begins at birth and
goes through infinity. Transition relates directly to the services that the students need to access very early on, in elementary school, with a clear expectation of getting more hands-on experiences in middle school, with actual visits to job sites, mentoring programs, and actual hands-on exposure to serious job skills in high school. The key, in her opinion, is awareness, that is, students’ awareness of what their disabilities are and how they are going to make them into abilities. Transition is the life, and life means forming social skills and all the other components that relate to positive adult outcomes, but the students have to do it as advocates for themselves. She expressed very strong feelings for self-advocacy because this is what empowers the students, and if they are to succeed in the work force, they will have to accomplish it without all the safety nets of parents, counselors, and teachers. She relates to Transition Services with a passion to early intervention programs, self-advocacy and a willingness to transition on the part of the students.

The employee explained that, in high school, she coordinated all the Transition Services for the students, that is, she was the direct link with the Transition Specialist, working with vocational rehabilitation and all the agencies for the more moderately disabled students. So, when hired by the district, she was the only person at the district level with the background in Transition Services at the high school level. In regard to pre-district employment and past perceptions, she explained that Transition Services were thought of solely along the senior high level but, since the district level employment, the perception of Transition Services has changed drastically because of the inclusionary process. Because of this changed emphasis on inclusionary practices, and because of IDEA, and the role that her county has taken, it is very
easy for her to train on inclusion and set up sites. The ultimate goal for transition, in actuality, is inclusion in the community and in the work force. So, the main change could be related to the fact that inclusion and transition are inter-related and are presented, as such, in the county.

Further, she explained that accomplishments of Transition Services thus far, relate to a particular vision of district programs, which is, the creation of a district web site, developed for ESE, that will act as a clearing house of information for parents and students. The second portion relates to development of a general handbook, “quasi-Bible,” for teachers to be able to use as a resource for community resources, professional resources, student and parent resources. The easy access of information, ensuring that all parties involved with transition is facilitated, is the major accomplishment to date.

With this in mind, there are areas of needed improvement still, in regard to awareness and access to information. The web site and teacher guide book need to be available to all parties, and continuous updating of the information is imperative. Further, you continually run across parents who know very little about the process and are totally out of touch in regard to the status of their children’s education and rights. On a positive note, she explained that Transition Services have effected the student population (ESE) positively through self-determination and student empowerment. These two areas present a major piece to the transition puzzle, with the other two pieces being parent involvement and the school performing its duties efficiently at all levels.

The final comments from the district employee from County 3 related to advice to new transition employees and collaboration and awareness issues. New employees need to fully
participate in this society and have a true sense of belonging, as opposed to "I'm in high school getting 'those' kids that nobody wants." Only through awareness and collaboration between all the different entities will a successful outcome for the students be ensured. Employers need to be as much a part of the process as the teachers. The schools need to understand the skills that the employers need, and train the students accordingly, so as to "fit" them into the business community.

It is obvious that all three district level participants have been involved in ESE for quite some time. All have advanced degrees in their specific field, and all were actively teaching in the classroom for six to twenty years prior to their current district level positions.

All of the district level participants had different past perceptions, based in part on their prior job responsibilities and areas of expertise. DC1 came from the MH arena and had strong vocational rehabilitation ties, which permeated throughout his answers. DC2 came from a strong curriculum background, that is, appropriate curriculum will give the basis for successful outcomes. DC3 had Transition Services responsibilities in her high school, and related her past perceptions solely to her past job in Transition Services.

There were varying degrees of noticed change, as far as the participants' perceptions of transition, from DC2 saying it's no different in his mind, to DC1 relating to the changes brought about by IDEA, and DC3 relating to the inclusionary process issues, as it relates to Transition Services.

All three participants seem to have the same themes in mind when it comes to accomplishments, that is, outside agency contacts and rapport, and getting information to the parents and students, as to what programs are available and accessible. DC1 developed
a new rapport with outside agencies and increased services for the students, and DC2 “revitalized” the interagency council, as well as creating a parent handbook to assist in questions and issues concerning Transition Services. DC3 has increased the amount of information available and accessible to all groups involved in Transition Services, via her web site. Plans are in place for a booklet to be created with comprehensive information on Transition Services.

Two of the three participants seem to have the same theme as needing improvement, that is, awareness issues. DC2 relates the lack of awareness as a function of employment and outside agency placement, that is:

“A kid with some cognitive issues is going into a sheltered workshop, and that’s not going to fly anymore, because these kids have been out in the community.”

where DC3 places awareness as an across-the-board issue for outside agencies, educational professionals, parents and students alike; specifically:

“The awareness, the awareness isn’t there... I still run across parents who say I don’t know what’s going to happen to my child when they leave.”

and DC1 places professional employee mis-placement as a particular drawback, that is, individuals that are “vocational rehabilitation types” that did not quite understand the different populations needs.

The three participants had similar opinions that the students were, in all three counties, effected in a positive manner. However, they differed as to what areas had the positive effect; specifically, DC1 felt that the positive effect came through increased awareness of agencies and
services, as well as an emphasis on family and students regarding interaction, opportunities and contacts. DC2 felt the positive effect was reflected in the number of placements with vocational rehabilitation and agency referrals, where DC3 felt that a renewed sense of self-determination and student empowerment generated the positive effects on students.

The responses were both philosophical and functional in regard to needed abilities to work in Transition Services. Outside agency contacts were important to DC1 and DC2, as well as understanding what services are appropriate and available. DC3 spoke from an emotionally philosophical perspective; essentially, don’t be an observer, be a participant.

Closing comments by the three participants spanned a variety of topics that are crucial to the success of the Transition Services program. DC1 expressed the need for competent and appropriate staffing levels, as well as the need to market the program to the district itself. This will eliminate the need to justify why a program that has no positive impact on FCAT scores, or increased academic skill levels, has value and purpose. DC2 felt that time to perform duties through increased staffing was essential to provide the needed services. He felt funding was the major issue that can make or break the program and feels also that a big missing piece is the lack of follow-up on the students after graduation. DC3 echoed the sentiment of the business community in their willingness to employ special needs students, if they have the basic job skills.
## PARTICIPANT'S DEMOGRAPHIC DATA

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Legend: (D) = District Employee  (C#) = County #  
#PC## : (#)=Interview Number  (P) = Parent  (C##) = County Number
Section Two: Parent Level: What are Transition Services, Effectiveness of Transition Services, and Categorizing (Labeling) of Post-Secondary School Students

As one looks at IDEA, included in the law's mandates is the provision of opportunities for the inclusion of parents in the determination of their child's educational programming. The primary vehicle for parent participation has been the Individualized Education Plan (IEP) meeting, in which parents are required participants. One of the major purposes of the IEP is as follows:

The IEP meeting serves as a communication vehicle between parents and school personnel, and enables them as equal participants to jointly decide what the child's needs are, what services will be provided to meet those needs, and what the anticipated outcomes may be . . . (Federal Register, 1981, p. 5462)

With this aspect in mind, it seemed only reasonable to interview the nine groups of parents/care givers involved in this process. Three groups of parents/care givers from County 1, County 2 and County 3 were interviewed and asked about their knowledge of Transition Services, whether or not (in their opinion) they worked, and if they believed in categorizing (labeling) of post-secondary students.

The first interview in County 1 was of a female parent over forty-five years of age who completed twelve years of education and received a high school diploma. She has been involved in Transition Services as a parent for six years and has a child who went through the Transition Services program. The parent was involved at her child's school as a room mother and volunteer at school functions. It should be noted that her child started transition at age fourteen.
The setting for the interview was at the residence of the parents and child. The home was in an upper middle class neighborhood with beautiful furnishings. A very cordial and pleasant environment existed during the interview of the parents; the mother tended to dominate the conversation and be very protective of the child. The mother explained that she has a male child who is normal, and her husband is twenty years her senior and lives at the same residence. Further, her disabled child goes to work daily with the father at the family business. The interview lasted approximately thirty minutes.

In regard to her understanding of what Transition Services constituted, it was a very general, emotionally-based response. Transition Services were important to her and to her child, but there was no articulation as to what the specifics were in regard to what they actually do or how they operate at the high school level. Admittedly, she expressed her lack of understanding and felt that it was incumbent upon the school to provide her with the needed information and explanation of the dynamics of the programs. It was her overwhelming opinion that Transition Services were an abysmal failure and, were it not for the family business, the student would be unemployed and at home.

Categorizing/labeling seemed to be important and necessary, in her opinion, because of the total mixing of all exceptionalities together by the different agencies. They all have different needs and ability levels that must be addressed and, only if labeling occurs, can they be grouped by these characteristics.

The second interview in County 1 was a female over the age of forty-five who was
college educated with a degree in psychology. She has been involved with Transition Services for six years and has two children who have participated in and completed the Transition Services program. She has been involved at her child’s school as a room mother and volunteer at school functions.

The setting for the interview was at the residence of the female parent. The residence was modest, but very beautiful and pleasantly decorated with an atmosphere of mild tension and apprehension. The interviewee was well-spoken and interacted well, without being overbearing or controlling. She had a very desperate, but determined, sense of purpose and appeared to be very tired. There were three off-spring, two girls both with Down’s Syndrome, and one boy who was ‘normal.’ There was no husband or male adult associated with the interviewee or children. The interview lasted approximately thirty minutes.

The explanation provided by the second parent from County 1, in regard to Transition Services, was more succinct and defined. Although somewhat general, it contained a core definition, expressed by stating that they help an individual person that has special needs to move from the school environment into the most appropriate job placement or day program. Student support pervaded throughout her understanding of what Transition Services relate to, specifically, in the area of employment or any problems they may encounter. With this in mind, she strongly expressed that Transition Services were, in her opinion, a failure due to the total lack of connection and coordination of all the agencies involved. With rare exception, once you leave high school, the job coaches do not follow the student to permanent employment, and the majority are relegated to sheltered workshops. Transition Services have an institutional
overtone, and prevent all but the extremely high functioning students from staying on their practice jobs after graduation from high school. This parent felt that categorizing/labeling was a needed criteria because of the many missing links for individual needs. Individual needs are not being met because all the students, regardless of their exceptionality, are being “plugged into one big pot.”

The third interview conducted in County 1 was of husband and wife participants, both over the age of forty-five, with the husband graduating from high school and the wife having a college degree in education. They have been involved with Transition Services for five years and had a child that went through the Transition Services program. They both were active members in the school PTO/PTA organization.

The setting for the interview was the residence of the participants, specifically, the living room. The residence was well-kept, in a middle class neighborhood, and a very quaint interior. There were many family pictures decorating the various parts of the living room with a large, docile dog asleep in the corner. There was a strong feeling of family unity, with a phone call for the student from the maternal grandmother occurring during the interview. Their son would pop in and out at various times during the interview, and they would lovingly direct him to return to his bedroom. Both parents were very soft spoken, and took turns speaking, and didn’t contradict each other. The parents responded well to the presence of the interviewer and appeared to be at ease and honest in their responses to the questions. Their son was the only child and, as they spoke about this, there was a feeling of remorse for not having any other children. However, they were devoted to his happiness and well-being and remained very protective of the student.
The interview lasted approximately forty-five minutes. The student works with his mother at the community church.

Both parents appeared to have very little specific knowledge as to what Transition Services represent. They felt they were to provide different opportunities for learning or a variety of opportunities to gain experience. They did not relate Transition Services to functional education, social integration in the community, or employment and independent living skills. However, they both felt that Transition Services did and did not work, to a certain degree. That is, they felt that learning occurred for their student at different job sites, where he learned skills that helped him stay on task. Admittedly, they felt that he received basic training and some minimal job skills that will, hopefully, help him in the future. Conversely, they expressed concern over the system’s general failure through contact with other parents in similar circumstances. “There are a lot of parents we have seen don’t know what their rights are and are left in the dark without any knowledge.” They felt that the schools intentionally kept the parents out of the loop and intentionally kept the expectations low for the students, so as to easily meet goals. There was a continuous problem with supportive employment due to transportation issues, thus creating an overloaded situation at the job sites. Further, they expressed a definite need for categorizing/labeling of the students. Consequently, as the student matures, there is a need to separate them by ability and exceptionality, to ensure that the individual needs of each student are met.

The first interview conducted in County 2 was with a female participant, over the age of forty-five, who was a college graduate (under-graduate degree). She has been involved in
Transition Services, as a parent, for seven years and has a child that has been through the Transition Services program.

The setting for the interview was at the residence of the mother and father of the student, an extremely large home and surrounding property, in a very affluent, upper class neighborhood. The home was exquisitely furnished with great family photos, plush tufted furniture and a baby grand piano in the great room. However, as large as the home is, there was a sense of family unity, and a caring environment was portrayed. Personal effects of all the family members adorned the walls and furniture and presented a feeling of strong family pride. The mother and the interviewer conversed in a quiet spot in the family great room. She was very soft-spoken and was very accepting of her son's handicap. She was well-educated and had no problems answering the questions, and was always extremely cordial. Even though the family was obviously in the upper economic levels and very successful, feelings of frustration and despair permeated the conversation. She has other children who are "normal", and the interview lasted approximately one hour. The student is currently not employed and awaiting placement through vocational rehabilitation.

When the mother was asked about her understanding of what Transition Services are, she gave a non-specific answer, relating to Community-Based Instruction (CBI) and job placement.

"Well they came and they interviewed us and gave us options. That was it, to try to get him a job"

She felt that transition related solely to CBI, leading to placement in vocational rehabilitation, and then being referred to an outside agency for job placement. She was quite emphatic that, in her opinion, Transition Services did not work. If they do place the student in a job, it's part-
time, ranging from eight to ten hours a week. The rest of the time, they sit at home or roam the streets.

"I see that loneliness and depression are big problems post-graduation. The students are bored with no alternative, and it is really sad. It seems that, without the support services, this population is not capable of maintaining a job, and they just fall through the cracks because there is no follow up by the school or agencies."

The parent expressed a definite need for categorizing labeling of the students by abilities and individual needs. They are placed after graduation in "one large cluster" and this includes the full range of exceptionalities. Categorizing the students by ability would definitely be a needed step in the right direction.

The second interview conducted in County 2 was of a husband and wife who were over the age of forty-five and both college graduates (under-graduate degree). They have been involved with Transition Services, as parents, for seven years and had a son complete the Transition Services program. They have worked as volunteers in the high school office for Exceptional Student Education.

The setting for the interview was the residence of the parents, which was an upper middle class home in a very nice neighborhood. The home was nicely furnished with family photos abounding. The home was very neat and clean and displayed memorabilia of all family members, with particular emphasis on the handicapped son. Both parents interacted well, taking turns speaking, and were very articulate, having no problems understanding and answering the questions posed. The parents were very upbeat and positive about their son's future and were extremely proud of his accomplishments. The son worked at the
same establishment as his mother, but in a different department. The interview lasted approximately one hour.

The parents provided a clear understanding of what they felt Transition Services were supposed to accomplish, but did not explain the basic rights of parents and students that should be provided through transition. They explained that, when the student was in high school, Transition Services provided him with vocational/educational training that helped the student perform certain skills, to an acceptable level. It was felt that services would be provided to help find him employment, either through a sheltered workshop or transitioning into a community environment, through the appropriate agencies which offered job placement and are amenable to his population. They expressed concern that Transition Services did not have a very good reputation, and they lacked a great deal of confidence in the placement capability. They felt it was incumbent upon them to find employment for their student, and were successful. However, on a positive note, great credit was given to the teachers that their student had and, if not for the teachers’ dedication and ability, their son’s strength and abilities would not have developed. From that perspective, they felt that Transition Services were marginally successful. Further, they felt that there was a classification problem throughout the entire system, and it is more predominant as maturing occurs. ESE is, unfortunately, a conglomeration of exceptionalities and varying issues, and for someone to be placed in this mix may not be the best solution. They were in agreement that labeling by ability group and exceptionality would have a positive effect on successful adult outcomes.

The third interview conducted in County 2 was of a female parent, over the age of forty-five, with a high school diploma. She has been involved with Transition Services, as a parent,
for six years, and her son has completed a Transition Services program. She has been involved at her child’s school as a room mother.

The setting was at the home of the mother, and it was in a lower middle class neighborhood. The home was neat and clean, but contained only the basic necessities. Many family artifacts were present, and you could sense the proud feelings she had for her child with the disability. Initially, the mother was a bit reserved but warmed up as the interview progressed. She tried to stay on track, but the visible frustration made it very hard for her because there was so much that she wanted to say. At times, it was difficult for her to speak, and it was evident that the subject was emotionally painful. Although the home did not contain many visible luxury items, she was very proud of her home and her child’s accomplishments. She had another child (female) that was “normal”, but there was no apparent adult male influence in the home. The interview lasted approximately one hour and closed with her stating that her son was not employed.

In regard to her understanding of what Transition Services were, as required by law, she was somewhat at a loss. She thought that Transition Services were different things, but mainly to get the student ready for after graduation, that is, getting ready for a job and enter the community, at large. She expressed confusion as to the exact nature of curriculum and services that were provided to her child. She expressed some minimally positive events in regard to transition working initially. The student seemed to be doing relatively well, and he was exposed to different experiences and jobs, through the school. However, as of now, the students just
seem “to fall through the cracks into a large hole,” and they get frustrated and quit the particular agency or workshop. The parents, she explained, are at a total loss as to the awareness of what is available in the form of services. There is a total lack of collaboration between agencies, schools, parents and students. When questioned about categorizing/labeling of students, she expressed an absolute desire for this to take place. To be thrown into a large group with varying degrees of exceptionalities tended to have the student regress to a lower level of functionality. She expressed that “categorizing is real important.”

The first interview conducted in County 3 was of a female participant that was between the ages of thirty-one and forty-five, who graduated from high school. She has been involved in Transition Services, as a parent, for six years and has two children who have been through the Transition Services program. She has been involved at her child’s school as a volunteer in the office.

The setting for the interview was at the mother’s residence, which was in a lower middle class neighborhood. The home was small, but kept very neat, displaying ethnic artifacts throughout. There were pictures of her children displayed proudly on the walls, and the dining room table was set as formally as possible for the main supper meal. The mother was a very nice, sincere woman who was concerned about her children’s education, as well as being involved in their education. She seemed to have totally given the children over to their own destiny and strongly felt that they will care for themselves without her assistance. The mother had somewhat of a difficult time initially answering the questions, but with prompting from the interviewer, successfully answered all questions. There were no interruptions during
the interview, and there appeared to be no adult male influence in the family, with the participant being the sole care provider to the children. Her oldest child was learning disabled, and she was very proud of his progress and accomplishments. The interview of the mother lasted one hour.

When the mother was questioned as to her knowledge of what the function of Transition Services was, she stated that it was never really explained. The mother guessed that transition had to do with working during school and learning new skills, through the assistance of a job coach. In regard to the success of transition, there were many negative aspects that were presented, specifically, that the only reason there was a modicum of success was due solely to the job coach’s dedication. From the perspective of the school, the mother was emphatic that it just did not work. She felt that the students were not able to “handle it alone” and presented an opinion that the principal of the school should become more involved at this level; however, “unfortunately, you have a ‘don’t care’ school.” With this in mind, she expressed strong concern for the need to categorize/label these students at this level. She stated that the system currently tends to force lower standards and goals on these students. Grouping by ability and exceptionality would tend to reinforce a better learning environment and afford greater opportunity to better oneself.

The second interview in County 3 was of a husband and wife that were over forty-five years of age, and both had graduated high school. They have been involved with Transition Services for six years, as parents, and have a child (male) who has completed the Transition
Services program. They have been involved at their son’s school as room mother and volunteer in the office.

The setting for the interview was that of a middle class residence in an ethnic neighborhood. The home presented a warm feeling when you entered, with family artifacts abounding. It was very neat and clean, and presented a strong cultural connection to the family heritage. The parents were very nice people who were willing to answer any questions, with the assistance of their daughter, who helped with the language problem. The conversation went well, and the parents were very mild-mannered. There were photos of their son throughout the immediate living area, and it was evident the mother was very protective. The son was working with friends of the family, and this was important to the father, but it seemed that the mother would rather have him at home. The interview lasted one hour.

When specifically asked what are Transition Services, the parents had a general idea as to the desired outcome, but minimal information as to what these services represented. Accordingly, their explanation related to preparation for “life after graduation.” This would be in the form of independent employment and some quality of life. There was some preparation by the school for this in the form of community integration activity and a variety of job site exposures, thus leading to a positive adult outcome. Unfortunately, their opinion, in regard to success or failure of Transition Services, leaned heavily on failure. Outside agency placement had not been able to provide meaningful employment, and he was not placed back at the practice job sites. Conversely, there was a positive event in regard to the job site exposure during high
school. Both parents felt that their student benefitted from the experience, but this is where the benefit ended. They concluded by agreeing that, at this level, categorizing/labeling would help generate positive outcomes. With all the different exceptionalities and ability levels grouped together, it virtually ensures failure for all but a few high functioning students. The mother was very strong when she stated, “Categorizing them by ability” would help the overall dynamics of the process.

The third interview in County 3 was of a female (parent) participant, over the age of forty-five years, with a two-year associate’s degree. She has been involved with Transition Services for six years, as a parent, and had a child (male) complete the Transition Services program. She was involved at her child’s school as a room mother and volunteered in the office.

The setting for the interview was in the upper middle class residence of the female (parent) participant. It was a gated community and very nice home that was bright and well kept. The living area had family photos and family artifacts throughout, but the house seemed void of happiness. It did not have a cordial, warm feeling, but rather a cold and hard appearance, almost as if it were staged to look familiar. The female (mother) participant seemed to be very alone, and there was no apparent male adult influence at the residence. She answered all questions politely and as completely as possible. The phone interrupted the interview a few times, but she returned and finished all answers. The mother was very protective of the child, but at times seemed exasperated. The interview lasted one hour; the son was an only child, and was not employed.
The first question regarding the mother’s knowledge of what Transition Services represents was met with some confusion. “Opportunities to get experience” was proffered, as well as, “learning different things” and employment after graduation. She had never had anyone explain to her what these services were, or what her rights were, under transition. She strongly felt that Transition Services did not work “because he doesn’t have a job!” There was an apparent failure after graduation to successfully place the student with an appropriate outside agency, and this seemed to exasperate the mother. She felt that categorizing/labeling of the students, at this level, would only lead to a positive adult outcome. By grouping all exceptionalities together, she felt that it tended to make the higher functioning students regress to the lower levels of their peers. Her opinion was to stimulate and elevate the group to help provide a reachable level of success.
## RESPONSE SUMMARY TABLE - PARENTS

<table>
<thead>
<tr>
<th>County</th>
<th>Understand</th>
<th>Did Not Understand</th>
<th>Transition Services: Worked or Did Not?</th>
<th>Categorizing/Labeling Post High School Students</th>
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**Legend:**

#PC##: (t) = Interview Number; (P) = Parent; (C) = County; (#) = County Number

Joseph A. Finley, Jr.
Quality of life has become an important public policy and service delivery issue within the mental retardation/developmental disabilities (MR/DD) field, where it has been called the issue of the 1990's (Schalock, 1990). The goal of an enhanced quality of life for persons with disabilities is the conceptual basis for quality enhancement techniques, quality assurance, and program evaluation. The Quality of Life Questionnaire was designed specifically to meet the need for an instrument to assess the quality of life in persons with mental retardation and developmental disabilities. The instrument was developed in the context of the four-component model (see model). The first component of the model (outer portion of model) reflects three cultural values currently impacting a person's quality of life: values commensurate with the community, legal foundations reflected in current public laws, and a paradigm shift characterized by inclusion, equity, and consumer empowerment (Luckasson, Coulter, Polloway, Reiss, Schalock, Snell, Spitalnik, and Stark, 1992). The model's second component reflects research findings indicating that a person's perceived quality of life results from three aspects of life experiences: personal characteristics, objective life conditions, and the perceptions of significant others (Goode, 1988). The perceptual component of the model recognizes that quality of life has a subjective component and cannot be inferred strictly from objective measures of life circumstances. Thus, it is important in quality of life measurement to have persons make a subjective evaluation of the life experiences that impact their personal beliefs about what is important and how the world works (Lehman, 1988; Milbrath, 1982). The instrument developed from this model assesses the quality of life from the perspective of the individual.
QUALITY OF LIFE MODEL

Provided by and with the permission of Dr. Robert L. Schalock
IDS Publishing Corporation
The Quality of Life Questionnaire was used to assess the degree of perceived satisfaction, independence, productivity and community integration of post-secondary school (0 - 2 years) students with Down’s Syndrome, classified as Educable Mentally Handicapped (EMH).

In general terms, under the category of satisfaction, County 1 students 2SC1 and 3SC1 had a high degree of satisfaction with their quality of life, expressing few problems, and were very satisfied with their living arrangements. Problems that were explained related to performance of household chores, sibling rivalry, day-to-day living needs, and lack of social activities. They considered themselves to be an important part of the family. Students 2SC1 and 3SC1 were from well-rounded, accepting, loving families, that provided a very secure environment for their children, thus creating this sense of importance. However, student 1SC1 was less enthusiastic about the quality of life that was available, and felt that she had more problems than other people. Student 1SC1 felt that she had more problems due to her unemployment, even though she worked at the family business. She appeared to be happy working with her father, but expressed, with some prompting from her parents, a desire for outside, meaningful employment. It should be noted that student 1SC1 was from a loving, well-rounded, successful family also. Additionally, student 1SC1 stated that she felt out of place in social situations, and that most things that occurred to her were only acceptable, at best. The student was exposed to various individuals at the family business during her work day and, at times, became frustrated when communications between individuals were nebulous. The lack of
cognitive ability on her part appeared to generate this feeling of inadequacy and sense of “out of place” in situations, thereby giving rise to the “only acceptable” answer for things that have occurred to her.

County 2 students 1SC2, 2SC2, and 3SC2 had a high degree of satisfaction with their quality of life, expressing few problems, or the same number of problems as others, and were very satisfied with their living arrangements. In relationship to the students’ comments regarding problems in their life, all relayed anecdotal variations of similar problems. These problems ranged from having to make their bed and keep their room clean, to cleaning the dinner dishes and trying to relate to other siblings. They considered themselves to be an important part of the family. An important aspect for all the County 2 students was the fact that they all had very secure, consistent and loving home lives. This consistent and nurturing environment provided a sense of security and well being, which translates into the level of satisfaction with the students’ quality of life, specifically, living arrangements. Further, student 1SC2 felt that life brought out the best in him and had fewer problems than other people. As earlier stated, the perceived problems experienced by student 1SC2 were those of domestic and family issues, particularly involving responsibilities in the home regarding cleaning and maintaining the living spaces in a neat and orderly fashion.

County 3 students 1SC3 and 2SC3 had a fair degree of satisfaction with their quality of life, expressing fewer or the same number of problems as others, and were very satisfied with their living arrangements. The quality of life that the students expressed can be related to the
living arrangements and care provided by the parent or parents of the students. The problem areas, once again, related to demands placed on the students by parents to help in the home with domestic functions, i.e., making their bed, sibling rivalry, etc., had minimal impact on their satisfaction as it relates to quality of life. The living arrangements as presented were in loving family homes, regardless of what level the family attained, and the students were incorporated in all daily family activities, as far as possible. They considered themselves to be an important part of the family. However, student 3SC3 felt that life didn’t give him a chance and had more problems than others. This student had no siblings and little opportunity to socialize because of the mother’s (single parent) schedule. This particular home environment, although loving and supportive of the student, contained an air of frustration and tension. This student’s perceptions seemed to feed from the mother’s frustrations and tensions, thereby possibly slanting the student’s views and opinions. Student 3SC3 expressed a high degree of loneliness and always felt out of place in social situations. He is the only child in the residence and has minimal opportunity to mingle with peers, due to working commitments of the mother. As far as feeling out of place, the student expressed a sense of awkwardness when dealing with individuals not previously familiar to him and became frustrated when trying to express his sentiments. This may be related to the verbal and cognitive impairment, which appears to limit his ability to express feelings and abstract concepts.

With regard to the category of competence/productivity, County 1 students 1SC1 and 2SC1 were unemployed and could not specifically answer the related questions. Student 3SC1
was employed and satisfied with his skills and related educational experience, as well as, the relevance of the work performed. The student worked at his mother’s place of employment and assisted with administrative and clerical functions in the front office of the business. As far as benefits, he was not satisfied and stated that the amount of pay created a situation where he had to wait to buy some items or not buy them at all. When he made the comments concerning the benefits and pay, unknown to the student the mother had previously explained that he did not get benefits and received a more symbolic amount of pay. Essentially, he was only employed in gratuitous fashion and not actually as a full-time employee with benefits.

County 2 student 2SC2 is employed and is satisfied with his skills and related educational experiences, as well as, the relevance of the work performed. He is employed at his mother’s place of employment, however, in a different department and works independently of his mother. He receives salary commensurate with his job skills and abilities and receives benefits from the organization. As a passing comment, he felt he did not earn enough money, but was very happy and secure in the position. As far as benefits, he was somewhat unsatisfied, and student 2SC2 reiterated that he definitely did not earn enough to buy what he needed.

Students 1SC2 and 3SC2 are unemployed and could not specifically answer the questions.

County 3 students 1SC3 and 3SC3 were unemployed and could not specifically answer the related questions. Student 2SC3 was employed and somewhat satisfied with his skills and related educational experience, as well as, the relevance of the work performed. The student was working in the Goodwill Industries, doing piece meal work and did not particularly think
that this would be the best job he would be able to acquire. The work was not extremely
cHALlENGING and was repetitive in nature, and at times the student seemed frustrated talking about
the conditions. The training that was given to the student while in high school did provide him
some needed skills for employment, but he was trying to learn as much as he could while at
Goodwill. When questioned on relevance, the parent intervened to help explain the question,
and the student did think that the work generally related to prior training. As far as benefits, he
was not satisfied and felt that he definitely did not earn enough to buy what was needed.
Accordingly, until placed with a business partner in the community, the referral agency did not
provide any benefits, and a small stipend was the representative salary.

When addressing the category of independence/empowerment, County 1 students 1SC1,
2SC1, and 3SC1 all expressed that they have a faIR amount of independence/empowerment, but
admitted that, in regard to monetary decisions, they received assistance from others, but
provided input as well. This independence/empowerment related directly to the ability and
oversight of the parents, in as much as all the County 1 students lived at their family residence.
Further, all were accompanied by someone, or someone else made the appointment, when using
health care facilities. Again, keeping in mind that the parents made all the arrangements for
these students on a daily basis and provided all transportation and financial support as well. All
three students have full- time guardians/parents and stated that life was somewhat planned for
them, having little to some control over every day things. As far as the control issue, all the
students had a certain amount of control delegated to them by their parents, and mainly related
to domestic choices, i.e., meals, clothing choice, television, music, etc.
County 2 students 1SC2, 2SC2, and 3SC2 all expressed that they had a fair amount of independence/empowerment, but admitted that, in regard to monetary decisions, they received assistance from others, with minimal input. However, again, this independence represents delegated independence, and was given solely by the parents and, essentially, the students were dependent upon the parents for all critical aspects of their lives. Further, all were accompanied by someone, or someone else made the appointment, when using health care facilities. All three students have full-time guardians/parents, and students 2SC3 and 3SC3 stated that life was somewhat planned for them, having only some control over everyday things. The activities that the students had the perceived control over related to leisure time activities, maintenance of their bedrooms, and certain aspects of the choice of meals. For all intents and purposes, the parents maintained control of all life decisions and provided for the health and well-being of the students. Student 1SC2 felt that his life was free, however, felt that he only had some control over everyday things. Student 1SC2 was provided a great degree of latitude by his parents in relationship to his discretionary life activities; i.e., social events, leisure activities at home, cooking and dining arrangements. However, they exerted total control in regard to his health and well-being in all critical areas, specifically, medical issues, work issues, and financial matters.

County 3 students 2SC3 and 3SC3 expressed that they have some independence/empowerment, but admitted that, in regard to monetary decisions, they received assistance from others. The perception of students 2SC3 and 3SC3 in regard to independence and
empowerment relates directly to the amount of discretionary latitude that the parents are willing to give, in regard to the freedoms available to the students. Keeping in mind that student 2SC3 does work in a community business with regular salary and benefits, and student 3SC3 is unemployed, there still is a great deal of parental involvement in both cases to provide a good quality of life for the students. Further, both are accompanied by someone, or someone else made the appointment, when using health care facilities. Both students have full-time guardians/parents and stated that life was somewhat planned for them, having only some control over every day things. Accordingly, this is reflected in the amount of parental control exerted over the students, regardless of the employment status, in order to provide a good standard of living and quality of life.

Student 1SC3 expressed that she has a good amount of independence/empowerment and admitted that, in regard to monetary decisions, she decides how the money is spent. The student was currently in a sheltered workshop, awaiting placement through an outside agency, and the parent encouraged as much independence as possible for the student. In regard to the student making her own monetary decisions, the mother explained that she was given an allowance and had discretion as to its distribution. Additionally, she is accompanied by someone, or someone else made the appointment, when using health care facilities. The student has a full-time guardian/parent and stated that life is free for herself, having complete control over every day things, however, the reality of the situation was that the mother made all life decisions, providing food, clothing and shelter for the child, and provided the student the vehicle to experience the perceived independence.
In the last category of community integration/social belonging, County 1 students 1SC1, 2SC1, and 3SC1 all state that their life is okay (student 1SC1) to very worthwhile (students 2SC1 and 3SC1). With this in mind the parents of the three students provide transportation to and from all social activities, as well as, to and from work for student 1SC1. However, in regard to clubs or organizations to which they belong, student 1SC1 is unsatisfied or very unsatisfied, student 2SC1 is somewhat satisfied, and student 3SC1 is very satisfied. There are relatively few clubs or organizations that this particular population has functional access to in County 1. Special Olympics, church organizations, and county-sponsored disabled youth groups are examples of organizations in County 1. Normally, small groups of parents, who have children with similar exceptionalities, tended to socialize and mingle regularly. All feel that their relationships with neighbors are very good or good, and they participate in recreational activities, usually most of the time.

County 2 students all state that their life is okay (students 2SC2 and 3SC2), to very worthwhile (student 1SC2). Once again, with this in mind, the parents of the three students provide transportation for all social activities, as well as, providing a mode of transport for student 2SC2 to and from his place of employment. However, in regard to clubs or organizations to which they belong, students 2SC2 and 3SC2 are unsatisfied or very unsatisfied, and student 1SC2 is very satisfied. Similarly, there are relatively few clubs or organizations that this particular population has functional access to in County 2. Special Olympics, church organizations and sporadic county-sponsored disabled youth groups are examples of
organizations in County 2. Accordingly, small groups of parents, who have children with similar
eXceptionalities, tended to mingle regularly. All feel that their relationship with their neighbors
is fair, and they participate in recreational activities from usually, most of the time (student
1SC2) to frequently, about half the time (students 2SC2 and 3SC2). It should be noted that,
unless the recreational activity took place at the residence of the student, the parent(s) of the
students would be responsible for transporting the student from activity to activity.

County 3 students all state their life is okay (students 2SC3 and 3SC3) to very
worthwhile (student 1SC3). Accordingly, the quality of life for the students was heavily
dependent upon the amount of involvement by the parents. The parents of the three students
provided transportation needs for all social activities, as well as, providing the only means
available for students 1SC3 and 2SC3 to get to their place of employment. However, in regard
to clubs or organizations to which they belong, all students are unsatisfied or very unsatisfied. It
should be noted that there are relatively few clubs or organizations that this particular population
has functional access to in County 3. Special Olympics, church organizations and limited
county-sponsored disabled youth groups are examples of organizations in County 3. Small
parent groups of children, with similar exceptionalities, tended to mingle and socialize regularly.
Relationships with neighbors range from fair (students 2SC3 and 3SC3) to very good or good
(student 1SC3), and they participate in recreational activities from seldom to never (student
1SC3) to frequently, about half the time (students 2SC3 and 3SC3). Keeping in mind that,
unless the social/recreational activities were held at the respective student residences, the parents
may or may not be able to transport the student, based upon other commitments.
All nine student participants have completed a Transition Services program and received a special diploma from their respective high schools, and all were placed, after graduation, into a county-sponsored vocational rehabilitation program. Five of the nine students are currently unemployed, with three of the nine working in a family-owned business, or at the parent's place of business. One of the nine students is currently working in a county-sponsored program. All of the nine student participants live with a parent(s) at the family residence, and eight of the nine student participants have a sibling.

The following charts represent all the answers provided by the nine student participants from County 1, County 2, and County 3. The forty questions have been broken down into groups of ten under the categories of Satisfaction, Productivity/Competence, Empowerment/Independence, and Social Belonging/Community Integration. The answers have been presented in the form of four distinct charts that represent the categories previously stated, in relation to student quality of life.

It should be noted that each student was presented with three possible answers to each question. A qualitative interview is an interaction between an interviewer and respondent, but not a specific set of questions that must be asked in particular words and a particular order (Babbie, 1998), however, the limited speech and cognitive ability of the students dictated that three choices be used. This enabled a framework for answers that could be refined when needed and stayed within the context of the Quality of Life Questionnaire.

The students are identified by using the following coding system: #SC## where (#) is interview number; (S) is student; (C) is the county, and (##) is the county number.
A point of clarification must be presented at this time in the category of Independence/Empowerment. A question was presented to the students regarding people living with the students who sometimes hurt you, pester you, scare you, or make you angry. Students 2SC1, 2SC2 and 1SC3 answered “yes” to this question and, when queried further, the basis for their response was sibling rivalry. At no point during the duration of this study was any type of child abuse or neglect ever uncovered.
<table>
<thead>
<tr>
<th>Question</th>
<th>1SC1</th>
<th>2SC1</th>
<th>3SC1</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Overall would you say that life:</td>
<td>Doesn't give you a chance</td>
<td>Treats you like everybody else</td>
<td>Brings out the best in you</td>
</tr>
<tr>
<td>2. How much fun and enjoyment do you get out of life:</td>
<td>Lots</td>
<td>Lots</td>
<td>Lots</td>
</tr>
<tr>
<td>3. Compared to others are you:</td>
<td>About the same</td>
<td>Better</td>
<td>Better</td>
</tr>
<tr>
<td>4. Are most of the things that happen to you:</td>
<td>Acceptable</td>
<td>Rewarding</td>
<td>Rewarding</td>
</tr>
<tr>
<td>5. How satisfied are you with your current home or living arrangements:</td>
<td>Very satisfied</td>
<td>Very satisfied</td>
<td>Very satisfied</td>
</tr>
<tr>
<td>6. Do you have more or fewer problems than other people:</td>
<td>More problems than others</td>
<td>Fewer problems</td>
<td>Fewer problems</td>
</tr>
<tr>
<td>7. How many times per month do you feel lonely:</td>
<td>Seldom, never more than once or twice</td>
<td>Seldom, never more than once or twice</td>
<td>Seldom, never more than once or twice</td>
</tr>
<tr>
<td>8. Do you ever feel out of place in social situations:</td>
<td>Usually or always</td>
<td>Seldom or never</td>
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</tr>
<tr>
<td>9. How successful do you think you are compared to others:</td>
<td>About as successful as the average person</td>
<td>About as successful as the average person</td>
<td>Probably more successful than the average person</td>
</tr>
<tr>
<td>10. Do your family members make you feel:</td>
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</tr>
<tr>
<td>Question</td>
<td>2SC2</td>
<td>3SC2</td>
<td></td>
</tr>
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</tr>
<tr>
<td>7. How many times per month do you feel lonely:</td>
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<td>Occasionally, at least 5 or 6 times a month</td>
<td>Seldom, never more than once or twice</td>
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<td></td>
<td></td>
</tr>
<tr>
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<td></td>
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<td>1SC1</td>
<td>2SC1</td>
<td>3SC1</td>
</tr>
<tr>
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<td>------------</td>
<td>------------</td>
<td>------------</td>
</tr>
<tr>
<td>1 How well did your educational or training program prepare you for what you are doing now?</td>
<td>Very well</td>
<td>Somewhat</td>
<td>Somewhat</td>
</tr>
<tr>
<td>2 How good do you feel you are at your job?</td>
<td>Unemployed</td>
<td>Unemployed</td>
<td>The same as other employees</td>
</tr>
<tr>
<td>3 How do people treat you on the job?</td>
<td>Unemployed</td>
<td>Unemployed</td>
<td>Unemployed</td>
</tr>
<tr>
<td>4 How satisfied are you with the skills and experience you have gained or are gaining from your job?</td>
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<td>Unemployed</td>
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</tr>
<tr>
<td>5 Are you learning skills that will help you get a different or better job?</td>
<td>Unemployed</td>
<td>Unemployed</td>
<td>Unemployed</td>
</tr>
<tr>
<td>6 How closely supervised are you on the job?</td>
<td>Unemployed</td>
<td>Unemployed</td>
<td>Unemployed</td>
</tr>
<tr>
<td>7 Do you feel your job or other daily activity is worthwhile and relevant to either yourself or others?</td>
<td>Yes definitely</td>
<td>Yes definitely</td>
<td>Yes definitely</td>
</tr>
<tr>
<td>8 Do you feel you receive fair pay for your work?</td>
<td>Unemployed</td>
<td>Unemployed</td>
<td>Unemployed</td>
</tr>
<tr>
<td>9 Does your job provide you with enough money to buy things you want?</td>
<td>Unemployed</td>
<td>Unemployed</td>
<td>Unemployed</td>
</tr>
<tr>
<td>10 How satisfied are you with the benefits at work?</td>
<td>Unemployed</td>
<td>Not satisfied</td>
<td>Not satisfied</td>
</tr>
<tr>
<td><strong>Question</strong></td>
<td>1SC2</td>
<td>2SC2</td>
<td>3SC2</td>
</tr>
<tr>
<td>1 How well did your educational or training program prepare you for what you are doing now?</td>
<td>Very well</td>
<td>Somewhat</td>
<td>Somewhat</td>
</tr>
<tr>
<td>2 How good do you feel you are at your job?</td>
<td>Unemployed</td>
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<td>Unemployed</td>
</tr>
<tr>
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</tr>
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</tr>
<tr>
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<td>Unemployed</td>
</tr>
<tr>
<td>6 How closely supervised are you on the job?</td>
<td>Unemployed</td>
<td>Supervisor present only when needed</td>
<td>Unemployed</td>
</tr>
<tr>
<td>7 Do you feel your job or other daily activity is worthwhile and relevant to either yourself or others?</td>
<td>Yes definitely</td>
<td>Probably</td>
<td>Yes definitely</td>
</tr>
<tr>
<td>8 Do you feel you receive fair pay for your work?</td>
<td>Unemployed</td>
<td>Sometimes</td>
<td>Unemployed</td>
</tr>
<tr>
<td>9 Does your job provide you with enough money to buy things you want?</td>
<td>Unemployed</td>
<td>No, I definitely do not earn enough to buy what I need</td>
<td>Unemployed</td>
</tr>
<tr>
<td>10 How satisfied are you with the benefits at work?</td>
<td>Somewhat satisfied</td>
<td>Not satisfied</td>
<td>Unemployed</td>
</tr>
<tr>
<td><strong>Question</strong></td>
<td>1SC3</td>
<td>2SC3</td>
<td>3SC3</td>
</tr>
<tr>
<td>1 How well did your educational or training program prepare you for what you are doing now?</td>
<td>Very well</td>
<td>Very well</td>
<td>Very well</td>
</tr>
<tr>
<td>2 How good do you feel you are at your job?</td>
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<td>Unemployed</td>
</tr>
<tr>
<td>3 How do people treat you on the job?</td>
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<td>Very satisfied</td>
<td>Somewhat satisfied</td>
<td>Unemployed</td>
</tr>
<tr>
<td>5 Are you learning skills that will help you get a different or better job?</td>
<td>Am not sure, maybe</td>
<td>Yes definitely</td>
<td>Unemployed</td>
</tr>
<tr>
<td>6 How closely supervised are you on the job?</td>
<td>Supervisor present only when needed</td>
<td>Supervisor present only when needed</td>
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</tr>
<tr>
<td>7 Do you feel your job or other daily activity is worthwhile and relevant to either yourself or others?</td>
<td>Yes, definitely</td>
<td>Probably</td>
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<td>Sometimes</td>
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</tr>
<tr>
<td>9 Does your job provide you with enough money to buy things you want?</td>
<td>Yes, I can generally buy those reasonable things I want</td>
<td>No, I definitely do not earn enough to buy what I need</td>
<td>Unemployed</td>
</tr>
<tr>
<td>10 How satisfied are you with the benefits at work?</td>
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<td>Not satisfied</td>
<td>Unemployed</td>
</tr>
<tr>
<td>Question</td>
<td>18C1</td>
<td>28C1</td>
<td>38C1</td>
</tr>
<tr>
<td>--------------------------------------------------------------------------</td>
<td>------</td>
<td>------</td>
<td>------</td>
</tr>
<tr>
<td>1. How did you decide to do the job or other daily activities you do now?</td>
<td>Someone else decided for me</td>
<td>Someone else decided for me</td>
<td>Only thing available or that I could find</td>
</tr>
<tr>
<td>2. Who decides how you spend your money?</td>
<td>I do, with assistance from others</td>
<td>I do, with assistance from others</td>
<td>I do, with assistance from others</td>
</tr>
<tr>
<td>3. How do you use health care facilities (doctors, dentists, etc.)?</td>
<td>Usually accompanied by someone, or someone else has made the appointment</td>
<td>Usually accompanied by someone, or someone else has made the appointment</td>
<td>Usually accompanied by someone, or someone else has made the appointment</td>
</tr>
<tr>
<td>4. When can friends visit home?</td>
<td>As often as I like or fairly often</td>
<td>As often as I like or fairly often</td>
<td>Any day with approval</td>
</tr>
<tr>
<td>5. Do you have a key to your home?</td>
<td>No</td>
<td>Yes, definitely</td>
<td>No</td>
</tr>
<tr>
<td>6. May you have a pet if you want?</td>
<td>Yes, definitely</td>
<td>Yes, definitely</td>
<td>No</td>
</tr>
<tr>
<td>7. Do you have a guardian or conservator?</td>
<td>Yes, I have a full guardian</td>
<td>Yes, I have a full guardian</td>
<td>Yes, I have a full guardian</td>
</tr>
<tr>
<td>8. Overall would you say that life is:</td>
<td>Somewhat planned for you</td>
<td>Some</td>
<td>Some</td>
</tr>
<tr>
<td>9. How much control do you have over things you do every day, like going to bed, eating and what you do for fun?</td>
<td>Little</td>
<td>Yes, and those problems occur every day or more than once a day</td>
<td>No</td>
</tr>
<tr>
<td>10. Are there people living with you who sometimes hurt you, scare you, or make you angry?</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Question</td>
<td>18C2</td>
<td>28C2</td>
<td>38C2</td>
</tr>
<tr>
<td>1. How did you decide to do the job or other daily activities you do now?</td>
<td>Someone else decided for me</td>
<td>Only thing available or that I could find</td>
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<td>Any day with approval</td>
<td>Only certain days</td>
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<td>5. Do you have a key to your home?</td>
<td>Yes, I have a key and use it as I wish</td>
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</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>-----------------------</td>
<td>-----------------------</td>
<td>-----------------------</td>
</tr>
<tr>
<td>1. How many civic or community clubs or organizations (including church or other religious activities) do you belong to?</td>
<td>None</td>
<td>One only</td>
<td>2 to 3</td>
</tr>
<tr>
<td>2. How many times per week do you talk (or associate with) your neighbors, either in the yard or in their home?</td>
<td>1 to 2 times per week</td>
<td>3 to 4 times per week</td>
<td>3 to 4 times per week</td>
</tr>
<tr>
<td>3. How often do you attend recreational activities (homes, parties, dances, concerts, plays) in your community?</td>
<td>3 to 4 per month</td>
<td>3 to 4 per month</td>
<td>3 to 4 per month</td>
</tr>
<tr>
<td>4. How do your neighbors treat you?</td>
<td>Very good or good</td>
<td>Very good or good</td>
<td>Very good or good</td>
</tr>
<tr>
<td>5. How satisfied are you with the clubs or organizations (including church or religious activities) to which you belong?</td>
<td>Unsatisfied or very unsatisfied</td>
<td>Somewhat satisfied</td>
<td>Very satisfied</td>
</tr>
<tr>
<td>6. Do you worry about what people expect of you?</td>
<td>Sometimes, but not all the time</td>
<td>Sometimes, but not all the time</td>
<td>Never or all the time</td>
</tr>
<tr>
<td>7. Do you have friends over to visit your home?</td>
<td>Fairly often</td>
<td>Fairly often</td>
<td>Fairly often</td>
</tr>
<tr>
<td>8. Do you participate actively in those recreational activities?</td>
<td>Usually, most of the time</td>
<td>Usually, most of the time</td>
<td>Usually, most of the time</td>
</tr>
<tr>
<td>9. What about opportunities for dating and marriage?</td>
<td>I have no opportunity to date or marry</td>
<td>I have limited opportunity to date or marry</td>
<td>I have no opportunity to date or marry</td>
</tr>
<tr>
<td>10. Overall, would you say that your life is:</td>
<td>Okay</td>
<td>Very worthwhile</td>
<td>Very worthwhile</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Question</th>
<th>1SC2</th>
<th>2SC2</th>
<th>3SC2</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. How many civic or community clubs or organizations (including church or other religious activities) do you belong to?</td>
<td>2 to 3</td>
<td>2 to 3</td>
<td>None</td>
</tr>
<tr>
<td>2. How many times per week do you talk (or associate with) your neighbors, either in the yard or in their home?</td>
<td>1 to 2 times per week</td>
<td>Never or all the time</td>
<td>Never or all the time</td>
</tr>
<tr>
<td>3. How often do you attend recreational activities (homes, parties, dances, concerts, plays) in your community?</td>
<td>1 to 2 per month</td>
<td>3 to 4 per month</td>
<td>Less than 1 per month</td>
</tr>
<tr>
<td>4. How do your neighbors treat you?</td>
<td>Fair (hello, visit, etc.)</td>
<td>Fair (hello, visit, etc.)</td>
<td>Fair (hello, visit, etc.)</td>
</tr>
<tr>
<td>5. How satisfied are you with the clubs or organizations (including church or religious activities) to which you belong?</td>
<td>Very satisfied</td>
<td>Unsatisfied or very unsatisfied</td>
<td>Unsatisfied or very unsatisfied</td>
</tr>
<tr>
<td>6. Do you worry about what people expect of you?</td>
<td>Sometimes, but not all the time</td>
<td>Sometimes, but not all the time</td>
<td>Seldom</td>
</tr>
<tr>
<td>7. Do you have friends over to visit your home?</td>
<td>Fairly often</td>
<td>Fairly often</td>
<td>Sometimes</td>
</tr>
<tr>
<td>8. Do you participate actively in those recreational activities?</td>
<td>Usually, most of the time</td>
<td>Frequently, about half the time</td>
<td>Frequently, about half the time</td>
</tr>
<tr>
<td>9. What about opportunities for dating and marriage?</td>
<td>I have no opportunity to date or marry</td>
<td>I have limited opportunity to date or marry</td>
<td>I have no opportunity to date or marry</td>
</tr>
<tr>
<td>10. Overall, would you say that your life is:</td>
<td>Very worthwhile</td>
<td>Very worthwhile</td>
<td>Very worthwhile</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Question</th>
<th>1SC3</th>
<th>2SC3</th>
<th>3SC3</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. How many civic or community clubs or organizations (including church or other religious activities) do you belong to?</td>
<td>None</td>
<td>None</td>
<td>None</td>
</tr>
<tr>
<td>2. How many times per week do you talk (or associate with) your neighbors, either in the yard or in their home?</td>
<td>1 to 2 times per week</td>
<td>1 to 2 times per week</td>
<td>Never or all the time</td>
</tr>
<tr>
<td>3. How often do you attend recreational activities (homes, parties, dances, concerts, plays) in your community?</td>
<td>1 to 2 per month</td>
<td>Less than 1 per month</td>
<td>1 to 2 per month</td>
</tr>
<tr>
<td>4. How do your neighbors treat you?</td>
<td>Very good or good</td>
<td>Fair (hello, visit, etc.)</td>
<td>Fair (hello, visit, etc.)</td>
</tr>
<tr>
<td>5. How satisfied are you with the clubs or organizations (including church or religious activities) to which you belong?</td>
<td>Unsatisfied or very unsatisfied</td>
<td>Unsatisfied or very unsatisfied</td>
<td>Unsatisfied or very unsatisfied</td>
</tr>
<tr>
<td>6. Do you worry about what people expect of you?</td>
<td>Seldom</td>
<td>Seldom</td>
<td>Seldom</td>
</tr>
<tr>
<td>7. Do you have friends over to visit your home?</td>
<td>Rarely or never</td>
<td>Sometimes</td>
<td>Sometimes</td>
</tr>
<tr>
<td>8. Do you participate actively in those recreational activities?</td>
<td>Seldom or never</td>
<td>Frequently, about half the time</td>
<td>Frequently, about half the time</td>
</tr>
<tr>
<td>9. What about opportunities for dating and marriage?</td>
<td>I have limited opportunity to date or marry</td>
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<td>I have no opportunity to date or marry</td>
</tr>
<tr>
<td>10. Overall, would you say that your life is:</td>
<td>Very worthwhile</td>
<td>Okay</td>
<td>Okay</td>
</tr>
</tbody>
</table>
CONCLUSION

This chapter has outlined the major findings distilled from interviews, observations and document analysis. There were fifteen major findings of this study. The findings were organized into three broad categories that reflect the external and internal disparities of the interpretive assertions of professional and non-professional participants, as it relates to what is found in the literature. At the district level, the application, implementation and basic understanding of the specific guidelines for Transition Services set forth by IDEA, appears to be a function of age, prior education expertise, time at the current position and the amount of multi-tasking required of the district employees. From the parental aspect, age, education level, socio-economic level, or ethnicity had little effect on their knowledge of the rights, responsibilities, and guidelines for Transition Services, as set forth by IDEA. This chapter concluded with the examination of the view points of the post-secondary school students, as to their specific quality of life after graduation. The next chapter will present several conclusions that can be drawn from the results of this study.
CHAPTER 5: CONCLUSIONS AND RECOMMENDATIONS

The purpose of this study was to investigate the effects of Transition Services on the quality of life for post-high school (0 - 2 years) students with Down’s Syndrome who are Educable Mentally Retarded. The investigation took the form of a qualitative, phenomenological study in a multi-case setting. Analysis of data was collected from formal interviews, observations, and documents, and attempted to capture the lived experiences of the participants, as to their perceived understanding of Transition Services and its effect on quality of life. Three Florida school districts were used as the basis of the study. Participants offered views of Transition Services and quality of life from several different viewpoints: district personnel, parents of students and students themselves. The analysis revealed fifteen major findings that could be separated, according to the level of the participant: district personnel, parents of students and students themselves. The Process Flow Chart (p.102) visually depicts the findings of the study.

The findings included:

District personnel distill Transition Services down to positive adult outcomes for success.

Selection criteria for district level Transition Services personnel varied between districts.

Past perceptions of Transition Services by district personnel shaped the current program(s).

Current vision of Transition Services by district level personnel varies by district.

Accomplishments of Transition Services at the district level shared concurrency.
Needed areas of improvement in Transition Services at the district level varied by district(s).

The effect of Transition Services in all three districts was perceived as positive.

The reason(s) for the positive effect of Transition Services varied by district(s).

The perceived qualifications of a district level Transition Services person varied by district.

Parents had little or no understanding of what Transition Services constitutes.

The majority of the parent participants felt Transition Services was a failure.

All parent participants wanted categorizing/labeling of students at this level.

Unemployment of student participants was a major issue.

All student participants lived with their families.

The majority of student participants perceived their overall quality of life as good, regardless of employment status.

The commonalities of the findings across the groups are that the district level personnel felt that Transition Services were working but need some overall improvement; parent participants knew little about Transition Services, from an application standpoint, and felt that, by in large, Transition Services was a failure. Further, the parent participants were in favor of categorizing/labeling of students at this level; the large majority of student participants felt that their overall quality of life was good. Conclusions and recommendations are based on these convergent findings and are examined in light of their implications for students with disabilities and their ability to provide answers about their quality of life after high school graduation.
Cross Group Findings

Does the Process Need Improvement

Yes

Did the Process Work

Yes

Predefined process

None responded negatively

Predefined

Legend

DC#: (D) District Employee (C) County (##) County Number

#PC#: (#) Interview Number (P) Parent (C) County (##) County Number

#SC#: (#) Interview Number (S) Student (C) County (##) County Number

Interviews

Transition Services

Quality of Life

Emerging Data

Results of Interviews

All Parents

Positive Adult Outcomes

End

Joseph A. Fiske, Jr.
Conclusions

Five major conclusions can be drawn from the findings of this study: (a) district level participants' comments spanned a variety of topics that are crucial to the success of a Transition Services program. All district level personnel felt that Transition Services worked from their perspective; however, there is an apparent gap between perception and reality. The district personnel related positive adult outcomes, by and large, to employment as the critical measure of success. District employee, County 1, refers to the effects that Transition Services should be having in the areas of:

“Employment, community, community participation, instruction, and independent living.”

However, he realizes that:

“It’s very important to market Transition Services, as they relate to the district. People have to know what these folks are doing in transition.”

It is apparent that he realizes that there are shortcomings in the system, and there is a need for appropriate staffing levels. He felt that, once the need to justify why a program that has no positive impact on FCAT scores, or increased academic skill levels is gone, then the value and purpose will come to the forefront. The district employee from County 2 felt that:

“Once the kids exit the school system, and we are hooked up with the right agency, we have done our job as a school system.”

However, the areas represented in IDEA for Transition Services transgress simply exiting the school system. Community integration, employment, post-school adult living, independent
living skills, all must be addressed via curriculum, while in school, to help provide for positive adult outcomes. Further, he realizes that, without a system to track post-high school students, it becomes impossible to monitor these outcomes. The district employee, County 2, admits that:

“We’ve got to figure out some way of tracking to find out which kids we have exited are sitting home doing nothing.”

While still keeping with the concept that positive adult outcomes largely relate to post-high school employment, district employee, county 3, feels that:

“Employers need to be just as much a part of the process as teachers. Employers come saying that they want these kids, they will train them; however, they need the skills to fit into the business community.”

Collectively, these comments must be tempered with the fact that, of the nine students interviewed, one has been placed in outside employment through a county-sponsored agency, three of the students work at a family-owned business or at a parent’s place of business gratuitously, and five are unemployed; (b) There is a total lack of understanding by the parent participants in regard to the basic guidelines for Transition Services and rights set forth by IDEA. In response to this question, six of the nine parents had no concept as to what Transition Services are or what rights they had under IDEA. Parents from Counties 1, 2 and 3 made the following comments:

1PC1 “If there are parents like us that are not aware of things, I feel there should be a person to give us a call, to say, ‘How are things going?’”
"Well, they came and they interviewed (the student) and myself, and gave us some options. That was it, to try to get him a job."

"This wasn’t really explained."

"To, you know, get a job, do something he can do and likes."

(c) Categorizing/labeling of post-secondary school students would help promote positive adult outcomes. All of the parents interviewed expressed a need and desire to have their children categorized/labeled at this juncture. The following comments tend to reflect the parents perspective as to this need.

"They are all different levels, you know, and for him, they should group them by ability, categorizing by ability."

This refers to the sheltered workshop environment, where students with varying exceptionalities and ability levels are placed in one group. The parents expressed concern that their student regressed to the lower levels, and not excelled to challenge their abilities.

"That would be great (categorizing). Get them to a higher level and push them up, not down, by grouping them all together (all exceptionalities)."

(d) The quality of life of the student participants can be directly related to the fact that they reside with their families, and not directly attributed to Transition Services. The simple fact of the matter is that all of the students residing at home have no visible means of support. The one student that has outside, independent employment, is still dependent upon his family for transportation, food, clothing, and medical needs, as well as the family providing social
activities and recreational activities. Essentially, the quality of life of the student(s) equated directly to the family, and not Transition Services. The same factors hold true for the other eight students in the study; (e) there is no post-graduation tracking system in place that would help diminish the high unemployment rate of these students. To reiterate the sentiment of the district employees, district employee, County 2, states:

“We’ve got to figure out some way of tracking to find out which kids we have exited that are sitting home doing nothing.”

Further, from the parents’ perspective, tracking is an issue also:

1PC2 “The kids seem to fall into a hole and get frustrated and quit, or don’t get placed, or have problems.”

1PC2 “Loneliness and depression are problems post-graduation. The kids come to my door, they’re bored, they have no place to go, and it’s really sad; they fall through the cracks.”

The majority of these conclusions support earlier studies on the various aspects of Transition Services and its effectiveness on quality of life of special needs students. The U.S. Department of Commerce’s study of 1994 and the U.S. General Accounting Office’s study of 1998 provided national statistics for adults with disabilities, and showed poor adult outcomes associated with this group of individuals. Specifically, rates of unemployment for people with disabilities range from 60 to 75 percent. Other studies echo the reports, unfortunately, that parents were still participating minimally, and performing roles secondary to professional
educators in the special education process. In this decision-making process for the education of their children, for many parents, their input is not significant nor are they part of a consensus process (Dinnebeil & Rule, 1994; Gartner & Lipsky, 1987; Gilliam & Coleman, 1981; Pruitt & Wandry, 1998; Vaughn, Bos, Harrell & Lasky, 1988). Further, Hasazi’s study of 1992 provided an analysis of post-secondary outcome studies which corroborated the findings that few students with disabilities are living independently, working full or part-time, or enrolled in post-secondary education.

Further, the study presented by Turnbull (1986) supports that the parents not only have roles and responsibilities during the transition process, but have economic responsibility, recreational responsibility, responsibility for self-identity, affectionate responsibility and socialization responsibility.

The first major conclusion regarding the perception of district level employees that Transition Services works may not be the reality of the situation. The approach by all three school districts to implementing Transition Services varied rather significantly. The district employee from County 1 related heavily to his past experiences in vocational rehabilitation and his past position as mentally handicapped coordinator for the district. This presents his reliance on services to promote positive adult outcomes, that is, his past dealings with program services in vocational rehabilitation flowed through in the current position as Transition Services coordinator. County 2, district employee, had a very strong past in curriculum at the high school level, and this permeated throughout his approach to positive outcomes. Curriculum will lead the student while in high school:
"There's a whole scope and sequence in getting kids ready. I can't divorce myself away from high school curriculum; they have a good foundation, which is the curriculum."

Whereas County 3, district employee, has a background in Transition Services from the high school level, and takes an inclusionary philosophy towards meeting these positive adult outcomes:

"Because of the emphasis on inclusionary practices, because of IDEA and the role that our county has taken, it is very easy for me to now train on inclusionary practices; the ultimate goal for transition is inclusion in the work force and community. If you want me to speak about inclusion, you also have to tie it into transition, because it's a package deal."

However, the necessary end result was to have positive adult outcomes. Under the law, (20 U.S.C. 140[a][19]), Transition Services relate positive adult outcome to a coordinated set of activities for a student. Post-secondary employment is but one of these activities; however, the three school districts tended to weigh this activity heavily as the criteria for positive adult outcomes. Supported employment, continuing and adult education, adult services, independent living, community participation and other post-school adult living objectives were not specifically addressed. The varied educational backgrounds, time at the current position, age, and the amount of multi-tasking, influenced how the district level personnel interpreted their responsibilities and duties for providing Transition Services, as set forth by IDEA.
This study concludes, secondly, that there is a total lack of understanding by the parent participants, in regard to the basic guidelines for Transition Services and rights set forth by IDEA. In all three school districts, regardless of age, education level, socio-economic level, or ethnicity, there was a critical lacking of parental enlightenment. Although legal mandates, through IDEA, provide opportunities for parents to participate in educational decision making, these opportunities have not been utilized. It appears that most professionals, in the three school districts at the high school level, felt that parent participation in IEP development should consist primarily of gathering and presenting relevant information, rather than contributing to the planning process. IDEA mandates the inclusion of parents in the transition process through their invited participation in their child’s IEP meeting. Additionally, because Transition Services must have an outcome orientation and be based on the student’s needs and preferences, parent participation in the development of the transition plan for their child is strongly implied. However, parent participation was relatively non-existent. Parents expressed that:

3PC1  “We always had problems; you were supposed to have certain people there (at the IEP) to represent the different aspects. As much as they could keep the parents in the dark, the less they had to do.”

1PC3  “Things weren’t really explained. You should get the head of the school out and see what is out there, but you have a ‘don’t care’ school.”

Third, this study concludes that the categorizing/labeling of post-secondary school students would help promote positive adult outcomes. After graduation from the respective high schools in the three school districts, the parent participants advised that their children
were referred to vocational rehabilitation. At this point in time, whether the parents had been advocates of inclusive or self-contained education, they all concurred that categorizing/labeling of their children would have greatly enhanced a positive adult outcome. Many of the students lacked basic job skills, and these students relied upon services provided by a supported employment provider. However, the parents expressed great concern that, due to the wide range of exceptionalities and ability levels, there was a tendency for the higher functioning students to digress. They explained that, at times, the targeted employment goal was very broad-based to ensure as many positive outcomes as possible. The higher functioning students became very frustrated and bored, and eventually dropped out of the program. Parents expressed that:

2PC2 "Yeah, there’s a classification problem throughout the entire system, and it’s probably more predominate at maturing."

2PC2 "ESE is, unfortunately, a conglomerate of disabilities and behavior/emotional problems; it didn’t help him being in that type of environment."

1PC2 "As they get up (in age), they need to be able to (label/categorize). It’s very frustrating for them if they don’t.”

2PC1 "They are not meeting the individual needs; they’re plugging them into one big pot."

Theoretically, the parents advised that services are provided based on an individual plan; the cumulative success and rehabilitation of the students is based on their movement through the vocational rehabilitation system and gaining employment. This is where the system falters, and the broad-based goal comes into play; the higher functioning child stagnates and disassociates.
Fourth, echoing Hasazi’s study of 1992, it was found that few students with disabilities are living independently; hence, the quality of life of the student participants can be directly related to the fact that they reside with their families. The families were responsible to generate income and to provide financial support for living costs and related payments. They had to meet the daily needs of food, clothing, health care and safety. They provided for the recreational needs of the students, as well as creating a sense of family belonging. They provided socialization to enhance the student’s interpersonal relationships and, for the large majority of the students, provided career selection and preparation. Regardless of age, education level, socio-economic background or ethnicity, all the families provided this type of support, at whatever level was possible, for their children. A minuscule amount of the actual quality of life of the student can be directly credited to the Transition Services program.

The fifth major conclusion is that there is no post-graduation tracking system that functions in place that would help diminish the high unemployment rate of these students. The district level employees in all three county school districts expressed similar concerns that, once the student enters into a vocational rehabilitation program, or other related adult service agency program, the district loses track of their progress. Follow-ups are not conducted and, unless there has been a personal connection established between the district level personnel and the student, there is no way to monitor any progress that is made towards positive adult outcomes.
Recommendations

Three major recommendations come out of the findings and conclusions drawn from this study: (a) further research is needed to verify the need to standardize Transition Services programs to meet the needs of specific populations; (b) a unified effort is necessary by parents of special needs children to become enlightened as to what their specific rights are under the Transition Services programs, (c) that an independent quality of life be developed for students with disabilities, aside and apart from their family surroundings and residence. It is incumbent upon the three school districts to create an environment where, through collaboration and cooperation of all parties involved in the transition process, provide the student(s) with the essentials needed to attain an independent quality of life. This section will present these recommendations.

The first recommendation is that further research into Transition Services at the district level be conducted. With the lack of standardized implementation of IDEA across the three school districts, it becomes difficult to make any specific judgments as to effectiveness of the programs. Further, with the varied backgrounds and demographics of the district level personnel involved in the decision making process, the appointment of additional qualified personnel becomes nebulous as to knowledge, skills and necessary abilities. More evidence needs to be collected on what specific backgrounds, i.e., standardized hiring criteria specific to, and only to, Transition Services, will place the most qualified, knowledgeable, and capable individuals in place.
Studies need to be undertaken that will collect more in-depth data about the attitudes, roles, and nature of the participation of the individual groups involved at the district level that are implementing the mandated guidelines for Transition Services, by IDEA. District level personnel need to be studied in greater numbers to obtain a fuller picture of their perceptions of their role as Transition Services program coordinators. A standardized system of implementing the mandated guidelines for Transition Services, across the board, district by district, may emerge and evolve. Questions that might be addressed are: What education work experience and educational degree best suits a Transition Specialist? How do you standardize the selection process for these district positions to ensure parity in ability from district to district? Do personnel at the district level have the ability to interpret the implementation of the mandates of IDEA correctly, or does their particular post-educational specialities color their judgment? A study such as this might lend insight into why there is such a broad-based spectrum of implementation techniques from district to district.

A longitudinal study might also be undertaken to follow a district level employee in Transition Services through the school year to observe the actual techniques utilized to implement the program, that is, to see if the district promotes the encouragement of students to look beyond high school and provide the needed academic support to meet the individual students’s needs, thereby ensuring that the student has self-advocacy skills and is provided the opportunity to practice these skills. All of this must be coordinated and consistent with federal and state laws and regulations. Knowing this would greatly help the standardizing process at the district level and provide the ability to maximize the amounts of positive adult outcomes.
The second recommendation is that a unified effort is necessary by parents of special needs children to become enlightened as to what their specific rights are under the Transition Services programs. Although legal mandates provide opportunities for parents to participate in educational decision making, these opportunities, by and large, have not been utilized.

Over the past twenty years, there have been many examples of how parents function as passive participants in educational decision making (Turnbull & Morningstar, 1993). Later reviews and analyses noted that professionals still do not employ suggested parent involvement practices to engage parents actively in their child’s educational program (Hilton & Henderson, 1993).

The implications of the 1978 study by Yoshida noted the need to train parents systematically to fulfill their roles and responsibilities, in conjunction with IEP development, and to train professionals to involve parents as full partners in the process. It is apparent that a key influence in successful transition is the network provided at home and by families. Parents have an important role in developing career goals and outcomes, as well as, concerns for their children. The potential for long-term effects on their child’s development will be wasted if parents are not actively involved. Parents should be provided opportunities to acquire knowledge and skills that are necessary for effective participation in transition planning through systematically planned parent education programs, which will improve the effectiveness and durability of parent involvement in the transition process (Wehman, 1985). Parental efforts can be greatly aided by professional advocates committed to service, as Hamre-Nietupski pointed out in a 1988 study.
The final recommendation of this study is that an independent quality of life be developed for students with disabilities, aside and apart from their family surroundings and residences. It is incumbent upon the three school districts to create an environment where, through collaboration and cooperation of all parties involved in the transition process, will provide the student(s) with the basic essentials needed for an independent quality of life. As Flexer (2001) points out, general issues such as community supports, better access to vocational services, curriculum enhancement and life skills instruction, and cross-training for students, parents, and professionals must be addressed. Further, the development of work experiences, strategies to empower youth with disabilities and their families, and strategies to empower minority youth with disabilities and their families, needs to be the focal point for a quality of life for students with disabilities.
REFERENCES


Coelho, T. (1998). Remarks at the Meeting of the Presidential Task Force on Employment of


County 1 School District (2001). Area 1, ESE Specialist, Anonymous, personal interview, 8/2/01. Florida.


Appendix A

Consent Form for School Administrators

1. **Title of Research**: A Qualitative Study of the Effects of Transition Services on the Quality of Life for Post High School (0 - 2 years) Students with Down’s Syndrome who are Educable Mentally Retarded (EMR).

2. **Investigator**: Responsible Project Coordinator: Joseph A. Finley, Jr., Lynn University.

3. **Purpose**: The purpose of this study is to investigate the effects of Transition Services on the Quality of Life (QOL) of post high school (0 - 2 years) Down’s Syndrome students. Other questions to be examined, specifically, are the QOL for students in the state of Florida, County 1, 2, 3, who are Down’s Syndrome (EMR), post high school (0 - 2 years) and received Transition Services. Also, the QOL for students in a cross-county comparison (County 1, 2, 3) who are Down’s Syndrome (EMR), post high school (0 - 2 years) and received Transition Services. The study hopes to gain a better understanding of what effect Transition Services has on the QOL of these students.

4. **Procedures**: As an interviewee, you will be asked to participate in one in-depth, formal interview, lasting approximately one to two hours at a mutually agreed upon time and place. This interview, after asking for some demographic information about yourself, will ask you about Transition Services, your role in Transition Services and some other general Transition Services questions. During the interview, I may engage you in casual conversation to follow-up on either a comment or observation.
5. **Risks:** There will be a minimal risk to you in this study. Minimal risk means risk that is no more than that encountered in daily life.

6. **Benefits:** One benefit of this study will be to help improve the understanding of what impact Transition Services may or may not have on QOL issues. A second benefit would be to gain further insight at the county level, as to commonalities between Transition Services in regard to effectiveness. You may withdraw from the study at any time. You may also withdraw your consent to have specific excerpts used after viewing the transcripts of the tapes without prejudice. Your withdrawal will not be noted to anyone besides the researchers.

7. **Data Collection and Storage:** Your interview will be audio-taped and transcribed by the researcher. Your participation and the participation of the school district will be confidential, and any participants' identification will be restricted for sue only by the authorized investigator. The only individuals with access to data collected will be the researchers, and the data will not be released in any way that will allow your identification without your agreement. You will have the opportunity to review the transcript of your interview and add or delete any material you wish. Audio-tapes and transcriptions will remain my property throughout the course of the research and publication and will be destroyed after five years.

8. **Contact Information:** For related problems or questions regarding your participation, contact Joseph A. Finley, Jr., at [ ]
9. **Consent Information:** In signing this consent form, I agree to participate in the research study outlined above. I am 18 years of age or older, and I understand that my participation is voluntary. I also understand that a copy of this consent form will be provided to me.

Signature of Subject: ___________________________  Date: ______________

Signature of Investigator: ________________________  Date: ______________
Appendix A-1

Consent Form for Students

1. Title: A study on how school helped you be happy with your life after you graduated.

2. Investigator: Mr. Joseph A. Finley, Jr., Investigator, Lynn University.

3. Purpose: To see if school helped you be happy with your life after you graduated. I will be talking with other students from your neighborhood to see if they are happy also. I want to learn if your school helped make you happy after you graduated.

4. Procedures: I am going to ask you some questions about how happy you are from a test I found. If you don’t understand my test questions, you can get help from your parent or friend. I may ask you questions not on my test.

5. Risks: You don’t have to worry or be afraid. This meeting we will have will not hurt you.

6. Benefit: This study will help people see if your school helped make your life happier. You can stop telling me your answers at any time, and you can tell me not to use the answers I have recorded.

7. Data Collection and Storage: I am going to tape record and write down your answers. No one will know your name or who you are except for me. You can go over your answers with me and take out anything you don’t like. After five years, I will destroy the answers.

8. Contact Information: You can call me (Joseph A. Finley, Jr.) at [blank] if you have any problems.

9. Consent Information: When you sign this, you are saying you want to help me. You are also saying that you are 18 or older. You will get this form to keep.

Signature of Student: ___________________ Date: __________

Signature of Investigator: ___________________ Date: __________
Appendix A-2

Consent Form for Parents or Care-Givers

1. **Title of Research**: A Qualitative Study of the Effects of Transition Services on the Quality of Life for Post High School (0 - 2 years) Students with Down’s Syndrome who are Educable Mentally Retarded (EMR).

2. **Investigators**: Responsible Project Coordinator; Joseph A. Finley, Jr., Lynn University.

3. **Purpose**: The purpose of this study is to investigate the effects of Transition Services on the Quality of Life (QOL) of post high school (0 - 2 years) Down’s Syndrome students. Other questions to be examined, specifically, are the QOL for students in the state of Florida, County 1, 2, 3, who are Down’s Syndrome (EMR), post high school (0 - 2 years) and received Transition Services. Also, the QOL for students in a cross-county comparison (County 1, 2, 3) who are Down’s Syndrome (EMR), post high school (0 - 2 years) and received Transition Services. The study hopes to gain a better understanding of what effect Transition Services has on the QOL of these students.

4. **Procedures**: As an interviewee, you will be asked to participate in one in-depth, formal interview, lasting approximately one to two hours. The interview will be based upon answers to a quality of life (QOL) questionnaire provided by the student participant. The interview will be at a mutually agreed upon time and place. This questionnaire may be answered independently or with assistance of a parent or care-giver. During the interview, I may engage you in casual conversation to follow-up on either a comment or observation based upon your reaction to answers of the questionnaire.
5. **Risks:** There will be a minimal risk to you in this study. Minimal risk means risk that is no more than that encountered in daily life.

6. **Benefits:** One benefit of this study will be to help improve the understanding of what impact Transition Services may or may not have on QOL issues. A second benefit would be to gain further insight at the county level, as to commonalities between Transition Services in regard to effectiveness.

You may withdraw from the study at any time. You may also withdraw your consent to have specific excerpts used after viewing the transcripts of the tapes without prejudice. Your withdrawal will not be noted to anyone besides the researchers.

7. **Data Collection and Storage:** Your interview will be audio-taped and transcribed by the researcher. Your participation and the participation of the school district will be confidential, and any participants’ identification will be restricted for use only by the authorized investigator. The only individuals with access to data collected will be the researchers, and the data will not be released in any way that will allow your identification without your agreement. You will have the opportunity to review the transcript of your interview and add or delete any material you wish. Audio-tapes and transcriptions will remain my property throughout the course of the research and publication and will be destroyed after five years.

8. **Contact Information:** For related problems or questions regarding your participation, contact Joseph A. Finley, Jr., at [redacted]
9. Consent Information: In signing this consent form, I agree to participate in the research study outlined above. I am 18 years of age or older, and I understand that my participation is voluntary. I also understand that a copy of this consent form will be provided to me.

Signature of Subject: ___________________________ Date: ________________

Signature of Investigator: ___________________________ Date: ________________
Appendix B
Interview Guide
Demographic Information

Thank you for allowing me to interview you today. As I mentioned earlier, please understand that anything you say in the interview today is strictly confidential and your name will not be used in any way. Thank you for all the time you have chosen to share with me.

General Information:
Gender: Male _____ Female _____
Age: Less than 30 _____ 31 - 45 _____ 45+ _____
Education: (Indicate highest level achieved)
High School _____ Community College _____
Undergraduate degree _____ Graduate degree _____ Other _____
Major field of study ___________________________________________

Transition Services Information:
Role in Transition Services: Director _____ Coordinator _____
Other _____
How long have you been involved with Transition Services? ______________
What function do you perform in Transition Services? ______________
Do you have children in Transition Services Programs? ______________

Other: (Please answer only those which apply to you)

If you are a District Administrator:
How long have you been at the District level? ______________
How long did you teach? ______________
How long have you been in the school system? ______________

If you are an Area Administrator:
How long have you been at the Area level? ______________
How long did you teach? ______________
How long have you been in the school system? ______________

If you are a parent:
Level of past involvement at your child’s school:
PTA/PTO Member _____ Room mother/father _____
Volunteer in office _____ Volunteer at school functions _____

If you are a graduated student:
When did you graduate? ______________
Did you have a Transition Services Plan? ______________
Appendix C

Open-Ended Interview Questions

1. When someone asks you what Transition Services are, what do you say?

2. Tell me how you came to become involved with Transition Services at this level?

3. Think back to when you were deciding to accept this position. What did you think then was the role of Transition Services?

4. How is your vision of the role of Transition Services different now than it was at the beginning?

5. Tell me what you think is the most important accomplishment of Transition Services since you have been in this position?

6. What do you wish Transition Services had accomplished but didn’t? Why didn’t it?

7. What effect do you think that Transition Services has had on the students?

8. What advice would you give to someone who was thinking of taking a position in Transition Services?

9. Is there anything else you think would be important to add to your comments?
# Quality of Life Questionnaire

Robert L. Schalock, Ph.D., and Kenneth D. Keith, Ph.D.

<table>
<thead>
<tr>
<th>Person's Name</th>
<th>Age</th>
<th>Gender</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person's Program</td>
<td>Evaluator</td>
<td>Test Date</td>
</tr>
</tbody>
</table>

## RESULTS

<table>
<thead>
<tr>
<th>Scale</th>
<th>Rater-1 (If Applicable)</th>
<th>Rater-2 (If Applicable)</th>
<th>Average Rater or Self-Report (Numbers in Circles)</th>
<th>Percentile</th>
</tr>
</thead>
<tbody>
<tr>
<td>Satisfaction</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Competence/Productivity</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Empowerment/Independence</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Belonging/Community Integration</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total Score</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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INSTRUCTIONS

The QOL.Q may be administered to persons with mental retardation who have adequate receptive and expressive language. The examiner needs to be sensitive to the possibility that the respondent may not understand some of the items or the meaning of some of the words. If this happens, it is okay to paraphrase the item to improve understanding. If this happens frequently, or if the person is known not to have adequate receptive or expressive skills, it is acceptable to have two persons who know the individual well complete the Questionnaire.

Instructions for Respondents

Read the following instructions to the respondent:

I want you to think about where you live, work, and have fun, and the family, friends, and staff that you know. Together, let’s answer some questions that express how you feel about these things. If you like, you can check the choices given for each item; if you like, I can check them for you after reading and discussing each of the three alternatives for each item. Please try to answer each of the items and we will take as much time as you need. There are no right or wrong answers. We want only to know how you feel about where you live, work, and have fun and the family, friends and staff that you know. Do you have any questions?

If the respondent consents, the examiner proceeds to administer the 40 items. When reading the items, pay close attention to the exact wording. You may paraphrase items and repeat them as often as necessary to ensure the respondent’s understanding of the item content.

Instructions for Raters

Raters should know the person well and should complete the Questionnaire “as if they were the person” (that is, rate how the person is perceiving things).

Raters should complete the Questionnaire independently and without any discussion of the items or the individual.

Special Instructions for Employment Items

If the person is unemployed, do not ask Questions 13-20 and assign to each question the score “1.” Sheltered workshop programs should be considered as jobs when responding to the Questionnaire.
<table>
<thead>
<tr>
<th>QUESTIONS</th>
<th>3 POINTS</th>
<th>2 POINTS</th>
<th>1 POINT</th>
<th>RECORD SCORE HERE</th>
</tr>
</thead>
<tbody>
<tr>
<td>SATISFACTION</td>
<td>Brings out the best in you?</td>
<td>Treats you like everybody else?</td>
<td>Doesn't give you a chance?</td>
<td></td>
</tr>
<tr>
<td>1. Overall, would you say that life:</td>
<td>Lots</td>
<td>Some</td>
<td>Not much</td>
<td></td>
</tr>
<tr>
<td>2. How much fun and enjoyment do you get out of life?</td>
<td>Better</td>
<td>About the same</td>
<td>Worse</td>
<td></td>
</tr>
<tr>
<td>3. Compared to others, are you better off, about the same, or less well off?</td>
<td>Rewarding</td>
<td>Acceptable</td>
<td>Disappointing</td>
<td></td>
</tr>
<tr>
<td>4. Are most of the things that happen to you:</td>
<td>Fewer problems</td>
<td>The same number of problems as others</td>
<td>More problems than others</td>
<td></td>
</tr>
<tr>
<td>5. How satisfied are you with your current home or living arrangement?</td>
<td>Seldom, never more than once or twice</td>
<td>Occasionally, at least 5 or 6 times a month</td>
<td>Frequently, at least once or twice a week</td>
<td></td>
</tr>
<tr>
<td>6. Do you have more or fewer problems than other people?</td>
<td>Seldom or never</td>
<td>Sometimes</td>
<td>Usually or always</td>
<td></td>
</tr>
<tr>
<td>7. How many times per month do you feel lonely?</td>
<td>Probably more successful than the average person</td>
<td>About as successful as the average person</td>
<td>Less successful than the average person</td>
<td></td>
</tr>
<tr>
<td>8. Do you ever feel out of place in social situations?</td>
<td>An important part of the family</td>
<td>Sometimes a part of the family</td>
<td>Like an outsider</td>
<td></td>
</tr>
<tr>
<td>9. How successful do you think you are, compared to others?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. What about your family members? Do they make you feel:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

TOTAL SCALE SCORE — SATISFACTION
### COMPETENCE/PRODUCTIVITY

<table>
<thead>
<tr>
<th>Questions</th>
<th>3 Points</th>
<th>2 Points</th>
<th>1 Point</th>
<th>Record Score Here</th>
</tr>
</thead>
<tbody>
<tr>
<td>11. How well did your educational or training program prepare you for what you are doing now?</td>
<td>Very well</td>
<td>Somewhat</td>
<td>Not at all well</td>
<td></td>
</tr>
<tr>
<td>12. Do you feel your job or other daily activity is worthwhile and relevant to either yourself or others?</td>
<td>Yes, definitely</td>
<td>Probably</td>
<td>I'm not sure, or definitely not</td>
<td></td>
</tr>
<tr>
<td>Note: If a person is unemployed, do not ask Questions 13-20. Score items #13-20 “1”.</td>
<td>Very good, and others tell me I am good</td>
<td>I'm good, but no one tells me</td>
<td>I'm having trouble on my job</td>
<td></td>
</tr>
<tr>
<td>13. How good do you feel you are at your job?</td>
<td>The same as all other employees</td>
<td>Somewhat differently than other employees</td>
<td>Very differently</td>
<td></td>
</tr>
<tr>
<td>15. How satisfied are you with the skills and experience you have gained or are gaining from your job?</td>
<td>Yes, definitely (one or more skills mentioned)</td>
<td>Am not sure, maybe (vague, general skills mentioned)</td>
<td>No, job provides no opportunity for learning new skills</td>
<td></td>
</tr>
<tr>
<td>16. Are you learning skills that will help you get a different or better job? What are these skills?</td>
<td>Yes, definitely</td>
<td>Sometimes</td>
<td>No, I do not feel I am paid enough</td>
<td></td>
</tr>
<tr>
<td>17. Do you feel you receive fair pay for your work?</td>
<td>Yes, I can generally buy those reasonable things I want</td>
<td>I have to wait to buy some items or not buy them at all</td>
<td>No, I definitely do not earn enough to buy what I need</td>
<td></td>
</tr>
<tr>
<td>18. Does your job provide you with enough money to buy the things you want?</td>
<td>Very satisfied</td>
<td>Somewhat satisfied</td>
<td>Not satisfied</td>
<td></td>
</tr>
<tr>
<td>19. How satisfied are you with the benefits you receive at the workplace?</td>
<td>Supervisor is present only when I need him or her</td>
<td>Supervisor is frequently present whether or not I need him or her</td>
<td>Supervisor is constantly on the job and looking over my work</td>
<td></td>
</tr>
</tbody>
</table>

TOTAL SCALE SCORE — COMPETENCE/PRODUCTIVITY
21. How did you decide to do the job or other daily activities you do now?

<table>
<thead>
<tr>
<th>QUESTIONS</th>
<th>3 POINTS</th>
<th>2 POINTS</th>
<th>1 POINT</th>
</tr>
</thead>
<tbody>
<tr>
<td>I chose it because of pay, benefits, or interests</td>
<td>Only thing available or that I could find</td>
<td>Someone else decided for me</td>
<td></td>
</tr>
<tr>
<td>I do</td>
<td>I do, with assistance from others</td>
<td>Someone else decides</td>
<td></td>
</tr>
<tr>
<td>Almost always on my own</td>
<td>Usually accompanied by someone, or someone else has made the appointment</td>
<td>Never on my own</td>
<td></td>
</tr>
<tr>
<td>Complete</td>
<td>Some</td>
<td>Little</td>
<td></td>
</tr>
<tr>
<td>As often as I like or fairly often</td>
<td>Any day, as long as someone else approves or is there</td>
<td>Only on certain days</td>
<td></td>
</tr>
<tr>
<td>Yes, I have a key and use it as I wish</td>
<td>Yes, I have a key but it only unlocks certain areas</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td>Yes, definitely</td>
<td>Probably yes, but would need to ask</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td>No, I am responsible for myself</td>
<td>Yes, limited guardian or conservator</td>
<td>Yes, I have a full guardian</td>
<td></td>
</tr>
<tr>
<td>Yes, and those problems occur once a month or once a week</td>
<td>Yes, and those problems occur every day or more than once a day</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Free</td>
<td>Somewhat planned for you</td>
<td>Cannot usually do what you want</td>
<td></td>
</tr>
</tbody>
</table>

TOTAL SCALE SCORE — EMPOWERMENT/INDEPENDENCE
### SOCIAL BELONGING/COMMUNITY INTEGRATION

<table>
<thead>
<tr>
<th>Questions</th>
<th>3 Points</th>
<th>2 Points</th>
<th>1 Point</th>
<th>Record Score Here</th>
</tr>
</thead>
<tbody>
<tr>
<td>31. How many civic or community clubs or organizations (including church or other religious activities) do you belong to?</td>
<td>2-3</td>
<td>1 only</td>
<td>None</td>
<td></td>
</tr>
<tr>
<td>32. How satisfied are you with the clubs or organizations (including church or other religious activities) to which you belong?</td>
<td>Very satisfied</td>
<td>Somewhat satisfied</td>
<td>Unsatisfied or very unsatisfied</td>
<td></td>
</tr>
<tr>
<td>33. Do you worry about what people expect of you?</td>
<td>Sometimes, but not all the time</td>
<td>Seldom</td>
<td>Never or all the time</td>
<td></td>
</tr>
<tr>
<td>34. How many times per week do you talk to (or associate with) your neighbors, either in the yard or in their home?</td>
<td>3-4 times per week</td>
<td>1-2 times per week</td>
<td>Never or all the time</td>
<td></td>
</tr>
<tr>
<td>35. Do you have friends over to visit your home?</td>
<td>Fairly often</td>
<td>Sometimes</td>
<td>Rarely or never</td>
<td></td>
</tr>
<tr>
<td>36. How often do you attend recreational activities (homes, parties, dances, concerts, plays) in your community?</td>
<td>3-4 per month</td>
<td>1-2 per month</td>
<td>Less than 1 per month</td>
<td></td>
</tr>
<tr>
<td>37. Do you participate actively in those recreational activities?</td>
<td>Usually, most of the time</td>
<td>Frequently, about half the time</td>
<td>Seldom or never</td>
<td></td>
</tr>
<tr>
<td>38. What about opportunities for dating or marriage?</td>
<td>I am married, or have the opportunity to date anyone I choose</td>
<td>I have limited opportunities to date or marry</td>
<td>I have no opportunity to date or marry</td>
<td></td>
</tr>
<tr>
<td>39. How do your neighbors treat you?</td>
<td>Very good or good (invite you to activities, coffee, etc.)</td>
<td>Fair (say hello, visit, etc.)</td>
<td>Bad or very bad (avoid you, bother you, etc.)</td>
<td></td>
</tr>
<tr>
<td>40. Overall, would you say that your life is:</td>
<td>Very worthwhile</td>
<td>Okay</td>
<td>Useless</td>
<td></td>
</tr>
</tbody>
</table>

TOTAL SCALE SCORE — SOCIAL BELONGING/COMMUNITY INTEGRATION
<table>
<thead>
<tr>
<th>DATE</th>
<th>LOCATION</th>
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<table>
<thead>
<tr>
<th>STARTING TIME</th>
<th>ENDING TIME</th>
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<thead>
<tr>
<th>SETTING</th>
<th>DESCRIPTIVE NOTES</th>
<th>REFLECTIVE NOTES</th>
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<th>PARTICIPANTS</th>
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<table>
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<tr>
<th>ACTIVITIES AND INTERACTIONS</th>
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<tr>
<th>FREQUENCY AND DURATION</th>
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<tr>
<th>SUBTLE FACTORS</th>
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</table>
Dear Dr. Schalock,

My name is Joseph A. Finley, Jr. and I am completing my dissertation for my Ph.D. in Education Leadership at Lynn University, Boca Raton, FL and purchased from IDS Publishing Corporation your Quality of Life Questionnaire, as well as the manual. I would to include, in my dissertation, the quality of life model from the manual as a figure contained in the actual body of the dissertation. I am requesting your permission to do so. Thank you for your past assistance and encouragement. My mailing address is referenced above and my phone number is [Redacted].

Sincerely,

Joseph A. Finley, Jr.
Ph.D. Candidate