DISSERTATION

TRANSITION FROM SCHOOL TO POST-SCHOOL ENVIRONMENTS FOR YOUTH WITH DISABILITIES: A CRITICAL ANALYSIS

Submitted by

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In partial fulfillment of the requirements

For the Degree of Doctor of Philosophy

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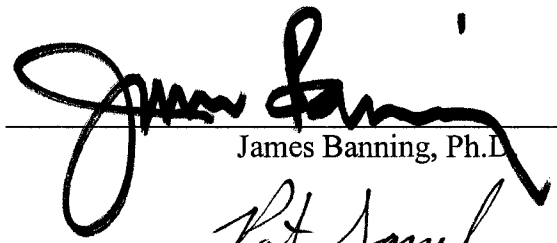

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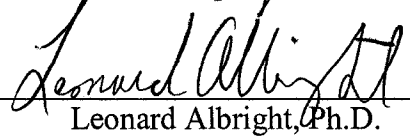

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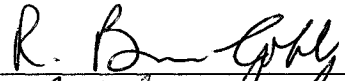

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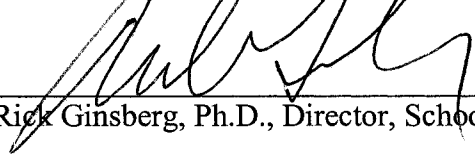

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ABSTRACT OF DISSERTATION

TRANSITION FROM SCHOOL TO POST-SCHOOL ENVIRONMENTS FOR YOUTH WITH DISABILITIES: A CRITICAL ANALYSIS

The past two decades encompass a transition movement in the United States; a time of widespread research, demonstration, and systems change initiatives and activities designed to promote and support the transition of youth with disabilities from school to post-school work, education and adult living environments.

The present study sought to examine the transition movement in the larger context of the process of transformation in society's relationship with persons with disabilities over time, through a critical and poststructural analysis of the lived experiences of six change agents active in the transition movement, and a purposeful sample of documents representative of the transition literature. Designed to complement and provide theoretical grounding for more traditional meta-analyses of successful interventions and outcomes, (i.e., 'what works' for youth with disabilities), two primary analytic techniques were incorporated: narrative analysis of the interviews, and constant comparative analysis of the documents.

Results were analyzed in terms of the thematic structures contained in the narratives of the participants, organized by their life/career stories, and the patterns across time in the documents, organized by the low and high incidence special education literature within and across age groups: public school, transition, and adulthood.

Themes were then integrated into three overarching constructs of *voice*,

interdependence and *inclusion* and represented in a model of "integral inclusion", highlighting some of the factors which support the transformation of society's relationship with persons with disabilities.

It was argued that given current social and political contexts impacting educational opportunities, transition outcomes, adult services, and barriers imposed by vestiges of (or in some cases, blatant) attitudes which marginalize persons with disabilities, we are not yet in an "era of inclusion and community membership", but we are headed in that direction.

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I am grateful too to friends and fellow doctoral students on the journey, especially Deborah Stein, Deena Koessl, and Debbie Craig, who each made the road brighter and lightened the load with their humor, understanding, expertise, and friendship.

My identity as both a special educator and researcher was formed early in my career, initially through my association and friendship with Dr. Pam Hunt. Through ten years of partnership on several research and teaching projects, I made my own transition into adulthood. As I carry Pam's inspirational mentoring with me in everything I do, her influence here is also evident (though she might not appreciate the association!). Other important early mentors were also instrumental in shaping my life's work, most especially, Dr. Lori Goetz, Dr. Wayne Sailor, Dr. Kathy Gee, Dr. Ann Halvorsen, and Dr.

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Thank you!
Fort Collins, CO
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DEDICATION

This work is dedicated to the many exceptional children and youth who have enriched my life beyond measure, and have also taught me what I know (and what I don't!).

CONTENTS

CHAPTER 1: INTRODUCTION

The last quarter of the 20th century was a time of sweeping changes for children with disabilities in the United States, unparalleled in our history. Events leading to, and the passage of, the Education of the Handicapped Act (EHA) in 1975 marked access for the first time to a "free and appropriate public education" for thousands of children experiencing disabilities nationwide. In the three decades since, interpretations of both "free" and "appropriate" have also changed radically.

Almost 10 years after the passage of the EHA, in 1984, Madeleine Will was appointed the Assistant Secretary of the Office of Special Education and Rehabilitative Services. Shortly thereafter her much acclaimed "Bridges" publication extended the EHA's promise deeply into secondary education (Cobb, Lehmann, Albright, Banning, Sample, & Alwell, 2001). At this time, the first wave of students with disabilities educated in public schools also reached transition age. The initial decade of educational access was overshadowed, however, by new research showing disturbing post-school outcomes for these youth. In spite of more opportunities than ever before, these "graduates" were typically unemployed, did not live on their own, did not participate in their communities (or did so on a very limited basis), and were dissatisfied with their limited social lives (Hasazi, Gordon & Roe, 1985; Rusch & Phelps, 1987).

The first federal initiative to facilitate the transition of youth with disabilities had been established in 1983, when Congress passed amendments to the EHA (became PL 98-189, and was later renamed the Individuals with Disabilities Education Act [IDEA]). Section C of the EHA authorized over five million dollars to be spent from 1984-1986 to

improve post-school outcomes for youth with disabilities, through provisions outlined in section 625 "postsecondary education programs", and more than six million dollars were to be spent annually for grants under section 626: "Secondary Education And Transition Services For Handicapped Youth" (Rusch, Kohler, & Hughes, 1992). Special education students' 'coming of age' to a lack of jobs, services, and quality adult living options impacted both the number and type of federal and state initiatives and activities intended to improve post-school outcomes for subsequent graduates. Those established through the Office of Special Education Programs (OSEP) in the late 1980's were intended to support a broad range of program development, personnel preparation, and research efforts (c.f. funding competitions: service demonstration models [CFDA # 84.158A] cooperative models for planning and developing transitional services [CFDA # 84.158B and 84.158C] and demonstrations in postsecondary education [CFDA # 84-078B and 84.078C]).

In fact, OSEP funded over 100 model projects between 1988 and 1990, whose primary goal was to enhance attainment of postsecondary outcomes for youth with disabilities: independent living, postsecondary education or training and competitive employment. They also provided monies for two other competitions related to secondary transition services at this time: youth employment projects (84.023D), and postsecondary projects (84.023G). Additionally, the Rehabilitation Services Administration (RSA) awarded five grants for Transition from School or Institution to Work Projects (84.128A).

In the 1990's, multiple demonstration initiatives in post-secondary education, multi-district outreach, dropout-prevention, and self-determination were established, augmenting the national focus on transition. A national research and dissemination

center was established at the University of Illinois at Urbana-Champaign, the Transition Research Institute (TRI), and a long-term meta-evaluation and technical assistance center was established at the University of Minnesota, the National Transition Network (NTN) (Cobb, et. al, 2001).

These two decades, roughly the mid 1980's to 2003, are generally considered a "transition movement" in special education.

A result of these widespread research, demonstration, and systems change activities in the area of transition during this time period is a comprehensive body of theoretical and empirical literatures, with a burgeoning volume of work appearing in professional journals, project reports, manuals, dissertations, theses and numerous textbooks.

What Works

The political climate at the start of the new century is one valuing and promoting high academic standards, achievement, and "evidence-based" research. The federal government is currently promoting "best evidence" syntheses of empirical works. The *What Works in Transition: Systematic Review Project*[1] is one such federally funded project, charged with the ambitious mission of collecting, synthesizing, and analyzing "what works" in secondary school outcomes for youth with disabilities in the United

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1

What Works in Transition is based in the School of Education at Colorado State University, and is funded in part through the U.S. Department of Education, Office of Special Education Programs (Grant Award No. H324W010005). The opinions expressed herein do not necessarily reflect the policy or position of the U.S. Department of Education, Office of Special Education Programs, and no endorsement by the department should be inferred. Brian Cobb is the Principal Investigator for the project; Morgen Alwell is the Project Coordinator and a Research Associate.

States. The central focus of this project is a series of meta-analytic reviews of research published between 1984-2003 (roughly the years of the transition movement) in the sub-study topical areas of secondary academic performance, dropout prevention, and secondary transition. Meta-analyses of this body of work should prove useful to practitioners and policy makers to interpret, within the limits of our present "body of evidence", which interventions contribute to what kinds of outcomes, for specific groups of students. They will also help to identify gaps in the research, and potentially influence policy, practice and future research directions.

There is little doubt that these types of systematic reviews offer a contribution, and the use of meta-analytic techniques within extends the rigor of more traditional narrative research syntheses (cf., Cook, et al. 1992; Cooper & Hedges, 1994; Hunt, 1997). Certainly too, the large body of evidence that has amassed in transition is driving the need for such a review. However, meta-analyses are based on a realist ontology, incorporate positivist techniques and assumptions, and pursue an independent, measurable and objective reality. From a different vantage point, it may be argued that research itself is a social construction. The dominant paradigm which privileges positivist and post-positivist methodologies tends to replicate and reinforce commonly accepted understandings of disability, intervention, and outcomes and the normative assumptions that undergird them (cf. Harding, 1986,1991; Lather, 1991; Lincoln & Guba, 2000). If we assume a critical or constructivist view, reality is assumed to be socially constructed, and inseparable from context. All "truths" are recognized as partial, local, and tentative (Guba, 1990; Lather, 1991; Lincoln & Guba, 2000); attention shifts from analyzing the measurement of interventions and outcomes, to examining the way in which individuals,

organizations, governments and societies construct meaning, and enact culture based on shared beliefs and values. Complexity, mutual causality, and the indeterminate nature of reality all necessitate an approach to research that embraces context.

In the critical paradigm, power relationships are deconstructed, including the value positions and social locations of researchers and participants. The impact of these on all aspects of the research design is made explicit. Subjectivity replaces the positivist objectivity implicit in quantitative, statistical approaches. Given the radical critique of science that has transpired over the past several decades, (e.g., Bernstein, 1976, 1983; Harding, 1986, 1991; Harre, 1981; Hesse, 1980; to name a few) more traditional meta-syntheses may be strengthened and complemented by adding critical dimension.

The central focus in this alternative analysis involves examining empirical, theoretical and policy perspectives impacting youth with disabilities as they make the transition from school to adult life from both critical and constructivist perspectives. Deconstructing the layers of context (historical, political, economic, social, cultural) that shape the way persons with disabilities are viewed and treated in our society becomes the central focus. Through this different lens, the fundamental study is not 'what works' but rather, how disability is constructed and 'treated' within our education system, and in work, recreation, and other community environments. By uncovering normative assumptions and cultural constructions about what is "normal" and "deviant", and critically examining normative understandings of life "quality" and "education" embedded in research, theory, and practice, this study decenters the modernist quest for "what works", and replaces it with the postmodernist goal of defamiliarizing, and the critical value of transformation (Lather, 1991). Studies of interventions and outcomes

related to transition of youth and adults from school to work and "independent" living may be considered within the larger context of transformation in society's relationship with persons with disabilities. The purpose of this study then, is to understand "transition" within the larger social construction of disability (a critical and constructivist perspective) through an historical, critical review of the literature and the perspectives of change agents.

This alternative analysis provides theoretical grounding and historical context for the meta-analyses of interventions and outcomes undertaken by the *What Works in Transition Project.* As noted by Skrtic (1995), attention to theoretical grounding is essential to systemic change in special education. He made the case that special education (like general education) is guilty of repeating problems in various guises (for example, the rise and fall of the special classroom approach, and the failure of the EHA and mainstreaming to resolve related problems of professional practice), and proposed that a likely explanation for these repeated failures is that change efforts continue to address models and practices, rather than theoretical grounding (Skrtic, 1995). Skrtic advocated instead for a "critical discourse on the level of grounding theories or paradigms that ultimately is concerned with the nature and effects of special education models and practices" (p. 67).

Norman Kunc (internationally acclaimed self-advocate and lecturer on disability) advised special education teachers and therapists interested in professional growth, "You don't gain the ability to deal with the complexity of people just by acquiring an abundance of strategies. You gain the ability to deal with the complexity of people from depth of thought. And many people avoid seeking this depth of thought because they are

too busy acquiring this endless library of disjointed strategies" (in Giangreco, 1996, p. 7). The present study is an effort to "think deeply" about the interwoven layers which influence change and shape quality of life for persons with disabilities in our society; to raise questions, rather than answer them.

Multiple discourses (e.g., disciplinary, institutional, and ideological) have shaped the social worlds of persons with disabilities (Biklen & Duchan, 1994; Allen & Allen, 1995). Several academics have advanced methods for deconstructing discourse in research. Lather (1991) in particular has analyzed the language/power relationship inherent in educational research and theoretical writing. She noted that "language is the terrain where differently privileged discourses struggle via confrontation and displacement" (p.10). For Lather, confrontation and displacement are illustrated in "the deconstructive text", where the deconstructive voice asks what roles a reader might play other than that of "swallowing whole" the author's authoritarian voice, explicit or implied (p.10). Postmodern research is intentionally evocative, and extended argument is displaced by what Lather called "... an oblique collage or bricolage of juxtapositions that remain skeptical of one another" (p.10). The contention is that exposing and wrestling with ambiguities enhances meaning. Poststructuralists also have examined the generation and legitimization of knowledge through our use of language, and advocate the dismantling of subjectivity, power, and resistance contained therein (Foucault, 1983; Weedon, 1996).

In the present inquiry, the process of transformation in society's relationship with persons with disabilities is explored through exploration of the discursive constitution of the world of persons with disabilities, particularly as it is represented in the literature of

the transition movement. At the heart of this work is the goal of generating more awareness about the lives and struggles of youth and adults with disabilities in our society. In the context of other critical works, there is also the underlying hope of contributing to more choices, more inclusion, and in some small way, ultimately to emancipation and transformation of society's relationship with persons with disabilities. Succinctly and perfectly articulated by Norman Kunc, it is my hope too that 'disability' might someday be viewed as an attribute, and simply part of the spectrum of 'normal'.

This study follows the tradition of scholars in education who have critiqued special education theory and practice, as well as the social construction of disability. For example, Skrtic (1986, 1991, 1995) presented a critical analysis of both modern education and special education, and using alternative paradigms - especially interpretivist and radical structuralist- theorized and reconstructed 'special' education. Ferguson, Ferguson, and Taylor (1992), Biklen and Duchan (1994), Allen and Allen (1995), Philips (1984, 1988, 1992),and Bogdan and Taylor (1982, 1992) also examined the social construction of disability, from various paradigms. These critical theories and methodological approaches have informed my work.

In addition, Bellamy (1997) designed a framework to conceptualize growth and change in a society's relationship to persons with disabilities over time. This theoretical lens provides a structure for the review of the literature on transition for youth with disabilities in this study, as well as a conceptual framework for guiding the selection of literature for review and data analysis.

The point of transition from school to post-school environments was selected as the focus for this work, with the most recent two decades as the sampling frame, for

several reasons. First, this time period encompasses the transition movement. It also roughly encompasses two paradigm shifts in special education and transition proposed by Bellamy (1997), from "protection to preparation", followed by "preparation to participation". Third, the transition movement is in some sense illustrative of the world of disabilities, typifying the complex and myriad issues faced by persons with disabilities in our society. Fourth, this lens provides theoretical grounding, critical analysis and an alternative perspective for the *What Works in Transition Project.* Perhaps most important, while there have been critical analyses of special education and the social construction of disability (e.g., Skrtic, 1995; Ferguson, Ferguson, & Taylor, 1992; Biklen & Duchan, 1994), these have not looked specifically at the point or process of transition, or the transition movement and related literature; nor have they utilized this specific approach (document review and the perspectives of change agents).

The current study, then, had three guiding questions:

1. Considering the transition of youth with disabilities from school to young adulthood, how have issues of inclusion and emancipation of these youth been framed, conceptualized, and critiqued in the scholarly literature, by key researchers, scholars, change agents, institutions, and by persons with disabilities themselves?
2. Are there patterns in these discursive constructions over time? If so, what are they?
3. How does a poststructural analysis of the transition movement increase our understanding of the transformation process of society's relationship with persons with disabilities?

CHAPTER 2: LITERATURE REVIEW

This chapter has three distinct sections. The first depicts the literature on transition from school to post-school environments for youth with disabilities, providing historical introduction and social context for the study. Following a definition of transition, Bellamy's (1997) 'braid of progress' is examined in some detail, in relation to the treatment of persons with disabilities in our society and an analysis of how change might occur in the relationship between society and persons with disabilities; this framework, then, is utilized to present a history of special education and transition in the last quarter century, through two subsequent paradigm shifts, leading to present day and the current study.

In the second section, works deconstructing 'special' education are reviewed, providing theoretical and methodological context for the study. Finally, works examining the social construction of disability are reviewed, also informing the theoretical and methodological assumptions and design of the study.

Transition: Definition

In the United States, the completion of high school generally represents the beginning of adult life, and public education is no longer provided for youth (NICHCY, 1999). Transition from school to post-school environments for youth typically includes postsecondary education, vocational pursuits, living independently and assuming responsibility for managing their own lives, while sustaining relationships with family and friends. However, this scenario is rare for youth who experience disabilities (Wehman 2000; 2001; Hughes & Carter, 2000). Despite two decades of intensive work in

the transition area, most young adults with disabilities still remain under or unemployed, and are grossly underrepresented and unsupported in postsecondary education. Most often these youth do not live independently; nor are they satisfied with their social lives following the completion of high school (Wehman, p. xiii).

Halpern (1994) provided a comprehensive and frequently cited definition of transition for youth with disabilities:

> Transition refers to a change in status from behaving primarily as a student to assuming emergent adult roles in the community. These roles include employment, participating in post-secondary education, maintaining a home, becoming appropriately involved in the community, and experiencing satisfactory personal and social relationships. The process of enhancing transition involves the participation and coordination of school programs, adult service agencies, and natural supports within the community. The foundations of transition should be laid during the elementary and middle school years, guided by the broad concept of career development. Transition planning should begin no later than age 14, and students should be encouraged, to the full extent of their capabilities, to assume a maximum amount of responsibility for such planning (p. 116).

Transition: Historical and Social Context

Treatment of persons with disabilities in the United States has paralleled that of other marginalized groups, most notably, persons of color, women, and gays and lesbians (Shapiro, 1993; Kliewer & Fitzgerald, 2001). Van der Klift and Kunc (1996) summarized this account in this way:

> Throughout history, people with physical and mental disabilities have been abandoned at birth, banished from society, used as court jesters, drowned and burned during the Inquisition, gassed in Nazi Germany, and still continue to be segregated, institutionalized, tortured in the name of behaviour management, abused, raped, euthanized, and murdered. Now, for the first time, people with disabilities are taking their rightful place as fully contributing citizens. The danger is that we will respond with remediation and benevolence rather than equity and respect... (excerpted from *A Credo for Support*).

Over a period lasting several hundred years, persons with disabilities historically endured lengthy and often brutal periods of control, oppression and frequent

victimization (cf. Lipsky & Gartner, 1997; Bellamy, 1997; Kliewer & Fitzgerald, 2001). A social upheaval (a revolution) and some kind of movement for civil rights can begin to raise societal consciousness about the plight of an oppressed group. Then, over time, typically in fits and starts, laws may be enacted supporting changes in status and opportunities might gradually become available (Shapiro, 1993). While providing access to previously inaccessible venues might address the most obvious of segregation practices, there still exist multiple levels and layers of oppression, internalized in various degrees (conscious and unconscious) in the attitudes of all persons involved. In many ways, these are much harder to eradicate, as they are often hidden in the very seams of a culture. Access often represents the tip of the iceberg; attention must then be paid to the many forms of perhaps less blatant discriminatory attitudes and practices, including (but of course not limited to) those embedded in language and discourse (Lather, 1991; Weedon, 1996).

The Braid of Progress

Bellamy (1997) proposed a theoretical framework in which to examine the growth between individuals with disabilities and modern societies, with the guiding question, "How do sustainable changes occur in the way a society responds to persons with disabilities?" (p. 2). Bellamy sought to "provide a coherent explanation that helps organize the multi-faceted developments in society's relationship with persons with disabilities and link those developments to existing knowledge, promote engagement in 'experimenting in practice' to select useful action strategies, and generate questions that assist in the development of new knowledge" (p. 3).

Named the "braid of progress", the framework consists of four interwoven postulates (1997, pp. 2-8), described in detail in the next section. Using this theory, Bellamy interpreted changes for children and youth with disabilities in the United States from 1975 to the present, proposing that we have experienced two paradigm shifts in the last quarter century. The first is a transition from *protection to preparation* (from pre-1975 to approximately the late 1980's); the second is a transition from *preparation to participation* (in the last decade or so).

The first tenet of Bellamy's theory is that there have been cumulative and systemic changes in the relationship between modern societies and people with disabilities. The second is that change occurs in four distinct arenas, ascending in scope and complexity: on the level of the individual/ procedural, the organizational, the governmental, and societal/ cultural.

The *individual* arena represents the day to day lives of persons with disabilities, their families, peers and teachers. Dialogue in this arena is grounded in a rich knowledge base of effective instructional interventions, such as task analysis, direct instruction, and community –referenced instruction. Action strategies involve solving practical problems related to curricula and instruction, and are informed through knowledge bases contained in education and psychology. According to Bellamy, the associated disciplined methodology here includes evaluation and validation of service methods, leading to better instructional technologies, greater personal control, choice and exercise of personal freedoms, and in turn, to self-determination and access to potentially unlimited environments (p. 4), insofar as concomitant changes occur in the next arenas.

The *organizational* level encompasses the organization, where knowledge is grounded in sociology and organizational theory. This arena includes possibilities for positive action by parents and professionals, for example, demonstrations that particular programs work (p. 5). In the disability field, organizations are challenged to achieve meaningful goals for individuals with very limited resources. Change here can stimulate broad changes in the expectations of consumers and policy makers (p. 5) by, for example, highlighting the discrepancies between current programs and other innovations that work, there is typically increased demand for better services that pushes the capacity of current programs and forces change. The primary method for change in the organizational arena is program evaluation. A case in point, conversion of [some] sheltered workshops to agencies that provide supported employment through job coaches in competitive worksites, as well as supports for living in independent or semi-independent residences has been precipitated by innovative programs offering these services, resulting in increased demand from parents, advocates, and consumers.

As individuals live within communities, organizations operate within a social policy context; the third vantage point in Bellamy's framework is *government*, where law, political science, and policy evaluation inform the knowledge base. Social action methods at this level include litigation, advocacy, policy making and evaluation, and dialogue explore whether the mandates, incentives, rights and support systems established by state and federal governments have their intended effect (p. 6). Actions in the governmental arena may include the work of professional and advocacy organizations, such as Berkeley's *Disability Rights Education and Defense Fund* (DREDF), and Oakland's *Protection & Advocacy*, as they "initiate legal challenges in

the courts to clarify, enforce, and extend the rights of individuals with disabilities and influence the political process, thereby promoting systemic change" (Bellamy, p. 6).

The broadest and fourth arena in Bellamy's framework is the *cultural.* Guiding questions here include: "What values underlie public policies, organizational structures, and professional practices that affect individuals with disabilities? How are conflicts among these values resolved?" (p. 6). Anthropology, philosophy and ethics comprise the knowledge base in this arena. Related action strategies include personal persuasion, dialogue, and the provision of information to the public; interventions may include media responsibility awards, public information campaigns, and sensitivity training. In the schools, interventions designed to build community, and uncover and address prejudices about differences with the explicit teaching of tolerance and interdependence are examples.

Bellamy's third postulate "is that the advances in the four arenas are *interdependen*t." He described the relationship among the four postulates... "as a dialectic process in which advances in each area create tension – an antitheses to existing perspectives—which stimulates new developments in each of the other areas" (p. 7).

His fourth postulate is that sustainable progress occurs when all four areas are structurally integrated (p. 8). "Major transitions in the leading paradigm governing society's relationship with persons with disabilities occur [especially] when advances in all four areas, above, are combined...lack of progress in one arena can arrest progress in the other three...for example, there is only a remote likelihood that new service approaches will be broadly implemented when organizational structures lag behind available procedures and cultural values" (p. 8). This fourth postulate encompasses the

dynamic complexity of systemic change. Lack of widespread availability of quality adult services for youth with disabilities, and lack of seamless transition to those services has been articulated by Wehman (2000):

> Despite 20 years of significant progress in special education, assistive technology, and vocational rehabilitation ....young people with disabilities continue to be unemployed and underemployed at unconscionably high rates. [And despite] the important laws passed to eradicate this problem [Americans with Disabilities Act of 1990, the Rehabilitation Act Amendments of 1992, IDEA of 1990/1997, and the School-to-Work Opportunities Act of 1994] ....there continue to be at least two major human services issues on which much greater work and effort must be conducted. First, we need a truly seamless system for moving [youth with disabilities] from secondary education to post-secondary adult life. Specifically, there needs to be a much better system of supports established in community colleges, vocational technical centers, 4-year colleges, and alliances with business and industry....in most communities; this type of seamless system is virtually non-existent. There are waiting lists, there are referrals, there are placements into dead-end centers and nursing homes, and there are programs that sound good on paper but have no meaningful outcomes associated with them (p. xiv).

Although there may be some services and supports in place for youth with disabilities on the level of the individual (student) and government (aforementioned laws), there are appear to be egregious gaps on organizational and societal levels, impeding overall progress with quality adult services. Tobin (2002) highlighted some of the related problems in adult service agencies, beginning with a lack of mandates and reasonable funding for these services, and compounded by low pay and status for workers, lack of training and adequate support, and high staff turnover in adult agencies.

In addition, Bellamy asserted that if *rights* are defined in such a way as to extend too far beyond the capacity of existing organizations and procedural knowledge (as well as cultural values), progress will be impeded.

In the next section, Bellamy's theory is examined in relation to the treatment of persons who experience disabilities, particularly since 1975.

History of Special Education and Transition Services

Paradigm Shift from Protection to Preparation

Prior to approximately 1968, persons with disabilities experienced an "era of protection", wherein society was protected from them (they were kept separate) and persons with disabilities were "protected" from society. The "protection" paradigm included provision of services that perpetuated exclusion, oppression and segregation. Lipsky and Gartner (1997, p. 81) traced the same historical development, describing the time period before the 1970's as the "era of institutions". People with disabilities were viewed as patients or inmates, and services were custodial, at best; a societal goal was control of this population. Kliewer and Fitzgerald (2001) traced the origins of this period to the time of the middle ages, when blatant subjugation and control of persons not in the dominant group prevailed. The practice of segregation remained intact through (and after) the advent of Western colonialism. Kliewer and Fitzgerald demonstrated the intersection between cultural and racial oppression and the oppression of people with disabilities. It was not until the middle of the 20th century that a shift away from institutionalization began to occur. As Bellamy observed, this change was precipitated by concurrent changes on multiple levels of government, individuals, organizations, and society, culminating in a paradigm shift, from protection to preparation.

On the level of *government*, change occurred through a series of court decisions and subsequent laws affirming the right to treatment and habilitation in the least restrictive environment for children with disabilities, and related changes for the adult community (e.g., the Rehabilitation Act, PL 93-112, of 1973, PL 94-142, and the

landmark Education for All Handicapped Children Act of 1975) (Lipsky & Gartner, 1997; Underwood & Mead, 1998).

Stimulated in part by compliance with new mandates, vast changes also occurred in the *procedural* arena. While students with mild disabilities had attended school for some time, this was the era of first mandated public school access for children with disabilities... up to this point, educational opportunities had largely been limited to segregated and residential institutions, and a smattering of segregated, day school programs (Sailor, Anderson, Halvorsen, Doering, Filler, & Goetz, 1989), especially for children and youth with more severe disabilities. Educational research settings moved from hospitals, institutions and clinics to special schools and classrooms, and resulted in an instructional technology largely comprised of operant conditioning of skills thought to be prerequisite to academic and vocational involvement. (There were exceptions, such as the work-study programs in the 1960's for children with mild mental retardation.)

Conversely, early life skills advocates (such as Brown, Nietupski, & Hamre-Nietupski, 1976; and Brown, Branston, Hamre-Nietupski, Pumpian, Certo, & Gruenewald, 1979) felt that "educators should prepare students to participate in integrated society" (Nietupski & Hamre-Nietupski, 1997, p. 41). This would necessitate a shift in curricula from "readiness" skills, to focus on the skills required to participate in the typical life spaces of adults in our society: domestic, recreation, vocational, educational and community environments.

The premise that students needed to be taught the skills necessary to successfully function as adults was also well documented in the literature on students with learning disabilities (Cronin, 1996).

In the late1980's, the national focus shifted to graduation outcomes and post-school adjustment for youth with disabilities, and curricula in K-12 settings went through important revisions. Lack of successful post-school outcomes precipitated the shift to more functional life skills curricula, along with intensive focus on remediation of skill deficits. Instructional strategies multiplied. Particularly for learners with significant cognitive impairment, instructional strategies commonly appearing in the literature included antecedent "errorless learning" strategies such as stimulus shaping procedures, time delay (or delayed prompting) (Touchette, 1971) and prompt/ fade strategies, in conjunction with chaining procedures and task analysis (Sailor & Guess, 1983; Sailor, et al., 1989; Downing, 1996). All were designed to highlight natural cues and then transfer stimulus control from the instructional cue to the natural one (Browder & Lalli, 1991). A second group of instructional strategies was classified as "consequent manipulations", and included error correction procedures and various schedules of differential reinforcement.

For learners with milder cognitive disabilities, such as mild mental retardation or learning disabilities, instructional strategies included group learning strategies (e.g., demonstration, modeling, role-play, guided practice, and scaffolding), direct instruction (Gersten, 1985) and mnemonic strategies (Mastropieri, 1985). A major contribution of this body of research was the documentation that with careful instruction, *all* children could learn, regardless of the severity of their "dis"ability.

On the level of the *organization*, this was a period of extraordinary movement; from deconstruction of large institutions to the development of differentiated, community-based services, as well as from a limited number of schools and relative lack

of school access, to integrated classes on regular school campuses. First, categorical classes for children with disabilities were placed in clusters on often chronological age-inappropriate school campuses (e.g., adolescents with moderate or severe cognitive delays were placed at elementary schools, because developmental ages were thought to match). Next, there was a shift toward integrated classes on regular school campuses (often in clusters and typically still categorical, until the concept of *natural proportion* emerged (Brown, et al. 1989) leading to further refinements.

Lipsky and Gartner termed this period the "era of deinstitutionalization" (p. 81). Persons with disabilities became students and clients as special schools, classrooms, and workshops multiplied. While the educational focus was on remediation of skill deficits, skill development, and behavior management, the ultimate goal was still behavior change toward a normal standard (cf. Lipsky & Garter). The shift toward preparation for independent living, gradual at first, gained momentum with increased access to educational settings, and related refinement of curricula.

On the *cultural* level, the concept of "normalization" was popularized (c.f. Nijre, 1970; and Wolfensberger, 1983). For the first time, access to some of the same opportunities and environments as typical citizens was considered for persons with disabilities (Nijre, 1970). Wolfensberger (1983) expanded the concept of normalization through "social role valorization" (in Tobin, 2002, p. 68). Not only might persons with disabilities have access to the opportunities and environments enjoyed by "normal" people, but additionally, they could and should develop social relationships and assume valued roles in the community. Reciprocally, these concepts influenced advocates and family members, who began in earnest the movement to "de-institutionalize", assisting

persons with disabilities to relocate from institutions and segregated settings, seek employment and establish lives in community settings (Tobin, 2002). While this movement represented progress in society's relationship with persons with disabilities, Van der Klift and Kunc (1994) elucidated the dark side of the normalization movement, that is, the tendency toward harsh remediation and sometimes condescending benevolence. Philips (1992) also articulated the constant pressure on persons with disabilities to be more 'normal'. During this period, preparation for independence became the focus of educational services for youth with disabilities.

Paradigm Shift from Preparation to Participation

In the late 1980's, however, reflection on the continuous state of "readiness programming" (Brown, et. al 1976) and continued unsuccessful outcomes resurfaced questions about the legitimacy of the preparation movement for youth with disabilities. These questions eventually resulted in the next shift, from preparation to evaluation of quality of life, and, for the first time, opportunity (at least theoretically) for full community participation. This time period corresponds with Lipsky and Gartner's "era of deinstitutionalization" to the present day "era of community membership". Some of the contributing factors are described next, again through Bellamy's model.

On the *procedural* level, as noted, an important contribution of the 1970's and 80's were numerous advances in instructional technology. Nevertheless, the emphasis on skills deficits, remedial instruction and meeting prerequisites for youth with disabilities led to the realization that for some groups, "pre" meant *never*, a concept popularized by a passionate Lou Brown, Professor of Special Education at the University of Wisconsin-Madison (1991). At the same time, a growing body of research in the early 1990's

demonstrated that students with disabilities educated in regular schools and classrooms were learning, and learning more (and different skills) than their peers placed in more restrictive settings (Hunt, Farron-Davis, Beckstead, Curtis, & Goetz, 1994; Hunt, Staub, Alwell, & Goetz, 1994; Baker, Wang, & Walberg, 1994). A new conviction emerged, supported by empirical data, that the more time learners with and without disabilities spent together interacting in the same environment, the better, and a number of strategies to promote positive interactions and relationships, and modify and adapt the curriculum to facilitate inclusive education were developed (this research continues today) (Neary, Halvorsen, Kronberg, & Kelly, 1992; Stainback & Stainback, 1990 & 1992; Hunt, Alwell, Farron-Davis, Wrenn, & Goetz, 1996; Putnam, 1993). There were also dramatic advances in augmentative and alternative communication and assistive technology during this time period, which expanded the number of typical environments accessible to children with disabilities, and changed significantly the quality of their participation (Beukelman & Mirenda, 1998; Blackstone, 1992).

As documentation of program effectiveness led to increased access and opportunity, more inclusive schools and classrooms were developed, and curricula shifted from preparation to participation, general education access, literacy, and numeracy (cf., Lipsky & Gartner, 1997; Downing, 1996; Snell, 2000; Winebrenner, 1996). This time control shifted from school personnel to children and youth with disabilities ... and the self determination and self-advocacy movements emerged (Ward, 1988; Halpern, 1993; Wehmeyer, 1992; Wehmeyer & Schalock, 2001). Lifestyle evaluation and personal futures planning replaced skill assessment as a means of determining curricula; these changes have reciprocally influenced more inclusive instructional contexts, and the

development of natural supports in natural environments (Forest & Lusthaus, 1990; Carr, 1993; Algozinne, Browder, Karvonen, Test, & Wood, 2001).

A recent development is a growing body of empirical research on intervening to change the attitudes and skills of nondisabled others in these environments, rather than "fix" the person with a disability (Staub & Hunt, 1992; Storey & Certo, 1996; Storey & Garff, 1997; 1999).

These changes in procedures stimulated change on the *organizational* level, precipitated in kind by the numerous federal and state transition initiatives of this period cited earlier. For example, collaboration between service providers influenced coordination of general and special education service delivery in the schools, which in turn has promoted cooperation and, in some cases, merger of teacher licensure departments in higher education and state departments, and the development of dual certification (general and special education degrees) in teacher licensure programs.

Although there is still a dire need for quality adult services to evolve (see, for example, Tobin, 2002; Wehman, 2001), we have begun to shift control from organizations, such as sheltered workshops, to individuals participating (with supports as needed) in meaningful, integrated work and other community environments (although perhaps this has been stalled or even reversed in the most recent political climate in the United States- as discussed in later chapters). Other changes at this level include downsizing community residences and provision of specialized services based on individual *preferences* rather than skills.

On the level of *government*, partly in response to the controversial Regular Education Initiative (REI) of the late 1980's (cf. Stainback & Stainback, 1984; Lipsky &

Gartner, 1987), the ADA victory of 1990, and because of continued pressure from outspoken advocates, parents and special educators, the REI evolved into the inclusive education movement. Despite the emerging data questioning the effectiveness of "pull out" programs and separate classes, as well as the research on the effectiveness of instruction in inclusive settings cited earlier, there were multiple litigious challenges to inclusive services; a series of *full inclusion* court cases (Lipton, 1994), and new laws: IDEA of 1990 and 1997.

In 1990, the EHA of 1975 and 1983 was renamed the Individuals with Disabilities Education Act (IDEA) and became PL 101-476. Several improvements were made to earlier treatises; critical among these were transition mandates explicating extensive planning and coordination of services for secondary-age youth with disabilities. These additions were in response to the effort to improve post-school outcomes. As IDEA was reauthorized in 1997, these transition mandates were refined and expanded; for example, the start of transition planning was lowered to age 14 (younger if needed), and for the first time, general educators were required to participate for in transition planning and share the responsibility for implementing students' programs with special educators.

In the *cultural* arena, we were indeed approaching the "era of community membership" (Lipsky & Gartner, 1997, p. 81), but more recent policies and the political climate at the start of the 21st century have apparently changed the forward momentum; clearly not all persons with disabilities yet enjoy equal access, adequate supports and meaningful opportunities. Unequal access and layers of prejudice notwithstanding, as a society, there are individuals and groups among us who do value persons with disabilities for who they are (rather than for whom they might become after we 'fix' them). Persons

with disabilities have some opportunity to live in more typical settings, with more awareness, willingness, and knowledge on the part of service providers to co-create supports centered on the needs and preferences of the individual. There is an emerging focus on changing the attitudes and skills of others (cf., Storey & Certo, 1996; Storey & Garff, 1997, 1999)— rather than the person with a disability, and to increase access to everyday environments, while improving the quality of participation there. However, while some people with disabilities are experiencing this greatly improved quality of life, many still are not. Kliewer and Fitzgerald (2001) argued that a majority of children and youth with intellectual disabilities, for example, still face harsh and delimiting educational segregation... "remedial training programs and fix-it teaching methodologies that exist in the 'nethermost' margins of the school" (p.453). While students with mild disabilities have historically fared better than those with severe, they too have been sorted, labeled, categorized and more often than not, removed from the mainstream. Complex causes are attributed to the lack of funding sources for quality adult services, as well as the lack of coordination among adult agencies currently in existence. Efforts are further hampered by recent reductions in already meager resources, especially fiscal. We are challenged to truly enter an "era of inclusion and community membership", addressing the multiple problems with inconsistent educational opportunities, less than satisfactory transition outcomes, insufficient adult services, and the barriers imposed by the attitudes of ignorant others.

The analyses of these two paradigm shifts illustrate the braid of progress and key issues in transition of youth with disabilities from school to post-school environments; the interplay between change and barriers in any of the four arenas (individual,

organizational, governmental, societal) reciprocally affecting movement and progress in the others.

Deconstructing 'Special' Education

Several scholars have examined regular and special education as a modern institution from various critical perspectives. In the 1980's, at the height of the qualitative research movement in the social sciences, questions regarding the theoretical assumptions underlying special education practices came to light (cf. Skrtic, 1986; Tomlinson, 1982; Kiel, 1995; Sleeter, 1986; Heshusius, 1984; Ferguson & Ferguson, 1995). This group was assembled for a pre-convention program led by Skritc at the Council for Exceptional Children (CEC) Annual Conference in San Francisco in April, 1989, and their papers eventually resulted in the 1995 publication of *Disability and Democracy: Reconstructing (Special) Education for Postmodernity.*

In Skrtic's (1995) comprehensive and critical analysis, he observed that problems with special education exist on a foundational level, which must be addressed before simply implementing new models or instructional practices. He recommended *pragmatism* to reform special education practices on the level of theoretical grounding, to address the practical realization of social goals:

> "Whereas the aim of modern social inquiry is to justify social practices and institutions by showing that they are based on a true representation of the world, the goal of pragmatism is to change social practices and institutions by reconciling them with useful and thus desirable moral ideals. Pragmatism circumvents modernism's problem of theoretical representation and postmodernism's alleged moral relativism by focusing on the consequences of social theorizing, on the question of whether acting upon a particular theory contributes to the practical realization of desirable social values, particularly those associated with democracy (p. xii).

Incorporating organizational theory from each of four modern paradigms, and his pragmatist approach to postmodern theorizing, Skrtic combined them dialogically to form a "postmodern meta-theory of school organization and change". In the process, he reinterpreted special education and disability from an organizational perspective, characterizing them as "organizational pathologies"... "Unintended negative consequences arising from the contradiction between the democratic ideal of universal public education and the bureaucratic structure of schooling in twentieth-century industrialized societies" (p. 195). Skrtic ultimately considered "the relationship between disability, democracy, and the necessary reconstruction of 'special' education in light of the historical contingencies of an emerging postindustrial political economy". He used his meta-theory to analyze the inclusive education movement in special education, ("a discourse on equity"), and the school restructuring movement in general education ("a discourse on excellence"). He argued that the point where these two movements converge is "the deconstruction of the institution of public education itself", and contended that the social goals of educational equity and excellence demand the same things of a reinvented public education: "A nonbureaucratic or "*adhocratic*" organizational structure and a pragmatic mode of professional discourse" (p. 257).

> Adhocracy and pragmatism provide the methods and conditions of discourse necessary to revive the idea of progressive education in postmodern nations, which in turn holds out the possibility of reviving the critical project of democratic renewal through cultural transformation and a social reconstruction of society, influenced by this reconstructed education (p. 258).

Skrtic also encouraged the development of new knowledge, discourses and alternative theories that promote the deconstruction of special education and the "twentieth century notion of student disability", reinventing schools that are more

consistent with the ideal of serving the best educational interests of *all* students and thus ultimately, reconstituting democracy in contemporary society.

Ferguson, Ferguson, and Taylor (1992) and Ferguson and Ferguson (1995) promoted an interpretivist framework, wherein "special educators listen deeply to the personal stories of persons with disabilities", and this deep listening leads to transformation of their practices and models.

Tomlinson (1995) presented a radical structuralist view of special education and disability, and argued that the expansion of special education is driven by attempts to restructure education to fit the needs of technologically based societies in which academic and technical elites are required, but in which larger numbers of citizens will be under or unemployed. If special education were grounded in this paradigm, its very existence would be questioned. Indeed, Sleeter (1986, 1995) used a radical structuralist epistemology to reinterpret the field of learning disabilities and asserted that the category was created ... "to explain away the academic failures of primarily white, middle and upper class students in the wake of post-Sputnik school reforms" (p. 131).

From the radical humanist view of special education and disability, Kiel (1995) criticized functionalism, charging that its dominance in the modern era "has retarded the capacity of humans for development, fulfillment, and self-reflection" (p. 138). Kiel argued that reform efforts should be concerned with achieving social justice in special education, and practices which contribute to the development of self-reflective, autonomous citizens.

Deconstructing Disability

In 1992, Ferguson, Ferguson and Taylor, collected a number of qualitative works in one innovative volume entitled, *Interpreting Disability: A Qualitative Reader.* The editors remarked that the collection substantiated a "thriving interdisciplinary field of disability studies" (p. 9); each story in the volume contributing to an understanding of how people experience and portray disability in our society. Grouped by themes, the articles examine *disability and the edges of life* (infancy, old age, social isolation); *disability and the community* (difference between physical and social integration); and *disability and culture* (the social construction and portrayal of disability on a cultural level); the theme *disability and the schools* is closest to traditional research in special education, and most pertinent to the present study. This section includes three studies; the first is a qualitative study with deaf youth in public schools (Higgins, 1992), which led the author to make recommendations about more skillful mainstreaming. It is followed by a collaborative action research project between a special education and general education teacher, working together to mainstream students with learning disabilities (Davis & Ferguson, 1992). The third is a case study of students with autism in one public high school working toward an inclusive model (Ferguson & Ferguson, 1992).

In 1994, Biklen and Duchan examined the social construction of mental retardation in a controversial article published in JASH. The authors compared and contrasted two opposing views of retardation—the normative view, wherein so-called normal children and adults serve as the basis for understanding those identified subnormal, and the competence view, that sees the behavior of persons with the label of

mental retardation as sometimes different, but not inferior to those diagnosed normal. They also compared epistemological differences in research approaches, and their relative influence on the social construction of disability. Allen and Allen (1995) responded to Biklen and Duchan's work, adding an analysis of symbolic interactionism to the discussion, and ultimately supported their premise that mental retardation and disability are social constructions.

In the last decade or so there has also been the emergence of the "new disability studies" in higher education.

> The new disability studies is attempting to build the scholarly, pedagogical, and institutional structures that will enable us to understand in fresh ways both the fundamental human experience of embodiment and the meanings we have given to bodily variations and changes. This ambitious field arises ultimately to foster a recognition of and respect for human differences, both in others and in ourselves (Thomson, 1999, p. 49).

From an historical materialist standpoint, Ervelles (2000) critiqued the "new disability studies" emerging in academe thus:

> Yet, even though critical theorists of education have privileged the theorization of the body along the axes of race, class, gender, and sexuality, they have consistently omitted any mention of the "disabled" body. Such omissions reflect the historical practices within American public education that continue to marginalize the issue of disability by maintaining two systems- one for disabled students and one for everyone else. Based on these discriminatory educational policies, more than five million students with disabilities have experienced segregation that is both separate and unequal (p. 26).

These works and others are explored in more detail in subsequent chapters.

CHAPTER 3: DESIGN AND METHODOLOGY

The purpose of this study is to understand the process of transformation of society's relationship with persons with disabilities through an examination of the transition movement. From a critical theorist and poststructuralist perspective, the study has three guiding questions:

1. Considering the transition of youth with disabilities from school to young adulthood, how have issues of inclusion and emancipation of these youth been framed, conceptualized, and critiqued in the scholarly literature, by key researchers, scholars, change agents, institutions, and by persons with disabilities themselves?
2. Are there patterns in these discursive constructions over time? What are they?
3. How does a post-structural analysis of the transition movement increase our understanding of the transformation in society's relationship with persons with disabilities?

To explore these questions, two primary data sources have been selected; a set of empirical and theoretical works, and the personal narratives of participants, experts, and change agents.

Conceptual Framework

Feminist Sociology

Feminist sociology (Laslett & Thorne, 1997) includes the critical study of how social movements happen through examination of the connections between individual

experience, human agency and historical events. "Life histories [and narratives] draw attention to the specificities of historical contexts and the ways in which they are implicated in social action"(p. 2). "The narrative is a partial story- a representation, governed by a host of complicated determinants- we have an obligation to historicize and contextualize it" (Armitage & Gluck, 1998, p. 10).

A prominent feminist sociologist, Liz Stanley (1993), articulated the opportunity for conceptualizing and encouraging social change within her discipline thus..."A product of re-thinking the relationship between individual practice and social structure, not only relating selves to social collectivities, but also recognizing the part that selves play in constructing structures as well as being mediated by them"(p. 44). For Stanley, the "sociological agent [or researcher]... is concerned with constructing, rather than 'discovering', social reality and sociological knowledge" (p.49). She asserted that feminist sociology necessitates a reflexive concern with gender; as well: "The use of 'I' explicitly recognizes that such knowledge is contextual, situational, and specific, and that it will differ systematically according to the social location (as a gendered, raced, classed, sexualitied [*and abilitied*] person) of the particular knowledge-producer" (p.49) .

Feminist scholarship in particular "uses a revisionist approach to re-examine traditional interpretations, conventional wisdom and existing frameworks" (Safarik, Wolgemuth and Kees, 2002, p. 769). As noted by Safarik et. al, "Feminist critical approaches can enhance the review process by questioning the research assumptions, theoretical and methodological foundations, and research implications simply by including *gender* in the analysis" (p. 769). In the present study, questioning the *able*-as-

norm frameworks and adding the importance of *ability* to the social construction of knowledge, as well as gender, has added critical dimension to the analysis.

Critical Theory

Social transformation is implicit in the work of critical theorists, who hold that the social construction of race, class, gender and sexuality are central constructs (Erevelles, 1997, 2000). Analyses focusing on the social construction of *disability* - particularly mental retardation - have been conducted for some time in fields outside of education, especially in sociology (cf., Farber, 1968; Mercer, 1973; Bogdan & Taylor, 1982; Conrad & Schneider, 1980). More recently, analyses of the social construction of disability have emerged within education (e.g., Allen & Allen, 1995; Biklen & Duchan, 1994; Erevelles, 1997, 2000; Ferguson, Ferguson, & Taylor, 1992; Skrtic, 1995). These researchers have examined the context through which social reality takes shape. Some maintain that disability is not an entity waiting to be discovered, rather, it is an experience waiting to be described "Or, more precisely, a multitude of experiences" (Ferguson & Ferguson, 1992, p. 113). From an interpretivist paradigm, their guiding question is "What is the experience of disability?" Others have asked such questions as, "How is 'disability' a social construction?" "Does 'mental retardation', for example, exist without the socially agreed upon rules that label people thus?" "In what ways is disability related to other socially marginalized groups (produced by race, class, gender, sexual orientation)?" "What does disability mean within our cultural practices and beliefs?" "... within the current global capitalist economy?" "How has global capitalism historically maintained the marginal otherness of persons with disabilities?" (cf., Ervelles, 2000; Sleeter, 1986;

Algozzine & Ysseldyke, 1983). These questions have been particularly applicable to my analyses of documents.

Feminist and radical poststructuralism are specific theories within critical theory which have also informed my methodology. Both offer examples for analyzing discursive influences and exploring where issues of race, class and gender intersect with disability (Weedon, 1996; Sleeter, 1986; and Tomlinson, 1995). In feminist poststructuralism, the role of language, power, and subjectivity are crucial to understanding social change processes. Sleeter promoted these types of analyses, "...because they reaffirm the need to confront racism and classism in schools and society, to support practices that treat all students fairly, and to celebrate diversity" (p. 131). Feminist and radical poststructuralism have offered ontological, epistemological and methodological premises to address my guiding questions.

Finally, critical policy analysis (Marshall & Peters, 1999; Ball, 1994; Codd, 1988) was also germane and foundational to my methodology -particularly for the document analysis. Ball (1994) raised critical questions about the nature of policy, and the dilemma inherent in policy analysis. He compared policy as *text* vs. policy as *discourse*, and the nature of their interaction. Policy as text he equated with structure; policy as discourse he equated with agency. Rather than representing two poles of a continuum, Ball contended that agency and structure are implicit in each other. Further, policy as text is not necessarily clear, closed, or complete; it is the product of compromises at various stages. It is the "cannibalized product of multiple influences and agendas" (p. 18).

In elucidating policy as discourse, or the *effects* of text, he said ... "Discourses are about what can be said, and thought, but also about who can speak, when, where and with what authority" (p. 21).

Critical policy analysis also includes examination of power relations.

> "Power is multiplicitous, overlain, interactive and complex, policy texts enter rather than simply change power relations: hence, again, the complexity of the relationship between policy intentions, texts, interpretations, and relations" (Ball, 1994, p. 20).

A pertinent question to this approach is to ask of a given policy, *whose reality is privileged?*

Codd (1988) noted that "the analysis of policy documents may be construed as a form of textual deconstruction" (p. 236). In this sense, the task of the critical policy analysist is one of policy [*textual*] deconstruction. For Codd, fitting questions include: "What is implicit in the processes of production? What is the origin of the discourse which constitutes it, and the strategies by which it masks the contradictions and incoherences of the ideology that is inscribed in it?" (p. 236).

In contrast to the materialist conception of language, wherein the term *discourse* has come to embody "both the formal system of signs and the social practices which govern their use" (p. 235), Codd argued that "...The traditional approach to policy development is based upon idealist assumptions about the nature of language itself, which take it to be a transparent vehicle for the transmission of information, thoughts, and values" (p. 235). A policy document contains a plurality of meaning; the task for the critical analyst is not to prove which is correct; rather, to shed light on the various constructions. ... "to consider them all as evidence of the text's inherent ideological

ambiguities, distortions, and absences. And to expose the real conflicts of interest in the social world which they claim to represent" (Codd, 1988, p. 246).

Although comprehensive critical policy analysis is beyond the scope of this project, it still offered me a framework for asking, not only what *is* contained in the literature, but, what's missing? What are the accepted norms, implied or made explicit? I incorporated this approach to guide my analyses of the literature, asking, *how is the accepted 'treatment' of persons with disabilities constructed in these works, and, when and how are inherent norms challenged?*

Transpersonal Psychology

In addition to these theoretical and methodological frameworks, I have incorporated other works to guide my design and analysis; for example, from transpersonal or integral psychology, concerned with the development and transformation of individual and group consciousness (Wilber, 2000). In some 22 volumes, Wilber presented, among other concepts, several detailed models of the evolution of human consciousness; of particular relevance to my work is his conceptualization of the process of transformation contained in his "integral theory". Like Bellamy, Wilber proposed that change must occur on multiple levels for it to be sustained, and these levels are informed through various disciplines; the focus of Wilber's framework, however, is more complex and encompassing. Created through "a cross-cultural comparison of most of the known forms of human inquiry" (Integral Institute, 2005), Wilber developed a comprehensive map of human capacities. His systematic analyses of the map led to the discovery that it contained five major aspects that represent qualities available to all human beings. These Wilber depicted through quadrants, levels, lines, states, and types. One of these aspects-

quadrants- is shown in Table 1. The quadrants depict the first, second, and third pronouns contained in all the major human languages (i.e., I, you/we, and it). Wilber saw these as "dimensions of reality", expressed through, for example, art, morality, and science (his aesthetic 'I', moral 'we', and objective 'it'). He added a fourth dimension by representing "it" as plural.

Table 1

Wilber's Quadrants Representing Dimensions of Reality with Bellamy's Levels from the Braid of Progress

Upper-Left Quadrant	Upper-Right Quadrant	Bellamy's
"I"	"IT"	Individual/ Procedural
Interior-Individual	Exterior-Individual	
Intentional Informed by, e.g., phenomenology, psychotherapy, meditation, emotional intelligence, personal transformation	**Behavioral** Informed by, e.g., empiricism, scientific analysis, quality control, behavior modification	
Lower -Left Quadrant	Lower-Right Quadrant	
"WE"	"ITS"	Bellamy's Organizational Governmental Societal (systems)
Interior-Collective	Exterior-Collective	
Cultural Informed by, e.g., multiculturalism, postmodernism, world views, corporate culture, education culture, collective values	**Social (Systems)** Informed by, e.g., systems theory, social systems analysis, techno-economic modes, social networks, systems analysis	

Adapted from Integral Institute (2005)

A central tenet of Wilber's model is that *all* of these approaches are correct; however, exclusive attention to just one part of the quadrant is partial or incomplete—resulting in change efforts which are not sustained over time.

> "Therefore any truly comprehensive or integral approach would want to [incorporate knowledge from] all of these important dimensions, because they are in fact operating in people in any event, and if we do not include them in our analysis, we will have a partial, fragmented, and broken approach to any proposed solution" (2000, p. 468).

In addition, human development also occurs along several *lines* (Wilber identified two dozen or so), through various *levels*, or stages...depicted in Figure 1:

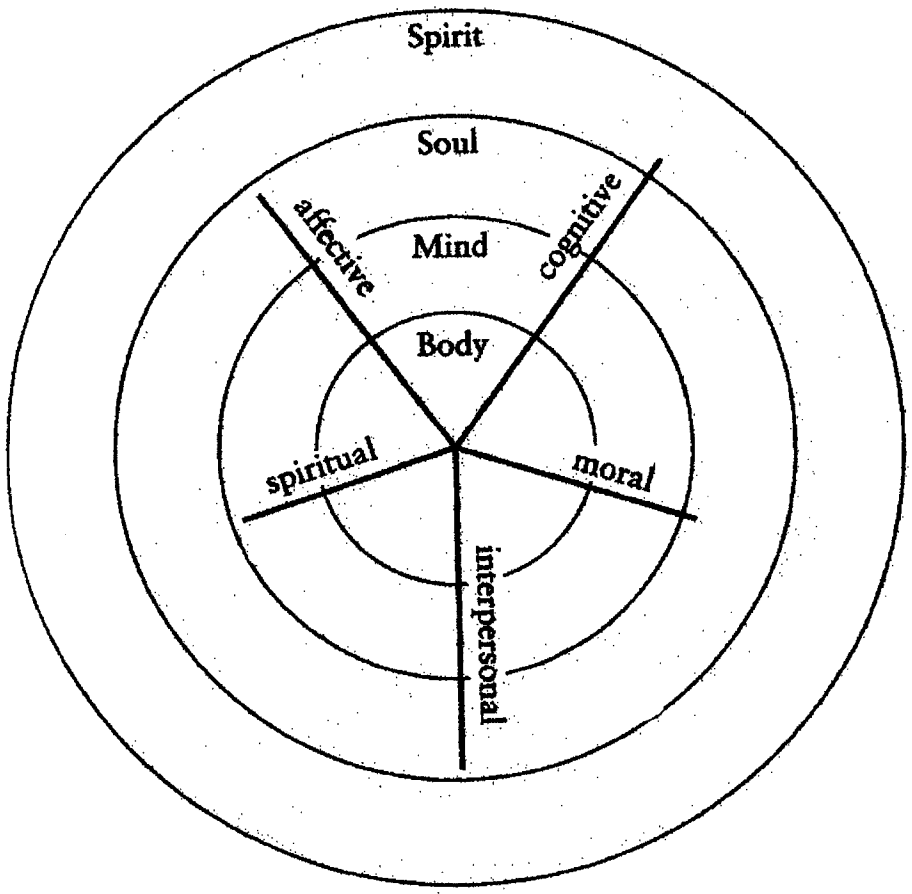

Figure 1. Integral psychograph, with 5 lines of development as examples (Wilber, 2000, p.451).

The lines in this graphic depict various lines of development in Wilber's model, through a spiral model (shown by the concentric circles); the spiral is intended to be hierarchical, in that each of the higher levels encompasses the lower, but not the reverse; therefore, the higher are more holistic. For Wilber, development through the lines, however, is non- hierarchical (or *heterarchical*) nonlinear and interactive, and may occur

at different speeds in one person...e.g., an individual may be more developed cognitively than morally or spiritually.

Two additional aspects of the integral theory of development are "states" and "types". *Types* refers to different types of awareness, for example, the masculine type has been portrayed as more autonomous and analytic, and the feminine, more relational and embodied. Integral theory acknowledges different ways, or vantage points, of viewing a problem.

Not only do humans appear to have various types of consciousness, they also seem to have numerous *states* of consciousness- the final major aspect of the model. The most obvious examples of these are waking, dreaming and sleeping.

Wilber summarized the application of his model to change efforts in this way:

> The integral approach looks at any problem- personal, social, ecological, international- and attempts to identify all of the important variables that are contributing to the problem in each of the five major domains (quadrants, levels, lines, states and types). A truly integral approach might draw equally on systems theory and meditation, technological innovations and emotional intelligence, corporate culture and behavior modification- the full spectrum of potentials in all of the quadrants, all of the levels, all of the lines, all of the states, all of the types (Integral Institute, 2005).

Like Bellamy, Wilber asserted that for *stage or level* change to occur (change or learning which is sustained, or integrated) a person must have firsthand experiences (not unlike standpoint theory; cf. Harding, 2004; Cosgrove, 2003) which expose her to new ideas (a *state* change) and multiple (or particularly powerful) state change experiences eventually push one into a new level of development. This might happen through repeated exposure, as through education, the impact of a significant relationship (such as a mentor), or through crisis, loss, or other firsthand experiences, such as having a

disability. Also, all the quadrants are depicted as dynamic, interactive and interdependent ... and like Bellamy's levels in "the Braid of Progress", change in one quadrant (or line) may positively or negatively impact change in the others.

Deconstructing Attitudes toward Persons with Disabilities

> The meaning of disability in *special* education (italics mine) goes far beyond alleged physical, behavioral, and psychological differences. Disability has symbolic meaning that must be looked at in terms of what society honors and what it degrades. Society's thoughts about intelligence, confidence, beauty, and winning must be understood to understand what we mean when we mockingly call someone "retarded" or "blind as a bat" [or 'diss' someone...].Our society traditionally has been structured to bring shame to people with alleged disabilities . . . only a small part of problems of discrimination-providing physical access to wheelchairs ... is technical. The problems of disability are much more social, located much deeper in the seams of our society . . . (Bogdan and Knoll, 1995, p. 694).

Of particular relevance to my research questions is Wilber's *affective* line of development, visible in relationship to individual and collective attitudes toward persons with disabilities. This has been delineated in multiple works including those by Van der Klift and Kunc (1994), Turner and Louis (1996), and Gallagher (1995). In *Hell-Bent on Helping: Benevolence, Friendship and the Politics of Help*, Van der Klift and Kunc (1994) offered an in-depth analysis of society's perceptions and responses to persons with disabilities over time. They asserted that four primary attitudes toward disability may be found in our society, historically as well as today. These are: disability as *deviance*, *deficit*, *tragedy*, or *diversity*. They also identified underlying motivations or goals and related actions associated with each perspective. These are found in the first three columns of Table 2, p. 47 [in this document].

A key feature of this model is that the attitudinal positions depicted are somewhat hierarchical, from the most biased to the most enlightened.

Historically, larger numbers of people have shared more biased attitudes (i.e., disability as deviance), and in western societies, we are now shifting away from this; however, there remain exceptions. And certainly while disability as diversity is a postmodern notion gaining increasing acceptance, the intermediate attitudes, disability as deficit, and/or as tragedy, remain prevalent and show up in various guises culturally.

Turner and Louis (1996) also articulated several ways of thinking about differences (inclusive of, but not limited to, disability) in the United States. The first corresponds with Van der Klift and Kunc' category "disability as deviance": *Difference as diversity excluded or marginalized.*

Their second category, *Difference as costly or "taking away"*, refers especially to detracting from resources for people *without* disabilities; an example follows in Gallagher's work. There is ample evidence that this attitude is common in public education today, for example, in the belief that special education is depleting resources needed by general education. Yet not everyone feels this way. An insightful parent of a general education student educated in an inclusive classroom with students also receiving special education services made this comment:

> Physical proximity is the start of what could be invaluable and positive learning about the value of differences. I believe that children with disabilities do not take away from other children. They do not diminish the community....[they] have the potential to contribute enormously to my son's learning and growth- but only if the environment and people take advantage of this opportunity (in Turner & Louis, p. 134).

Turner and Louis called their third category: *Difference as advantage.* That difference is a way of preserving status in our society and thus valued by those who are privileged has been examined in some detail by critical sociologists (e.g., Bennett & LeCompte, 1992). There is motivation to preserve differences ... "where observable

differences are identified with a group that is *less able"* (p. 135). This is a notion related to the concept of "cultural capital", which has been defined as "the knowledge, language skills, norms, and values that are acquired largely outside of formal education but that give advantage to certain groups" (p. 136). For example, in the United States, being white is an advantage conferred even before birth; for members of minority groups, however, "the very process of becoming competent in the culture of the dominant group is itself an obstacle" (p. 136). The very existence of an underclass, sometimes referred to as a 'surplus population', may be seen by some as an advantage in our society, where the workforce requires large numbers of unskilled laborers to perform service level jobs.

The fourth category articulated by Turner and Louis is *Difference as a dichotomy vs. matter of degree.* They argued that dichotomies tend to create the illusion of impermeable boundaries (p. 54), which is well established in popular thinking (e.g., thinking that is "black and white" sees people who are disabled or not). Yet successful living in heterogeneous societies requires thinking in less rigid terms. Duster (1991) described *cultural competence* (discriminating, e.g., appropriate behavior and hidden meanings in different circumstances in a particular culture) in terms of navigating more fluid boundaries (p. 54):

> Competence is a pluralistic world will mean being able to function effectively in contexts people had previously only read about, or seen on television. It will mean knowing how to be "different" and feeling comfortable about it; being able to be the "insider" in one situation and the "outsider" in another...Defined this way, pluralism in America can only be achieved if everyone does some changing. Every group will need to learn new ways of navigating into territories in which they do not have the power to define what is normal (p. 54).

Turner and Louis noted that "Exclusionary boundaries created by *categorizing difference* will need to be more permeable and flexible in order to foster the building of

more pluralistic communities" (p.54) [emphasis added]. However, more subtle layers of prejudice still exist even when labels are diminished, replaced, or even removed. By itself, creating more permeable boundaries is insufficient. "These [layers of prejudice] need to be teased out and addressed directly for deeper acceptance to occur." This is no small task.

The flip side of *Difference as advantage* (for the dominant group) is their final category: *Difference as identity preservation.* Minority culture may serve to assist members to feel a critical sense of belonging and pride, and may include unique language, stories, values, traditions and other cultural aspects...an example of this may be found in Deaf culture in the United States (cf. Ladd, 2003; Valios, 2002; Peters, 2000). This may preserve a sense of self worth and may be used as a means of personal and group agency by oppressed minorities.

Alternatively, minority groups might also develop "oppositional cultures", predicated on the "valuelessness of the majority culture as a means of preserving the worthiness of their experiences", a notion which includes more dysfunctional aspects.

For Turner and Louis, our society's perspectives toward differences reflect responses ranging from persecution, exclusion, and marginalization, to diminishment, devaluation, perpetuation of disadvantage, and the creation and maintenance of stereotypic boundaries (p. 137).

In *Slapping up Spastics: The persistence of social attitudes toward people with disabilities*, Gallagher (1995) examined the attitudes that led to the horrific killing of upwards of 200,000 persons with disabilities and mental illness in the Third Reich, with methods later emulated in the slaughter of Jewish people. These attitudes included a

widespread belief that people with disabilities, especially severe disabilities, were "useless eaters"; persons with "lives not worth living". At least initially, it was portrayed as "humane" to murder them, although it was not called murder- it was called "final medical treatment" and the "children's campaign" (p. 403). The original killings were intended to be conservative, administered by typical physicians without awareness or pain to their "patients", and carefully documented. However, historical records reveal that they quickly escalated into terrible killings of "wholesale lots" of human beings.

Gallagher noted that the psychological reasons German physicians had for willingly participating in mass murder in the 1930's and '40's were complex and based in economics and science, "including eugenic 'principles', social Darwinism, and a humane concern for persons judged by their doctors to have lives not worth living" (p. 407). Three pervasive attitudes, albeit often unconscious, which he compellingly argued persist today, contributed to the latter. One he called *Otherness* by which one group is deemed better than another; the second, *Spread*, referring to the tendency to assume if a person has, for example, spastic quadriplegia and can't do one thing, he can't do anything...or think (or feel); and the third, *Devaluation* is the assumption that because a person is "flawed", she is therefore devalued...she cannot contribute and is a drain on limited resources. The title of Gallagher's work came from the not uncommon practice of neo-Nazi youth *today* who practice attacks on persons with visible disabilities (and homosexuals), calling these attacks "slapping up spastics". They spit on them, assault them, and in some cases, bludgeon them to death - all the while chanting, "You are wasting my tax money", "You are a worthless liver" and "Under Hitler, you would have

been gassed" (p. 408). These are not limited to Germany or even Europe. Gallagher himself has polio quadriplegia, and noted recent incidents in the Washington D.C. area.

In 1993, Tracy Latimer, a 12-year-old with cerebral palsy who lived with her family on a farm in Saskatchewan, Canada, was murdered by her father. The subsequent series of trials and appeals by Robert Latimer launched nearly a decade of national public debate in Canada. Latimer received an enormous amount of support (including large monetary donations from friends, neighbors, and total strangers to cover his legal expenses) from people who empathized with him that he had "put Tracy out of her misery". Kunc (2001) commented that "The public support of Robert Latimer is not based on accurate understanding of events surrounding Tracy's death, but comes out of our society's unfounded and catastrophized dread of disability... that life with a disability is a fate worse than death (p. xx)."

A summary of the foregoing work on attitudes is depicted in Table 2.

Table 2

Perceptions and Responses to Disability

Van der Klift & Kunc (1994)			*Turner & Louis (1996)*	*Gallagher (1995)*
Perspective (**Disability** as…)	Motivation/ Goal	Actions	Perspective (**Difference** as…)	Perspective
Deviance	Marginalization (out of sight, out of mind)	Extermination Aggression Segregation Avoidance	Excluded or Marginalized	Devaluation
Deficit	Reform (you can be with us only if you are like us)	Rehabilitation Remediation Assimilation	Excluded or Marginalized (also costly)	Devaluation
			Advantage (for dominant group)	Otherness (one group is better than another)
Tragedy	Benevolence (we must help…)	Tolerance Burden Resignation Patronization	Costly (detracts from dominant group)	Otherness/ Devaluation
			Dichotomy vs. Matter of Degree	Spread (if you have a disability, you can't do *any*thing)
			Identity Preservation (for minority group)	
Diversity	Support Innovation Valuing (Disability as Normal)	Respect Understanding Acceptance Appreciation Equal worth Mutual Benefit Belonging	Mutual Respect/ Inclusion	

Adapted from Van der Klift, E. & Kunc, N. (1994).

Social Access and Relationships

There is an extensive and rich developmental literature base documenting the role of interpersonal relationships in cultivating self-esteem, learning and social competence for all children, including those with disabilities (Asher & Gottman, 1981; Tharpe & Gallimore, 1989; Grenot-Scheyer, Staub, Peck, & Schwartz, 1998). Meyer, et al. (1998) asserted that in our society, families and schools teach children foundational skills necessary for successful contributions in various adult roles, while peers and acquaintances of all ages are critical for the provision of the supports and contexts needed for mastery of the social skills and behaviors in increasingly diverse and complex social environments. For adults as well as children, in addition to family members, the important personal relationships that nurture essential interdependence and social competence in diverse community roles include our friends, colleagues (or peers), mentors, and benefactors.

A related body of work on social relationships and the impact of limited access to them has been developed by Marsha Forest and her colleagues in Toronto (Forest, 1988). By depicting relationships in a sociogram, (see Figure 2) Forest was able to illustrate the relationship between disability and the impact of restricted access to critical relationships. For example, the more pronounced a person's disability, the better the chance that his or her life space was limited to relationships in the innermost and outermost circles in Figure 2 (especially during or before the 1980's). (And for many institutionalized persons, their access to relationships might be further limited to paid service providers only).

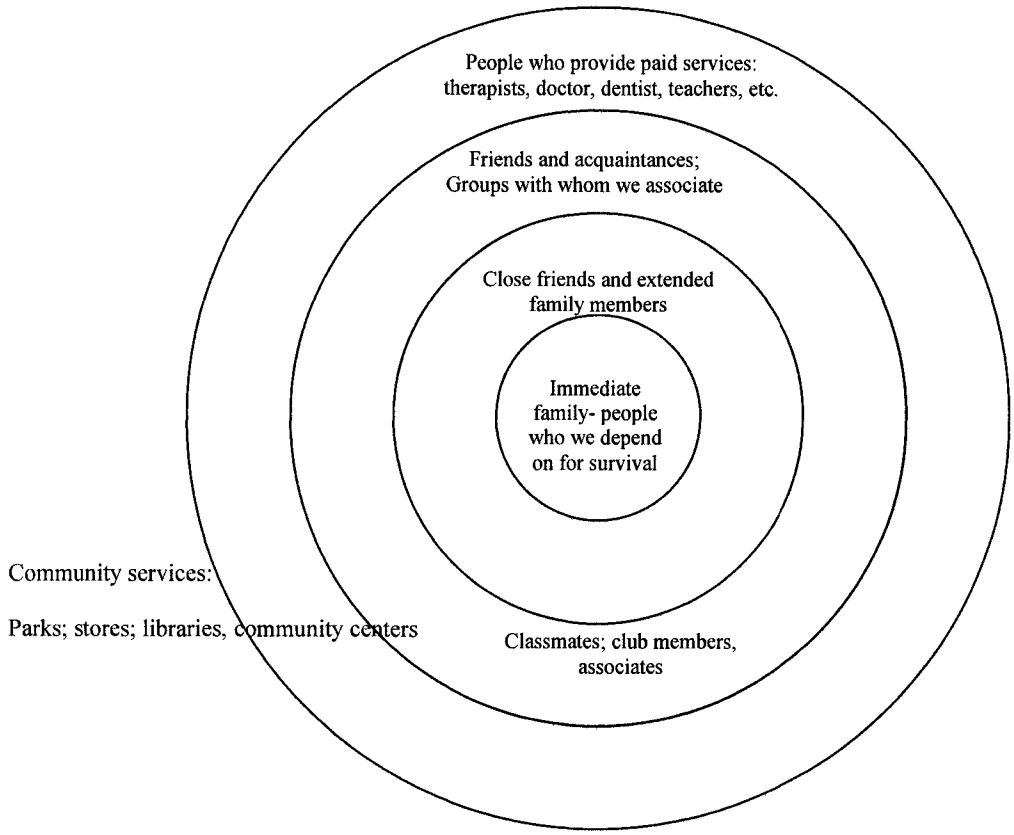

Figure 2. Circles of support (adapted from Forest et al. 1988).

Since attitudes and relationships are central in both my interviews and document analyses, each of these conceptual lenses is important in the next chapters.

Methodology

Narrative and Life Stories

> Narrative is "...a special kind of fiction in which memory and imagination conspire to reconstruct the truth of the past" (Eakin, 2004, p. 125).

The primary way individuals make sense of experience is by casting it as a narrative (Riessman, 2002). This is especially true of life transitions (challenges, difficult situations, and trauma). Precisely because they are meaning-making structures,

researchers are challenged to preserve narratives, respecting informants' ways of constructing meaning. One purpose of narrative analysis is to examine how respondents impose order on the flow of their experience to make sense of events and actions in their lives (p. 218). The object of investigation is both the story itself, and how the story is told.

Personal narrative is talk organized around consequential events (Riessman, 2002). The open-ended, face-face interview lends itself to this, because the informant is not interrupted by formulaic questions, and is free to organize her thinking in any manner she chooses. Because narratives are representations, they invite interpretation. In reflecting about each interview transcript, I have examined both the content and the composition of each informant's story, use of linguistic and cultural resources, and whether the stories seemed authentic (p. 220), asking, *Why was the story told, by this person, at this time, in this way, to me*?

Life histories are a form of personal narrative incorporated in my methodology which also bring forth unique experience and voice, linking personal perspective and experience with public events. Laslett & Thorne (1997, p. 2) called them "a resource for social theory and for the sociology of knowledge", useful for examining the contextual nature of social life. Individuals articulate life events as they have occurred in particular historical contexts, as well as "contingency, contradiction, and ambivalences". They have an open quality, presenting the speaker's understanding of her experiences, but with enough texture and detail to support other interpretations as well (p. 3). "Life histories can broaden the literary conventions of sociology by helping to construct a 'blurred genre' of sociological writing, one in which personal narratives and social theory come

together"(p. 2). Additionally, "They demonstrate intersections of social structure and human agency in ways that are more empirically rich and theoretically nuanced than other techniques" (p. 20).

Pamphilon (1999) developed a comprehensive framework for the analysis of life histories. Using the metaphor of a zoom lens in photography, she demonstrated how the researcher might move between different "focal lengths" to examine the multiple levels and layers contained in a narrator's story. For example, the broadest view may be obtained with the *macro* zoom (using this as a sociological term, Pamphilon acknowledged that this is actually the opposite with a camera), in which the dominant discourses, narrative forms, and "cohort effects" may be viewed. The dominant discourses refers to the taken for granted meanings available in specific times and places. The narrative forms refer to the "cultural archetypes of storying available in a given culture" (p. 396); in western cultures, these most commonly take the form of the male monomyth, the epic, Romanesque and/or the picaresque (these are defined later). What Pamphilon called the "cohort effect" is the impact of large historical events experienced at different ages by groups of individuals (impacting individuals in the group differently).

In contrast, the *micro* zoom enables the researcher to focus on the smallest details, such as the length, number, and placing of pause in the discourse, and predictable, incongruent, or revealing emotions. The *meso* zoom focuses on the individual's *process* of storying, in which the researcher listens for the style of narration, as well as the themes constructed by the individual across the narrative which bring coherency to her life.

Finally, the *interactional* zoom "invites the researcher to acknowledge the transaction between the informant and the researcher: a unique joint product between two

particular people" (p. 396). This focal point reminds the researcher to acknowledge her contribution to the "co-creation of knowledge" in the interview. Here too the researcher privately makes note of her reactions; where there is, for example, empathy, distress, and/or confusion.

Bruner (1987) advocated a constructivist approach to narrative analysis; acknowledging that narrative reflection is a continuing interpretation and reinterpretation of our experience. "'Stories' do not 'happen' in the real world; rather, they are constructed in people's heads" (p. 11). And, like Pamphilon, Bruner asserted that "Life imitates art", that is, using the forms available to us through cultural knowledge, we construct meaning through story-telling. The telling depends not only upon plot or events, but also on language ..."for language constructs what it narrates, not only semantically but also pragmatically and stylistically (p.17). Story structure is composed minimally of agent, action, goal, setting, and instrument...(Bruner, p. 18). Conceptualizing narrative in this way invites the analysis of, for example, agency; *Is the actor driven by intention? Active ? Passive? What are his underlying values?* Bruner too invited contextualization through description of the "landscape" in which the action unfolds... the political and cultural setting and events.

Bruner suggested that a first step in narrative analysis might be to "see how one's self-told life is converted into an extended tale through what uses of language, and what genre"...(p.18), while next steps include the analysis of other story themes.

There appears to exist a general consensus in the literature about narrative analysis that the researcher's task is not to confirm the absolute legitimacy of events as they happened, (and thus verify the informant's recall) since narrative involves (at best)

... "a selective achievement of memory recall; beyond that, recounting one's life is an interpretive feat" (Bruner, 1987, p. 13). Rather, it is to give voice to the narrator's interpretation of his or her own meaning-making in their lives, as well as those interpretations posited by the researcher (while attempting to avoid what Bruner called "academic navel-gazing"). Eakin (2004) acknowledged the role of memory in re-telling one's story in this way: "Identity's twin supporting structures are narrative and memory." In this vein, he called autobiography a "discourse of identity" (p. 122). He commented further that, "Autobiographical memory permits a constantly updated and revised aggregate of dispositional records of who we have been ...and who we will be in the future" (p. 127).

The advantage of multiple stories gathered around a particular social movement is the opportunity to compare and contrast various constructions of social events and knowledge. As Bruner asserted, "Life stories must mesh...into a community of life stories; tellers and listeners must share some "deep structure" about the nature of a life" or there is misunderstanding both about what the speaker is saying and the listener is hearing...(p. 21). My challenge has been to both to make sense of and "mesh" oral and written accounts of the transition movement.

A final note important here refers to interviewing experts. Most of the critical and constructivist literature on narrative analysis focuses on empowering marginalized persons to re-examine their circumstances with the implicit goal of transformation (Kezar, 2003, p. 395). There is little on the technique of interviewing experts, called "interviewing up" or interviewing "elites", beyond questions of access. Kezar's work is a notable exception. By definition, elites are mired in leadership and governance situations,

and as a result, have typically developed a public self separate from their private selves. This fact, and the limited time available from most experts, poses particular challenges to narrative researchers, something I encountered. Much of the interview data I was able to collect reflected "proper" or public selves. (I have reflected on this in the last section of this chapter.)

Epistemological Stance

Differences between qualitative research and quantitative lie not only in the methods employed by the researchers, but in their fundamental world views (as well, in their different locations in Wilber's quadrants), especially in relation to ontological (form and nature of reality), epistemological (relationship between knower and what can be known), and methodological premises (Lincoln & Guba, 2000). Based on their beliefs, values and preferred methods, researchers typically align with either positivism or one of the pluralistic alternatives: post-positivism (most traditional and closest to positivism), critical theory (and related ideological positions), or constructivism (most antithetical to positivism). Both the critical theorist and the constructivist believe that the relationship between the investigator and the research participant is *transactional* (i.e., they interact with and influence one another), and subjectivistic (as opposed to objectivistic). The critical theorist believes *values mediate findings* (this is where the traditional distinction between ontology and epistemology blurs), while the constructivist believes "findings" are *co-created in relationship with participants* (the distinction between ontology and epistemology disappears altogether) (p. 111). My epistemological stance lies somewhere between these two perspectives.

The goal of this study, and the methods selected, are more aligned with critical theory. According to Lincoln and Guba (2000), critical theory methodology employs dialogic or dialectical methods, and is considered transformative; for example, the inherent dialogue elicits underlying assumptions for examination and clarification, and more informed consciousness is a goal (e.g., seeing connections, and what actions may be taken to create change). The constructivist uses hermeneutical and dialectical methods, wherein individual constructions are elicited and refined only through interaction between and among the investigator and participants. Varying constructions are interpreted, compared and contrasted through dialectical interchange. The goal of constructivist inquiry "is to distill a consensus construction that is more informed and sophisticated than any of the predecessor constructions" (including that of the investigator's) (p. 111).

Using the beliefs, values and methods of critical theory to guide my conceptual framework, the theoretical framework described earlier has informed my research methods. Bellamy's framework provided a starting point for data collection, and an initial construct for organizing and analyzing my literature set and narrative transcripts. Van der Klift and Kunc' (1994) and other critical lenses and techniques (e.g., Skrtic, 1986, 1991, 1995; Ferguson, Ferguson, & Taylor, 1992; Ferguson & Ferguson, 1995; Laslett and Thorne, 1997; Pamphilon, 1999, 2002) assisted me in the process of deconstructing the interwoven layers within each piece, placing each in social and historical context and examining such things as use of language, author, and treatment of persons with disabilities. Wilber's work on the development and transformation of consciousness provided further insight and grounding; additionally, a theoretical

framework for reconstructing themes in my analysis into "integral" understandings about the transformation of society's relationship with persons with disabilities over time.

My Perspective as the Researcher

I am a White woman in my mid- forties, heterosexual, married. I grew up in middle class neighborhoods in two urban areas in the upper Midwest. Neither of my parents attended college. My father was a sales manager for a regional company which sold business forms. My mother did not work outside our home when I was growing up, but had traveled on her own as a young woman pursuing secretarial jobs in Washington D.C. and San Francisco. I was born the fifth child of seven, with a mild physical disability (congenital hip displasia) which brought me into contact with many other people with disabilities as a child, through frequent visits to the formerly named *Shriner's Hospital for Crippled Children*. At a time when I encountered no other children with disabilities in my schooling, these hospital and clinic visits profoundly impacted me and shaped my early familiarity with differences. During one extended hospital stay in particular I made many friends, leading to an early recognition that we are all the same on levels that matter.

Intrigued by several fields of study at once when I entered college, I finally decided on two majors, psychology and education. Then faced with a career choice to pursue one or the other post-graduation, I chose education. At the time I felt it was more holistic, with what I perceived to be an emphasis on building on strengths, rather than uncovering pathologies.

As a young elementary school teacher, I was drawn to students who struggled in the mainstream for one or more reasons—the curriculum was too difficult, their behavior

interfered, or their very access was denied. So I pursued graduate work in special education, first in mild disabilities, then in severe and profound. I spent the next twenty years working with and learning from children and youth with (and without) disabilities in public schools, mostly in large, urban, and relatively poor, racially and culturally diverse school districts (San Francisco, Oakland, Richmond, and Berkeley). My first teaching assignments were in segregated settings (disability only), next in integrated (regular school campuses but special classrooms), and finally, inclusive (my students were members of general education classes with supports brought to them). During this time, my graduate coursework at San Francisco State University afforded me the opportunity to work with some brilliant and prolific mentors, whose vision and work were nationally recognized and who also deeply informed my knowing about difference. These relationships led to many years of work in higher education, as well, teaching pre-service teachers, and, with a close mentor and friend, conducting research in classrooms and community settings. Throughout this period I continued to teach children part-time and work as a consultant and advocate in schools and for families. As we helped create more inclusive opportunities for children with disabilities in the public schools in the San Francisco Bay Area, relationships with other "inclusion support teachers" and university personnel were also influential and invaluable in shaping and supporting my work (and my life).

A move to the high mountains of Colorado in 1995 afforded me the opportunity to work in rural poor school districts (the Roaring Fork Valley, Rifle, and Parachute) and an extremely affluent school district (Aspen), encountering issues of ability, poverty, and class on new levels.

In 1999, I enrolled in a doctoral program, wanting to devote the next part of my career to further work in higher education. I took my first courses in a distance format while continuing my teaching job, and eventually left teaching to come to campus full time. There I was fortunate to assist with a grant proposal written collaboratively by several faculty members that resulted in the *What Works in Transition*: Systematic Review Project. In my employment with the project, I have had the great luxury of immersing myself in the literature on transition, while collecting, reading, coding, and organizing literally thousands of research articles with other project staff members. Now in our fourth and final year, we have begun to write multiple systematic reviews, the culminating step in the review process.

I bring these firsthand experiences and accumulated ways of knowing to the study of the transition movement, as well as passion and conviction about the inclusion of persons with disabilities in all areas of society. My perspective as a learner, teacher, researcher, teacher-trainer, advocate and change agent for persons with disabilities has undoubtedly influenced my research, including my conversations with experts, data analysis and the conceptualization of themes. Certainly, I have incorporated safeguards against the misuse of my biases, for example, attempting to represent participants and documents as accurately as possible and acknowledging through memos my reactions where participants' and authors' beliefs and values have echoed or conflicted with my own. I have also relied on input from committee members and close friends to keep a balanced perspective throughout. But I have also borrowed emergent, constructivist, and interpretive elements of grounded theory, and framed the research through these lenses. I offer the reader this information so that she or he might further deconstruct my biases.

Design

My overall design is a combination of poststructuralist critical approaches (radical, feminist) to reviewing, analyzing and deconstructing the literature on transition and a life story/ narrative approach to understanding social transformation. My study includes a purposive sample of literature published between 1984 and 2004 related to the transition movement, as well as interviews with selected change agents. Laslett and Thorne (1997) observed that life histories of intellectuals can provide insights into the social processes through which knowledge is created, transmitted, and changed. Also, the literature review and the interviews were somewhat interactive, as participants were asked for their recommendations for important documents to include, and for their perspectives on pivotal pieces.

Data Collection

Literature [Document] Selection

I selected the period from 1984-2003 because it encompasses the transition movement in special education, a time of several federal initiatives promoting transition activities, and the development of numerous demonstration programs and research efforts nationwide (and matches the time period selected for meta-analyses by the *What Works in Transition:* Systematic Review Project). A systematic search and purposeful sampling of current electronic databases, textbooks, hand searches of journals and a subsequent search of bibliographies of selected works completed over a two year period for the *What Works Project* resulted in a collected set of important works for review in this study, including theoretical pieces, essays, program evaluations, policy analyses, empirical works and invited commentaries -- with publication dates between 1984 - 2003.

Informants and other experts in special education and transition were also asked to recommend articles, and all of their recommendations were included.

Specifically, my initial plan was to select approximately 10 pieces from each 5 year period (1984-1988; 1989-1993; 1994-1998; 1999-2003); but as I reviewed the literature, I altered the number and evenness of this sampling process slightly, based on works cited frequently in articles, recommendations of others, and articles obtained as analysis proceeded and themes emerged. I completed the document analysis process when no new themes were surfacing...at that point, I had systematically reviewed some 60 documents (see Table 3; and Appendix A: References used in document analysis). Documents were published primarily in periodicals representing different viewpoints, including those of researchers, scholars, practitioners and advocates, in a wide range of publications, in special education and related fields.

Perspective of Change Agents/ Participants in the Transition Movement

I planned to interview approximately five experts/ change agents [2] in the transition movement, both to solicit their life stories and their story of the transition movement; and I was able to interview six. This group was selected with careful attention to varying gender, ability, backgrounds, life experiences, and areas of specialization. By no means are they representative of all who have contributed to the transition movement of the 1980's and beyond (nor was this my intention in their selection). But rather than "straightforward accounts of agency", the life stories and personal narratives I did collect "put more food on the table, and offer[ed] more food for

[2] To me, a change agent is someone considered an expert in a particular field or fields of study, who has consciously worked to improve conditions in that discipline in some way; in this case, an expert in special education and transition, and who had worked for access, equity and social justice for persons with disabilities.

analysis" (Laslett & Thorne, 1997, p. 5). Each contributed a unique version and perspective of a shared past, current events, and visions for the future, and each offered the possibility for discovering "the intersection of life histories with social action and institutional forms" (Laslett & Thorne, 1997, p. 21).

My list of potential interviewees included some combination of persons who embodied these roles:

1. Person with a disability and a change agent.
2. Parent of a child with a disability and a change agent.
3. Person of color -with a disability, and/or an expert in transition.
4. Administrator of transition programs/research dollars at federal level.
5. Professor of secondary special education- high incidence disabilities.
6. Professor of secondary special education- low incidence disabilities.
7. Director or researcher of national project related to transition.
8. Adult service provider- Vocational Rehabilitation or other agency—and expert in transition.

I identified and solicited the participation of interviewees first through professional contacts (I asked my committee members and others versed in transition to identify change agents); I followed up with a request for the interview via an email letter. During the latter I explained the purpose of the research, the nature and length of the requested interview(s), and provided some information about me (current position and vitae) [see Appendix B]. In two cases, committee members contacted interviewees by telephone prior to my email introduction; in one case, I knew the interviewee through the

What Works Project, and invited her to participate in person. I contacted eight persons overall and six responded positively. They were:

1. **Dr. David Johnson**: Professor, Department of Education Policy and Administration, College of Education and Human Development, University of Minnesota, and Director of the National Center for Secondary Education and Transition (NCSET) and the University of Minnesota's Institute on Community Integration.
2. **Dr. Bill Halloran**: Secondary Transition/ Postsecondary Team, Research to Practice Division, Office of Special Education Programs, Office of Special Education and Rehabilitation Services (OSERS), U.S. Department of Education.
3. **Ms. Madeleine Will:** Director, National Down Syndrome Society (NDSS) National Policy Center; Chairperson, President's Committee for People with Intellectual Disabilities, U.S. Department of Health and Human Services, Administration for Children and Families; formerly the Assistant Secretary of OSERS under President Reagan.
4. **Dr. Michael Ward:** recently left the Arizona Governor's Council on Developmental Disabilities; formerly chief of Special Education Secondary Transition Services at OSEP (years).
5. **Dr. Romie Tobin:** Transition Specialist, Colorado Department of Education and Research Associate, *What Works in Transition*: Systematic Review Project.
6. **Dr. Susan Hasazi:** Professor, College of Education and Social Services, University of Vermont and Director, National Institute on Leadership, Disability and Students Placed at Risk.

With each participant, I conducted two rounds of interviews. With a single exception[3], the first was a face-face, semi-structured (guided by the informant, structured only by the introduction of a few key topics) conversation, approximately one to two hours in length, using the following interview guide (Holstein & Gubrium, 2003).

[3] Dr. Hasazi requested a telephone interview in lieu of a face-face meeting.

1. Their stories, particularly as they were drawn into the world of disabilities:

Tell me about your life's work.

What got you interested in special education/transition (other)?

(Ask to collect copies of their CV's.)

2. Their version of the transition movement, society's relationship with persons with disabilities, and the change process:

What is your perspective of the current status of persons with disabilities, particularly for those of transition age?

What critical events or activities may have contributed or led to this?

What do you think contributes to/impedes progress or transformation?

What vision do you have for the future for persons with disabilities?

3. Their recommendations for important documents to include:

Do you have recommendations for any pivotal (or other) works for me to include in this research? (personal, biographical, professional.)

Figure 3. Interview guide.

The second "interview" was through follow-up email (in three cases) or a second face-face conversation (in the other three cases), clarifying points made earlier and asking additional questions I had as analysis proceeded.

Each participant had a choice whether to be identified or remain anonymous (with the understanding that they might be recognizable by some in the disability community

even unnamed, because of their positions and significant contributions to the field). All agreed to be identified. I recorded each interview with a digital audio recorder and transcribed the interviews and notes from the follow up contacts.

Once transcriptions were complete, I sent them to respective informants via email, and asked them to review, edit, or expand material as they wished. I incorporated their suggestions, which were minimal, with one exception. One of the audiotapes was very difficult to hear due to background noise and the speaking style of the participant; in this case I sent him my complete transcription with multiple sections highlighted with further questions. He was kind enough to fill in supplemental information in detail. I used participants' curriculum vitaes and other documents to support the interview data, and also had committee members read drafts and subsequent revisions of my work.

Data Analysis

Data analysis consisted of iterative rounds of reading, reflecting, and coding, leading first from thorough reading and reflection of each document and transcript, to analytical interpretations and levels of abstraction, and eventually to the development and integration of themes and theory building. The analysis process began as soon as data collection had begun (with the interviews and subsequent transcriptions), guided subsequent data collection and analysis of documents and follow-up conversations with participants, and was ongoing throughout and beyond the data collection process.

Narrative Analysis

Reissman (2002) commented, [interview] "analysis cannot be easily distinguished from transcription" (p. 253). "How we arrange and rearrange the interview text in light of our discoveries is a process of testing, clarifying, and deepening our understanding of

what is happening in the discourse." Two strategies she presented for data reduction and interpretation are *reduction to the core narrative* and the *analysis of poetic [linguistic] structures* (p. 254). Essentially, to privilege the teller's experience and avoid the tendency of the researcher either to read for content or read for evidence of prior theory, Reissman advised that analysis begin with the *structure* of the narrative, a suggestion I found most helpful. "Start from the inside, from the meanings encoded in the talk; identify underlying propositions that make the talk defensible, including what is taken for granted by both speaker and listener" (p. 256). *Then* situate the narrative in social, cultural and institutional discourses. This approach to analysis accomplishes the goals of preserving and respecting the informant's way of constructing meaning, and attending to how respondents impose order on the flow of their experience to make sense of events and actions in their lives (p. 218). Reissman also cautioned to keep in mind conceptions of power, and whose voice is represented in the final analysis (p. 256). I recognize that despite privileging the narrators' voices, my interpretations are linked to my research questions and theoretical /epistemological positions, and even to my personal biography - -as is the nature of interpretive and hermeneutic inquiry (Reissman, 2002; Laslett and Thorne, 1997).

Integrating Reissman's approach with Pamhilon's (1999) Zoom Model to narrative analysis, I approached the transcriptions first through elements of both the *meso* and *macro* zooms, looking for underlying structure and taken for granted meanings, as well as underlying values contained therein, being careful to favor the informants' voices as opposed to my own. Then I looked for narrative forms in the way participants told their stories. Pamphilon (1999) delineated four common in western cultures: the

monomyth, epic, romanesque and picaresque. The monomyth was first articulated by Gergen and Gergen (1993) and refers to "a story that places the character as central to a heroic trajectory"...the dominant model of Western life histories. Gergen (2001) noted that this is particularly more common to men's process of storying; women *tend* to present information in a more recursive, relational and less unidirectional manner. "The epic model is one of conformity that identifies with the core values of the culture" (Pamphilon, p. 398), while "the Romanesque constructs a life where change has been possible through notions of progress and individual challenge" (p. 398). The picaresque form contains challenges to the hegemonic cultural values.

Once I had examined the narrative forms within the interviews, I looked for evidence of social/ cultural themes and contexts. Next I moved between the *micro* and *interactional* zooms, focusing on pauses, emotions, omissions, and the impact of my comments and presence on the interviews, asking not only, what does each participant have to say, but how are they saying it? (Not so much as what their accounts are *about*, but *how* the narrators construct their stories, and thus, themselves.)... How do they structure their retelling? What do they leave out? How do they give form and meaning to their lives? Are there words or concepts that suggest a particular world view? Which cultural values are elevated?

Across the narratives, I had the hermeneutical advantage of six narratives that "spring from a common landscape"...the shared history and context of special education. In comparing them my intention was not the "ontology of verification"--- rather, as Bruner asserted, the advantage was in narrative power and possibility... "for one world

view cannot confirm another, though, in Geertz's evocative phrase, it "thickens it" (Bruner, 1987, p. 24.)

Since too I was interested in the "intersection of personal stories, human agency and historical events in the shaping of a social movement", specifically, the transition movement; I was interested in each person's telling of that story, his or her contribution to it, and perspective on it, as well as what he or she thought about the change process, and each informant's vision for persons with disabilities; however, I was careful to see what was there before imposing this agenda.

As analysis proceeded, I made interconnections with the literature I was also reading and analyzing, discovering whether and where the stories within the interview transcripts connected to the literature I was reading; where there were contradictions, and formulated additional questions and points for clarification I had for each interviewee, using my initial analysis to shape the second contact with informants. The analyses of the interview transcripts were ultimately integrated with the literature analyses, weaving both into some holistic understanding of the transition movement, and the transformation process.

Document Analysis

Using constructivist grounded theory methodology, I approached data analysis of selected literature (empirical, theoretical and policy pieces) through iterative cycles of reading and reflecting, identifying connections and contradictions with other documents and interview transcriptions, and eventually, reconstruction through the development and integration of themes. A careful reading of each document included querying various sections, defining actions or events within it, and annotating tentative codes in the

margins. Charmaz (2000) suggested that the purpose of initial coding is to "develop 'sensitizing concepts'---way of seeing, organizing, and understanding experience embedded in our disciplinary emphases and perspectival proclivities" (p. 515). Utilizing critical perspectives, different layers were important, and such questions, as, *Why* was this written? What does the piece tell about the social perspective and state of consciousness at that historical moment? How do I know this? Where was it written? By whom? What does this tell me? How is language used? How does the language used figure into social change? What are the layers of construction of the piece—political, economic, social, historical? What is present? What is left out? What are the normative assumptions?

This process enabled me to begin to identify patterns as well as inconsistencies, and to develop and refine codes. Initial codes were emic, found in the interview transcriptions – open coding of all transcriptions resulted in some 743 codes, developed using NVivo software. I printed and analyzed all codes with contextual information and synthesized these to 50 or so; then began to develop and apply extant codes, both theoretical and methodological. At the same time, I was collecting and organizing the documents to be used for analysis. I repeated the process with each document, drafted a coding thesaurus, and applied and refined codes. I developed matrices for all documents included in the analysis with these headings (Table 3), and entered information on each of several large sheets of chart paper. This allowed me to begin to examine patterns across documents, and select those most salient as possible themes for development.

Table 3

Chart Headings Utilized in the Document Analysis

Author(s)/ Title	Year Published	Type of Document	Area of Specialization (Disability group? Setting?)	Who wrote it? Where? Why?	Other important information; connections; inconsistencies; reactions, kinds of interventions, etc.

As analysis proceeded, I further revised the coding process, comparing and contrasting themes discovered in the data with works by Bellamy, Skrtic, Kunc, Turner and Louis, Wilber, and other theories as they became relevant. At that point I listed the salient analytic themes, drafting analytic memos for each. I returned to the data to ensure consistency and accuracy as my themes were developed.

All data was managed through a combination of paper and electronic files, carefully indexed and organized. This process was also helpful, enabling me to carefully review all files, and clarify important themes, contradictions, and connections. Reviewing the matrices and files, I began to develop themes by literally cutting up analytic memos and rearranging them under various potential theme headings. This assisted the process of develop the narrative of integrated themes, and the eventual reconstruction of the ideas contained therein into more holistic understanding and theory.

Reflective Memos

Throughout data collection and analysis, I also kept a reflective journal, noting such things as insights, contradictions, connections, and questions; I reread these annotated notes frequently and took next steps prompted in the process. This form of in-

process analytic writing is helpful in explaining, interpreting, or raising questions about the data (Emerson, Fritz, & Shaw, 1995). This journal also gave me a vehicle to reflect on methodological processes, rigor, and issues, and to develop visual descriptions of my conceptual framework as it evolved. My notes were incorporated into the data analysis.

Evaluation of My Research

The merit of critical works is that they are aligned with social justice goals, and/or have the potential for social change (Lather, 1991). This work was conceptualized with the goal of generating more awareness about quality of life for youth and adults with disabilities, and to add to theoretical understanding about the complex nature of transformation in society's relationship with persons with disabilities over time. It is presented in the larger context of, in some small way, contributing to more choices, inclusion, and ultimately, emancipation and transformation of society's relationship with persons with disabilities. It is my profound hope (and standpoint) that one day, 'disability' might be viewed as an attribute, an integral part of the spectrum of 'normal'.

To this end, I have conducted an in-depth analysis of a variety of data sources (empirical literature, theory and policy pieces; interviews with selected change agents/ participants in the personal narrative genre; and reflective memos). While my literature set is limited in quantity due to realistic time constraints, purposive sampling across the years selected helps to ensure representation of the twenty year period. Also, soliciting other sources from interviewees contributed to the data set, and as analysis progressed, new data sources were added, until themes recurred in such a way that it seemed the literature search was exhaustive. "Interpretive inquiry involves continuous comparative

textual analyses until an understanding of the phenomenon is achieved" (Jensen & Allen, 1996, p. 557).

I also encountered multiple challenges "interviewing up", introduced in the preceding section on Narrative Analysis. These manifested in two primary ways. One was that I was able to spend limited time with each informant, and the other had to do with their well-developed and in some cases, seemingly rehearsed, public portrayals of themselves (as well, my position as a doctoral student). I had hoped (somewhat naïvely) for richer interview data from all participants, providing a window into their private selves, and at least some sense of how these were integrated with their public lives. These challenges were compounded by my research questions, since I was not interested in changing the perspectives of the persons I interviewed; instead I was interested in their perspectives on the transition movement, as well as the story of their more personal journeys. Given the way I set up the study, and our respective positions, I felt that I had to respect both the time limitations and professional boundaries unspoken but nevertheless present in our interactions. The interviews I conducted where I had some acquaintance with the participants prior to this study were the richest, and seemed to help reduce some of these barriers. If I were to conduct such a study in the future, I would ask for more time at the outset (e.g., multiple interview sessions), offering participants perks in exchange, such as copies of research articles in which they might have an interest. I might also choose to preserve anonymity, and as well, at least acknowledge our respective positions verbally to make them more explicit. These changes might then provide a more complete picture of the intersection of public and private selves, and

richer data for the examination of the reciprocal contribution of individual agency and social change.

In post-positivist qualitative research, credibility is typically addressed through the use of prolonged time in the field, use of peer debriefing, triangulation, member checks, and time sampling (Anfara, Brown, & Mangione, 2002). In critical works, credibility might be addressed through multiple data sources and methods, member checks, and reconciling findings with extant theory. Certainly, the question for me was *not*, "How trustworthy are the conclusions that are drawn from the data, and do these match 'reality'?" Rather, I asked, "Have I adequately portrayed multiple perspectives, and examined multiple, alternative explanations...?" To some extent I also conducted member checks (by providing participants with interview transcriptions for review, and by using participants' vitas when provided) and certainly I made systematic and copious efforts to reconcile my findings with extant theory.

Regarding external validity, or transferability in qualitative research, post-positivists ask, "How well can these conclusions be generalized to a larger population?" This is clearly antithetical to the foundational premises of critical theory and constructivism. Still, I have kept detailed information on each step of my process, for example, all files, tables, and matrices should provide sufficient information that another researcher might clearly see and corroborate the connections and interpretations I have made. I documented each step of my research process to leave a clear and transparent audit trail; from notes about what literature has been selected and why, to requests for interviews and subsequent transcripts, as well all coding schemes attached to original data and related theme development.

Evaluation of cohesiveness, persuasiveness, and thematic consistency are central to narrative research. Reissman (2002) noted that "Interpretation of meaning is constrained by the text in important ways, offering a check on ad hoc theorizing" (p. 260). Theoretical claims must be supported with evidence from informants' accounts and alternative interpretations considered; both of these contribute to persuasiveness. As well, global, local and themal coherence are all important to quality narrative research. Works with all three types are said to be 'thick with coherence' (Resissman, p. 260). Global coherence refers to the overall goal a narrator is trying to accomplish by speaking, or the speakers' beliefs and goals. In this study, my clarity of purpose, interview guide and rapport with informants (as noted, in some cases better than in others) helped to elicit this type of coherence. Local coherence refers to what a narrator is trying to effect in the narrative itself, such as the use of linguistic devices to relate events to one another. To the extent that I have been able to analyze and compare the structure of particular narrative transcripts, local coherence has been strengthened. Themal coherence involves identifying recurrent themes that unify the text. Themes should surface in important and repeated fashion. This was dependent on my ability to look for and recognize important themes in the transcriptions, and elicit further comment from participants to clarify meanings. If the narrative is understandable in terms of all three types of coherence, the interpretation has been strengthened.

CHAPTER IV: NARRATIVE ANALYSIS

Personal and Public Selves

Introduction to the Participants

In this chapter, I introduce each of my informants at the point where their respective interviews began[4]. Then I expand on each interview as participants shared with me the story of their working selves. (The next chapter includes an analysis of their views on transition for youth with disabilities). Several considerations are noteworthy here. One, although I did not specifically request this, each informant opened their interview with their own transition from school into adulthood. And, as they spoke, the past virtually disappeared into what Smith (2000) called, "a narrative structure of plots, turns and symbolic motifs that embed the speakers in particular discursive communities (p. 349). The recurrent images found in multiple interviews reveal the symbols of a discursive community and collective knowledge garnered through shared experience, and multiple retellings (Smith, 2000). All the participants used language and expertise from the present to reflect about the past (Reissman, 2000; Smith, 2000); terms unique to special education, person-first language, and disability labels are examples. Pamphilon also noted: "Because the nature of life history is both individual and shared, cultural patterns and shared discourses will be evident. However, within each life history there will be movement and repositioning" (1999, p. 397). In this collection of interviews, cultural patterns and shared discourses are evident, as well as individual life constructions, movement, and repositioning.

[4] With the exception of Michael, whose interview began with his career; I have first introduced information about his childhood, something I asked him about later in the interview process.

Lastly, by way of introduction, it is interesting to note that despite the fact that each of these individuals are elite change agents, working in special education and related fields, there are distinct differences in the way that they approached reconstructing their histories for me. Two of the women, for example, began their stories with the birth of their children; the third, with her relationship with a young woman with autism as an adolescent. Without exception, the men commenced their narratives with their first jobs. The culturally dominant discourse seems to still be that men work, and women relate...are wives and mothers, as well as workers. I have attempted to explore how each informant conformed, challenged, countered or thrived (Pamphilon, 2002) within underlying dominant influences, such as this one. My informants were a diverse group of systems change agents.

The senior member of the group was Dr. Bill Halloran, born around 1940... his narrative begins with his own transition to adulthood, coming of age in the late 1950's and early 60's in the time of the Kennedy era... civil rights for African Americans and the war on poverty, from a large working class Irish- Catholic family in Connecticut. His narrative style includes elements of the monomyth (Pamphilon, 1999); initially a linear chronology tracing the progression of his career. Yet he was also somewhat self-effacing, and presented himself a bit of a "tough guy" or rebel, a recurrent theme in his narrative (more reflective of a picaresque style), evidenced in both why he says he was hired at a juvenile facility (he could "kick kids' assess"), and proud of his low G.P.A..

> Bill: I got my Bachelor's Degree...[5] in four years; no summer schools; I graduated in four years; my grade point average was about a 2.2. My first two

[5] In each of the interview excerpts, dashes represent pauses; '...' represents deleted text; care has been taken to not omit anything that detracts from meaning of the excerpt.

> years of teaching were at a juvenile facility where at the time they liked to hire people who could kick kids' assess. Then I got a Master's degree in special education and taught in the public schools for 4 years. Then I went to Vermont, the State Department of Education, I was in Special Education there for 6 years. That was 29 years ago.

Bill also could relate to and enjoyed the "tough and wacky kids", as evidenced in this excerpt:

> MA: *What drew you into special education in the first place?*
>
> Bill: It was basically the juvenile facility I was at, the kids that I worked with were all "special ed". I used to teach a self-contained group that were too wacky to be part of the included, the general population.

While he did not specifically say it was a particular relationship with a person or persons with disabilities that drew him to special education as a young man, he alluded to the relationships he had with "those kids", as well as an atypical group of parents of children with severe disabilities in Vermont, who elected to keep their children out of institutions- at a time when this went against the societal and cultural norm in the United States (cf. Bellamy, 1997). These parents and others like them eventually instituted a cultural shift.

> Bill: Also when I first started in Vermont, I used to work with parents with kids with severe disabilities. And these were a very unique group, because at the time it was progressive, the families- this was the 1960's—the families were advised by their families, the clergy and by their doctors to institutionalize their children. They were people who, in spite of taking the recommendations, decided that they wouldn't. They were a small number, compared to everybody else. They were a unique group of people. We did programs together in Vermont to serve those kids.

Another motivating factor for Bill to persevere in special education as a career was access to formal education; government-sponsored programs designed specifically to train qualified special education personnel, at a time when the education of children and

youth with disabilities was just beginning to be recognized as a valid need in America's schools (cf. Lipsky & Gartner, 1997). (Dr. Susan Hasazi commented too on the federal vision for fiscal support to train high quality personnel -presented later- she and another informant, Dr. David Johnson, also took advantage of these opportunities.) He eventually took a position in Washington D.C. working for OSEP, on the Secondary Education and Transition Team, which he headed for a time in the 1970's, and from which he plans to retire in the near future.

Although the majority of his career has been spent in a position of power in the federal government, throughout Dr. Halloran has reportedly (personal communication with Michael Ward and Leonard Albright, July, 2004) remained aligned with the "common person", often engaging in grassroots advocacy efforts; for example, helping out in local group homes for persons with disabilities, and helping to establish community supports and more residential options, as well, advancing the careers of colleagues.

Ms. Madeleine Will was born perhaps eight or so years later, in the late 1940's. In contrast to Dr. Halloran's narrative style, hers is more female and relational. Most often, she used the pronoun "we", and moved between telling her story in a linear fashion (in a "monomythic" and perhaps male-identified style) and including other people, events or stories that impacted her path – at times her story "bulges out sideways" (Pamphilon, 2002). Her narrative is illustrative of a sense of inter-related cycles and themes; she included both Romanesque elements (change has been possible through notions of progress and individual challenge), and picaresque (questioning position to the hegemonic values of the culture), particularly in her own career as a political leader -at a

time when women were just becoming more visible in public office, and her profound understanding of the oppression of persons with disabilities and related advocacy work. Ms. Will also included some emotional content in her interview, something largely silenced in Dr. Halloran's and Dr. Johnson's; the latter with the exception of the traditionally culturally-sanctioned emotion for men in our society: anger.

Madeleine comes from a background in which education was valued, and presumably there were resources available to her as she pursued degrees in history, political science, and international relations. Her narrative also evidences some integration of her personal and professional lives, as she began her story both with career highlights, and the birth of her first child in 1972, a son with Down syndrome. The following excerpt shows gendered expectations from her peers at the time, "They kept trying to put me into fund-raising; fashion shows, you know..." presumably because she was female- until her intellectual interests and gifts were apparent.

> Madeleine: I was the Assistant Secretary for not quite 7 seven years under Reagan. I had a child with Down syndrome in 1972. In 1974, I started volunteering for the ARC, in our neighborhood, or in our county. And they kept trying to put me into fund raising; fashion shows, you know, fund raising development, which I did not like - I was sort of pulling away from it, when one of the guys at the ARC said, "Would you like to do some work on the government affairs committee?" And - I was really excited to do that. I had wanted to do some work in Washington. - I had a background in history, political science and international relations. And I worked for a think tank, writing monographs on various foreign policy subjects.

The birth of her son was life altering. It changed her family, her circle of friends, and her career focus. She became a political activist for persons with disabilities. Her response to my question, next, also shows her underlying spiritual focus, something echoed by Dr. Hasazi- with whom she later became friends.

MA: *What do you think was pivotal in drawing you in to the whole world of disabilities? Do you think it was your son?*

Madeleine: Oh absolutely. It totally transformed my life, up-ended my life. My friends, my family circle, my professional life. I would *never,* I would not have focused on this policy if it were not for John. I feel I was chosen, I mean, I didn't choose this, I was chosen.

Like Madeleine, Dr. Susan Hasazi was born in the late 1940's. She too began her narrative with her own transition, at age 16, from "chance" work for a service organization in high school at a group home for adolescents with disabilities, where she was deeply affected by a relationship she formed with a 13- year- old girl with autism. In the process, she recognized her desire to become a special educator. This excerpt also introduces a recurring theme for Susan, her belief and personal value that it is important and central to her to give to her community, to help change things for the better.

Susan: I got interested in special education very early in my life. Actually, when I was in high school, I was involved in a service organization. I volunteered to work in what was then the first group home for children and youth that were labeled as autistic. I did that on the weekends. I think I was 16 years-old at the time. - And I just felt that this was something that I really wanted to do when I left high school. I guess I was one of those rare people - fortunate to have a career path from the moment I entered college. Very unusual. I was that affected by my experiences, particularly with a young woman that I worked with who was about 13 or 14 years-old, almost my own age. I just knew that when I went to college I was going to be a teacher and I was going to be a special education teacher.

Dr. Hasazi's narrative style was less recursive than Madeleine's; more similar to the monomyth, linear and chronological, in which she highlighted the development of her career. At times, however, she digressed into the picaresque, like Ms. Will, especially in relation to her extensive advocacy work for persons with disabilities. In contrast to Madeleine and Dr. Romie Tobin, who will be introduced shortly, she did not share information with me about her personal life. In terms of Pamphilon's (1999) "interactional zoom", this may have been due to the lack of face-face contact I had with

her, and the subsequent limited opportunity to build rapport; as well, the relative difference in our positions and her highly developed "public self" (see Kezar, 2003). As Smith (2000) noted, "Narrators are also aware that they speak through their interviews to a larger audience" (p. 363). I think this was particularly true for Dr. Hasazi. As a result, her responses and elaborations were at once articulate, polished and instructive. Her reference to having an explicit career orientation as a young woman in the late 1960's was atypical at that time.

The next informant I will introduce is Dr. Michel Ward. He too was born around 1949; in Brooklyn, New York, with cerebral palsy. This was more than two decades before the passage of PL 94-142; a time when many children born with recognized disabilities were still being sent to institutions. In contrast, Michael's family not only kept him at home with them, they provided him with a deep sense of normalcy and wholeness.

> Michael: When I was young, my parents tried to make my childhood as normal as possible. I had two sisters and I had to do chores along with them. (I got on my knees to vacuum and dust the moldings.) Dad took us everywhere and showed me everything. He didn't know what I would be able to do, but he wanted me to be able to tell someone else how to do something I needed done.

Dr. Ward attended a regular elementary school- a special class for children with physical disabilities. This was not the neighborhood school that his sisters attended; he had to be transported (also typical for that time – see, for example, Brown, 1989; Sailor et. al, 1989; Lipsky & Gartner, 1997).

The class was ungraded, and there were few expectations for him to progress academically (reflecting internalized and most likely unconscious "benevolent" attitudes

by school staff that what these kids needed most was "caring"). However, he did not express regret about this.

> Michael: I went to a special unit in a regular school. What you have to remember is that this was way before P.L. 94-142 and public schools were not required to do **ANYTHING!** NYC Board of Education started me at age 4! The classes were ungraded and there weren't any expectations to perform. Many of my peers still express anger that they were cheated out of an education. Hell, I don't see it that way. I cannot stress enough, there were no role models! Our teachers and parents were in uncharted waters and didn't know what we could become. "Special education" was a new field and not an exact science. However, I never met a more dedicated group of people and if we were ready to learn, they were up for the challenge. I bet among my cohort group, that the percentage of us who went to college equals or exceeds any current cohort of students with physical disabilities you find today.

While Dr. Ward did not feel that he was "cheated out of an education", it seems to me that the reaction of his peers was more typical. These were times when public education for children and youth with disabilities – when offered at all- was frequently little better than childcare (Brown, et al. 1976). He and his classmates were kept at the elementary school until high school age, while his peers without disabilities went to junior high school. Even though children with disabilities were clustered at the elementary school with less regard for their educational progress and their chronological ages than their peers without disabilities, it was progressive in the 1950's to offer placement at a regular elementary school *at all* (Brown, et. al, 1989; Lipsky & Gartner, 1997); and clustering was still commonplace in the 1960's. In contrast, Michael's high school experience was fairly progressive for the time. This was a time when he began to blossom.

> Michael: There was no junior high. We went from elementary to high school and high school was more of a resource room situation. We went to regular classes and had a special education teacher in our home room where we could get the

> support we needed. He was a wonderful man and advocate. He encouraged non-disabled students to volunteer with us and every year he would organize a weekend bus trip somewhere for all his students and volunteers. (I experienced my first hangover on one of these trips.) I think for some of my peers, the "transition" of going from an ungraded, segregated class in elementary school to a regular class in high school where there was increased competition for grades was too much. I actually did quite well and enjoyed the challenge.

The "hangover" Michael is proud of might be considered part of the typical adolescent's rite of passage in our culture. His personal sense of normalcy is evident too in the following excerpts, as he reflected that he was unable to connect or identify with two groups of persons with disabilities with whom he had contact as a child- either as peers or as role models.

> Michael: Okay, this is weird: but the only role models I remember were from the "Brownsville Boys Club" which had like a day activities center for very people with severe physical disabilities. For some reason, I couldn't identify with them or didn't want to identify with them. A second group was a Catholic group that met one Sunday a month for Mass and socialization. It had a kids' group and I do remember some of the adults with mild disabilities had jobs. Until I was about 14, I was uncomfortable in both groups and didn't identify with them as role models.

Michael's narrative style is male in that he most often uses the pronoun 'I', and places himself central in his career path; however, in contrast to Dr. Johnson and Dr. Halloran, he included both varied emotional content and vulnerability in his story, and his narrative was less linear. He also shared on a more personal level, his words reflecting a willingness to reveal more aspects of his personhood. Like Wilber's theory of human development, standpoint theorists believe that knowledge and wisdom are often derived from firsthand experience (cf., Harding, 2004; Gergen, 2001). The standpoint position is reached through the process of "intellectual and political struggle against societal oppression" (Gergen, p. 31). Certainly experiencing a disability firsthand has caused

Michael struggle in his own life, and his narrative reflects this. Consider his response to coworkers' unsolicited advice after he received burns recently (in 2003) that required extensive skin grafts by spilling hot liquid on himself while preparing a meal.

> Michael: But I want to say one more thing about the Council. I can't believe the way they treated me after my accident. They thought I should not be able to cook for myself, because of my disability! They thought I should have an attendant! It was bullshit.
>
> *MA: Isn't that up to you? You can do whatever you want.* [6]
>
> MW: Thank you. Now you know what the mindset is in Arizona.

In this next excerpt, Michael referred to a time when he was left sitting on the tarmac after deplaning in Washington D.C. when he returned from a trip this past summer.

> Michael: I think I put up with more bullshit now, than I did 10 or 15 years ago. I would not have had to sit on the tarmac for twenty minutes the other day and nobody came to tell me what was going on. It was hot, and it was noisy. Maybe they thought I couldn't hear because I have a disability. I got so pissed off. And then, when I said, "I need a bus to get to my car!" They looked at me like, "You have a car?!" And I said, "Yes, I have a car."

Michael's comment, "Maybe they thought I couldn't hear because I have a disability." and the shock that he could drive a car, reflect Gallagher's (1995) notion of "spread"(if a person has a disability, it must be pervasive and preclude all other functioning) [likewise, Turner & Louis' 1996 *difference as dichotomy vs. matter of degree*]. This incident is also upsetting because it shows disregard for his personhood by the airlines employees.

Because his disability has put him in a minority role in our society, his is not the discursive style of the dominant able-bodied White male. The amount Michael has

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[6] I recognize that my comments here are not neutral; I present them in the interest of preserving honesty.

experienced oppression and personal struggle has presumably enabled him to present himself differently.

Dr. David Johnson was born in 1951 in south Minneapolis. By his own account he grew up in a working class neighborhood. Of all the participants I interviewed, Dr. Johnson's narrative style was the most classically monomythic and unidirectional... reconstructing his career trajectory with himself as the central character.

In the following excerpt he shared information about his family and an older brother with severe disabilities whom his parents elected to keep at home- at a time when virtually no one else did this (1945) and there were no support services available to his family. Despite the enormous burden this must have been on them – his brother required "constant supervision"- David's retelling was largely impersonal- even using some third person language and clinical terms. Yet it is likely that growing up with a sibling with a severe disability contributed to his development as a special educator (and related roles), evident first with his volunteer work at a state hospital for persons with developmental disabilities in Minnesota as an adolescent. As noted by Pamphilon (1999), "Events happening in childhood often affect fundamental values and expectations, such as family values and assumptive frameworks. In adolescence and early adulthood, effects will be seen on opportunities and life choice awareness and identity choices, such as vocations" (p. 399).

> David: My own personal family orientation to disability is very immediate, and I think that's not uncommon with other people. You know I have my brother who is now deceased, 6 years older than me, ah - was part of our family home. He, his disability was very pronounced - it would be regarded as profound mental retardation. He was ambulatory, but in - born in 1945, in that era it was more common to institutionalize children than it was to keep them at home. So she -my family, my mother and father, decided to retain him in the family home. Of course

there were no educational services, there were no social services, or residential, nothing really in the community at that point so you - it was a major decision - I never really understood it then.

MA: *It was against the doctors, right?*

David: All the doctors told them to have him put into Cambridge State Hospital you know in Minnesota here – ah - she fought that- they fought it- you know, and he, you know the nature of his disability was such, it was so severe that he needed 24-hour supervision, so it really required a pretty heavy load on my mother as well my brother and my other brother and I, for care and all that; anyway, it makes a big impact on you. So I don't know; you know I basically went through ah - you know public school - and did some volunteer work up at Cambridge State Hospital when the population there was over three thousand. So it was some connections there, over the years; no real intent to stay in any disability related professional career.

The youngest of my group of informants was Dr. Romie Tobin, born in the mid-1950's in Denver, also into a large Catholic family. She is a gifted storyteller, using multiple anecdotes and reenactments which bring both a sense of immediacy and engagement to her narrative. Her style is also markedly relational, reflecting integration of her personal and professional selves. Like Madeleine, she used the "we" pronoun throughout, in a personal and very thoughtful recursive account of her history. And, like the others, her narrative opened with the story of her own transition from high school to post-school experiences.

Romie: When I started into college, I had no clue what I wanted to do with my life, and so, um, headed up (I remember this so clearly, it's funny) to the University of Wyoming for orientation. And I thought it was like getting oriented to the layout of the campus and where the sororities and fraternities were. Anyway, when it came time to do our pre-registration, I had never looked at courses, I had no idea what I was doing, and it was very scary, and I ended up interning as chemistry major. That's how I started school. After my first semester - you know, I did it because that's what I had excelled in, in high school was sciences, I also think I was pretty shy - and the reason I say that is it will be important as we go through this- after my first semester, then I decided to go into food science and nutrition.

MA: *How'd that happen?*

> Romie: Well, this is one of those things I'd rather not remember, but that's okay, I won't say "don't quote me". Dan, my former husband, we'd started dating in high school, like at the end of our junior year, and his Mom was a registered dietician, and so, I guess it was the summer between my junior and senior year, I worked at [the] hospital where my dad was on staff, and Dan's mom worked as a dietician. So I was a dietary aide, and I kind of got the feel for what hospital dietetics was all about and stuff. So I mean, there wasn't anything else that I really had huge visions about, and I guess now when I look at education for all kids, whether its kids with disabilities or your typical kid, I think <u>everybody</u> needs better career prep in school! Oh yeah! Because I didn't have a vision, <u>any</u> vision of what I would be doing. I mean, I guess that I thought that I would work, but I didn't know what career options were -- I just thought college was the next step of what you were supposed to go and do, but I wasn't thinking of it in terms of being prepared, you know, preparing for my career.

At this transition point in her life, Romie was largely unfocused, naïve about college, and had not entertained career dreams for herself. Also, despite the fact that her father was a medical doctor, which may have helped her get her first job, she identified with her boyfriend's mother and worked as a dietary aide- probably a gendered choice, reflecting the dominant cultural discourse of the 1970's: women work outside the home, but they still largely do women's work; teachers, nurses, dieticians are examples. She also theorizes about her past with contemporary knowledge (Dr. Tobin is currently a transition specialist working for the Colorado Department of Education - recognizing what she did not know in her own transition, and now helping to change that for others.) As we will see, her lack of real direction changed dramatically with the birth of her first child, also a son born with Down syndrome. At that point, two years after beginning college, her life came into sharp focus, and she developed into a self-directed intellectual and advocate for her son -as well as other persons with disabilities, and a remarkable mother.

Career Paths & Personal Agency

Recall that narrative analysis "can demonstrate intersections of social structure and human agency in ways that are more empirically rich and theoretically nuanced than other techniques" (Laslett & Thorne, 1997, p. 20). As well, they offer a methodology for linking personal perspective and experience with public life. Smith (2000), too, acknowledged that "Oral history experiences tap into a continuous outpouring of words that provide matrices defining both community and individual identity" (p.347). In this section, I have examined participants' career paths as they have been influenced by the transition movement, and because of their individual elite positions in valued professional roles, have in kind helped to shape it.

These informants know the conclusion (i.e., they know where their careers have taken them); they also knew of my interest in the transition movement; as a result, they have structured their telling in events that made sense to them leading to their current roles/ identity related to youth with disabilities and their transition from school to adult living. Where they shared information with me about their personal lives and families, I included this as well.

There are other common themes across the informants' stories: relationships with persons with disabilities, the influence of various mentors, relationships with colleagues and family members, and common understandings about society's relationship with persons with disabilities and the history of the transition movement. All of the change agents have had a high degree of formal education, and numerous professional (and

personal) experiences which have contributed to their leadership skills and ability to make a difference in their careers.

Bill

Once Dr. Halloran had told me some about his career, his interview style was conversational, and he did not answer many of my questions directly. While this was initially challenging for me, when I let go of my agenda, it allowed me to see both how he constructs meaning, and glimpse what is important to him. He kept refocusing our discussion toward the larger context of social problems, and the relationship between poverty, race, class, crime and disability in our society. A social justice theme was also prevalent.

> Bill: If you want to know "what works", study poverty. It's not about getting students to stack cups or stamp envelopes! *It's the system that is very sick.* Look at our prison populations. We have over 2 million adults incarcerated in this country—more than any developed country. And our poverty level is set twice as low as any European country. We need [a different administration].

There were also references to his family members, revealing the caring at the core of this man. He has three daughters, one of whom I met; and two are pursuing special education related careers (undoubtedly because of his influence). He is also quite involved with and proud of his grandchildren. Respect was a central theme throughout Bill's narrative; as well, there was an underlying sense of his spirituality. Respecting persons with disabilities – and other marginalized groups- as whole people seems a core value. Another recurrent theme for Bill is recognition and appreciation of the complexity of human beings, and his impatience with others who don't seem to get this.

> Bill: Bellamy and a lot of folks in early voc[ational] work with students and young adults with disabilities were totally enamored with Skinner [B.F. Skinner]. Sure, we can get people to do certain tasks a certain way given certain conditions, but how respectful is that?! I would say to him, "You have no faith in human

beings, the way you operate! You gotta have faith. Everything doesn't fit in a neat little box!"

Bill: I have problems with operant conditioning, because it is disrespectful to people. I also have problems with people who codify and oversimplify information. There are hundreds of ways to slice a pickle, and more ways than that to view the slices. Counting the green bumps is only one.

Over the course of his career, Dr. Halloran has worked with and for all kinds of children and youth with various "special" labels. In the next exchange, he referred to a time, some 25 years ago, when curricula for youth with more severe disabilities was focused on a "functional life skills" approach (consistent with the literature; see, e.g., Brown, Nietupski, & Hamre-Nietupski, 1976; Sailor, et. al, 1989). Teachers and related service personnel often conducted "ecological inventories" of adult environments, determined the skills needed for successful participation there, and then identified skills for instructional focus which matched current and future environments for youth- a practical approach to curriculum development which made sense to Bill. There were also several outcomes studies being done on graduates of special education at the time (cf. Hasazi, Gordon, & Roe, 1985; Hasazi, Gordon, Roe, Finck, Hull, & Salembier,1985; Rusch & DeStefano, 1989) which reported what Bill mentions- there were interminable waiting lists and an alarming paucity of services- especially quality support services for young adults with disabilities.

MA: *In your career work, you've focused on transition-aged youth with disabilities?*

Bill: Yeah, pretty much.

M.A. *And milder cognitive disabilities?*

Bill: No, not really. The whole range. For a while I was a lot more interested in the most severe. This was 25 years ago, and the whole things was, you take the skills that you need to live and work in the community, and lattice backwards to

> the secondary curriculum. You were looking at an adult environment; you needed to know that to do the curriculum. One of the things I found out in my research there, was... what happens when people with the most severe disabilities leave school... and basically what was happening was, at that time, they were screwed. The bus didn't come; they joined waiting lists for services that were far longer than any chance of getting into community based services. That was fun—and I do think it did bring about a lot more focus. I also worked with a community-based organization that operated community-based residences for kids with severe disabilities. Initially it was for people who were elderly parents who had disabled children; their question was "*What's going to happen when I die?*" It was also for people who were being institutionalized. It was a long time ago.

As mentioned, Bill advanced his career advanced through the benefit of federal training initiatives.

> Bill: About 1964, there was just the emergence of a real call for special ed at the time; that was 10 years before 94-142; actually, myself and about four other colleagues, somebody told us about this Masters program, it was completely paid for and that sort of thing, and we did it together... By the way, all of my degrees have been supported by certain federal programs that came along- after identifying critical need areas for personnel...my doctorate was in Administration of Vocational Education. They paid me ... to go. I made more money going for my doctorate there than I did working.

Bill's comments then turned toward current political and social contexts, in his view, for youth with disabilities in our society. For this reason, the remainder of the analysis of his narrative is integrated into the next two chapters.

Madeleine

Several themes emerged in Madeleine's narrative. She shared bits about her son and his progression through school, as well as his transition to adult living, and although this was woven throughout our conversations, I have pulled out those excerpts and begin this section with them. Then I have analyzed information she reconstructed for me about her career.

John

Both Dr. Tobin and Madeleine gave birth to sons with Down syndrome. Madeleine's son John was born in 1972, 3 years before the passage of P.L. 94-142 (the EHA). As noted, education was not well developed for children with disabilities (and public school access was not yet the law); there was an even bigger lag between the medical and education communities in their treatment of persons with disabilities. Many medical professionals still advised their patients to institutionalize babies born with known differences, although this was changing (as evidenced in both Madeleine and Romie's experiences.) Madeleine sought support to keep her son at home; in her words:

> M.A.: *When your son was born* [in 1972], *did the doctors advise you against taking him home?*
>
> Madeleine: It was a mixed message that reflected where we were socially, societally. Some people said institutionalization, but we had a neurologist who talked about the fact that he knew some families that had taken their child home. And that it could be done if we wanted to do it. That was very wonderful to hear at that point. So we did. We brought him home. He was a part of us.

Like Romie, Madeleine went through a period of significant adjustment with the birth of her son. She had to seek out services on her own and experience personal angst and waiting lists until she was able to find support, a pattern repeated at each new stage of his development. (In many places today [large urban centers in the United States], when a child is born with identified disabilities, appropriate social service and early intervention agencies are notified, and they send workers to new parents to inform them of services that are available.) This was not true 30 years ago [and is also not a given today, as funding for social services and early intervention have recently been reduced and in some cases, eliminated] (personal communication, Julie Nesnansky, Early Intervention Specialist; August, 2004).

> Madeleine: We didn't have any prior early intervention, so we enrolled John in Georgetown University in the summer and it was supposed to start in the fall and they called in the summer and said that he was put on the waiting list. I remember crying my eyes out because I was counting so much on him being able to get early intervention ...they ultimately accepted him...maybe they got more money, I don't know what they did.

Madeleine's son experienced many "firsts" in terms of educational opportunities, newly developing in the 1970's. Like other parent groups banding together across the country, she worked with like-minded parents to advocate for, and develop services (cf. Lipsky & Gartner, 1997). The next excerpts elucidate some of her son's educational experiences and progress. Madeleine mentioned "Bud and Ann Turnbull", parents of a son with a disability who also have a national reputation in the disability community for advocating for and successfully creating new opportunities for their son, and other children with disabilities. And despite the fact that John's programs did not have "all the glitches worked out", Madeleine reflected on them with her current knowledge, understanding and acceptance [wisdom] - "That's where they were in their development."

> Madeleine: So his life sort of parallels what was going on in those decades. He was in the first integrated preschool in our county, which we parents created. He was in the second class of a group of children in a regular elementary school and the same followed through in high school, the same thing. Do you know Bud and Ann Turnbull? Their son Jay had been in high school the year before John. They were doing some kind of work in Washington. And John was in the first class of the post-secondary program at the community college, which was not very good, a very weak program, but it was there.
>
> MA: *He's been on the cutting edge all the way through school?*
>
> Madeleine: He's been able to, you know, he's had some good opportunities. I wish that all the things that he's participated in had been, had all the glitches worked out. But at least he, that's not where they were in their development, and he did benefit from these opportunities, for inclusion and innovation. And he always had a focus on reading instruction. Just the teachers we had were always willing to do a lot of work on reading. For that I'm grateful. We had wonderful transition services, too -- without asking, without doing anything, they were just done. They were great.

MA: *Was the transition program in Washington, DC?*

Madeleine: Well, we lived in Maryland. Montgomery County has a huge school district, the tenth largest in the country. We have very good transition services.

It was very unusual to have reading instruction for children with developmental disabilities until the 1990's, when inclusive practices and access to general education classes and curricula became more commonplace. It was also unusual to have high quality transition programming in place in 1990. Describing the discrepancies between school districts in terms of resources and services in his interviews, Dr. Halloran commented that the school district Madeleine was from was an affluent one.

Bill: You don't know what happens around here. She's from Montgomery County, Maryland- a very affluent area that has services. Fairfax County, Virginia has services that are just fantastic. The DC public schools have [nothing]!

I asked Madeleine whether John's high school provided some career planning, and community-based instruction. She replied:

Madeleine: They did all that. He had internships in school; he had done a series of internships out of the school. He went right into the government at age 21 -- they got him the job at [National Institute of Health] NIH. But it didn't work out, because I don't think he was ready. I don't think he had the skills and it wasn't a good match for him. It required him to be on a shuttle, going around a campus and delivering mail, by himself. That was not a good match for John. He needed to be more in a nest, not be on his own all the time. His next job was with a nonprofit organization that had a grant from the Federal Government -- the National Consumer League. They do a lot of work around consumers' credit card law, and that sort of thing. And John, he was one of a few people who worked on this grant. That was a much better fit. He did very well there. He worked there for five years. The grant ended and he lost his job last year.

In the next section, using reenactment in her retelling, Madeleine talked about a solution to John's current joblessness, her parenting style and obvious affection for her son evident.

> Madeleine: So he is going back to the post-secondary program in the fall, for a year at least, maybe two years. You know we're hoping that the job internships that he'll have in the afternoon there will be a springboard to a new position. So he says, "Mom, homework?! No!" So I say, "John, have you ever heard of this phrase, continuing education?" "No." So I said, "Well, sometimes people have to go back to school to learn new things, brush up on things, so they can move forward in their career, change directions. It's called 're-tooling'." So he says, "New hammer?" [She laughs.] So we'll see.

Madeleine has her own dreams for her son that are perhaps slightly different from what he wants, shown in the next example- yet she recognizes and appreciates who he is and values his sense of community, and is able to balance what she wants for her son with his preferences.

> Madeleine: He lives in an apartment with a couple roommates. He loves that. It's sort of interesting. I would love for him to have his own home. He doesn't want that. He loves where he is. He loves the people, he loves the apartment complex. There are about 500 people who live there. And sixteen of them have disabilities and they're in apartments two or three to an apartment. They have a wonderful time with each other. They've made a lot of other friends in the complex, but I don't rule out the home -- maybe later in his life he might want it-- he has a girlfriend, and he wants to get married. We don't control that.

John's "supported living" situation represents the ideal of what is possible in our society currently for adults with developmental disabilities. While there are many variations of his apartment complex situation, more often than not quality supported living options are not readily available to everyone...it takes *at least* an educated, caring and persistent advocate, good fortune, and ample resources to create and maintain such an opportunity.

Madeleine's Career

The narrative of Madeleine's career progression holds several important themes. Firstly, meaningful or righteous work is very important to her; work that impacts societal transformation, access and support for persons with disabilities. Relationships with

colleagues are important to her too, as she frequently acknowledged others' skills, talents and contributions. In the following excerpt, she described mentors who influenced her before her work in Washington D.C., when she worked for the state legislature in Annapolis, Maryland.

> Madeleine: It was very educational; I had wonderful mentors. I had one of the principal founders of the ARC as a mentor. And another wonderful attorney - they were both attorneys- in their then, 70's and 80's. They had lived amazing lives. One had come to Washington to work for the Office of Strategic Services (OSS)[7] during World War II, and the other had been a very distinguished civil rights attorney; had worked in the south, and had had his life threatened many times. He worked for the Department of Transportation that was integrating buses and planes; not very popular work at that time. They were both brilliant attorneys and political lobbyists, so I learned a lot.

Madeleine is credited with bringing transition issues for youth with disabilities into focus nationally, during her tenure as the Assistant Secretary at OSERS under Reagan. (Romie referred to her as "the Mother of Transition".) Madeleine was quite strategic about this; she went to visit programs where adults with disabilities were working, and also sent colleagues; she invited experts in systematic change to brainstorming sessions in Washington D.C., and garnered support to draft transition regulations, develop transition policy, and secure and channel sizeable federal dollars into multiple transition initiatives (reviewed in chapter 2).

> Madeleine: [Tom Bellamy's] a great man, one of the people who demonstrated originally (in the '80s) that people with significant disabilities could work. So exciting...
>
> Madeleine: I hired him. He came to Washington to be the Director of Special Education programs; but before we hired him, I knew of his work. I had gone out to visit programs he had set up where people with significant disabilities were working. It must've been in Oregon, the Portland area. And it was so exciting to see; so transforming. I then had to convince my staff that this wasn't crazy. 'Cuz they were buried in bureaucracy and were not captured by this concept at all. So I

[7] Although the OSS was dismantled in 1945, it was eventually replaced and it's mission expanded by the establishment of the CIA in 1947.

> sent a couple of them out -- they also didn't accept inclusion, so I sent them to see that [too]. So once I had a cadre of people who were on board, we could accomplish a lot.
>
> Madeleine: I have fond memories of Tom and the impact that he and others like him had.

In the next excerpt, Madeleine reflected on the purpose of her "Bridges" publication—created with a group of informed others.

> Madeleine: It was to articulate what we were doing. We were starting new programs using discretionary monies...putting the emphasis on these areas in addition to supporting employment -- without a voice -- it would've taken a lot longer. So we had to lay it out for people, explain it to people, what we were trying to do, and what the future was. That paper - I'm not an academic, but I understand academia - you need a paper; you need to have something people can receive and criticize and cite. We had two different teams that worked on developing this paper. It also was useful for us because in the course of our discussions, issues arose that we knew we needed to address. Like professional issues, that would have implications for professional development. We were advocating what we were creating. We focused our discussions on a lot of things like that. So we had a series of meetings on issues and conferences where we brought in people from the field, advisors to help us think through -- if we were going to change the world, what were the logical steps we would have to go through to enact change. So those papers got people thinking.

They did indeed. With the publication of "Bridges" and the attention it received, as well as the activities described above, Madeleine and her cohort were able to incite a national movement. This was corroborated by the other informants. Virtually each of whom, independent of one another and unprompted, identified the publication of this paper, and this time period, in this way. For example, I asked David:

> MA: *Do you identify a time period as the "transition movement" for youth with disabilities?*
>
> David: Yes, in 1984, with the Madeleine Will declaration of transition as a priority, probably is an absolute capstone moment I think that led us there... I think since that time, we've always had the focus around severe disability-transition really was for many years a priority focus around kids with more significant disabilities... 1990 [IDEA] opened up the game to everyone. It took almost a decade to get us to a point where –in examining the performance of

> states in relation to a set of regulations about transition really did transcend high incidence and low incidence disability, so transition now is very much framed as a total movement for total –issues for all kids in special ed.

And Susan commented, "Madeleine Will's article was absolutely pivotal, because it set the policy agenda." Romie referred to 1984 and Madeleine as the "mother of transition"; although Michael gave less iconic praise (consistent with his narrative style), he did say, "I will give Madeline Will, Regan's second Assistant Secretary for OSERS, credit for highlighting the emphasis on transition and early childhood education".

After her appointment in the federal government ended, Madeleine actively sought new learning and continued ways to make a difference for persons with disabilities at home and abroad. She wanted to see "other education systems" and instead learned something else; even when she encountered blatant examples of unevolved attitudes toward persons with disabilities in Europe, she was nonjudgmental; instead her narrative reflects understanding of the complex nature of oppression and her appreciation of others working for societal transformation.

> Madeleine: After government, I spent four years traveling in central Europe, working for AID-funded organizations that were trying to train professionals working with people with disabilities in those countries, Hungary, Czechoslovakia, Russia, Bulgaria. ... I wanted to look at different systems of education. I had misgivings about our law and the problems with our law on the way to implementation. I had many important insights that came from my work in Central Europe, but not necessarily the ones that I expected, because they were -- it was like stepping back in time. They were so far behind. They had statutes that forbade people with disabilities from going to school. So we were actually working on the development of new legislation. But I learned a lot about social attitudes, how these attitudes have developed and how they can change. I saw people put their arms around kids, bring their kids to them, because a person with a disability was walking by. So the contrast between where they were and where we are was quite dramatic when I arrived in Eastern Europe.
>
> Then going every year for a period of several weeks, they were desperate to change. They knew that they had missed important developments. They hadn't been permitted to participate. They transformed their societies. Now then, you

> know, they have a long way to go. But it's fascinating to me that the people who were instrumental in the leadership for change could change these bad laws -- eliminate the bad laws, create programs -- were often people who had suffered under the Communist regime.

The motivation to "transform their societies" stemming from personal suffering that Madeleine describes is a tenet found both in Wilber's theory of human development and spiritual growth (Wilber, 2000), as well, in standpoint theory (e.g., Harding, 2004); a particularly striking example follows.

> Madeleine: For example, one man, who became the minister, deputy minister, in the Ministry of Education, had had a family member in a prison camp for years and years and that person became physically disabled as a result of the bad treatment that he received as a political dissident in the prison camp. It caused this man who became the deputy minister to completely refocus his life and to empathize. He saw that just the aspect of the tyranny and the oppression, which he understood, but he looked at disability separately and objectively, and began a whole transformation of the society.

After this work, Madeleine returned to the United States to assist with the reauthorization of IDEA. This was the one time in my conversations with her that she expressed indignation; it was toward what she articulated as "the backlash against people with disabilities" evident in the fight she and colleagues had developing and passing the revisions. She felt that this was indicative of a more pervasive devaluing of people with disabilities.

> Madeleine: So then I came home, so to speak, and worked on IDEA '97. My friend who had been the deputy in OSERS said, "Madeleine, we're having a hard time with this law, could you come work with me?" She was then with the National Parent Network on Disabilities, and I said, "Yeah, Patty, I've got four months." Four and a half years later, we were still struggling with that statute. It was the most- it was the hardest thing I've ever done. Emotionally, physically, in every way.... It started in about 1994 -- it took 3 years -- it was supposed to take one year.
>
> MA: *Why?*

> Madeleine: Because it was a contentious, nasty, bitter fight. What you had was a backlash against people with disabilities. We are, you know, we like to minimize things -- the expense, the hostility towards this population -- especially when it involves inconvenience and cost. It's [angry tone] ultimately about the value of these people.

For the next four and half years or so she worked for Community Options, a regional provider of adult services, employment and housing based in New Jersey, with a research arm in Washington, where Madeleine focused on grant writing and employment innovations; this excerpt again reveals her purposeful self-directed learning and insight.

> Madeleine: And the reason I did that work was that I wanted to understand the issues from the provider side - and then that was a very enlightening experience for me. The absence of capital for providers to create alternative or innovative programs, the impact of the horrible bureaucracy on their ability to be dynamic, to do anything, you know that was really different.

She is currently with the Policy Center for the National Down Syndrome Society.

> Madeleine: " I've been on the board -- I was on their board for about 6 years and now - they wanted me at the Policy Center and I wanted to be a part of creating that, because I have very strong views about how we reorganize the grass roots. I have 170 affiliates, you know the ARC structure and the UCPA [United Cerebral Palsy Association] structure, there are often -- I was a part of those battles in the '80s when we were struggling between "Do we provide services or do we just do pure advocacy?"-- Most of the ARC and the UCPA went in the direction of providing services. That gives then a funding stream and the ability to organize at the local level. And then we have the state ARCs. Most of the organizations that represent disabilities that are *not* providing services; they do not have the resources to organize particularly at the state level -- a state level kind of coalition -- and that was severely hampering our ability to bring about the policy change we wanted. So that's something we'll be working on for the next few years.

Three final themes were prominent in Madeleine's narrative; one is her profound belief in social justice and access for persons with disabilities; another is her inspiring perseverance with the disability movement -- she feels a sense of personal and spiritual responsibility to stay involved, and that this is the higher purpose of her life; and the last

is a concern that this work will continue with the next generation. Madeleine was the only informant who addressed the latter directly. Erickson (1982) noted in his model of human development that this concern comes at the highest stages of mature personal development (concerns with "generative versus self absorption and stagnation")(in Dacey, 1982).

> Madeleine: Sometimes I've gotten tired, after IDEA '97 I was so tired. I've pulled away, but I always come back. There's something compelling in the morning, when I stand up in the morning, if I'm not thinking about this or working on this, I'm not happy. I'm not totally happy with myself. Maybe I'd like to do something else. There are times when I'd like to go do my international relations work, but this is a revolution in our history. It's so important in the history of civilization. And our country is in the forefront.
>
> Madeleine: How can I say, "Oh well, I did part of it, and now I'll go play golf or something". *It's just -- it's not over yet -- not by a long shot.* So I never have to think whether the work I'm doing is important, which a lot of my friends do have to think about. What's hard is we're outnumbered. We don't have the resources, and all those things. But we have wonderfully committed people and I hope a younger generation taking the controls. For awhile I was very discouraged because I'd go to meetings, there's me, and Patty who's in her 70's, and people who have [age-related hindrances] -- all gray hair -- where were the younger people? In the past couple years I have seen a big change. There are young people coming up and they're very competent and committed; they're going to do great things. So it's fun to be a part of that.

Susan

Another powerful change agent who has influenced the transition movement through her teaching, advocacy work, and prolific research (especially in the areas of special education and transition policy analysis, personnel preparation and collaboration, and follow up studies of special education graduates) and dissemination activities, Dr. Hasazi's narrative reflected her strong sense of personal and professional agency- her confidence and expertise in identifying needs, finding solutions, and implementing

change. Her voice was active throughout her interview; she used multiple causative expressions.

Obviously very bright, Susan understands the complex forces which contribute to and drive systems change. She values education, understands the relationship between policy development and implementation and sustaining change; she too has helped to shape the transition movement as much as her career has been shaped by it. Originally motivated by her concern for her graduating students with disabilities - *What happened to them?* , she has conducted several follow up studies of special education graduates (e.g., Hasazi, Hasazi, Gordon, Hull & Johnson, 1989; Hasazi, Gordon, Roe, Finck, Hull & Salembier, 1985; and Hasazi, Gordon, & Rose, 1985), studies which have been instrumental in redefining the parameters of quality transition programs at the secondary school level, in Vermont and across the United States. In her words:

> Susan: We continued from 1982 on, 'til probably 1992, developing transition programs throughout the state, putting together core transition teams, conducting follow-up studies. Using these follow-up studies from all of our school districts to actually drive change by reporting back to all the districts what had happened to their students once they left school and actually providing technical assistance through a 5-year grant from OSEP to use our data and our system of collecting the data to drive change at the local level.

In spite of the lack of information shared with me about her family, Susan spoke of several relationships important to her and her career, with women and men. Dr. Hasazi majored in special education and elementary education in college, obtained a teaching license, and taught first in California, in a self-contained class for students with various disability labels as a regular elementary school, and then in Miami, Florida, where she was immersed in a multicultural environment. She then moved to Vermont and

pursued a Master's degree... through an innovative Master's program offered at that time through the Bureau of Education for the Handicapped.

> Susan: At the time Ed Martin was the Director of the Bureau of Education for the Handicapped [BEH was the predecessor to OSEP]; he was the first governmental advocate to head this new bureau. He had decided that one of the ways to ensure that children with disabilities were treated appropriately in schools (and were, in fact, *in* schools) was to prepare a very competent, highly skilled workforce. So he advocated with the Congress to provide fellowships to train highly skilled special educators who would be able to consult with general education teachers as well as special education teachers. It was a 60-hr Master's degree with internships all along the way. I would say that over my 35-year career, it was really one of the most rigorous programs I ever participated in. It formed a basis for me, learning to understand how systems work, as well as organizations, and it went way beyond just the content of special education. It was a 2-year program funded by the Bureau of Education for the Handicapped.

The program attracted talented students and refined their skills in such a way that each of them worked in leadership roles afterward. Comprised of experiential learning, these students applied their new skills to institute "real" social change during their graduate work. The efficacy of this model for adult learners is consistent with the success of experiential learning for children in the literature (cf. Chow, Fleck, Fan, Joseph, & Lyter, 2003; Rogers, 2002). The cohort effect was also powerful; Susan is still in touch with some of her peers.

> Susan: It's interesting... [that] the majority of us, many of us who went through that initial program, I would say over the first 7 or 8 years of that program, most of them are in leadership positions: superintendents, principals and a few commissioners. I think the basis of that consulting teacher program, which was very intense, very applied, very research-based, attracted a lot of amazing people -- most of whom came from outside Vermont, not from Vermont. They've just continued to be in major leadership positions ever since then. The training was so good.

During that time, Susan met and developed an important relationship with a mentor that continues today.

> One of the advocates in the state at that time, and still is, was a Sister of Mercy. She began the first preschool program for children with disabilities. This was way before 94-142. She also was the Director at the time of the ARC (Association for Retarded Citizens) ... She worked together with the government and the legislature, and all of us that were part of that first cohort of consulting teachers, our internships were actually working in the legislature and in our communities to make sure that the law passed.... she was one of the most brilliant strategists I'd ever known regarding policy issues and how to make things work at the state and even the national level. She was and is a powerful woman mentor. We are still the dearest of friends and are involved in advocacy issues together.

Following obtaining her Master's degree, Susan's skill repertoire rapidly expanded and included several leadership roles, eventually leading to a flourishing career in higher education.

> Susan: From then on I was a special education teacher, consulting teacher working with general educators; then I became an administrator in special education. I could just see that my policy experience had allowed me to think in a different way. While I deeply cared about children and families, I came to a point in my career where I saw myself as a policymaker (school, state, national level).

> Susan: After about eight years in the public schools in various positions in Burlington, Vermont, I moved on to the University of Vermont and became an instructor here and taught special education courses and supervised interns in the same program I'd gone to -- the Consulting Teacher Program. I did for that about 18 years.

A theme common across the change agents I interviewed, Susan turned around and trained others in what had been so influential for her - the experiential consulting teacher's program. (Romie became a "transition specialist"; David, a change agent and advocate for family supports; Susan's comment that ..."Madeleine's focus on transition was a natural outgrowth of where she was with her son." and Michael's legacy is the movement toward self-determination.)

> Susan: I completed my doctorate in the meantime at Boston University, became a professor, was tenured and over time I became a full professor. I have engaged in about $20 million worth of grant writing; a lot of research projects and personnel preparation projects – along the way I got very interested in the whole transition movement. I had started working in high schools in Vermont, and my colleague,

> Sister Janice Ryan, who was the advocate I told you about, she and I started wondering what happened to some of these young people who were in high school in these specialized, vocational programs, who were labeled mentally retarded. I had applied for some funding from OSEP and conducted several research projects, both funded by OSEP and NIDRR (The National Institute of Disability Research). I conducted several follow-up studies, the only contemporary studies that had been done.

In 1982 Susan accepted a Kennedy fellowship and was working in Congress when Madeleine appointed the Assistant Secretary of OSERS. Their relationship proved to be a powerful and productive alliance. When I questioned her about her contribution to the transition initiative which resulted, Susan credited Madeleine. Her response also reveals her spiritual focus, an orientation she shares with Madeleine: "I feel like sometimes things happen for a reason."

> Susan: I have to say that Madeleine influenced me more than anything... I think we were an influence on each other. I feel like sometimes things happen for a reason. Madeleine was the Assistant Secretary at the time and I was so blessed to be in Washington at the time that she was there. Because I had so many connections with families in Vermont, and I always saw myself not only as a researcher but a family advocate, Madeleine and I got along famously from day one. ...Madeleine was the one who was experiencing issues of transition with her own son. Her interest came from a natural evolution of her son and where he was in the transition process. She knew better than I what needed to be done. So the two of us teamed up together -- her from the Executive branch and me from the Legislative branch. We were able to accomplish a lot of things.

Michael

Themes central to Michael's narrative include a normal childhood and internalized sense of self; a wonderful supportive father who taught him to believe in himself; the importance of meaningful work – which for Michael, constitutes impacting leadership in special education nationally, and thus influencing positive change for other people with disabilities; and valuing personal freedom, control, and self-determination. Michael is passionate about his work and his opinions (the latter seeming to have gotten

him into some trouble over the years). He has a good sense of humor, and laughs at himself; and was less protected in our exchanges, than certainly David or Bill, as discussed.

In the first excerpt presented here, he speculated about what might have happened if he had made a different career choice; his sense of both isolation and exhilaration at being "out there" on his own in college are evident, as well as his early interest in supporting self-esteem for people with disabilities.

> Michael: I kind of wonder what would have happened if -- I had made a different career choice. I was about 22, in 1970 or '71, I was in college. There were no other people like me...
>
> MA: *True for most colleges*[8].
>
> Michael: Yeah, I know. Especially then. I didn't know anyone like me! I had no role models, for getting an education, and living and working in the community. I wanted to see what I could do... it was incredible. I did sensitivity training for people with disabilities. And also I was always interested in attitudes. Other peoples' attitudes, and people with disabilities' attitudes about themselves.
>
> MA: *Do you mean self-advocacy?*
>
> Michael: No, not self- advocacy, but self-value. If you don't feel good about yourself, you can't project that.
>
> MA: *What do you attribute your ability to persevere in college, without role models? Did you have supportive parents?*
>
> Michael: My dad, much more than my mom. My mom was very, very overprotective and overanxious. But my dad was incredible! He never said this to me, but I got the feeling that he was supportive of any effort, any idea I came up with. I could try. And if I didn't get it the first time, I could do it over again. And at that time, there were no people like there out me. Which might be a good thing [joking].

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[8] Yes, I wish I would not have interrupted, so that he might have had the opportunity to elaborate. Unfortunately, I think I interrupted a lot in Michael's interviews- perhaps I was a bit nervous over the wait time with his difficulty with speech, and so offered ideas to help him along. How disabled-ist of me! It is humbling to acknowledge this.

After college, Michael applied for and got a job working for the Council for Exceptional Children. The lack of assistive technology at the time made any written work very difficult for Michael. During this time a professional relationship with Bill Halloran grew into a friendship which has endured nearly three decades.

> Michael: I applied for a job at the Council for Exceptional Children. It was an unusual job, but it was a good job. It was a good job, but trying to write was awful. I had to type everything.
>
> MA: *When you use the computer now, do you have an adapted keyboard?*[9]
>
> Michael: Yes. And I can type shorthand, and the computer translates it.
>
> MA: *What happened during, and after CEC?*
>
> Michael: Well, I was working for a very wonderful man named Bill Halloran. It was 1978. We became friends then, and we've been friends since 1979. This was in the Division of Assistance to States, Part B, Monitoring and Technical Assistance. But Bill got me involved with a lot of voc. ed. issues and that was great.

I asked Michael what accomplishments he was most proud of during his time at OSEP, and also what he found most challenging[10]. His responses to both questions reveal core issues and values- his struggle with physical challenges and his ability to reflect on what has been most important in his own life and to teach others about that.

> Michael: I arrived at OSEP prior to personal computers- [this was most challenging]. I used a typewriter, but because I was so slow, I used a made-up shorthand. Some of the secretaries understood it and retyped my work, but it was still slow. Around 1982, by accident I got an adapted computer that would allow me to type a similar abbreviation and generate output on the screen - the actual work or phone. What a difference it made in my productivity and independence! Later on, the Self-Determination Initiative is my legacy. While I definitely had help and support doing it, if it wasn't for me, it wouldn't have happened. The field wouldn't still be working on it today.

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[9] Another of my inappropriate "interview hijackings".
[10] Maybe my future lies in interviewing beauty pageant contestants.

Able to delineate self-determination (Ward, 1988; Wehmeyer & Ward, 1995; Field, Martin, Miller, Ward, & Wehmeyer, 1998a, 1998b; Ward & Meyer, 1999) *and* embody it, Michael has directly influenced instructional content and values of the transition movement. In the next section, he reflected on the political climate while he was working at OSEP in the 1980's and early 90's, and since.

> Michael: I've seen it all. Under Carter, there was much activity and energy to aggressively implement P.L. 94-142 and even the "handicapped set-aside" in the Perkins Voc Ed Act. As soon as Regan came into office, we began deregulation and the erosion of the rights of children with disabilities. In my opinion, this erosion has continued to a great or lesser extent with each successive administration, even Clinton. I will give Madeleine Will, Regan's second Assistant Secretary for OSERS, credit for highlighting emphasis on transition and early childhood education.

The change in political climate and "erosion of rights for children with disabilities" that Michael speaks of will be explored more in the next chapter. Next, he talked about pursuing his doctoral degree, while still working for OSEP, and in retrospect, expresses amazement at his accomplishment.

> In 1980/81 I got bored. I went back to school. I went to the University of Maryland; I went part-time, and I was still working full-time during the day. How I did that, I don't know!

I asked whether his program was funded[11].

> Michael: No, since I was a Federal employee, I couldn't benefit from funds from the program. However, the Department of Education had career development funds. I had to show that a particular course would improve my ability to perform my job ...so the department paid for about half of my courses.

We also discussed the influence of mentors in his doctoral work. Once again, Michael's normal self view is evident in that it does not occur to him that "he was given a lot of flexibility" because of his disability.[12]

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[11] Of course this was motivated by this theme in other interviews already completed at the time.

> Michael: ...I had advisors who helped me plan my course of study and got me through the "hoops," (Brian Cobb was one), but all in all, I was given a lot of flexibility compared to what I hear other doctoral students go through. [oh yeah.] Perhaps it was because I was working for OSEP.
>
> Michael: So I was still bored at the department. And I wanted to get out of it. So I became a project officer in the severe disabilities area. For OSEP. I did that from '81 or '82 to 1987.

Michael earned his doctorate in 1987 from the University of Maryland, in special education, with an emphasis in severe and vocational education.

> Michael: I got my degree in '87. And Bill Halloran was acting head of transition and he didn't want to do it anymore. And they were looking for a new chief... and that was me. So I did that from 1987 to 1996. Then they had a reorganization in OSEP, and I didn't like what I saw. And I said I wasn't going to do it; so I went back to being a project officer. And I was having a hard time at work. It was monotonous and I wanted a change. I applied for a different job [in school-to-work], and when I went to meet with the director of that program, she would only offer me half-time. She wanted me to split the position with OSEP. I think it was because of my disability. If I didn't have it, she wouldn't have done that. And I said to her, "Why are you only offering me part-time?"

This reaction (that he was being discriminated against based on his disability) on Michael's part was largely inconsistent with other self-constructions in his narrative, in which he does not consider his disability. He decided to file a discrimination lawsuit, and while it was tied up, he left Washington D.C. to pursue work in the Portland area.

Unlike the other informants in my study, Michael has not thrived professionally within a particular professional capacity. No doubt this is in part due to his challenging the hegemonic culture and values at various workplaces, at times successfully, and other times, in ways which have left him at odds with more mainstream views and practices.

> Michael: ... I was already gone when the suit was settled and they wanted me to come back, but I said no. I was hurt. It was settled out of court while I was Portland. I was there from '97 to 2000. And my friend, or my former friend, ...she invited me to do an interagency internship. I was only supposed to be

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[12] Not that this *was* the reason; I was simply impressed that he did not consider this as a possibility.

there for 6 months, but then I got on a project, and I stayed. It was for the Administration on Developmental Disabilities (ADD), and self-determination.

Although he enjoyed this work, he expressed disappointment at the disconnect between what he wanted to do and his perceived job description.

Michael: Yeah, I liked Portland and Oregon to live and I liked much of my job and most of the people, but after a while, it got weird. I was working for the UAP, or whatever they're called, and I got totally disillusioned, and I was trying to make more community connections and build more collaborations. I was told--warned over and over again that my community activities weren't "billable" to any of the grant I had FTE [full time equivalent] on. I was working with adults with developmental disabilities. I like doing my own thing. And I think I'm good at it. But I was told by- well, I won't name any names- she and I had a different approach to doing things.

MA: *So you've always pushed the envelope?*

Michael: Yes. So the project was ending. It was a 3 year project, for the Administration on Developmental Disabilities. I didn't want to do anymore federal projects, because there were too many hassles involved. I was hoping to work for the state. And when the project was ended, I was offered a half-time salary, but I didn't think it was enough to live on. Besides, I was offered a full-time position with the Arizona Governor's Council on Developmental Disabilities. I went to visit Phoenix in February. It was nice there then. I hated in July.

MA: *It's really hot there, huh?*

Michael: You have no idea! I applied for the position in Arizona with no real intention of going there. I wanted to stay in Portland...I had done a lot of work with the Developmental Disabilities Council in Oregon and other places (including Arizona), so that's how I made that connection. I ended up working in Phoenix for the Governor's Council on DD for three and a half years. So I hated Arizona. It was really weird there. I worked with the board, and we would have meeting after meeting, and we could never get anything done. Everyone would bring up issues about why we couldn't do something, and we'd go over and over and over it. It was dumb!

MA: *How frustrating.*

Michael: Anyway, then I had my accident [the burn incident mentioned earlier]- I was going to leave anyway, because I didn't respect them, and I didn't feel respected.

Later, Dr. Ward revisited his reason for leaving OSEP in 1997—he felt that because of the reorganization in the department, he was no longer able to have an impact on leadership in the field, which, again, is very important to him. In the next section (the last presented here from Michael's narrative), he turned his attention from his career to the more current climate of conservative political climate, a theme which is elaborated in the next chapter.

> Michael: ...the reason I left in 1997 was because you see it was during that time that the reorganization was in OSEP and IDEA took away the discretionary program part of transition regulations --and it really had nothing to do with --- with OSEP, but if I could not have an impact on the leadership in the field-- I didn't want to be there!
>
> MA: *Madeleine Will mentioned to me that she worked from '94 to '97 on the reauthorization of IDEA, with other people, and that it was a very difficult struggle. The government and other people at the time were trying to chip away at it.*
>
> Michael: I agree with that! I agree with that! But it was very clear that people in the administration were caving into this movement.
>
> MA: *Which movement do you mean? Do you think they were pressured by the whole movement toward standards?*
>
> Michael: No --they were pressured into it by Congressional leadership who believed that the federal government should be telling the state governments what to do...Education is the only profession where the professionals have no control over its direction. Now we have a national policy over what education should be. We aren't going to get anywhere...If you look at the federal government, up until maybe 5 or 6 years ago—policy at the federal level was much more humanistic than at the state or local level. All that has changed now.

David

David also clearly values quality work- work which ultimately makes a difference in terms of state and national policy and systems change. Undoubtedly he also values personal and professional relationships with colleagues and family members. The first

half of his narrative is progressive and sequential as he recreated the story of his career, a multifaceted history into which he has been able to integrate multiple professional and personal interests.

An aspect of David's narrative that surprised me on reflection was his use of language as he told his career story - he often used a passive voice, describing opportunities that happened *to* him, with himself as an almost random recipient. This contrasted sharply with his active self- self as agent –he has been extremely productive and influential in his career. Once he articulated, "it happened, you know", his voice then changed to the active as he described his agency within these opportunities. Opportunities "happened to him", and he then turned them into ventures.

Like Dr. Halloran's theorizing about societal problems, David's instrumental voice left little room for more intimate emotional reflection. Still, when he spoke about his brother, in a quiet tone, there were a number of thoughtful pauses, indicating unspoken content ("silences and other ruptures point to aspects of experience not fully mediated by group interpretation of past events") Smith, 2000, p. 349.

Later, too, he told me about his son who has a learning disability, with a lot of passionate emotion evident, as well, picaresque questioning.

> David: My kid has ADHD; my happiest day was when he graduated from high school. I mean, his was too, I assure you! (laughs.) I was sick of the fight. I was tired of the fight. We have different fights now, postsecondary, but you know, I was just tired of fighting with the high schools. I mean we parted on good terms with his high school, but …

Like Romie and Madeleine, David understands the transition process not only through his professional expertise, but also intimately through his experiences with his son.

> David: My own kid has to take 3 developmental math courses at a community college up in Duluth, before he can take his first, for credit, math course. You know what kind of pain we're looking at?! I'm going to have to hire tutors, all that kind of stuff, to get him through it, because he has very low math skills. But a lot of kids, over half the kids in this country who leave public school, not just half the special ed kids, half of all kids, who enter community colleges and technical colleges, have to take at least one or more developmental courses, non-credit courses, to catch up to the curriculum requirements of postsecondary programs that were not met somehow in their high school experience. They all take a pretest before they go into community colleges now- they rank them. So I took my kid down to the Minneapolis Community College to get tested –he got tested- when we walked out of there, he had to do, just math. He was missing three – they said he'd have to take three math courses. I mean, Jesus Christ, what were they doing in high school?!

David spoke of a famous mentor in college who influenced him and introduced him to the notion of social reform, which became central in his career.

> David: One of the cool things that happened to me during my undergraduate program was that I picked up an advisor by the name of Tom Mertons. …if you've seen the movie, Brubaker, he was Brubaker… Robert Redford played the lead, and it was about the Arkansas State Prison Scandal. He revealed the "Potter's graves". These were unidentified gravesites that were part of the penal prison farm in Arkansas …containing prisoners who'd just simply been killed by guards or other inmates …[Mertons] revealed that whole Arkansas scandal around the use of prisoners on our system of prison farms -- there was slave labor, that kind of stuff, so I was influenced by him…He was very much a reformer, you know, he really dealt with institutions and reform … the best schooling I ever had on deinstitutionalization was from him, and the whole area [of reform].

One way to analyze narrative relative to career paths is through what Smith (2000) called, 'syntagmatic analysis'- or plot analysis. Anecdotes may be presented in terms of offline (complications) choices and online (resolutions) …online choices are those steps taken that ultimately lead to the narrator's career goal, while offline choices represent digressions. Events that occur before the narrator is aware of his career goal, as well as those that may be considered "online", *all* take their meaning from the conclusion- apparent to both researcher and informant from the start (p.355). For

example, while David started out expressing an intention to work in corrections, and to assist draft dodgers (David came of age during the Vietnam war, and was impacted by this) he ended up not working in a prison where draft dodgers were incarcerated in Fairbanks, Alaska, but setting up jobs for persons with disabilities in Jamaica. Perhaps this was no accident- in any case, his compassion, varied skills and early familiarity with differences served him in this capacity- he knew how to relate to these people and how to assist them to help themselves. In Table 4, I have presented an analysis of some of David's early "offline" and "online" choices.

Table 4

Analysis of David's Early Career Choices

Origins: "My own personal family orientation to disability is very immediate...my brother['s] ...disability was very pronounced."
Complication 1: "I had no real intent to stay in any disability related professional career."
Resolution 1: " I came to the University of Minnesota in 1969 and ...took a specialization in corrections here at the University of Minnesota and wanted to go to work with adjudicated youth. I did a year long internship with the Minnesota Department of Corrections working in a variety of settings- some employment related and some half-way houses. I worked as a probation officer for awhile, under a probation officer, just getting my feet wet..."
Complication 2: "When I graduated, there were no jobs for BA generalists like that. There was a recession in 1973. The Vietnam War was winding down, and
Resolution 2: I put in for the Vista program. I wanted to work at the prison in Fairbanks, Alaska, that was incarcerating draft dodgers; I wanted to work in that context to see what was going on. I was actually heading toward prison administration."
Complication 3: ... "but the actual letter I got from the U.S. State Department was an invitation to go into the Peace Corps, and go to Jamaica- the West Indies. I never made it to Fairbanks."
Resolution 3: "So I decided, " Alright, I'll go to Jamaica."...So I went down there, and I was brought in as a B.A. generalist, to help establish guidance and counseling programs in junior and senior highs in Jamaica."

The juxtaposition of the complications with the resolutions created dramatic tension in David's reconstruction of his early career. This time period [the early 1970's] was several years before the transition movement's inception in 1984. In the next section, David described interagency collaboration and vocational training experiences he had which later proved invaluable to transition and his career.

> David: When I arrived there, there was an opportunity that I took advantage of - it was after I was there for several months. The United Nations and the International Labor Organization and the Partners in America Program combined efforts to establish what they called a Caribbean-wide Vocational Rehabilitation

> Program. In addition to that I became a friend to a Peace Corps volunteer who had been in Jamaica for about 8 or 9 years...who had a special ed background, and was establishing the first special education program outside of an institutional setting in Jamaica. --Kind of a community based or community school for special ed kids.

In this next passage, David's alternation between passive and active voice is again apparent, as well, his choice of the verb /object "landed there" symbolizes grounding.

> David: And so I landed there; I was actually living in that community...and so I got connected to both her, and then to this other larger group of people and ended up, by the end of my first year, transferring into and setting up a U.S. Peace Corps component to the Vocational Rehabilitation Program, and actually had a chance [passive] to lead that part for them, so brought in 9 volunteers [active], who I was able to supervise and then train to work on that Vocational Rehabilitation Program.

In Jamaica in the early 1970's, all disability groups were lumped together in "poor" houses. The conditions in which these people lived evidence attitudes of devaluing, "spread" and "otherness" toward persons with disabilities by the general public in Jamaica at that time, but they are also perhaps more indicative of a third world culture, where most people's lives are consumed by working to survive, and they are simply unable to do much more than that. David worked with residents of these homes, setting up micro-enterprises, or "cottage" industries. In the process, he experienced first hand working toward many of the components that comprise quality transition programs today (cf. www.NCSET.org): interagency collaboration, setting up jobs, facilitating natural supports, and creating meaningful work...and despite the horrific conditions created by abject poverty and the lumping together of every "discarded" person, he was not overwhelmed or immobilized, instead he went to action/solution, and worked to change the system. In the process, David saw that work provides meaning, structure and

purpose to living, as well as some subsistence remuneration ...yet he was not yet conscious of his status and natural ability as a change agent.

> David: Disability is not well-defined there -- if you have a disability and you cannot you know earn enough income to live on-- in the community, you really can find what are called alms houses, or poor houses, where it doesn't matter if you're mentally ill, mentally retarded, or just physically incapacitated in some way, you live there, in bed after bed after bed of just horrible conditions, wards. There could be guys shot for drug trafficking in Kingston with spinal cord injuries who end up in wheelchairs that can't make any income, who are provided food and shelter and that's it...then they have a government check they get of $2.00. That was in 1973 - so they get 2 dollars a month from the government, then a bed and meals, and that's it; no medical care whatsoever. It included children and adults and aging and everything else.
>
> If you look at the pronounced nature of how we look at classifications of kids adults or adolescents, it was all one type of a deal [there]. So we kind of got interested in a kind of cottage industry, trying to teach agricultural skills; learning how to raise chickens and bananas...what we now call sheltered work. They were actually making coconut shell jewelry and buttons and stuff like that and selling them to tourists on the north coast. So it wasn't much, but they were certainly making a lot more than 2 dollars a month, and we were actually able to pay them checks.

He and his staff built in natural supports for the clients— a concept which did not emerge formally in the literature until the 1980's (cf., Storey & Certo, 1996).

> David: We operated out of all kinds of places ...for the kids, we set up a workshop and farming area adjacent to the special ed school, [it] had maybe 30 kids in it. So we took adolescents and some young adults from the community and kind of worked them in, integrated them into the whole environment; then we had several locations around the country, where, in Kingston and up on the north coast and all over the place that were kind of either, parts of churches, or schools, or community-based organizations that would grant us, well, you know, give us space to do it. So we had about 5 or 6 of these places going across the island ultimately. We were trying to actually teach entrepreneurialism ... a couple of them, I think are still running now. And just to take advantage of local resources, converting the resources into some marketable commodity and selling it. That it was just for people with disabilities at that time was not a big deal.

An outgrowth of relationships he had which led him to new professional experiences, in 1974, David took advantage of another sponsored training program (like

Dr. Halloran and Dr. Hasazi); his was a Master's degree program offered by the Rehabilitation Service Administration (RSA). Still, his account of this reflects his understated self image at the time, as if he literally wandered into the degree program.

> David: The International Labor Organization brought in some really highly talented people. They were permanently there as full time people to implement this program. It was good. Then I became friends with the Partners in America program-- ...western New York state is partner to Jamaica. So, I got to know a guy from one of the people from the state VR office in New York, who told me about a program, a Master's degree program offered by the Rehabilitation Service Administration and it was free. So I thought, "You know, I'm just a poor kid from south Minneapolis; I have no big resources, this sounds cool, okay." So I took a degree in Vocational Rehabilitation Counseling out of Mankato State.

David returned to the states, where his career then took off. One of his first jobs with his Master's degree was in a capacity jointly funded by the school district and adult service agencies- something he recommends today for promoting collaborative service delivery; and something he understands experientially. His use of the verb/object "picked up" seems symbolic.

> David: And, while doing that, I had an opportunity to do a year-long internship with the St. Paul Public Schools as a Vocational Adjustment Coordinator. And that took me into kind of a school-rehab framework. And there I've been, since then, basically... I actually got picked up and hired by the St. Paul Public Schools in 1976 after the Rehab Program. I worked there for five years, in a special ed, career and tech ed, voc rehab role ...I worked with kids. The main job I ended up having was to develop and coordinate a Vocational Assessment Center. I began to work a lot with boys on house correctional and drug treatment programs, as the program that would transition kids back into the school district from these alternative, correctional and drug treatment programs. [This] linked me back to my interests.

In the next excerpt, David mentions an abuse of the use of disability labels bring much needed resources in correctional facilities.

> This was just after PL 94-142 was passed...and crazy things were happening like, in Minnesota's correctional facilities, basically everyone was labeled as LD. So they could get special ed services into the programs and centers. That's not true now.

The next step in David's career was a move into a position where he influenced the national focus on transition statewide, through research and teacher training. (Again note the jump from the opportunity expressed impartially, and how his voice becomes active once he is in the position.)

> Then an opportunity arose at St. Cloud State University for a faculty member to come in and build a transition program, it was vocational special needs program, teacher preparation, continuing ed outreach. So I taught in a lot of different communities in northern Minnesota-southern and well, central and northern Minnesota, courses on career assessment, career preparation, and school to work [content]. At that time also, I became interested here with wanting to pursue a doctorate and ...so I went into the special ed administration program here at the University of Minnesota. In 1978 I started taking coursework so that went on for a period -[did both] my job in St. Cloud and taking coursework at the U of M, and by 1985, I had an [another] opportunity.

During the course of his tenure at St. Cloud and through his doctoral work, David made many professional connections. One of these resulted in an offer to help start a transition institute at the University of Minnesota... where he would end up conducting research, publishing, giving trainings, identifying other needs, and influencing policy and future research directions at the federal level. He employed reenactment to relay this story, signaling its importance to him.

> Bob Bruininks was now president of this University gave me a call. I had worked on a couple of consulting things with him over the years. And he called me up and said, "I'm trying to start this new thing, do you want to come down and talk to me a little bit about your area of interest, cause I think it's really important to what we're trying to start." So I said, "Okay." --So I came here and Bob Bruininks basically said, "I want to start the institute here, on community integration." So I worked with him, and three or four other people here. We began this in 1985. I took the area of transition, secondary education and transition. At that time, it was called a University Affiliated Program, a UAP. Each state had at least one, some states, particularly Massachusetts, has two of course because of the Kennedy influence. There were a lot of opportunities in 1985 to start centers, like the one Bob Stoddard started in 1985.

David and colleagues competed for and won a federal award to establish the Center for Community Integration – times were changing for people with disabilities. This was just before Bellamy's paradigm shift "from preparation to participation" and Lipsky and Gartner's shift to "era of community membership". There is no doubt that David's center and others like them contributed to these shifts. (I remember reading publications he and colleagues produced as a Master's student in San Francisco in the late 1980's.) Apparent too is the move from medical-based resources facilities for people with disabilities, to education centers (one that symbolizes a shift from attitudes about persons with disabilities as defective or diseased, to valued participants). Additionally, at this point, as David matured into the national change agent he is today, his voice changed from passive to active, and he used "we" a lot, as with colleagues he took charge of multiple systems change activities.

> David: So there was a group of us who began these new centers that were not medically or hospital-based; but rather, within colleges of education or ad hoc to University Vice President's for Research, or whatever...they're dedicated to take on life cycle interests, so we built an early childhood component, we took on a school-age component, kind of a transition to adult component, and an adult services component. And those still remain here, intact. These are large program areas and [many of the original] people have all been here since the inception of the center, so - we've had the benefit of some critical core people. We began development, and I had the responsibility for writing grants, centered around all of these issues on transition. We had three or four training grants always going; we had a lot of work around the state department of education, state rehab organization; we worked through supported employment; all these issues. On and on--In about 1991, we started the National Transition Network. In 1990, the IDEA finally came forward with some language around transition and by 1992 the regs fell into place; and in 1991, the year prior, OSEP funded this major program around transition systems change. So ultimately 46 states and the District of Columbia received these half a year, half million dollar times five; five-year awards--$2.5 million total for each state. We were set into play to provide technical assistance and evaluation; so, [brought in other change agents] and we got together, and divided up the states and started working with them individually.

> ... and that led to a lot of research, ... continuing research on former special ed students in terms of post-school outcomes...We've done work on cost benefits of service delivery models...A lot of things were happening simultaneously as we were chipping away at that grant. And then with the School-to-Work Movement came the funding of the National Transition Alliance...in 1995, which went to the University of Illinois... Our role in that was to do a lot of the direct technical assistance to states, and then, again, a lot of research and related activities.
>
> [This] was all state focused work. A lot of our work here is state focused in policy; state level technical assistance, systems design, management of information [and the like] ...we do very little local practitioner work. We're conducting a ten year longitudinal, a ten year study, really--intervention work on dropout prevention and intervention. And then we've done lots of other work on social inclusion; person-centered planning and [things] like that which relate more to direct individual and family support, practitioner support. And a lot of work on assessment. -- But our work around here is more regarded in terms of national and state policy--that's where we've put a lot of our focus, into that picture. In 2000, they funded the National Center on Secondary Education and Transition [NCSET]--we competed for that, and got that, and here we are. It's all been straight forward -- so basically my entire career has been spent in some way or another dealing with adolescents, and their education and transition; it's been good. It's been fortunate. I really enjoy this area.

Along with colleagues at NCSET and the Centre for Community Integration, and as well in his multiple academic endeavors, David has impacted the transition movement for youth with disabilities directly through multiple large scale systems change activities; in the process, he is helping to reform society's attitudes toward persons with disabilities in the direction of respect, support, and appreciation for what it means to be "disabled".

Romie

Romie's narrative style is as recursive as David's is monomythic. Her use of language is richly adjectival, and these descriptions often cluster around inner states. As she first talked about heading to college without real direction or purpose, her voice was passive, depicting almost a sense of drifting. She wasn't sure what college was really about, she went because that was what you did after high school; she had no career dreams for herself. When she got pregnant, she quit school and followed her husband to

Fort Collins. I got the sense that had Ben not been born, she might have continued to drift somewhat unconsciously through her life. However, Ben's birth was riveting. Romie's voice changes to active as she rapidly develops into a self-directed learner, advocate, mother and eventually, change agent. She and Ben grow up together, and in facilitating his growth and transition, she facilitates her own as well, into the professional she is today. She is good at creating a "you-are-there" sense of immediacy in her storytelling. Her narrative stands out because she is a gifted storyteller.

Romie's experiences with the birth of her son in 1975 also reflect where we were as a society in relationship to persons with disabilities. She had then had little experience herself with anyone with a disability. Her pediatrician suspected that her son might have a "birth defect", and sent her to a large hospital in an urban center to have him tested. She and her husband were just 20 years old at the time; Romie expresses in rich detail her initial reaction to the news that her child had Down syndrome.

> Romie: ...I was at the University of Wyoming for 2 years, then got pregnant with Ben, that summer of my junior year. Then we got married, in the fall, it was like in September. .so I quit school and we moved here to Fort Collins because Dan was here in school. So I didn't do anything; I worked in some retail, part-time jobs, and then after Ben was about 6 months-old, I went back to school, and I finished in Food Science and Nutrition.
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> Romie: ...I was *terrified* when Ben was born. I was just terrified. And really, you know, Morgen, when I think back on it, Dan and I were kids. You know we were 20 years-old, we weren't done with college. We really were just kids. And so by the time Ben was born in March, and I didn't turn 21 until May. So basically I was 21, but I was a stupid 21, or naïve. I was really a naïve 21 year old. I was terrified to know that I was going to have a baby in the first place, but then I figured I came from a family of seven kids...I guessed we could handle it. Ben was about 3 weeks early. The pediatrician came in and said, well, he's really small, but his heart's good, his lungs are good, everything looks good." and then he said, "BUT, then I look at him out of the corner of my eye, ... and something is peculiar." And you know, I about took the guy out! "What do you mean, something looks peculiar?!" And he said, "I can't tell if he looks peculiar to me

> because he's small and he's pretty wrinkly, or if I think that there's something else going on." And so we talked about what he thought was going on; you know, he suspected Down Syndrome but his partner came in and said "Nah, I don't think so; I think he's just an FLK."

Romie's statement: "I was terrified to know that I was going to have a baby in the first place, but then I figured I came from a family of seven kids...I guessed we could handle it." encapsulates both her fear, which she discloses without judgment, and provides a glimpse of her inner strength and identity, not yet developed- but present, nevertheless.

> Romie: I said, "What's an FLK?!" and he said, "Funny Looking Kid." And so, that's how we first found out what was going on with Ben. And so, we took him to Denver when he was 5 days old. I felt like death warmed over at that point. You know, your first baby, you're really stiff and sore, and then emotionally, I think I'd been crying for 5 days. So we went to [the hospital]. It was March, Ben was born on March 1st. And Dan had finals for the quarter, and so he couldn't go with me ...he was going to meet me there after his final. So my folks went with me to the birth defects clinic ...and met this wonderful doctor... they did the blood test on Ben and then they had a whole bunch of other doctors looking at him. It was probably only a few hours, but it seemed like it took all day long. At the end of all of it, she said, "You know, I want to let you know what we're thinking about, so you don't have to wait for the results for 2 weeks. ...Based on all the input from all these doctors, we do think he has Down syndrome." ... I just *totally* shut down. I couldn't hear anything else. I just felt kind of like I was suddenly in a bubble, or wrapped with Saran. It was just like everything went numb. And even when I remember it, it was like that s-l-o-w-m-t-i-o-n voices, you know, in my head. And All I wanted to do was escape. My mom was with me, and *her* experience with anyone who had a baby with a disability was they took the baby away from the parents before they ever got attached. So of course she ... started to cry and said, "Well, do you have to take him away?" and you know, then I perked up. It was like, *"WHAT?!"* and the doctor said "No, no, we don't do that anymore. The best thing for these kids is for their parents to take them home and love them, and you know, just make them part of their family."

Romie's description of her reaction is similar to others experiencing traumatic news. However, the thought of losing her child broke through her defenses and mobilized her, quite literally. The doctor's advice "to just take him home and love him"

symbolizes the paradigmatic shift from protection to preparation happening in society at that time; that is, Ben did not need to be removed to an institution, but would still not amount to much beyond being loved and protected by his family. In the next excerpts, Romie describes the drama happening after Ben's birth, in which her husband, parents and in-laws all align with her in keeping her son, especially her husband--an alliance which gave undoubtedly gave her strength to begin to discover what it meant to become Ben's mom.

> Romie: My mom and I went home and I was a mess. 20 years old, and I'm just a mess. So then our pediatrician called, later that day. And when they did the blood stick for Ben, they also checked his bilirubin, and it was high, so they called our pediatrician here, and he called me in Denver and said, you know you need to give Ben more fluids... and then go back to...[the] hospital and get another blood test...and if it's down, he can go home, and if it's not down, we're going to have to put him on an IV and keep him in the hospital. So [we] did that. And Dan was on his way back; he went to his folk's house, and his mother had talked to my mom on the phone, and Dan's mom was still under the impression that they might take the baby away. And she thought maybe they were going to take him away ... when we went back to the hospital. So there's this side drama of stuff going on. Dan met me in the parking lot going into Children's Hospital, and he grabbed Ben out of my arms and he said, "We're getting the hell out of here." And I was like, "What is the matter?!" and he said, "I think they're going to try to take him away." And I said, "No, no, no, that's what my mom thought, and your mom and mine have probably been talking, but they're not going to do that." And Dan said, "Well, nobody's going to hold him but me!" And so we went in, and they usually want to take the baby cuz it is hard to watch your baby get stuck, you know, they cry, but Dan wouldn't let anybody else hold him. Oh, it can still make me cry when I think of it. That was a hard hard time. [At this point in her retelling, her eyes filled with tears, congruent with the content of her story.]

Next Romie began the process of educating herself about Ben's disability. In 1975, there was not a lot available for her to read. While she sought out information and processed her grief, her deep sense of a normal life trajectory for her son also began to appear, evident in her wanting to look ahead and see what was possible for him.

> Romie: But anyway, we found out he had Down syndrome, and had no clue what to do with him. I remember trying to find stuff to read… and it was like an approach/ avoidance thing. I'd start reading something, and then I'd start crying. Most of the stuff you could get in 1975 was not very good stuff. When the doctor called us two weeks later to confirm the blood work, she recommended a book. And I got this book, and you know, it had the technical information, but it was written for parents. So it was pretty straightforward. You could understand the chromosome layout. And it also had some scenarios at the back of the book, and some stories about adults with Down syndrome, teenagers with Down syndrome, and children. I was trying to get a vision of *what is the future going to hold for this kid.*

In the next excerpt, Romie described trying to find supports for her son. She contacted a local hospital and discovered that they wouldn't work with Ben unless his "condition" was "acute"—they didn't want to "treat" long term "cases". The person on the phone used medical language that the young Romie didn't understand- and left her feeling stupid. The specialist could have apologized once she realized Romie misunderstood, and chose different terms; instead, she let it go, using language in a way that maintained her power in the interaction (I think inappropriately), reinforcing the distance between herself as the "specialist" (in this case, medical) and Romie as the "ignorant" common person (also indicative of societal norms in 1975).

> Romie: Somewhere in this book I read about infant "stimulation". I had no clue what that was. As I read it, contextually, it sounded like physical therapy. I called the hospital… and I said, do you have O.T.'s [occupational therapists] and P.T.'s [physical therapists]? And they said yes. So I talked to them and said, "I have a baby with Down syndrome, and from the stuff I'm reading, it sounds like he should have infant stimulation." This is how dumb I was. She said, "we only do acute, not chronic." And I said, "well, Ben's cute…!" God, that's how dumb I was. But *we only want people we can fix,* is what it amounted to.

But Romie is anything but stupid, as her last statement indicates, "But *we only want people we can fix,* is what it amounted to." She persevered, and began to figure things

out. One of her best sources of support came, somewhat surprisingly- given the last excerpt- from Ben's pediatrician.

> Romie: ... There was a point where I thought, "I'm going to have to be a therapist." Maybe I should go back to school in OT. And then I thought I should go to school as a teacher and learn about special ed, and I think I really believed that special ed teachers knew what to do. It was probably back in an old medical model of being able to "fix it". If you were a special educator, you knew how to teach the kids with disabilities.
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> Romie: The best advice I ever got was from our pediatrician. And he said, "You know, you don't have to be an O.T., you don't have to be a P.T., you don't have to be a special educator, the thing you need to be for Ben, that nobody else can be, is his Mom." That was a very freeing thing for me. I probably would have gone into O.T. or P.T. just for Ben.

The next excerpt shows the paradigmatic shift happening in the medical world[13] (still in process today) where power is being transferred from the professional to the consumer, evident again in the language used to describe the lay person- from "patient" (passive recipient of unquestioned advice) to "client" (partnering with health professionals in one's "treatment") to the self-directed and informed "consumer".

> Romie: Our pediatrician was great. I think he just instinctually knew things – what we would call now self- determination, with patient care. After been was 3 or 4 months old, he said, "You know, you guys seem to understand everything about Down syndrome.", and we talked about therapy...he said, "There's not much literature, but I guess it wouldn't hurt, so you know, go ahead." Later he was totally sold on it, and there was a family who had a baby with Down syndrome after us who he started on infant stim at one month old, based on the progress that Ben had made. And now they start infants in the home with stuff to do. So it was pretty cutting edge at the time. Anyway, our pediatrician was great.

Later, Romie made reference to the fact that, through other examples, he also taught her to question so-called experts' opinions about Ben and make her own choices, "to be a

[13] This parallels a similar shift in education (albeit not fully realized), where power is being transferred from the teacher as knowledge-dispenser, to the co-creation of knowledge between teachers and students, to students as self-directed consumers of quality educational services.

good consumer of things". Romie's knowledge seeking and intuition are further evidenced in the following excerpt.

> Romie: But I found a book on baby exercise. It even had some pictures. It showed you how to roll up a towel...make a little kind of a bolster thing, and lean him over it, put some pressure on his arms, so we did that. And things to rotate and stuff like that and I was just doing that on my own. I had no clue what I was doing, but it gave me something to do, to play with, it was fun. And then when he was about 2 months old, I took him out to Foothills Gateway[14] and I don't even remember how I found out about Foot Hills Gateway. I guess I heard it was another place they had therapists.

Like Madeleine, Romie was drawn into the "world of disabilities" by the birth of her son. In fact, while she was grateful for the support and information provided by professionals, she was also fearful of "losing her son to them" (something I have heard other parents describe). In the next excerpt, she theorizes about her fear in retrospect, that she was grieving losing her "perfect child", a notion supported in the professional literature on the birth of a child with a disability (see, for example, Turnbull, et al. 1993).

> Romie: I still remember crying after the first or second time out there [the facility that provided early physical therapy for Ben]. ... I remember telling Ben, who was sitting in his baby seat, "I'm not going to let them take you away." ...With all of this talk about disability and therapy and Down syndrome and stuff, it felt like they were trying to take him away into this world of disability and I wanted to keep him back where he was just my perfect child. At home, I could forget about disability, because he was just a baby, and he nursed, and he played and he cooed, and he did all those baby things. And then we'd go to therapy.

As Ben grew, so did Romie's repertoire of skills; pursuing training in large part so that she could advocate for him.

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[14] Romie: " Foothills Gateway was started by families, through an ARC (Association for Retarded Citizens). ... There was a place in Loveland called Foothills, and a place in Fort Collins called Gateway, or it may have been the other way around, and they got together and decided that they needed a school and built Foothills Gateway, and it became a sheltered workshop. At the time, it was halfway between Loveland and Fort Collins. There was nothing out there. It was just a big field. So it was a very sheltered, protected place." Romie's description is "thick" with the protectionist attitude prevalent toward persons with disabilities in our society in the 1970's.

> Romie: I think that my awareness and my career path followed the same curve as Ben, based on his age. When he was little, I was very interested in infant stimulation. As he got into elementary school, I was looking at elementary curriculum and what they were doing. ...the older Ben got, the more interested I got in things that were school-related. I got very involved in the movement around inclusion for kids. And of course, he kept growing up and I started to look ahead a little bit and the future looked really scary. I didn't see very many people here in Fort Collins with developmental disabilities that were out in the community.

> Romie: I can remember going to a meeting when Ben was about 2 or 3 years-old, out at Foothills Gateway, and the director of special ed from the school district ... came to this meeting and he was telling families who had kids in the school program there... (They had a full school program... I don't think you'd call it K-12; but you know, we jokingly call it "womb to tomb". It was preschool through school and then they could attend the sheltered workshop. Ben was the first baby that they ever did infant stimulation on.) Anyway, he came in, and [said], "Why would you ever want to take your kids out of this nice controlled safe setting and put them in a public school?!" Basically he painted a picture of "The school district will just make the janitor's closet into a classroom, put them at the end of the hall and ...nothing good will come from inclusion." That was pretty much the status quo here.

In 1977, the "womb to tomb" model of "educating" persons with developmental disabilities that was "pretty much the status quo here" was about to change.

> Romie: So five years after Ben was born, he was among the first group of kids to move from Foothills Gateway, to a public school.... They grouped all the "low" kids with Down syndrome altogether and it didn't matter how old they were.... There were other cognitive disabilities too. [Even so] that was where my vision for his potential started to expand. I was probably pretty scared and pretty protective of Ben, when he was little. And I don't think I had very big dreams for myself – I don't think I could imagine what was out there for Ben. I guess one thing that we did do- I had kind of forgotten this- when he was about 4, the year before he went to public school, we had him 2 days a week in a regular, local preschool here. They had a childcare/ preschool program at the community college, and they were willing to have Ben come a couple days a week. He was probably only there for about a semester, but I could not believe the gains that he made socially, verbally. It was just amazing! So I guess that's probably why, when they were ready to move him to the public school, I had pretty high hopes that it would go well for him.

In the preceding excerpt, Romie described something she had "almost forgotten", her experience when Ben was in a typical preschool and the gains he made- one of the

rationales today for inclusive education. Trusting her own observations rather than heeding the administrator's advice, she enrolled him in public school. There, Romie continued to seek out and align herself with professionals who "got it"- something she recognized instinctively- and learned to question authors' and educators' knowledge and perceived expertise.

> Romie: I came to realize that, oh, one of the books I read said that kids with Down syndrome, because of mental retardation, they can't think in the abstract. So those kids will do very concrete play and they won't ...use their imagination to play. Because they don't have that cognitive capability to think in the abstract. So we always got him trucks. He could play with trucks. I don't know what I was thinking, but I never got him a tea set, or anything like that. So one afternoon I look in the living room, and Ben's got coasters out. He's laid them all around the coffee table, and he's got nothing in his hand, but he's reaching in and walking around the table, and putting something imaginary on each coaster, saying, "And some, and some". Oh yeah. So it was like, Throw that idea out! And the older he got, *everything that I read was not true.*
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> It was kind of a crap shoot, I think, as to what they should be teaching these kids. ... I really started to question whether or not they really knew what they were doing at the school. I thought that they did, and I wanted to believe that they did. But eventually, it didn't take very long, he had been in school maybe two years, I was really questioning if anyone knew what they were doing in school. Then started the battle of *What are you doing in school, and does it make sense?*

This discourse reflects the inner struggle Romie was experiencing, wanting to be a "good girl" and to go along with the dominant cultural value (experts know what they are doing, and respecting them includes not questioning that)- evidenced in her statement, "I thought that they did, and I wanted to believe that they did." But Romie eventually accumulated too much evidence to the contrary, which led her to question and counter her internalized hegemonic beliefs, and begin to challenge Ben's teachers.

> Romie: They did try to teach Ben how to print his name. He did learn how to print. But they didn't work on much in terms of reading ... They were having him write his name over and over and over again, and then he was having behavior problems. I took him to a therapist here in town, and she said, "Bring me some of the work he does in school." So I had a stack of papers probably an inch to two

> inches thick, and it was all just ...writing his name. She was horrified. She said, "...No wonder he's having behavior problems! He's bored out of his skull, he already knows how to write his name, and they're still having him do it. He doesn't have the physical dexterity or control to do it any neater, or stay on the lines! He's going to go outside the lines and they have to deal with it!" That was the end of Ben writing his name on the same worksheet every day.

Having resolved her internal struggle with questioning "experts", Romie blossomed into Ben's advocate.

Remember that Madeleine mentioned that her son did get some reading instruction in school; in contrast, Romie was continually frustrated with the low academic expectations for her child, which continued in junior high.

> Romie: It used to make me so mad, that *twice* a week, Ben's ...self-contained class in junior high would watch a movie. Videos came out then, and twice a week they would have an afternoon movie. They called it their rec. and leisure! ...You know, that's an abomination of that kind of stuff! I know that there were times when Ben had down times at school—but don't PLAN them! They planned down times! That just made me crazy. But, they didn't have time to instruct him in reading. And I asked specifically for that. We did actually get it on his IEP [Individualized Education Plan] a couple of years, and they started to do something. But I asked the teacher, "Really off the record, in this last semester, how often do you think Ben got reading instruction?" She said, "Maybe fifteen minutes, every other week." Well, no wonder he doesn't know how to read very well. Can you imagine, with that level of instruction? I don't think they knew any better. Some of that's a function of their training. They didn't have expectations for kids with cognitive disabilities.

In the following excerpt, Romie's deep sense of Ben's wholeness and normal sense of his life trajectory again emerge... "I love Ben, but I didn't want him to live with me forever; that sounded like torture."

> Some of the people that I did know that were adults that I knew their families ... were living at home. I love Ben, but I didn't want him to live with me forever; that sounded like torture. And Ben's a pretty high need little kid, and I was running out of energy. That was part of it. And then the thought of him living with me always, and needing that kind of energy level, scared the heck out of me.

> So it was a probably a real selfish reason, to start thinking in terms of what's going to be next in his life. But luckily, appropriate.

Romie's continued seeking and increasing knowledge not only enlarged her view of what Ben might be able to do in the future; as well, she began to train other parents.

> Romie: So I did some work for the Colorado Department of Education, and I got involved in the PEP (Parents Encouraging Parents) Conferences.
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> MA: *When did those start?*
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> Romie: PEP conferences had been going on for, probably when Ben was born. They had been going on since 94-142, I'm sure. Brian McNulty used to always tell the story that, the first PEP conference, Pete Fanning was the Dir. of Special Ed. for the state at the time, and he thought it would be a good idea to get families together to teach them about 94-142 and legal aspects of the law and stuff like that. So they had the first PEP conference, and about 3 days later when the dust settled, they realized that parents had more to teach them, than they had to teach families. So they changed the whole framework. ...So Dan and I , we volunteered to help with the PEP conferences. And those were ...4 weekends a year.

The preceding excerpt provides a pertinent example, akin to feminist standpoint theory, in which professionals realized that "parents had more to teach them, than they had to teach families." which led to restructuring the format of the conferences; co-organizing and facilitating them with parents whose firsthand experience could offer invaluable information and insight to other parents navigating the world of disability. In the following excerpts, Romie's vision for what might be possible in Ben's life expanded further through attending conferences, hearing other parents' experiences, and relationships with other families struggling with similar issues.

> Romie: And then the National Down Syndrome Conference was in Denver, and I happened to listened to Bud Fredericks- he had a son with Down syndrome who was probably about 10 years older than Ben- Ben was pretty little at the time- talk about his son's progression over time and how his own expectations grew as his son grew. I was pretty impressed. They were starting an entrepreneurial job

> for their son. They lived in Oregon or Washington, something like that. He started an egg business. They lived out in the country and he had chickens and he sold his eggs. So you know, here's a kid who's working, learning how to use money, has his own little business going, but still living at home. So I think it was experiences like that. You know, going to like the National Down Syndrome Convention. [And later, the Inclusion Conference, which started around 1987]. Listening to families who had bigger dreams for their kids... getting to know families in Colorado who were pushing to have their kids included and thinking more about their life after school. ... I think my dreams for Ben started to expand. Maybe he could live in a group home, with some other people.
>
> Romie: I still am under the belief that Ben's going to need support for the rest of his life, because there are just too many details. There's not anything about his daily living skills that he can't do, but it's the organization of it, to get it all done. If it takes you all day to fix your meals, and do your laundry, and take care of your place, then let's get somebody else to do that so Ben can have some quality of life, or that he cooks with somebody so that it actually gets done. So I think that it's the organization and the amount of time that it takes. I'd like Ben to not have to spend all day just doing his basic care. I know I have expectations of Ben working in the community. And he's had experiences where he has worked in the community, and he's done really well with it. *But he does need support.*
>
> Romie: ... But as [Ben] got older, and my interests expanded, I think because of the experiences with Next Steps, and with PEP- I knew families all over the state. So my vision for what the future could be for Ben really started to grow and expand. I expected him to grow up and learn how to do a job and live away from home and have a good life.

The notion that Ben can contribute to his community through work *and* still require support is one we are not quite comfortable with as a society. This theme is developed and examined in the next chapter. The final excerpt selected for inclusion here highlights a portion of the progression of Romie's career development, which, in her words, "paralleled Ben's growth".

> Romie: I think my history paralleled Ben's growth. In '86, I started a nonprofit resource center ... and was the Executive Director and did that part-time for 6 years. At the end of that 6 years I decided to go back to school ... at that time, Jean Lehmann had gotten a grant for a [Master's program to become] a transition specialist - so ... from the Parent Center, I had done some training on a program called Next Steps, which was transition training for families, and Jean and I worked together. That's how we met - to do those Next Steps Conferences, and

> that was supported by the State Department of Education. ... So I had some lovely mentors, to say the least.

Eventually Romie earned her doctorate in Educational Leadership and became a Transition Specialist for the Colorado State Department of Education. In this capacity she is directly influencing transition programs for youth with disabilities throughout Colorado and the western mountain region, acting as family advocate for quality transition services, designing systems for collecting follow up data on special education graduates, and helping to develop policy to ensure quality options for young adults with disabilities as they leave public education.

CHAPTER V: TRENDS IN THE LITERATURE

From exclusion to inclusion, from marginalization to tolerance...

Borrowing Madeleine Will's bridge metaphor to depict *transition*, as it has been defined in my study, it has one base in public education and the other in adult living; therefore, attention to each section of the bridge is implicit in the study of the transition movement. This chapter, then, has three sections, examining themes gleaned from the documents I reviewed, as well as excerpts from the narrative analysis / participant interviews, regarding: first, K-12 schools, second, the "span" of transition from school to adult living, and finally, adult living.

While this chapter builds on themes introduced in the preceding chapter on narrative analysis, one notable exception is important here. That is a lack of reporting gender analysis with regard to the documents reviewed. I did look for gender differences as one method of deconstruction in the ways in which various authors presented information, but was unable to find any consistent patterns. This may be due to the limits of my literature sample, the constraints of scholarly writing, and/or the fact that many of the documents were written by both men and women. Even those pieces written by single authors, or authors exclusively female or male, seemed balanced across relative positions in my literature sample; for example, both female and male authors advocated for and against inclusive education, both sexes authored pieces with feminist perspectives, and likewise, both authored works highlighting the importance of

relationships and belonging for children and youth with disabilities. Other patterns that were consistent in the literature reviewed follow.

Public Schools (K-12)

"Segregated environments as children lead to segregated environments as adults." (Brown, Long, Udvari-Solner, Davis, VanDeventer, Ahlgren, et al., 1989, p.1).

Historical Perspectives

One of the documents included in my sample explored the relationship between segregated service delivery systems for children and youth with disabilities and social attitudes at the turn of the twentieth century (Turnure, 1990). In 1896, the commissioner of the common schools in New York City had this to say about the purpose of public education:

> To take up and gather together all the heterogeneous elements of this cosmopolitan population, and through the crucible of the public school to fuse and weld them into one homogenous mass, obliterating from the very earliest moment all the distinguishing foreign characteristics and traits which the beginners may bring with them as obstructive, warring and irritating elements" (p. 186).

The "obstructive, warring and irritating elements" referred to here were the personalities and customs of *typical* children of immigrants. It follows that children with disabilities were institutionalized.

As noted, historically society's response to differences of all kinds, whether ethnicity, race, gender, lifestyle orientation, or ability, has historically been to attempt to 'obliterate' or whitewash it, and when that was not possible- separate and marginalize it (Ervelles, 2000; Van der Klift & Kunc, 1994; Kliewer & Fitzgerald, 2001). The following example of New Hampshire's historical "services" for children with disabilities closely parallels national trends, and depicts the establishment of residential institutions

for persons with disabilities, as well as their treatment while contained there (Turnure, 1990).

> The New Hampshire School for the Feebleminded was established in 1903 in a rural area about 35 miles north of the state capitol. The school was a typical farm colony, located on a prime agricultural tract near Lake Winnipesauke. The original legislative intent in creating the school was to provide special services for children only, but adult "defectives" were soon admitted as well. The school was to "act as a safeguard whereby society may protect itself from the vice, corruption, and licentiousness with which it is threatened when anyone of this defective class is left unrestrained and unprotected in the community" (Second Biennial Report of the Trustees of the New Hampshire School for the Feebleminded, September 30, 1904, p. 21; cited in Garrity and Gallen 1981).

That the purpose of this "school" was to "act as a safeguard whereby society may protect itself from the vice, corruption, and licentiousness with which it is threatened when anyone of this defective class is left unrestrained and unprotected in the community" is a blatant example of what Van der Klift and Kunc (1994) called "disability as deviance" seems self evident, ...and the corresponding social actions associated with this view included "aggression, segregation and avoidance." These are evidenced in the description contained in the "commonly accepted treatments of each era" at the school which follow.

> The school grew steadily from its original 60 residents in 1903 to a peak of 1,167 residents in 1970. In 1979, when a suit was filed in federal district court by Legal Assistance attorneys and the U.S. Justice Department on behalf of residents and their parents, 564 residents lived at Laconia State School, as it is now called. Eighty of the residents (14.2%) had been institutionalized for more than 20 years; 32% had been there for 10 to 20 years.
>
> During its 82-year history, the school practiced the commonly accepted treatments of each era, from mandatory sterilization to physical restraints to heavy reliance on tranquilizers and barbiturates for behavioral conditioning techniques. Testimony entered by the plaintiffs during the trial (Garrity v. Gallen, 1981) provided vivid illustrations of long-term resident abuse, developmental regression, unsanitary conditions, inadequate and untrained staff, little effort to place people in communities, unaccredited and unsafe facilities, few treatment programs, and

> little attention or support from the state legislature. Expert witnesses described the school as either representative of similar institutions in other states or somewhat worse in comparison (Mallory & Harrick, 1987, p. 298).

This facility was not closed until 1985. The devaluing of persons with disabilities it describes may be deconstructed and analyzed on a number of levels. Recall that language is one way dominant groups exert power over marginalized groups (Lather, 1991; Weedon, 1996; Sleeter, 1995). Certainly, the use of labels such as "feebleminded" and "defective" is indicative of underlying values about persons with disabilities. What is the implied definition of the use of the word, "school"? Whose power and authority does the school represent? And whose perspective is privileged? Surely not the persons with disabilities who "lived" there. These residents were stripped of personal choice, their life space was severely limited and basic rights, to education, protection, and human connection- things enjoyed by persons without disabilities as their birthright--in the name of 'protection' for society, were denied. They also suffered general maltreatment, and repeated occurrences of explicit abuse. These are travesties indicative of the subhuman status of persons with disabilities.

While public institutions like these have largely closed (there still are a few), and we no longer use words like 'feebleminded' or 'defective' to describe persons with disabilities, education has gone through many phases of labeling children by nearly as stigmatizing terms. Consider Colorado's SLIC label, still in use today, for students with cognitive delays. It stands for, "significantly limited intellectual capacity". And more subtle layers of this protection mentality are still prevalent today. For example, many parents feel that inclusive or integrated settings are unsafe for their children, something Dr. Tobin commented on.

> Romie: As young adults are working and living in the community, and some of those safety issues get to be huge. And over the years I've talked to families who've made choices to have their kids in more self-contained settings, because they've gotten into community settings, and they've been taken advantage of. Especially young women. I think it can make them very vulnerable, and if we don't address what makes them vulnerable, then they are hugely at risk. But I can see if your daughter was raped, that you might not want her living independently. You might want a sheltered living situation.

On closer examination, however, the use of the word "sheltered" might be considered euphemistic, since, as noted by Stainback and Stainback (1984), placing a person in a separate category or system of education, it becomes possible to treat a person in ways that would not be tolerated were he or she a fully accepted member of the "normal" or "regular" group (p. 110). Sheltered situations are simply not all that safe, either (see, e.g., Turnure, 1990; Mallory & Harrick, 1987). The difficult but critical work, then, to which Romie alludes, is to "address what makes [persons with disabilities] vulnerable." There is no choice other than ferreting out and changing the attitudes and practices that privilege some and marginalize others, because marginalization, in and of itself, constitutes maltreatment, and engenders a host of secondary effects, as well.

Despite the ongoing prevalence of veiled protectionist attitudes in our society, in the 1980's, the voices of several visionary scholars emerged - primarily from the low incidence[15] disability community, questioning the existence of special education as a separate system as an issue of social equity. Dubbed the "Regular Education Initiative" (or REI), these works provoked an explosive national debate. Stainback and Stainback

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[15] While I am not necessarily advocating the use of these labels, the special education literature is replete with these terms, and frequently is organized in this way, so is useful here. Low and high incidence are at least less value laden than other terms. The federal definition of "Low incidence" refers to disabilities occurring in 1 -2 % of the general population, including these disability categories: deaf, blind, deaf-blind, severe & profound mental retardation, multiple disabilities, orthopedic impairments, and autism spectrum disorders.

(1984) provided a detailed rationale for the merger of general and special education, based primarily on two constructs: the inefficiency, cost and stigma associated with operating a dual system, and their assertion that the instructional needs of students do not warrant separation. They observed that:

> A review of the history of special education indicates the trend is in the direction of eventually eliminating the dichotomy. This has been reflected in the past several decades by the emergence of concepts such as deinstitutionalization, normalization, integration, mainstreaming, and zero rejection. ... one steady trend that may be described as progressive inclusion (p. 110).

Lipsky and Gartner (1987) noted that P.L. 94-142 was designed to provide access to an education, not summarily keep entire populations of students from the mainstream. Originally intended as a sub-system of general education, special education grew instead into a comprehensive and separate structure. Some twelve years after its inception, one of the key authors of the EHA wrote:

> If the law has been massively successful in assigning responsibility for students and setting up mechanisms to assure that schools carry out these responsibilities, it has been less successful in removing the barriers between general and special education. It did not anticipate that the artifice of delivery systems in schools might drive the maintenance of separate services and keep students from the mainstream (Walker, 1987, p. 109; in Lipsky & Gartner, 1987, p. 69).

Stainback & Stainback (1984) asserted that we have incorrectly dichotomized children into 'normal' and 'exceptional'. Yet, they argued, there are not two distinct types of students, 'special' and 'regular'. There are simply children who differ from one other along the same continuums of intellectual, physical and psychological development (p. 104), regardless of any arbitrary cutoffs. Further, the dual system also discriminates against *typical* children; by labeling some exceptional and removing them to specialized services, denies the right of *every* child to an education meeting their unique needs.

> In general, the instructional needs of students do not warrant the operation of a dual system. On the contrary, the instructional needs of students would support the merger of the two systems into a comprehensive, unified system designed to meet the needs of every student (Stainback & Stainback, p. 104).

Ervelles (2000) observed that the REI might be viewed as a "border pedagogy", challenging the dominant discursive constructions of disability.

> The Regular Education Initiative initiated by some practitioners in special education has actively challenged dominant discursive constructions of disability by exploiting pedagogical practices, such as individualizing curricula, using cooperative learning groups, and reworking assessment procedures in order to highlight the potential of even the most severely disabled students. By radically exploring the potential of disabled individuals in creative ways, these practices have also played a major part in redefining concepts of "disabled" and "normal" and have therefore done extensive work in constantly redrawing the borders of "special" and "regular" education. Thus, it could be argued that the Regular Education Initiative [might] ideally be perceived as one example of a border pedagogy that acts to reinscribe the terrain of difference in new and radical ways (p. 36).

Schools have the opportunity to reconstruct difference in creative and dynamic ways, potentially impacting emancipation for persons with disabilities- for *all* students; yet, most often, they recreate institutions that reflect and perpetuate societal attitudes instead (Bowles & Gintis, 1976; Ervelles, 2000). It is impossible to transition young adults with identified disabilities into "receptive communities", if they are leaving intolerant ones; schools operating separate systems, where they may have spent many years relegated as second class. As children are sorted, labeled, and dichotomized... they cannot help but learn that there are some who have access because they are good enough, they belong; and there are others who are not quite worthy- they are defective in one or more ways; moreover, they detract from the advantaged group by their presence when included.

Chang (in Martin, Jorgensen, & Klein, 1998), author of *Adolescent Life and Ethos: Ethnography of a U.S. High School*, found that, in high school,

> An individual's social status was often determined on the basis of clique affiliation, types and degrees of involvement in activities, appearance, and academic performance...Popular cliques included ...athletes, brains, pretty faces, and good bodies, who tended to be "high" class... those classified as "unpopular" included smokers, [the tough kids], and special education students, who were regarded as "low" class (*p. 149).*

The work of REI proponents (e.g., Stainback & Stainback, 1984; Lipsky & Gartner, 1987; Brown, et al. 1989) rocked the special education world. REI eventually metamorphosed into the "full inclusion" or inclusive education movement, facilitating the paradigm shift from preparation to participation (cf. Bellamy, 1997; Lipsky & Gartner, 1997).

In the field of high incidence disabilities[16], as well as in general education, there was a vehement reaction to the REI / inclusion (e.g., Kauffman, 1988; Lowenthal, 1990; D'Alonzo, & Boggs, 1990). The Council for Learning Disabilities published the following position statement in 1993.

> The Board of Trustees of the Council for Learning Disabilities SUPPORTS school reform efforts that enhance the education of all students, including those with learning disabilities (LD). The Council SUPPORTS the education of students with LD in general education classrooms, *when deemed appropriate by the IEP team.* Such inclusion efforts require the provision of needed support services in order to be successful.
>
> One policy that the Council CANNOT SUPPORT is the indiscriminate full-time placement of ALL students with LD in the regular education classroom, a policy often referred to as "full inclusion". CLD has grave concerns about any placement policy that ignores a critical component of special education service delivery: Program placement should be based on an evaluation of that student's individual needs. The Council CANNOT SUPPORT any policy that minimizes or eliminates service options designed to enhance the education of students with

[16] "High incidence" disabilities refer to those occurring in approximately 10% of the general population; the largest disability label associated with this term refers to students with specific learning disabilities (US Department of Education).

> LD and that are guaranteed by the Individuals with Disabilities Education Act (p. 126).

Yet, proponents of the REI were not advocating *removing* services, rather, delivering them in ways that were more habilitative, and without the stigmatizing concomitant effects of a separate delivery system. On this topic, Dr. Halloran voiced a perspective that was *a*typical among the persons I interviewed:

> Bill: I think that the least restrictive environment provisions of 94-142, we used to interpret them as want to strike a balance between least restrictive and more inclusive. And most responsive. So, making placement decisions should have been primarily an easy go, and made on individual decisions. So it's not that way anymore... they say all kids should included. The more included, the better we're doing.
>
> Bill: Inclusion stuff has been going on for years, I think that clearly, I saw in my career, slowly moving away from the needs of the individual, to this whole thing of being included. And it certainly should have moved to the extent that it could move, away from segregated facilities. But now we're saying, inclusion for everyone. Regardless of how sick general education is. -BH

Opponents to the REI (and more recently, inclusive education) generally cite protecting the rights of children and youth with disabilities to access specialized services, and that the EHA was designed to ensure those rights. They assert also that students with disabilities have instructional needs which require specialization, that would be lost if the "institution" of special education was removed (Lowenthal, 1990; Kaufman, 1989). The arguments both for and against inclusive education may be analyzed in terms of where they originate- in different quadrants of Wilber's heuristic. Inclusive education addresses educational theory and societal implications, as well as pedagogy (three of Wilber's quadrants) whereas the latter (arguments against inclusive education and in favor of more separate services) seem contained in educational pedagogy more exclusively (the upper

right quadrant). Opponents feel that special education is working, and want to maintain the status quo. Yet, there are a plethora of outcomes studies of special education graduates that indicate otherwise; young adults with disabilities are largely under or unemployed, are on waiting lists for services (even segregated ones), and fare poorly in widespread community acceptance, access, and meaningful involvement (cf. Hasazi, Gordon, & Roe, 1985; Hasazi, Gordon, Roe, Finck, Hull, & Salembier,1985; Phelps & Hanley-Maxwell, 1997). There are also multi-layered issues around identification for services; who gets services and who doesn't.

Bill's argument is a twist on the same theme- that general education is "sick", so let's protect our students from it. A critical perspective also recognizes the toxicity in our current system, yet feels a responsibility for healing it, such as re-thinking and reconstructing educational services that meet the needs of *all* students, without the ramifications of separate and unequal systems.

High Incidence Empirical & Theoretical Themes

A repeated theme in the learning disabilities (LD) empirical literature is a focus on individuals with disabilities —Wilber's two individual quadrants (upper left and right), as opposed to either of the lower quadrants— school service delivery systems, culture and/ or society. For example, Summers (1986) reviewed some 2300 empirical studies published on LD in various scholarly journals between 1968 and 1983, and found that the vast majority focused on instructional strategies, as well as attributes, evaluation and classification, and assessment. There were also studies on affective measures, such as perceived locus of control; lack of belonging, isolation, and loneliness.

More recently, Stowitschek & Laitinen (1999) documented teaching self-determination to students with learning disabilities, embedding opportunities in curriculum using natural teaching incidents, and taught in a resource room setting.

There have been a comparatively small number of empirical studies which have included settings as a variable (e.g., Smith, Adelman, Nelson, Taylor, and Phares, 1987; Scanlon, Deshler, & Schumaker, 1996; Zhang, 2001), exploring, for example, whether skills easily taught in resource room settings might be taught by general education content teachers. Scanlon et al. (1996) found that general education teachers who agreed to incorporate strategy instruction to facilitate content learning in their lessons failed to do so much of the time, and consequently students with LD in their classes were largely unsuccessful in learning and applying the strategy. The authors discussed several potential explanations for the inconsistent and insufficient instruction by the inclusive content teachers, despite their willingness to teach students with disabilities in their classrooms and their positive beliefs that these students could learn there. A chief barrier was a conviction held by the teachers that they needed to arrive at a certain point in the curriculum by the end of the school year, and to expedite this, they relied on whole class instruction as opposed to incorporating methods which differentiate for various skill levels of learners (p. 56). Scanlon et al. concluded that "the demands facing inclusive content area teachers may serve as a barrier to full and effective implementation of strategic instruction" (p. 56).

Zhang (2001) examined whether students with mild mental retardation are more "self-determined" in regular classrooms; and found that they demonstrated more self-determination in resource rooms (contrary to their hypothesis). Iterating several possible

reasons for this, most had roots in differences between general and special education pedagogy; for example, unlike regular classroom teachers, resource room teachers are trained to elicit choices, decisions, and other self-determined behaviors from students. Zhang concluded that students with mild mental retardation need to be taught these skills before being able to apply them in general education environments (remediate the individuals) rather than change the general education environment. In a different study, Smith et al. (1987) demonstrated that adolescents with learning disabilities attending a special laboratory school felt that they had more choices and a better sense of control than their peers with and without disabilities attending public schools. Results were discussed in terms of the control over the curriculum available in the private lab school, where opportunities for personal preferences and decision-making, and reflection, were built into students' programs; a luxury not readily available in public schools more tied to narrowly prescribed curricula.

The conclusions drawn in these studies seem at least more considered than those reached by Kauffman (1989), e.g., that "regular education initiative proponents use the issue of civil rights mainly as an emotional appeal to create an image of moral superiority"; and

> ...Separateness may be required for equality of opportunity when separation is based on criteria directly related to teaching and learning. Were this not so, all manner of grouping for instruction would be struck down as inherently unequal. Public Law 94-142 guarantees procedural rights, not rights specific to curricula or services, because only the procedures designed to effect appropriate education could be prescribed for so diverse a population as handicapped children (p. 262).

Kaufman fails to address theoretical grounding, and the harm incurred by separate services, despite our best intentions and methods.

Others have argued for the maintenance of special education because general educators are resistant to working with students with special needs, and/or are ill equipped to handle such students. For example, Davis (1989) observed that regular educators do not feel ready for the "added burden" of students with special needs. Lieberrman (1985) asserted that the REI is a special education initiative, and "We cannot drag regular educators kicking and screaming into a merger with special education...This proposed merger is a myth, unless regular educators...decide that such a merger is in their own best interests" (p. 513). (Again, the implicit theoretical questions not addressed here: *In public education, do educators get to decide who they want to teach, and which needs they will address? Whose perspective is privileged?*)

Almost twenty years later, although clearly we have made many inroads toward collaborative and more inclusive services for children and youth with disabilities, many of these same issues remain unresolved. Dr. Johnson commented on this:

> David: Historically we've evolved special education as a subsystem of general education, replete with its own administration, fiscal accounting mechanisms, data management systems, and expectations. The model was all pull out, special classes, places that are away from general education. We created the monster. We created an era of specialization denoting that special education as a field or a discipline is special and unique, and that kids with disabilities are, because of that, the domain and interest of special education, and need to be dealt with by specialists. ... We've dismissed general education's role. Now we're asking them to take a role. And it's going to take awhile.

A common theme across the high incidence empirical literature included in my document analysis was a failure to question the purpose of general education, or to hold general educators accountable to accommodate for the needs of atypical learners...as well, to address the underlying assumptions which established special education originally, the mission of schooling, and the implications for society (Skrtic issues). As

noted, Skrtic (1995) proposed that a likely explanation for repeated failures with multiple reform efforts is that they continue to focus on models and pedagogy, rather than theoretical grounding (Skrtic, 1995). He advocated instead a "critical discourse on the level of grounding theories or paradigms that ultimately is concerned with the nature and effects of special education models and practices" – issues integral to all of Wilber's quadrants, and especially include the lower right: *societal.*

In addition to many studies documenting the efficacy of various instructional strategies, the LD literature contains a proliferation of studies identifying and categorizing students with learning disabilities. (In the *What Works in Transition: Systematic Review Project*, we found a large number of attribute and assessment studies in the LD literature). Algozzine and Ysseldyke (1983) commented that ... "when these definitions and statistical concoctions are deemed most impressive they have included every imaginable human characteristic and scores on a myriad of tests" (p. 246). Stainback & Stainback (1984) replied:

> At this point in the progressive inclusion trend, it is time to stop developing criteria for who does or does not belong in the mainstream and instead turn the spotlight to increasing the capabilities of the regular school environment, the mainstream, to meeting the needs of *all* students (p. 110.)

Yet categorizing and classifying students by ability is hard to give up. In *Special Education as Developmental Capital*, Deno (1970) asserted that categorization is

> ...deeply entrenched in the social commitments of categorically defined special interest advocacy groups; in the structure of health, education, and welfare programs at direct service levels; in the staffing of teacher training institutions; in other professional training programs; and in general public thinking (p. 39).

Low Incidence Empirical Focus

The empirical literature focusing on low incidence disabilities also contains a wealth of information on instructional strategies deemed effective for different sub-groups within this group of learners. A persistent theme emerges across the past couple decades, however, from a focus on behaviorism and skill deficits, to environmental deficits and instruction in multiple natural settings to increase access, and eventually to changing the environments so that meaningful participation and relationships may be established and maintained. In the process, theoretical grounding has been addressed. The instruction of "conversation skills" provides a case in point of this evolution.

In 1984, McGee, Krantz and McClannahan taught "positive and negative assertions" in the context of 3 adolescent boys with autism playing a ball and card game. While they used "naturalistic" teaching opportunities, they were taught in a segregated setting (day school at a residential treatment center) with only other peers with autism, and incorporated age-inappropriate games (e.g., bouncing the ball to a partner and calling his name). In 1985, Downing trained 3 adolescents with moderate mental retardation to initiate topics and continue a conversation by cueing an adult listener to speak (using materials and a context more appropriate for the adolescents' chronological ages than the preschool game just cited), but the trainer and conversation partner were the same person, and the setting was also segregated (a center for students with developmental disabilities in a regular school district). The author measured generalization of conversation skills to other adults. In contrast, Staub and Hunt (1993) taught interaction skills to high school students without disabilities, and then measured concomitant gains in social skills made by their high school peers with severe disabilities. This represents movement toward

facilitating belonging for the students with disabilities at the site, since it gave the peers information about how to interact with students who communicated differently, indirectly increased the skill repertoire of the students with disabilities, and was taught in a typical high school setting.

Peer relations studies have also evolved, from those incorporating general education peers as tutors (in a helping role to students with disabilities, e.g., Slavin, 1988), to establishing reciprocal relationships (Grenot-Scheyer, Staub, Peck & Schwartz, 1998). Perhaps the biggest change over the last two decades has occurred in curriculum, from first obtaining access for students with disabilities to typical classes, to refining the expectations for their participation there; for example, adding academic learning outcomes such as literacy and numeracy—reflected in the conversation I had with Dr. Ward regarding inclusive education.

> MA: *What do you think about "inclusion"?*
>
> Michael: Well, I used to be very much against inclusion. But now, I'm a little more open-minded, I think. Now I think it could be wonderful, but not if all we're about is trying to pass the test.
>
> MA: *I used to be something of an inclusion zealot. I think I've mellowed –but only a little- because I still believe that there's absolute value in bringing special ed and general ed together; we have a lot to learn from one another. And I think all kids have a right to and need access to the same environments.*
>
> Michael: But not if they say, don't bring that kid in here, because he detracts from me trying to teach to the test! Or, if you do bring that kid in here, it's only because he has to sit down and do the test. …I get the impression that for a long, long time, that inclusion was pushed for the socialization. And that's not the outcome of education—well, it is an outcome, but it's only one.
>
> MA: *Yes, I agree… but I think we've come a long way since then… I think at first we only included kids for lunch and art and recess…nonacademic activities…but we started to see kids developing skills we hadn't expected—like literacy skills—and now their participation is or can be much more meaningful. And it had raised the bar for those kids, particularly with academic skills.*

Michael: I agree with you.

MA: *And of course there needs to be a balance- especially for older kids- working toward a career, and career choices...which all kids need, by the way...*

Michael: I was appalled when some other inclusion Nazis[17] were pushing for inclusion in high school... [because of the increased emphasis on academic tests].

There is a growing body of literature which documents that inclusive settings lead to positive outcomes for kids with and without disabilities (e.g., Hunt & Goetz, 1997; Hunt, Hirose-Hatae, A., & Doering, K., 2000; National Study on Inclusive Education, 1995). Using a host of academic and other measures, not one of these has concluded that students educated in segregated settings fare better. Similarly, Falvey, Blair, Dingle and Franklin (2000) conducted a comprehensive review of the extant literature and were unable to find even a single research article which found that segregated settings are better than inclusive for students with severe disabilities (on a host of measures, including academic achievement), in contrast to those cited in the high incidence literature.

Low Incidence Theory

Relationships/ Friendships as an Example of Quality of Life

One of the outcomes of inclusive education is the possibility for students with disabilities to develop friendships; not just restricted to other children with disabilities. "Friendships may form a network of relationships that will allow children with disabilities to grow up; go to school; and live, work and recreate within communities of their choice (Grenot-Scheyer, et al., 1998). Strully and Strully (1985) based their advocacy of inclusive practices on the experiences of their daughter, who experiences

[17] While I am sure that Michael's choice of the term "inclusion Nazis" meant no more than "inclusion zealot"; the implications are more harsh...and the term has racist connotations. Oops.

multiple disabilities. She attended a special class at a regular elementary school, and then was fully included in typical classes in junior high. They observed that when children have the opportunity share daily typical experiences, there is the opportunity to develop friendships. Since their now classic article appeared in 1985, a wealth of literature has emerged on examining what contributes to the ability to make and keep friends (e.g., Asher & Gottman, 1981; Tharpe & Gallimore, 1989; Grenot-Scheyer, Staub, Peck, & Schwartz, 1998; Meyer, et al.,1998; Jorgensen, et al., 1998). These agree that part of what is critical at the elementary school level is proximity (as in class membership) and shared activities; as students get older, shared interests and experiences form a basis for relationships. In 1985, there was recognition of the extremely limited social circles experienced by most persons with special needs, especially those with severe disabilities.

> For too long persons with developmental special needs have been isolated and lonely. There have been very few people to care about them except for their immediate family (in most cases), paid human service workers, and possibly other devalued people with whom they associate. ...the persons we are concerned about need others in their lives because they want a relationship rather than because it is part of their job (p. 224); (cf. Forest sociogram, *this document*, p. 50).

Strully and Strully addressed what it takes to form relationships and in the process, addressed what constitutes a worthwhile life. Disability awareness as an add-on[18] to the "regular" curriculum failed.

> It will be relationships such as this (Tanya and Shawntell's) that will ensure that Shawntell will be an active member of her community and it will be relationships, not attitudinal gimmicks (e.g., large puppets and blindfolds), that will create change in typical children such as Tanya (p. 224).

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[18] This refers to the then common practice in public schools of educating typical children about disabilities through annual or biannual disability awareness fairs or sessions, in which children would move between stations presenting various disability information, perhaps trying out a wheelchair, or experiencing being fed, or walking blindfolded with a friend as a guide. Alternatively, current thinking recommends infusing examples of disability throughout general education curricula, so that it is regularly encountered as part of the diversity of life—instead of being encountered just once a year at a special session.

In 1989, the concept of attending neighborhood or "home" schools emerged in the literature (Brown et al.). A "home school" has been defined as the one a child with disabilities would attend if he or she were not disabled. (In contrast, a clustered school is a regular school attended by an unnaturally large proportion of students with intellectual [or other] disabilities, but it is not the one any or most would attend if they were not labeled 'disabled'.) Brown et al. (1983a) cite this rationale for home school attendance:

> Students who have disabilities should attend home schools so that (a) all children can be prepared to function in a pluralistic society; (b) the most meaningful and individually appropriate instructional environments and activities can be used; (c) parents, guardians, brothers and sisters can have reasonable access to schools and services; and (d) a wide range of social relationships with students and others who are not disabled can be developed, maintained, and enhanced over long periods of time (p. 16).

As an elementary school student, Dr. Ward did not attend his neighborhood school.

> Michael: Yeah, most of my friends were from the special education class and since we didn't go to the neighborhood school, our parents had to drive us somewhere to meet. They didn't seem to mind. Also, I and my best friend, Dan, who has the same degree of CP as I do, were always staying over at each others' houses.

In *Restructuring High Schools for All Students*, Jorgensen (1998) had this to say about the conditions necessary for youth with disabilities to develop friendships:

> The first essential condition for friendship is full inclusion. "When people with disabilities are kept apart from society-educated in separate classrooms or schools, employed in sheltered workshops and engaged in separate leisure activities-there are few opportunities for friendships to develop" (Tashie et al., 1993, p. 6). Because friendships do not simply materialize from thin air there must be a logical first step-sharing time and space. Students have told us that it is only when they share academic classes or are involved in the same extracurricular activities that common bonds are discovered, such as family background, life experiences, shared acquaintances, and current interests and activities (p. 151).

While employment remains a high priority theme and outcome of education for youth with disabilities, relationships are equally valued, if not more so. As Strully and Strully (1985) articulated:

> Some human service professionals would argue that productivity and employment are the major outcomes that Shawntell will need to achieve in order to be successful. That is not to say that we do not want Shawntell to work or to be as independent as possible, but in reality, is that what is really critical in her life? The answer of course is no! What is most important is friendship and interdependence (p. 226).

Shift from Independence to Interdependence

A final theoretical pattern in the low incidence literature over the previous two decades is movement from dependence, to independence, to interdependence... akin to the paradigmatic shifts delineated by Bellamy (1997), from protection [dependence] to preparation [independence] to participation [interdependence]. Kim and Turnbull (2004) provided an applied example, recommending the merger of two practices to better address the complexity of transition planning for the adolescent with disabilities: person-centered planning (from the transition literature), and family-centered planning (from the early childhood special education literature), into "person-family interdependent planning" (p. 53). This merger would bring to bear on the challenges of transition the best of both...and in my analysis, are representative of the general trend toward increased collaboration and interdependence across various persons, roles, groups reflected in the literature- as well, the shift from modernist to pluralist thinking.

High Incidence/ General Education Policy Context

Bill: *When people ask me about the mainstream, I say, how big is the stream? And it couldn't be any more restrictive than it is right now.*

There is little doubt that current policy context in the United States has significantly impacted public education for all children and youth, with and without disabilities. Since the early 1980's, general education reform efforts have focused largely on a policy strategy commonly referred to as the "standards movement". It includes emphasis on consistent, statewide curricular frameworks and content specific to each grade level, implementation of statewide standards-based assessment measures, and the use of state-initiated consequences for schools failing to demonstrate adequate yearly progress toward standards-related academic achievement (Cobb, Lehmann, Tochterman, & Bomotti, 2000).

In contrast, special education reform efforts during this same period have focused on various approaches to increase student access to general education environments (Lipsky & Gartner, 1997), promote meaningful participation in general education classes through the use of curricular accommodations and modifications (Neary, Halvorsen, Kronberg, & Kelly, 1992; Roach & Caruso, 1997); enhance the quality of supports for students in general education environments through initiatives designed to increase collaboration and consultation among and between special and general educators (e.g., Pugach & Johnson, 1989; Downing, 1996), and implement a variety of transdisciplinary teaming models using preferential interventions and teacher assistance to reduce special education referrals and support students at risk for academic failure (Safran & Safran, 1996; Furney, Hasazi, Clark-Keefe, & Hartnett, 2003).

Furney et al. noted that over the last half of the 1990's there was growing concern over the apparent disconnect between general education and special education reform efforts, and new research confirmed the largely negative impact of standards-based

reform on children with disabilities (e.g., McDonnell, McLaughlin, & Morison, 1997). More recently, new federal policies have come into play to address this, including the IDEA 1997 amendments (discussed in chapter 2) containing requirements that students with disabilities have access to general education environments, curriculum and state assessment programs, and that general education teachers are involved in their educational programs; and the No Child Left Behind Act (NCLB) of 2001, which emphasizes the use of standards-based measures to improve student achievement with related incentives and disincentives for schools based on student performance. According to NCSET, 2004:

> This act [NCLB] redefines the federal role in K-12 education with the goal of closing the achievement gap between disadvantaged and minority students and their peers. It is based upon four basic principles: stronger accountability for results, increased flexibility and control, expanded options for parents, and an emphasis on teaching methods that have been proven to work. The law specifically addresses the importance of structuring implementation to include every child (p. 4).

Furney et. al (2003) conducted a longitudinal policy analysis in Vermont examining how the positive outcomes associated with a 1990 state special education policy had fared in the face of the shifting policy context of standards-based assessment and accountability. They found that while schools continued the use of educational support systems and teams associated with the 1990 policy, other quality indicators were subsumed as evidenced by increased special education referrals and more restricted special education placements. Their study highlights the need to recognize the shared *and* competing goals among educational policies; they also recommend exploration of a variety of approaches for expanding the capacity of general education to better support students within the context of standards-based reform. Even better would be to share

policy development with representatives of all constituents who will ultimately be affected by its implementation, so that, as Ozga (1990) noted, the micro-level of peoples' lived experiences might be addressed.

> It is important to bring together structural macro-level analysis of education systems and education policies and micro-level investigation, especially that which takes account of people's perceptions and experiences (p. 359).

When queried about current issues related to the successful transition of youth with disabilities, all of the informants interviewed in my study talked about the challenges engendered by the recent standards and accountability movement; as well, they also expressed potential or realized benefits from the focus on accountability.

> Susan: We were on our way to full community participation and membership for youth with disabilities... things were changing. Somehow, we have stalled out, or even retreated a bit, as the political climate of the late 90's and the new millennium has a different feeling, priorities, and national focus.

Several related themes emerged, including a narrowing of the curriculum - almost exclusively toward academics and test preparation, and in the process, omitting what we already know about good transition practices.

> Susan: Currently the policy initiatives related to education in this country are very single-minded. They're focused mostly on No Child Left Behind. All the incentives related to NCLB are directed at academic achievement. As such, teachers, leaders, community members and so on, are feeling, as you know, more and more pressure around academic achievement. I think that much of what we learned about and learned from the model demonstrations and the research that we did in the '90s, has gone by the wayside because the incentives are no longer there. In fact, the entire educational policy system is designed now to virtually punish schools and states whose kids are not performing at a particular level or standard.

In spite of the idealistic language contained in the brief description of the NCLB (p. 156, above) and in the Act itself, there are multiple issues across the country with its implementation. I spoke with David about some of these.

David: ...I think No Child Left Behind has been beneficial from the standpoint of the raised expectations—putting people on notice that we need high expectations for all, I think that's been important. It's been terribly difficult to work through, we're not done.

MA: *I heard recently that some 25 states have filed for exceptions—that for one reason or another, they are unable to comply with some elements of the law.*

David: Yeah, it's a law heavy on policy and requirements, and low on resources. Thinking that states can simply...I mean, the time lines are also very quick. Systems change takes longer typically, so, in the absence of any additional infusion of resources, states are claiming that they're having difficulty. Even with general capacity issues, how to get people up to speed, on assistance for data collection, credentials for teachers, that sort of thing. Some of the issues in that discussion surface around, you know, how do you include kids with disabilities in standards and assessments? How do you think about graduation requirements, standard diplomas and alternative diplomas?

MA: *It seems that every issue is so complex.*

David: Yes, terribly complex. Do you create diplomas other than the standard diplomas simply for kids who can't make it through the standard? And if you do that, to what end --- what is the value of those credentials? I mean, it's crazy, you have states evolving things like occupational diplomas for kids with disabilities only. Which I think is a violation of civil rights law, but that's beside the point. This is my opinion, but I think the issue is, that states are trying to figure out how to get through here. And there's a lot of decision making that's going on that is, you know, it's not, it's not driven by research, I can assure you. It's not driven by good understandings or evaluation information, it's being politically driven, by state legislatures or commissioners that are now deposed, here in Minnesota; that take on very radical stances, ideologically driven or whatever, you know that are –that's part of the vulnerability where we're all at... The issue of trying to get kids more aligned now with, you know, kind of trying to move this whole transition thing, the interagency mechanisms, the professional development systems, the systems of general education and special education collaboration, are terribly complicated.

The lack of resources associated with this policy is in contrast to its purported intent—that the education and the achievement of all students is truly valued.

Referring to policy development, Ball (1994) noted that "The state can only operate on the basis of other, already existing power relations, like [internalized] racism

and patriarchy" (1994, p. 19). Given the conservative nature of the social policy context within the current federal administration, the almost exclusive emphasis on positivist research methodology, the lack of special education participation in its inception, and the widespread controversy surrounding the impact of the NCLB, it is likely that the policy, *as it was originally drafted*, was designed to serve the interests of dominant groups within our society (rather than the interests of *all* its constituents). Speaking about an earlier reform effort, School-to-Work, David articulated the challenge frequently faced by special educators in general education reform efforts; that is, we are not included in the policy development phase; rather, we are "added on" later. "We'll include students with disabilities once we figure it out for everybody else" (David). This is indicative of a lack of power and value, not unlike that faced by our students.

> David: School-to-Work was a general ed movement, that called for the collaboration across nine different federal laws and programs , including special ed and rehab, but you know, again, it was so riddled with assumptions about, you know, I had many many conversations with states the basic message was, once we figure it out, we'll start including students with disabilities in that conversation. So once we figure it out in terms of programs and services and supports we need for all other kids, we'll come back to kids with disabilities. And you know, that's historically kind of a big kick in the pants we get , because we set up a separate system. Now, the conversation that we're trying to engage in here, is really with organizations like NEA, AFT and the National Association for Secondary School Principals, trying to, I hate the word seamless-- but to try to view it as each and every child can indeed be worked with, and students with disabilities really as they exist within the general education framework , the 90% with mild disabilities are the responsibility of general education , we need to be able to support and serve general education in serving them, you know I mean that's a whole other model.

Susan saw this differently- as not so much that we weren't included in the policy-making process, but that the law subsumes what we know to be good practice for students with disabilities.

> Susan: I think that's true, but on the other hand, in spite of a somewhat flawed bill, which every bill is when you get to ultimate implementation because implementation of any law depends on a confluence of leadership at the local and state level. That being said, this particular national focus has really subsumed all educators in terms of academic achievement. ...it's not so much a result of a law that may not have promoted inclusion as much as what we wanted it to do, it's about a current policy context regarding NCLB that provides a disincentive from doing the kinds of things we think kids with disabilities need.
>
> David: A lot of people still feel like they're competing with the academic programs to build in transition programs. Current tech ed people feel that they're competing with the academic programs to get any of their course work, you know, open for students who are in high schools now.

Part of the problem, as Bill sees it, is that general educators do not see transition services/ curricula as their responsibility.

> Bill: When you look at the definition of transition services, the definition says, "it shall include community-based training, occupational and independent living skills; ... But then if you ask general ed, "Do you see it as your responsibility to provide community-based training, development of occupational skills, development of community living skills?" They say, "No, we don't do that." And it's gotten really bad now, because we only do what we have on the test. None of that stuff's included on the test, so it's not in the picture. Therefore, we can expect that there are a lot of people being deprived, because the first NLTS 1 found that those who had the vocational type things are significantly better off than those who didn't.

Susan elaborated on the theme that because of the current policy context we can't provide the kinds of services we know students need because there are fewer resources for special education, particularly for students with severe disabilities, the curriculum is not as rich as it once was, there are fewer transition personnel and training programs...

> Susan: Particularly for kids with more severe disabilities, I think there are fewer resources for them, because most of them aren't taking the standards-based tests. 1 or 2% of the more severely disabled young people. The curriculum is not as rich as it once was. We used to have transition specialists in schools, and from the research we've done over the past decade, we've learned some things. Such as, those schools that have transition-based specialists are more likely to have enriched programs for kids. There are fewer transition specialists in schools than there have been. And there are fewer personnel-preparation programs that are funded by OSEP and other places to prepare transition specialists, because the

> entire focus is on academic achievement. So I think that national policy context has been totally detrimental particularly to kids with severe and moderate disabilities because the resources are just not there.

Whether or not the treatise of the NCLB was more or less well intentioned or politically motivated, the complexity and messiness of its implementation is to be expected, even welcomed, as the policy has entered the policy discourse or implementation and revision phase. Recall that Codd asserted that the term *discourse* has come to embody "both the formal system of signs and the social practices which govern their use" (p. 235); that is, not only the meaning of language, but the real effects of language use: the materiality of language. A discourse is the domain of lived experience (p. 242). "Policies pose problems to their subjects, problems that must be solved in context." and solutions posed by policy text will be localized and should be expected to display adhocery and messiness (Ball, 1994, p. 18). Further, "The translation of the crude, abstract simplicities of policy texts into interactive and sustainable practices of some sort involves productive thought, invention and adaptation" (p. 243). The best policies invite social action in response, not "robotic reactivity or implementation".

Current Social Climate- Fear

A sub-theme related to the current policy context is the system of incentives and disincentives for academic performance engendering fear. School performance scores are published in newspapers and on websites, and teachers and administrators often feel that their reputations are on the line. And not all kids are faring well...

> David: It's not just kids with disabilities that are getting caught up in the shuffle, but it's you know, but it's a fairly significant percentage of kids. I know we had one statistic come out of Minneapolis public schools, this was a year ago, that with the then existing math, reading and writing exams, that something like two-thirds of the African-American students in the Minneapolis public schools had not passed ANY of those exams, by their 11th grade. That would be enough to scare

> you. African American kids make up 25% of the school district. So 25% of your exiting students are not passing those exams, at all. And now they're 11th graders. What do you do? That's horrifying, you know. It's not a good statistic to be holding; it's good information to have about how well or not you're doing, but I mean its like, is this the right criteria to be weighing in on the total experiences of these African-American kids? Or other kids? There are all kinds of issues.

Because of increased public scrutiny, teachers and administrators are motivated to ratchet up test preparation, with the effect of narrowing the curriculum. So instead of being able to individualize curriculum, and focus on what individual students might need, (like contextual learning), the focus is more frequently on passing the test. Educators' reputations, and in some cases jobs, are on the line. As Susan said, "The motivation just is not there for public school administrators [or teachers] to get on the bandwagon for transition."

> David: I think the issue of self determination and empowerment is a scary thing for school administrators, by the way. Maybe it's really self- directed self knowledge, things like that ....it's difficult to fit these into the mandated curricula issues we're now facing.

Michael commented that the academic focus has subsumed the self-determination movement.

> Michael: ... In the 80's and early 90's it was all about personal choices and self–determination...I promoted that because I was really concerned that youth with disabilities find out what their interests and talents are, and pursue that. Now it's all about standards and assessments that have little to do with personal interests or preferences... and I'm sorry, but there are kids who are never going to pass those tests. Kids need to feel good about themselves and what they have to contribute. And that's what education should be about.

And Romie expressed concern that career education and contextual learning were compromised by the exclusive focus on academics.

> Romie: The challenge that I see now -- at one point it was just access to the building. Then it was access to curriculum. And now what I think what needs to happen for all schools, is for all schools and kids to be thinking of school as a

> transition to adult living. Citizenship, career ed, daily living things -- that a lot of kids don't get in high school because it's all academics.

As the academic achievement movement has gained momentum, there has been an associated movement away from vocational education or technical programs, impacting community colleges...

> Romie: There are maybe a few programs out at Front Range Community College, but that used to be a vocational technical school, and then it became a community college. So as they want to position themselves, and be seen as more of a college and more of an academic setting, they've kind of pushed the vocational programs off to the side. They're the ugly step children, you know? But really needed. That's a common thing across the country too.

There is also the concern that curriculum is being driven by assessments, instead of the reverse. And a general consensus that we also need to remember what we know about quality assessment and its uses; for example, should evaluations provide a snapshot or a motion picture of students' progress? ... And assessments should inform teaching and learning, not just evaluate teachers and schools.

> Bill: Look at the assessment data in secondary schools. Less than 15% are coming close to making adequate progress. You have to take the assessments. First of all you have to have your curriculum. Then you have to have your assessments that reflect the curriculum, and all this crap. So another area that is being affected by all of this is that area we've studied for so long in our field and that is preparation for people to live and work in the community. Acquisition of vocational and occupational skills, all of this has gone away.

> David: The curriculum is narrower; [it's] focused around courses and coursework or preparatory experiences related to passing state exams. There's a high stakes kind of testing environment; Minnesota has several exit exams. We are several. We have three, we're going on four ...this commissioner came in under the new governor, and developed a whole new system of standards, also, which is nuts. It's just nuts. Yeah, all that stuff is going on...so you have less opportunity in terms of time commitment to do it. If a kid starts failing one of the exams, the whole system pays attention to how we're going to get Billy or Mary to pass his exams... --the high school experience has really has become a much narrower set of coursework and preparatory experiences than it once was, illustrated in his own son's experience.

> David: Math continues to be, continued to be for my kid, from the 8th grade on, a series of attempts to boost his scores, through pretty rote learning experiences, seat time, and class work. You know, worksheets, or more homework, or things like that.

The American Dream: A College Education

In my analysis of themes related to the standards and assessment movement, a theme I had not considered previously emerged; containing the underlying cultural discourse that "*You've gotta have a college education!*".

> Bill: Well you have to remember that the dream is, under the right conditions, everybody will go to college. [But] what we know is that a little bit less than half the people who leave secondary school, go on to college (when I say college, I mean a community college or a 4-year-college- rather than trade school). We do have the data; it's just general population data. And of the group who goes to college, after 5 years, only 1/2 of that group has gotten a Baccalaureate degree. So basically, 25% of people who go to college, or a community school, and transition to college, graduate in 5 years. What I'm getting at, is half the people never go beyond secondary school. And of the half who does go beyond, only half of them acquire a degree in 5 years. But we've totally focused our educational system on those people.

Despite the focus on college preparation, a majority of students never complete college, especially, of course, students with disabilities. The statistics that Bill has cited are corroborated by NCSET (2004), who state that while the number of youth reporting a disability in postsecondary schools has grown from 2.6% in 1978 to nearly 19% in 1996—this remains at 50% lower than it is for the general population (p. 18). Further, of these 19%, most have not received special education while in public school, and virtually none of them have cognitive disabilities—so the statistics are very misleading.

> Bill: Already, we have just -- at least 95% of youths with disabilities are not going to go to college. When you say college, you have to qualify it because there is data that people who are disabled attend college. The number of people who are disabled in colleges and universities has increased. But, those are not people who had IEPs, and who were in special education. Some people would have you believe, well, look at the number of people with disabilities going to college; it has increased. So, we are doing something right. But when we

> disaggregated the data, the greatest number of people with disabilities in college was emotionally disturbed. And that's self-identified, and people with physical disabilities. Which are two very, very strong groups. The number with learning disabilities is very low. And students with more severe cognitive disabilities are nonexistent. So, the statistics can be very misleading.

Benefits

While there are numerous issues associated with the standards and accountability movement, there are also recognized benefits. One of these is "a framework to hold people more accountable", as David said. Another is the potential for increased collaboration between general and special education. Because of, in some cases, decreased access to general education environments, special educators are also being pushed to examine their assumptions about general educators...perhaps this will help to bridge the gap.

> David: If you were to ask, what is the secondary ed curriculum, for which students with disabilities should have access? I think that's a tough question to answer. There's been kind of this movement toward standards and assessment and things like that that have provided I think a framework...and a template to hold people more accountable ---now the issue is, who's being held accountable to it. And there are consequences to it, too... general ed and special ed collaboration is really an important development. The 1997 regulations in IDEA speak to it, in terms of policy, access to general ed curriculum, but the whole thing is in how to operationalize this...you know, we're finding that even though we have ideas about general ed-special ed collaboration from our own view—that what we really mean about general ed and special ed collaboration has to be thought through far more carefully. We operate with a lot of assumptions in special education about what general education ought to be doing for kids with disabilities, and indeed those are probably not unworthy assumptions, or invalid assumptions, but they're assumptions that are not yet grasped-- they're not the same assumptions that general ed holds about itself, toward those kids...

A potential benefit too is awareness that increased instructional time impacts achievement—so let's increase it, provided the instruction is *meaningful* instruction--

> Romie: The good thing about accountability and things like CSAP testing, -- it used to be when we would do things like the Iowa Test of Basic Skills, any kid on

> an IEP was automatically exempt. You cannot exempt kids now just because they're on an IEP. Boy has that ratcheted up the educational access that kids with disabilities have now! They're actually getting literacy. So I think that's good. I really do think that's good. I'm in favor of accountability. I'm not sure I'm in favor of doing as much testing as what we do. At the state High School Summit, they took a calendar with every month shown on one page, and all of the days. And they started to black out holidays, testing, and anything that is not an instruction day. And it turns out that it's something absolutely bizarre, when you count up the hours- kids actually have instruction for 3 weeks [out of the year]!

Meaningful instruction includes balancing academics with other curricular goals, like vocational and career education, in multiple contexts and real world environments, and including student and family preferences in choosing a course of study… and measuring these, too. "There's a phrase that's appropriate here: 'you treasure what you measure' (Romie).

> Romie: You know it's really interesting, a school district that I visited as part of a team for accreditation, is really looking at a broader definition of standards, so that what they've put in there is contextual learning. But it's basically career ed. And they've put citizenship in there, and they do service learning, and they get experience in world of work and researching careers; and they've made a set of standards that go along with that, and that's what they call contextual learning.

And, as David pointed out, there's the opportunity now for special educators to "get it" that *academics matter*.

> David: This is a critical point now, absolutely a critical point emphasizing the academic aspect of transition --which still hasn't sunk into many transition personnel, you know, teachers across the country. They still view academics as separate from transition. Like there's a set of "transition" programming, you know like work experience, service learning, functional academics, all that jazz—it's still not detached from academics---they don't relate it to the preparation for adulthood. It's like they think- oh, the academics, is done to satisfy requirements concerning diploma, or graduation, but it doesn't necessarily relate to the fundamental transition to – are the kids taking preparatory courses for college? Are they even engaged in courses that will benefit them once they go to college? My own kid has to take 3 developmental math courses at a community college up in Duluth, before he can take his first, for credit, math course… I mean, Jesus Christ, what were they doing in high school?

TRANSITION from School to Post-School Environments

(Post-secondary education; work; community participation; relationships; home life)

Transition Policy Context

Chapter 2 included a summary of some of the federal policy and other initiatives enacted over the past two decades to support youth with disabilities as they transition from school to postsecondary education, employment, and community living. In this section, I have provided a brief description of the federal policy initiatives summarized by NCSET (2004, pp. 3-4). The simplistic seeming and positive language characteristic of the text of these policies notwithstanding, they effectively illustrate at least *the intention* to provide services, access, and supports for persons with disabilities in our communities. As Ball (1994) noted, policy as text is not necessarily clear, closed, or complete- rather it is the product of compromises of various constituents at different stages. Policy as effect or agency is more concerning, and despite these many policies, again, outcomes studies of special education graduates still indicate that both the transition process and adult living are fraught with numerous, and in some cases, insurmountable challenges—evidence that although well intentioned, implementation is inconsistent, challenging and complex.

> ***Rehabilitation Act of 1973***. The intention of this law is to provide comprehensive services to all individuals with a disability, regardless of its severity, and prevent discrimination against citizens with disabilities.
>
> ***Technology-related Assistance for Individuals with Disabilities Act of 1988***. This law assists states in developing comprehensive programs for technology-related assistance and promotes the availability of technology to individuals with disabilities and their families.
>
> ***Americans with Disabilities Act of 1990***. As noted, this landmark legislation "guarantees" *equal* opportunity and "assures" civil rights for all individuals with

disabilities. The law mandates "reasonable accommodations" for individuals with disabilities in areas including employment, access to public facilities, transportation, telecommunications, and government services.

Carl D. Perkins Vocational and Applied Technology Education Act of 1990. This act requires states to provide special education students equal access to vocational education, and that local districts ensure the "full participation" of these students in programs that are approved, using Perkins money. States receiving federal vocational education monies must actively work to eliminate gender bias, stereotyping, and discrimination in vocational education.

Goals 2000: Educate America Act of 1994. This law established a new framework for the federal government to provide assistance to states for the reform of educational programs. It encouraged the establishment of high standards for all children, including children with disabilities, and specified eight national education goals for all children.

Workforce Investment Act of 1998 (WIA). WIA creates a comprehensive job training system that consolidates a variety of federally funded programs into a *streamlined process* allowing individuals to *easily access job training and employment services*. [It's amazing!] As outlined in Section 106 of WIA, states and localities are required to develop and implement workforce investment systems that *fully include* and accommodate the needs of individuals with disabilities.

Ticket to Work and Work Incentives Improvement Act of 1999. This act makes it possible for individuals with disabilities to join the workforce without fear of losing their insurance coverage (Medicare or Medicaid), with two new options for states: First, it creates a new Medicaid buy-in demonstration to help people whose disability is not yet so severe that they cannot work. And, second, it extends Medicare coverage for an additional four and one-half years for people in the disability insurance system who return to work.

The last of these policies described here is the Ticket-to-Work, and since a few of my informants initiated discussion of this policy, I have used their comments and my related analysis to attempt to shed light on reasons for the typical disconnect between the overwhelmingly positive policy text, and the less successful policy discourse. In this first excerpt from Madeleine's interview, she voiced what I suspected regarding the impact of the Ticket.

> Madeleine: *The Ticket-to-Work actually isn't working very well.* It's a very very small percentage, less that 1% that have used it so far. Particularly because the upfront costs for the provider are very high. You don't get a reimbursement unless the person is off the disability rolls *for 5 years.*

"The Ticket" has been available for 5 years, and *less than 1% of persons with disabilities have used it so far.* David elucidated several other reasons for the under-utilization of this act. In the first section of this excerpt, he discussed the "benefits trap" that plagues adult services for persons with disabilities.

> David: The thresholds have always been so nominal, that even if you capped, you know you hit the benefit notch where you're one dollar over what you're allowed ---therefore are off the program-- it's still not enough to maintain self-sufficiency...so the annual earned income, you would make, and then exit off the SSI program, would not be enough to live on. And the big catch is the loss of health- care benefits. Because if you're eligible for SSI, you're obviously eligible for medical assistance as well. And that's your national health care program. So if you have a disability, or something which requires ongoing medical attention, employers have not picked up that part of these programs. So young people who go to work, are not working 40 hours a week, they're working 20 or 8 or 10... a lot of places, like the University of Minnesota, you have to work 79% time to receive benefits. So you have to work 30 hours a week, and that's not always the case.
>
> MA: *So how does the ticket help?*
>
> David: It's one of many work incentives, trying to give opportunities to people to move beyond current earned income thresholds, before they lose benefits, it's one of those experiments. I mean, the problem with a lot of these work incentives programs, and there are plenty—the Ticket, Real Choices, Consumer—there are all kinds of programs—Navigator, Benefit Planning ---on and on, Medicaid Incentive Grants (MIGs), all kinds of things are out there. *They're complicated as hell to figure out – you almost have to be an attorney or accountant or something like that* to figure out—I make this amount of money, I'm trying to work within, and achieve eligibility within these different programs for incentives —to establish and then maintain and manage all the paperwork associated with that is incomprehensible to many people and families. So these benefit programs like ticket are currently under pressure because they're under-utilized, --- [the Ticket] has been under a lot of scrutiny right now for under-utilization. Many people aren't on the ticket—*it's just too complicated.* It's an incentive to some people and it's not an incentive to someone else. When one looks at an incentive program like the ticket or anything else, or other kinds of work incentives, it's so individualized. Because cash streams ...go into cash benefits, like SSI multi-

> checks are often complemented by like in Minnesota, the Minnesota supplemental assistance programs food stamps, and rent subsidy, and other things, which are construed as earned income as well, which count against your SS—it's so complicated, it's a wonder. *Then put a lot of the decision making in the hands of families, consumers, individuals with disabilities, it's incomprehensible. I don't even understand it.*

Recall Codd's (1988) instruction to analyze policy from various constituents' perspectives, and its impact on them. David is an expert in special education, transition and adult services, and still he said of this policy: "It's complicated as hell to figure out!" How much more so would it be for persons with disabilities and their families who are likely not as well-informed as David? This example illustrates another issue in youth and adult services; that subsidies for youth and adults with disabilities are often disjointed and complex, from various funding sources, and there is no streamlined system for the provision of these.

Themes in the Transition Literature

Themes contained in the transition literature parallel the same patterns as those in the K-12 education literature, that is, the paradigmatic shifts delineated by Bellamy (1997), from protection [dependence] to preparation [independence] to participation [interdependence]. The early work literature focused on instructional strategies to teach specific work skills, like task analysis and various prompting strategies. With the shift towards real work in real integrated work environments [paralleling the shift toward inclusive education] building of natural supports in the work place was a new emphasis [similar to the emphasis on peer supports in general education.] More recently, there has been another shift, from getting just any job, to career planning, and changing the attitudes and skills of others in work settings (cf., Storey et al., 1996, 1997, 1999) rather than trying to "fix" the person with the disability. As well, there is increasing focus on

building quality relationships in the workplace [resembling the focus on building relationships in grades K-12].

A related theme is the gap between knowledge and implementation (for example, there are lots of "buzz" words, like 'interagency collaboration' but frequently these are very complex and difficult to implement or operationalize).

> David: "Our transition program's going to be based on self-determination." Cool. You know, that's like a bouquet of flowers on the table. Who could dispute its beauty? But operationally, *what the hell do you mean?* Where does it fit? How are you going to do it? Is it simply, more nice rhetoric? How are you going to measure it? What does it have to do with schooling, and career prep, and youth development, and family participation and interagency support -- you've missed all those other domains of interest here, how does this all relate?

The biggest changes in the literature surrounding employment include issues addressing quality of life; the movement toward inclusion, belonging and the importance of relationships.

Relationships as Central: In work

In the chapter titled, *Social Relationships or No Relationships*, Park, Chadsey-Rusch, & Storey (1998) shared the story of two young adults with developmental disabilities, both with outgoing personalities, similar interests, and abilities, then working in different job sites in the community. One worked as a helper in a small restaurant, and had caring supportive relationships with the family-like staff. He loved his work, reporting that it was "cool" and he was happy. "This is the best place" (p. 317). The authors contrasted this with a young woman who worked as a helper in a cafeteria, a largely impersonal worksite. She reported that she talked to her boss briefly about her assignment for the day, and then was on her own; despite the presence of other workers, she did not interact with them. Although she was reportedly good at various tasks and

was given increased responsibilities over time, she wanted to leave her job because she was unhappy. She had no friends. Relationships matter.

Relationships as Central: In postsecondary education

Steczak, Mullins, Singh, and Bostick (1987) examined educational and vocational barriers faced by Vocational Rehabilitation (VR) clients who matriculated into postsecondary educational programs. Fully half of their respondents had physical disabilities; some were hard of hearing or had a visual impairment; a small percentage had identified learning disabilities. There were virtually no clients with mental retardation. The biggest challenge they reported was a lack of emotional connection or relationships with classmates- *of relational support or contact.* Again, for these young adults, physical access was *not* the barrier—the barrier was lack of social connection. This is a theme repeated in the literature on employment for persons with disabilities.

Patterns over Time in the Workplace Literature

Low incidence disabilities: Supported employment. In 1988, Nisbet and Hagner reexamined the basic premises of supported employment, in particular, the role of job coaches in supporting and supervising workers with special needs. Based on studies of the supports and informal interactions between typical workers in employment environments, they proposed several potential models for developing and implementing more *natural supports* in the workplace, including the use of mentors, training consultants, job sharing and the use of an attendant; each involving the active participation of job supervisors and co-workers to a greater degree than had been done in the past. Also in 1988, Gaylord-Ross developed job placements for students with low incidence disabilities and incorporated intensive worksite development and training of

staff...with a focus on transferring support to natural supports and facilitating interactions with co-workers without disabilities.

More recently, Mank, Cioffi, and Yovanoff (2000) reviewed four earlier research reports regarding typical employment features and their relationship with employment outcomes for persons with disabilities. Investigating the issue that high levels of direct support are associated with less typicalness, integration and lower wages, they demonstrated that wages may be increased, and integration outcomes improved even with substantial direct support when there is coworker training. Each of these studies reflects the continued emphasis in the low incidence literature on the importance of establishing and maintaining relationships for persons with disabilities in varied settings.

There are also studies in both the low and high incidence literature focusing on task acquisition in the workplace, demonstrating that students with disabilities can perform *real* work (i.e., work that someone else would have to do if the worker with disabilities did not do it [Brown, 1989]). For example, in a study with adolescents with various disability labels (from mild to severe), Gaylord-Ross, Forte, Storey, Gaylord-Ross, and Jameson (1988) trained 12 students to perform work behaviors in a technological work setting; the chemical lab at a large Chevron plant. The authors were interested primarily in skill acquisition and a social validity measure, *Did the students appear more competent after training*? (The latter represents attitudes more prevalent in the 1980's than today, that is, perceived competence by persons without disabilities as an important outcome of employment for persons with disabilities. While this is understandable since this is the first time persons with severe disabilities had access to real work environments (certainly a major step in valuing and respecting these persons!),

it perhaps reflects some subtle devaluing of these persons; i.e., their worth measured in part by whether "they looked good".)

High incidence disabilities. An unexpected parallel emerged in my analysis between the literature on employment for youth with disabilities and the K-12 curriculum, with regard to differences in focus and "treatment" for low and high incidence groups. Like the focus in K-12 curriculum, the work literature for students with high incidence disabilities reflects a focus on remediating the individual characteristics of workers, whereas the low incidence literature contains a clear emphasis on changing the environment to facilitate inclusion for the worker with severe disabilities and promote interdependence between all persons in the work setting. For example, in a theoretical piece examining the skills students with learning disabilities need to transition into work settings, Sturomski (1996) asserted, "Transitioning should focus on outcomes that make each individual a more *independent* and productive person [emphasis added]. [lack of interdependence]...He further stated, the individual needs to be able to function in a meaningful employment setting in which he is *qualified* [vs. partial participation]. "Accomplishing transition into a life of *independence* is a process that involves *proficiency in basic academic skills* and *competence in goal setting*" [prerequisite skill focus]. "An individual should have a *realistic* understanding of vocational and educational goals" [a focus on the individual's limitations, rather than his or her abilities] (p. 37).

In a similar vein, Montague (1987) investigated job-related social skills training for adolescents with mild to moderate disabilities by teaching social skills in classroom-based lessons, and measuring application of the skills in *simulated* work environments.

The social skills taught included: ordering job responsibilities, understanding instructions, asking a question, asking for help, asking for assistance, offering assistance, giving instructions, convincing others, apologizing and accepting criticism. While the skills selected for instruction in this study are representative of some skills needed in the workplace, they are largely devoid of skills foundational to building relationships with co-workers – especially since they were taught in simulated work environments! This reflects the dominant discourse in the LD literature—identify and teach specific skills missing or deficient in the individual student's repertoire.

There are differences too in the literature on transition assessment; for example Sitlington (1996) recommended these assessment practices with students with lower incidence disabilities:

1. Broaden focus of transition assessment to include future work, living, education environment, as well as natural supports;
2. Begin assessment process early age;
3. Move from "heavy reliance on formal assessment systems…to stronger emphasis on assessment tied to the curriculum and to the individual's performance in the community";
4. Do not rely on single assessments- collect ongoing assessment data throughout lifetime;
5. Include family and individual;
6. Move from set assessment sequence (one size fits all) to individualized sequence based on future living, working and educational environments by family and individual;
7. View transition assessment as integral part of ongoing assessment for all students (not add on);
8. Transition assessments as the joint responsibility of all special educators, not just transition personnel;
9. Include transition assessment skills into teacher training coursework;
10. Integrate efforts with general educators, including reform efforts;
11. Integrate with efforts of adult service providers; and
12. View assessment as a critical component transition planning and implementation process! [emphasis original].

Spruill (1993) presented this approach to assessment and transition planning for students with learning disabilities (p. 131).

1. Assessment is individually planned annually over a 7-year period. [like low incidence];
2. Stresses the use of informal methods that are relevant to instructional decision making and curriculum planning [like low incidence];
3. Data gained from informal curriculum-based assessment practices make clear the functioning level of students [identifies students "functioning" level/ needs];
4. A summary of findings may be presented to the transition coordinator in the post secondary environments [if there is one];
5. Assessment plan designed by diverse group of IEP team members, includes academic, vocational, and other life skills as needed [like low incidence];
6. Data are contributed by a variety of persons including the student's self-assessments [Akin to low incidence, but not as holistic, i.e., does not include the student's or care providers' dreams, preferences; emphasis is more toward what's realistic based on the students' skills];
7. Process depends on the skills of the coordinator to plan and collect data, analyze and communicate findings, and make modifications as needed;
8. Analyses of informal data may be used to support decisions regarding student eligibility for special education services [dissimilar to low incidence]; and
9. Assessment data facilitate decisions about post-secondary plans, [again, based on student skills] and a summary of findings may be presented to the transition coordinator in the post secondary environments [again, if there is such a person in such a position].

While there are multiple similarities and some convergence in these examples, a clear and progressive theme is evident in the low incidence literature that is not yet consistently evidenced in the high; that is, the underlying discourse is the movement toward emancipation, personal freedom, personal choice, quality of life, social justice, access and interdependence for persons with disabilities.

Current challenges

In 2003, at the request of staff at OSEP, leaders at NCSET convened a diverse group of transition experts for a summit on "current challenges facing the future of secondary education and transition services for youth with disabilities in the United

States". The following are excerpted from their discourse (NCSET, 2004, pp. 5-17; sans the associated topic development, citations and recommendations contained in the original document). These are included here because they hint at the multifarious issues surrounding transition, and provide a glimpse into what transition experts are currently discussing, and what they value.

> Challenge 1: Promote students' self-determination and self-advocacy.
> Challenge 2: Ensure students have access to the general education curriculum.
> Challenge 3: Increase the school completion rates of students with disabilities.
> Challenge 4: Make high school graduation decisions based on meaningful indicators of students' learning and skills and clarify the implications of different diploma options for students with disabilities.
> Challenge 5: Ensure students access to and full participation in postsecondary education and employment.
> Challenge 6: Increase informed parent participation and involvement in education planning, life planning, and decision-making.
> Challenge 7: Improve collaboration and systems linkages at all levels.
> Challenge 8: Ensure the availability of a qualified workforce to address the transition needs of youth with disabilities.

NCSET staff persons are currently circulating this paper in the hope that, like Madeleine Will's Bridges publication, it will promote awareness and encourage discourse and action by various constituents across the United States. For my purpose, what are the underlying normative values represented by the eight challenges cited here?

For one, there is valuing of persons with disabilities as whole, representing movement toward Van der Klift and Kunc' appreciation of *disability as diversity*; they privilege the perspective of the individual with a disability- evidenced by identifying "Promote students' self-determination and self-advocacy" first and foremost and in the normal life trajectory apparent across the challenges; and the perspective of family members (challenge # 6). They also value education, authentic assessment, and access to and quality participation in typical community environments for persons with disabilities.

The challenge of collaboration and coordination of adult services is also reflected. Finally, they address the Skrtic-raised issues of reform based on theoretical grounding, implicit in the text and its purpose- inviting discourse in the larger community.

Adult Living

Bill: *"Isn't the real question reliance on a receptive community?"*

The most salient issues and trends in adult living for persons with disabilities are related to a lack of resources, and the challenges inherent in interagency coordination. The most dramatic theme in my analysis was the relationship between disability and poverty.

Social/ Political Climate

The same social and policy contexts currently delimiting resources for transition in the United States have, of course, impacted adult living in similar ways. Susan articulated it this way:

> Susan: I will tell you that as strapped as education is to address transition, I think human services are even worse. There have been *enormous cut backs* all over the country, enormous waiting lists to even get kids into any kind of service -- whether it's residential or day services or whatever. Some states are just completely overwhelmed and don't have the resources to do it. It's obvious that in order for these young people who are leaving schools and move into a rich environment and learn and maintain vocational skills and careers and so on, we have to have high quality people in human services, but the people in human services get paid even less than our teachers do!

Disability and Poverty

The relationship between poverty and disability was another finding in my analysis- more profound and pervasive than I had imagined or realized. All of the participants talked about the recent eroding of services for persons with disabilities in the United States, as well as escalating poverty.

> Susan: I've just been visiting, on another project, some schools around the country both in urban and rural areas. I've visited about 14 schools that in the past 2 years, where the poverty level has increased so dramatically that you wonder how these schools can even stay open. And at the same time, they are being pushed to achieve higher and higher outcomes when the families who send their kids there have lost jobs, have lower incomes than they've ever had before... I was stunned ... seeing what the lives were in these urban and rural high schools and how little hope there is.... I just don't understand why this hasn't become an issue of greater concern on the part of Congress.
>
> Romie: We are creating a society of the haves and have nots. There's no middle ground anymore. We have the really, really wealthy, and then we have people in poverty. And somehow, the message is, those people who are in poverty deserve it. That's my bottom line, is that if you're poor, or if you have a disability, then somehow you deserve it. And boy, if you're making a good living, then you shouldn't have to pay taxes. People take so much for granted. They are so disengaged from the political process that I think they have no idea what their taxes go for!
>
> Bill: Yes, but [poverty] exists, and it's growing. There's a bar graph in the paper I told you about [referring to Hodgkinson, 2003]. It shows how the number of people in the top 5% have grown in the last 5 years, and also those in the lowest 5%. It's staggering. The lowest 5% is extreme poverty. That's people who are living at *half* the federal poverty level, which is already life threatening.

Ervelles (2000) asserted that schools recreate our capitalist society's economics and social class...which has... "contributed to the continued unemployability of disabled people in a highly competitive market economy and thus the conditions of poverty in which many of them live" (p. 26).

In *Schooling in Capitalist America*, Bowles and Gintis (1977) argued that the history of public education in capitalist America is a reflection of the history of the successes, failures, and contractions of capitalism itself. Rather than attempting to meet the needs of citizens, our schools have instead devised administrative, curricular, and pedagogical practices that reproduce subject positions and that sustain "exploitive class hierarchies". An historic example was the extensive and inappropriate use of biased IQ

tests has helped maintain the stereotype that "The poor are poor because they're stupid" (Ervelles, p. 27).

Noted Erevelles, "Schools socialized the working class poor to accept individual responsibility for the conditions of poverty and discrimination that continue to prevent them from even meeting their basic needs. In this way, schools legitimize the existence of an unequal social division of labor that locates the source of economic failure, not in the social and economic structures of capitalism, but, in the individuals themselves (p. 27).

Criticizing critical theorists in education, she contended that although they acknowledge the social construction of disability, "They fail to place the locus of economic success and failure in the economic structures of capitalist societies" (p. 27). Yet, persons with disabilities, especially those with more severe disabilities, have seldom been included in the market economy because their "real" physiological and cognitive differences are thought to affect the productivity of their labor and as a result impede the "efficient and rapid accumulation of surplus". (Likewise, according to Ervelles, people with disabilities have historically received a separate and unequal education in segregated settings in public schools, on the grounds that their "individual deficiencies" prevented them from realizing the educational gains that a regular education typically provided to "normal" students).

> Depending on the severity of their disability, the skills learned in these segregated special education classes have allowed a few disabled people to be employed in jobs locate at the lowest rungs of the social division of labor, while many more swell in the ranks of the permanently unemployed, dependent on the welfare state for their daily survival (p.27).

Stark and Goldsbury (1988) analyzed the labor market- projecting needs for the next decade, and predicted "a surplus of low paying, low skilled jobs"... which they noted was "good for the mentally retarded" (p. 365).

In the following excerpt, David discussed in detail the kinds of jobs available for adults with disabilities in our society, and the push to get them off entitlement programs and into the workforce, rather than first investing in training for these people. Yet the types of jobs available without training are entry level at best; perpetuating the cycle of poverty. The lack of investment in training is representative of a devaluing of the persons needing entitlement programs in the first place. The issues are complex.

> David: ...If we look at what type of jobs-- even the jobs creation now that is being viewed as significant indicators of economic health – if you really look at those jobs- they're entry-level, service oriented jobs, for which you'd have to work 80 hours a week to make a living. ... We have public policies like the 1996 Welfare to Work Bill that absolutely established ... a public policy that said, *work first.* If you look at the average earnings of all those individuals who are on welfare programs that did go to work, most of them are in jobs that require little or no training. Consequently, they're in low paid, low end jobs. There's a 50% attrition rate on that. [There is the] very explicit message of, *do not invest in training*! [Yet] we all know that training is the ONLY thing that is going to lift you from, you know, poverty into semi-poverty, to at least a living wage, whatever, it's going to move you up. Skills. ...I don't know what to do about this, it's a mind set...just getting people off these entitlement programs, or off these federal programs by gaining them the equivalent of cab fare and a newspaper, and a resume – as if that's enough. It's not. It's a short term fix.

Outcomes contained in the second National Longitudinal Transition Study (NLTS2), led Dr. Halloran to comment, "The majority of people who need special ed or rehab are joining the underclass."

> Bill: One of the things that you'll find out from them, in their most recent study [NLTS2], is that vocational course taking and things like that have really gone down. The curriculum is more academic now. And that's what the law says-- NCLB, and the standards movement. One of the things that's happened is, and it's the same with poor people and minorities and that sort of thing, when you're talking about having opportunities to acquire skills to assist in employment and all

> that kind of stuff, that's tracking. Everyone's gotta have a college education; when we know that one third of the jobs pay less than $8.70 an hour....so these people, if they get a job, it's certainly not going to pay much. Mentally, I'm going off the deep end in saying this, but the majority of people who need special ed or rehab are joining the underclass.

A sub-theme within the 'relationship between poverty and disability' construct is the notion that "poverty begets poverty". For example, that the poorest schools have the least skilled teachers was a theme contained in both my literature sample (e.g., Kozol, 1992; Finn, 1999), and with participants.

> Bill: [There is] Plenty of evidence that poor people go to their neighborhood schools; they have the poorest schools, least experienced teachers, least degreed teachers, lowest pay scales, poorest facilities, highest turnover of teachers, and the highest turnover of kids.

> Susan: Approaching inclusion? I think that's not true at all. And I think it's not only not true for kids with disabilities, but it's also the case for kids who are poor. They're relegated to mostly schools that are under-resourced and there's also some evidence that the quality of the teaching in those under-resourced schools is not what it could be.

In the next excerpt, Romie alluded to associated problems with schools in high poverty areas; the difficulty with attracting and maintaining skilled teachers because they are held accountable for their students' performance, and the relationship between low academic achievement associated with poverty, evidenced on standards-based assessments.

> Romie: But what's the incentive to teach there [in poor schools]? And now its worse, because they will be evaluated based on their students' performance, and discredited. So who wants to stay in a school of poverty? ... We're not doing it just to kids with disabilities [marginalizing them], we're doing it to kids in poverty, too. The CSAP [Colorado State Assessment Program] data in the state is *exactly* aligned with economics.

Bill, Michael and Romie specifically discussed harm caused by the current political climate in the United States, heavily influenced by the religious right.

> Bill: One of the things that is going on is the promulgation of Christian values. I don't know who their Christ is, but it's not the Christ I know about. Everyone is created equal, where is that? And even though people will disagree on the surface, all of their actions and behaviors are saying, *some people are just more privileged than others.*

> Romie: Conservative politics are detrimental to kids with disabilities, specifically in Colorado. I think the issue around here seems to be kind of the mentality of the old west, you know, "pull yourself up by your own bootstraps, and if you can't, you deserve to be poor, and not enjoy the same quality of life as people who can". It's almost a mean-spiritedness ...that somehow if you have a child with a disability, and you need support; or if you are an adult with a disability, that you deserve to live in poverty.

No doubt the relationship between poverty and disability is multilayered and complicated. A final example here is one on which Romie commented; that lacking adequate resources, disability organizations have often resorted to charitable contributions—unfortunately helping to reinforce the association between poverty and disability.

> Romie: It still presents kind of a mindset, because most ARCs, at least in the Denver Metro Area, they make their money off of ARC Thrift Stores. So you give your poor discards to that poor association for those poor people with disabilities, you know? It's kind of like the mindset of the Jerry Lewis telethon. It just perpetuates that mentality of "those poor people". And the ARCs make a lot of money. Those thrift stores make a lot of money. So they can't afford to let it go.

Bureaucracy/ Agency Themes

> David: *"Everybody's set up on this basic premise: spend everybody else's money before you invest your own agency's dollar."*

The issues here may be summarized as again, a lack of resources, and the impact of the bureaucracy which presents barriers for creative solutions; the "silo mentality"

(individual agencies not sharing information or resources to solve collective problems) – failing to see or invest in their interconnectedness to solve common problems. There are also barriers posed by complicated funding formulas, funding streams and application processes, and related difficulty in maintaining funding once obtained because of associated paperwork. Personnel issues, such as low pay and lack of quality training, are other themes.

I have included here two issues related specifically to Vocational Rehabilitation. The first, discussed by David, is related to capacity; while special education has grown in the past two decades, VR has not, and so has been unable to accommodate the increased demand for services. The other is their resistance to working with people with cognitive disabilities—who tend to be the least valued in the world of disability. Madeleine spoke to this issue.

> Madeleine: (After the reauthorization of IDEA in 1997) I then worked for about 4, 4.5 years for an organization called Community Options, which is a national provider of adult services, employment and housing in New Jersey, but they had programs in 10 states, and they created kind of a think tank, research arm in Washington. We did a lot of grant writing and refocused on employment innovations. And the reason I did that work was that I wanted to understand the issues from the provider side and then that was a very enlightening experience for me. *The absence of capital for providers to create alternative or innovative programs, the impact of the horrible bureaucracy on their ability to be dynamic, to do anything you know that was really different.*

A goal of the current administrations is: "getting people off these entitlement programs":

> David: But they're far more concerned about young adults and older adults who are on SSI or who get on SSDI, that never return to work, or never go to work initially for fear of losing their benefits. A goal of the current administrations is: "getting people off these entitlement programs" compounded by, if you get off one, you often lose other benefits. Because cash streams, they go into cash benefits, like SSI multi checks are often complemented by like in Minnesota, the Minnesota supplemental assistance programs food stamps, and rent subsidy, and other things, which are construed as earned income as well, which count against your social security- it's so complicated, it's a wonder."

An issue with all adult benefits is that the forms are "complicated as hell to figure out", mentioned previously. As guardian for his brother, even David had a very difficult time navigating the paper stream associate with benefits. They are "well- intentioned, but really need a lot of clarification for the consumer as well as advocates."

> David: My brother, I was his guardian for 18 years before he died, I'd always get these Medicare forms and stuff like that , because he was on SSI-you know, the state got 99% of it back, he got to keep maybe $35 a month for special needs or something but I'd have to fill out all these forms, and I'd have to call , and I know some things about this... god, I'd feel like a child when I'd read some of this stuff--- because it's so complicated. If this, then this will happen to you, and if that happens to you, then this will happen to you, and this will affect your benefits this way.

Personnel Issues

David: *"Personnel and professional development are ... the nemesis of all assistance programs."*

In the following excerpts, Romie shared two examples from experiences with her son that are representative of personnel issues in adult agencies. In the first, once she finally secured 'respite services' for Ben, she realized the workers had "no idea what to do" ; and in the second, she talked about issues with Ben's job coaches.

> Romie: They started CSLA- Colorado Supported Living Agency. And now they call it SLS- supported living services. It was Colorado's version of taking money from some slots, and dividing it up based on what people needed. They could pay somebody to come in the afternoon, and meet Ben after school and do some activities with Ben. But what I realized then was, that the people who they were hiring *had no clue what to do and they were relying on me* to come up with plans.

> Romie: The people they hire for job coaches, are frequently not people that even have a Bachelor's degree. But they happen to be good at interacting. But when you think about it, if Ben has a job coach and he starts to do well in a job, then he doesn't need his job coach. The person is actually putting themselves out of a job. Most of the job coaches that Ben has experienced up to this point have kind of made him pretty dependent on them.

Interagency Collaboration

David: *"Agencies should view these as 'collective issues, or shared problems, across agencies'."*

David is particularly knowledgeable about interagency coordination issues- one of which is, again, that they're fraught with tasks which are very difficult to operationalize—another is the resources just don't exist.

> David: We talk a lot about postsecondary programs coming in- well, they don't have the capacity or the personnel dedicated to this. Who's going to pull them in, and educate them? There's no mechanism.

The next excerpt is representative of the "interagency collaboration rhetoric" ... the gap between what we know we should do, and what is really possible given the constraints of the bureaucracy and lack of resources in adult services.

> David: No, actually it's through, like Hennepin County here in Minneapolis. There are 87 counties in Minnesota, which makes it very complicated. But they, you know, everybody's set up on the basic premise of, spend everybody else's money before you invest your own agency's dollar. So, the counties across the country are waiting for these kids to exit special education so they can set up their 'individual service plans', they call them ISPs, and, you know, I mean, they don't come into the –they typically don't come in to conversations in schools about kids, particularly if they're not like 22 or just about ready to exit. They're just not there. We talk a lot about postsecondary programs coming in- well, they don't have the capacity or the personnel dedicated to this. Who's going to pull them in, and educate them? There's no mechanism. They talk about employers ...*what the hell is that all about?!*

Vocational Rehabilitation Issues

As an organization, VR represents the best known and the "catch all" of adult services. Yet it has its own operating constraints, some of which are externally imposed, articulated by David, and some of which are internal and attitudinal, articulated by Madeleine in the passage following David's comments.

> David: Special ed has grown as a national program. If you look at the enrollment in special education since 1978, it's probably doubled, if not tripled, putting more pressure on state systems. VR has not grown at all, in fact, I think its lost ground

> each year, because of, they kind of move them to funding levels that were parallel to the prior year, rather than cost of living increases and things like that, so they've lost ground, but not responsibility.
>
> Madeleine: We had a separate paper on supported employment, because it involved the Rehabilitation Act. Because we had had a huge argument about whether we should even go that route. Lots of people thought we should go through ADD (the Administration on Developmental Disabilities) although it didn't have much money -- it only had about, now it has maybe 135 million. Because the Rehabilitation system fought us tooth and nail. I mean I was "persona nongratta" -- I still am. *They did not want those funds, their funds, to be directed to serving this population. They did not see themselves as serving this population.* They saw themselves as serving mostly people with physical disabilities. That was their position. Going back to 1918, post World War I, when the Rehabilitation Act was passed.

Another trend found in my research is the challenge presented by the lack of benefits associated with part-time work, most often available to persons with disabilities.

> David: So young people with disabilities who go to work, are not working 40 hours a week, they're working 20 or 8 or 10... a lot of places, like the University of Minnesota, you have to work 79% time to receive benefits. So you have to work 30 hours a week, and that's not always the case.

Trend toward Consumer- Based Supports and Services

A positive trend in the adult literature is a shift toward consumer-based supports and services, similar to the focus on person-centered planning in transition. This shift reflects changing attitudes that are more respectful of individuals with disabilities.

> David: I do believe that we have a lot of positive things going on, that really kind of center the question of services and supports around the individual. With case management, an individual can move toward help and support.

Two final themes are introduced here. One is the overarching theme in our society that persons with disabilities are still not consistently valued, reflected in the state of adult services. The other is related to Turner and Louis' notion of "disability as dichotomy vs. matter of degree", and that is, we tend to see things in black and white; for example, either people are independent or they need support—it is harder to realize that

while they may be able to do some things independently, they might still need support in some areas. In the next excerpt, Madeleine talked about underlying assumptions about persons with disabilities in our society, leading to less than optimal attitudes.

> Madeleine: ...all of [our] traditional responses to differences, separation -- those instincts are all wrong. It's getting that message out and re-fashioning an image for a person with a disability in our society. There are more tolerant attitudes, certainly in probably all of history -- but they're not optimum. It's still not adequate, and not reflecting who these people are and what it is that they want. Attitudes are built on assumptions about people with disabilities. What it is that they can't do. And therefore, how little they can contribute.
>
> MA: *It's kind of the notion that grew out of industrialization-- that to be of value, you have to do productive work. We're still stuck with the vestiges of that, I think.*
>
> Madeleine: Right, exactly. We're still more comfortable with the notion of taking care of persons with disabilities; the charity approach, and we're conflicted about the notion that maybe they can work, but they need some public support. That's very foreign to us, we think in black and white.

CHAPTER VI: TOWARD UNDERSTANDING TRANSFORMATION

Bill: *"Let's fix the society that views them as broken."*

Why conduct a poststructural analysis of the transition movement? Has this study increased our understanding of the transformation process of society's relationship with persons with disabilities? How? And how have I as the researcher been changed in the process?

Poststructuralism implies no general characteristics (Poster, 1989). Applied to education, it shares some common themes with the term *postmodernism*. First is the rise of new social movements, independent of "some overlying notion of liberation and /or empowerment", and irreducible to the simplistic notion of the social relations of production (Marshall and Peters, 1999, p. xxii). There is a corresponding search for new forms of collectivity, and, Marhsall and Peters argued, a return of education reform and policy to the terrain of local contexts, because this is the only place that includes the diversity of communities and personalization of the "lived experience" of people.

Second, poststructuralism maintains that reason is neither absolute, nor universal. The authors contended that instead of a totality of reasons, we have a plurality (p. xxii). Consequently, there are no universal solutions; rather, there are solutions for particular individuals located in a particular places, times and cultural contexts.

Third, there has been a decentering of the subject, that is, the individual subject as the endower of meaning and the basis of epistemological certainty...in education, knowledge is dialogic; co-created between teacher and learner, and both are learners.

Fourth, and finally for my purpose here, Marshall and Peters noted that within ethnically or culturally homogenous communities there has been the emergence of very strong objections by cultural and ethnic groups against control or oppression by others, and for recognition and release, referred to as "the politics of difference" (such as women, lesbians and gays, and persons with physical disabilities) (p. xxiii). While detecting difference is a *cognitive* task, respecting difference is an *ethical* one. Poststructuralism, then, has provided "fertile ground" (p. xxiii) for the critique of univerlistic assumptions and approaches.

The present study offers insight into how and perhaps why individuals with disabilities have historically been marginalized in schools and post-school society in the United States, and identifies origins and vestiges of these attitudes still apparent today. In order to combat "absolutisms", and thus, look for "more effective and balanced solutions", I have attempted to entertain and incorporate aspects of many theories to elucidate the process of transformation of society in relationship to persons with disabilities, and the transition from school to post-school environments. Given my predilection for the poststructuralist's orientation to plurality of thought, and the complex nature of social change, in the conclusions I have drawn, I have also attempted to address *all* the quadrants, levels, lines, states and types in Wilber's heuristic to realize this complexity, or arrive at more effective and balanced solutions...revisiting an example (Integral Institute, 2005) applied to Wilber's heuristic may be helpful here.

Behavior modification may be said to focus exclusively on Wilber's upper-right quadrant by attempting to directly change personal behavior. While teachers using applied behavior analysis do possess a piece of the puzzle for effecting change,

interventions included under this umbrella do not appear to address upper-left quadrant issues relating, for example, to individual psychological development or spiritual development and values-based motivations. Nor is the context of a supportive culture necessarily addressed (lower-left quadrant) or organizational systems (lower- right). In effect, applied behavior analysis, then, leaves out at least three-fourths of the factors required, according to Wilber, for *sustainable or integral* change; in and of itself, therefore, behavior modification is an insufficient change strategy. Recall Bill's comment to practitioners of operant conditioning, "You have no faith in people, the way you operate. You gotta have faith."

In background material provided to clarify their conception of "integral" change, staff at Wilber's institute cited the work of Kegan (among other works) (Integral Intstitute, 2005). In his book, *In Over Our Heads,* Kegan (1994) observed that the demands placed on the average person by postmodern society extend beyond the developmental levels that experts (human development theorists) agree the majority of people have reached. Kegan identified five developmental levels, or "orders of consciousness" that define how a person constructs reality. The first three are similar to those articulated by other child and adolescent developmental psychologists: impulsive (2-6 years), egocentric (6-adolescence), and socialized or conformist (adolescence and beyond). According to Kegan, most adults reach at least the conformist level, what Wilber referred to as "third order consciousness", "where a person is able to internalize a value system, understand and respect the needs of others, and think abstractly" (Integral Intstitute, 2005, pp.1-3). Kegan added two other developmental stages to the first three: *autonomous* and *integral.* At the autonomous level, or fourth order of consciousness, a

person becomes self-directed, or "self-authoring", that is, they become capable of constructing their own value systems, as opposed to operating within those transmitted by their families, cultures, or workplaces. And, at the integral or fifth order level, "they begin to bring together and synthesize many different value systems into coherent and meaningful wholes" (p. 2).

Kegan's research in adult work environments demonstrated that democracy and democratic values emerge only with fourth order consciousness (Kegan, 1994, p. 213). Applying Wilber's model, it follows, then, that a significant number of individuals must have access to fourth order consciousness to change educational practices which contribute to the marginalization of youth with disabilities as adults. The maintenance of special education as a separate system, for example, is justified not necessarily because it is *right*, but might instead be attributed to a level of consciousness achieved by the majority of teachers, researchers and other 'players' in the system.

In *Voice, Collaboration, and Inclusion: Democratic Themes in Educational and Social Reform Initiatives*, Skrtic and Sailor (1996) asserted that the rise of constructivism and the decentralizing of conventional and remedial special education practices provide the opportunity for progress and renewal in education (and other professions) and in society (p. 142). They demonstrated how, in recent decades, the objectivist view has been decentralized by two main critical lines. One, it has become increasingly clear that teachers (and other professionals) don't always know what's right or best for their students (or consumers) (recall Romie's frustration with her son's education); and two, the questioning of positivism as the only and privileged scientific method.

Next, elucidating some of the positive implications of the rise of subjectivism for educational and social reform, they highlighted the social constructivist principles of *voice*, *collaboration* and *inclusion* across three interrelated levels of reform: structural reform at the level of school organization (through consideration of the school restructuring and inclusive education reform movements), pedagogical reform at the classroom level (through review of newer instructional approaches appearing in general and special education), and institutional reforms at the level of community (by introducing the "school-linked services integration movement"). In the process, they effectively demonstrated that... "Inclusion is far more than a new special education service delivery model. It is the new culture logic that corresponds to the emerging historical conditions of the 21st century" (p. 143).

Returning to the discussion of decentering objectivism, the authors examined the two lines of criticism in some detail. First, they argued that the notion of "client" has been found to be an artifact of an objectivist model in which knowledge was thought to be dispensed by a professional. Replaced with the concept of a "consumer", an emerging construct which reflects the shift of power from professionals to individuals – individuals are becoming more informed, making choices about what they want; more self-directed and autonomous- thus developing their *voice*. (Here recall the analysis surrounding Romie's pediatrician.) Skrtic asserted, "In the late twentieth century the very meaning of knowledge changed, opening new possibilities for achieving ethical practice and a just society" (p. 143).

> The more recent line of criticism regarding the objectivity of scientific knowledge radicalizes the earlier arguments for a consumer-oriented, interdisciplinary form of professionalism, both epistemologically and politically. Social constructivism implies far more than simply sharing

> knowledge among professionals and consumers. From this perspective, a consumer-oriented, interdisciplinary discourse is a radically inclusive and democratized form of social participation, a dialogical inquiry in which the professionals and consumers collaborate in the construction, deconstruction, and reconstruction of knowledge (p. 144).

Turning next to a discussion of the emergence of the dynamic global economy, the authors explicated the resultant new organizational forms happening during this same time period. These new postindustrial organizations have been called "adhocracies", or more recently, "learning organizations" (Senge, 1990), and represent the inverse of the bureaucracies that dominated the industrial period. Founded upon collaboration between various professionals, and between consumers and professionals, Skrtic and Sailor noted, "Collaboration is essential because invention requires reflective problem solving through discourse, a social constructivist process in which the voice and collaboration of each team member contributes to the construction of new knowledge (meaning) within the organization" (p. 143). Indeed, "adhocracies and learning organizations are premised on a discursive form of interdependence among [participants]" (p. 143).

> Bureaucratic interdependence is premised on a hierarchical and monological ordering of separate bodies of knowledge and skills within the organization. But adhocratic interdependence is lateral and dialogical and, thus more democratic. It is premised on reflective problem solving, which requires a multivocal discourse among equal-status participants with different knowledge and skills. ...Given that they are both premised on the principle of standardization, machine and professional bureaucracies are performance organizations-nonadaptable structures designed to perfect their existing practices and standard operating procedures. Conversely, adhocracies are premised on the principle of innovation; they are problem-solving organizations designed to invent new practices and procedures for work that is so ambiguous, that, initially, the knowledge and skills for doing it are completely unknown. ...Under these ...conditions, division of labor in an adhocracy is achieved through collaboration (i.e., by deploying various specialists on interdisciplinary project teams whose members work collaboratively and assume joint responsibility for their particular project of innovation.) ...coordination is achieved through mutual adjustment, or

> informal communication among team members as they construct, deconstruct, and reconstruct novel problem solutions on an ad hoc basis (p. 146).

They offered transdisciplinary teams and collaborative consultation models developed in the inclusive schooling movement as representative of school-based examples.

Presenting school restructuring as the second part of a movement toward excellence which began with an "effective schools" phase, the authors asserted that the effective schools movement sought to achieve *excellence* through further bureaucratization of schooling *without questioning the underlying structures*—producing more standardization and state control, with emphasis on standardized results and regulated teaching, while the school restructuring efforts emerged in an effort to reduce standardization, increase the adhocratic structure of schools; increase teaming, collaboration, and decentralize control, to local schools and districts. They argued that the goals of the latter are akin to inclusive education reform efforts. Inclusive education represents the second part of an *equity* movement, following the REI. Like school restructuring, inclusive education requires a restructured system of education, one that eliminates categorical special needs programs by eliminating the historical distinctions between general and special education.

> From a structural perspective, both reform movements are calling for the elimination of specialization, professionalization, and loose coupling, the determining features of the professional bureaucracy structure; both reforms seek an adaptable system in which teachers collaborate among themselves and with their consumers to personalize instructional practices. ...there are differences of *degree*, rather than *kind*, between them...On an organizational level, both reform movements are arguing for collaboration, mutual adjustment, and discursive coupling, the determining structural features of adhocratic form...for a consumer-oriented, interdisciplinary form of professionalism in the field of education and a postindustrial or adhocratic structure for schools, and thus for institutionalizing in

> public education the social constructivist principles of voice, collaboration, and inclusion (p. 147).

The authors made the contention that the point at which the inclusive education and school restructuring reform efforts converge is in the *inclusive school movement* and the discourse on teaching diverse communities of learners. Recently both general and special educators and their corresponding research communities have developed a number of innovative instructional strategies. "Whole language, constructivist math, and the inquiry-based science curriculum are examples of educational models with democratic themes." In constructivist classrooms, teachers are viewed as agents who encourage students to think and discover with them, involving them in the "whole problem-solving enterprise" (p. 148).

The inclusive school movement has apparently, like the transition movement for youth with disabilities, been subsumed by the current social and political focus in the United States on the standards and accountability movements, such that they have, as Susan says, "disappeared off everyone's radar screen for the moment". Because they address social equity, social justice, and emancipation for *all* persons, including those with disabilities, I am confident that they will reappear. [19]

I turn now to themes contained in the literature and in the views of change agents toward realizing fuller participation. Given that prejudices are deeply rooted and very difficult to change, what does contribute to changing attitudes and minds? Several thoughtful streams appear in the literature, including new and innovative ways of

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[19] At the time of this writing, new IDEA legislation has moved through Congress and is awaiting final acceptance, and the subsequent development of associated regulations. The identifying characteristic of these revisions, the first since 1997, is the emphasis on a return to local control (*Education Week*, 12-1-04).

explicitly teaching about difference, teaching tolerance, and building classroom and school communities where everyone is valued and everyone belongs.

Responding to Ways of Viewing Differences

In their discourse on ways of viewing differences, Turner and Louis (1996) identified a number of implications for transformation. Among them:

First, schools must address as an educational priority the internalized images of difference that students bring with them to school, as well as those they construct in response to their school experiences. Not just a matter of teaching about difference, or surveying various disabilities as we used to do (much like the tourism mentality in early multicultural training efforts); it must involve *confronting assumptions directly* with students as the makers of new meanings about difference and similarity. "Personalizing the nature of difference and helping students [to] identify their fears about stigma provide a foundation for both personal and interpersonal understanding" (p. 140).

Second, the issue of student subcultures needs to be addressed as an integral component of all efforts to facilitate inclusive schools. "Merely integrating students with different characteristics into the general education classroom will not ensure the development of communities that value differences, especially ones in learning and performance. Assumptions internalized by students regarding difference need to be surfaced and discussed, especially among older students" (p. 140). Studying social interactionism, Berger & Luckmann, 1966 contended that meaning exists ... "only as a consequence of the social fabric that permits the testing of assumptions" (p. 27). To re-construct meaning, assumptions must be made conscious, tested, debated, and reconstructed, in light of new information.

Third, the authors argued that schools need to embark on the critical work of building a genuine community, and not just in the classroom, but throughout the school. This must be based on an ongoing priority to explore difference and similarity, and the value of each member. Community means much more than simply celebrating food and holidays; it means creating a strong emphasis on caring relationships as foundational and central to the culture of the school, as well as collective responsibilities for the good of the whole (p. 140).

Finally, Turner and Louis asserted that the common patterns of social responses to difference (see chapter 3, this study) suggest that the goal of creating inclusive schools should *not* focus on the needs or concerns of students with disabilities, per se. Rather, issues related to disability should be embedded in the broader context of difference and similarity, in response to the needs of all students. "Only when we recognize the value of all differences that children bring to school will we be in a position to move toward the goal of cultural citizenship for a diverse society" (p. 140).

The literature is clear that grouping children based on race, class or gender is discriminatory (e.g., Rist, 1996; Hallinan, 2001; Dillabough; 2003). It appears much more difficult to grasp that this is true for abilities, too. Of course, homogeneous ability groups are easier for teachers, and schools to manage... yet to address the needs of a pluralist society, schools must be redesigned for children and teachers to co-create knowledge, rather than simply convenient for teachers to teach (based on the modernist notion of objective knowledge dispenser) (Skirtc & Sailor, 1996). Through the process of conducting this research, my own conviction that we cannot afford to pretend that we are not teaching values in the ways that we interact with children, including those with

disabilities, has been strengthened. Our every action contains a wealth of information for children about what we believe matters, whether explicit or not. And children emulate these values. It is clear to me that this is the subtext of public education curriculum, the passing on of cultural values, beliefs, and customs. It seems critical that we become conscious of the subtext, and to choose more consciously, rather than simply teaching or reinforcing hegemonic values.

Toward this end, in recent years there has been a hopeful movement toward teaching tolerance across many schools in the United States (see, for example, www.tolerance.org). Tolerance has been defined in the literature as "recognition and respect for the opinions, practices, or behavior of others" (Thomson, 1999). Thomson asserted that by definition, tolerating others is comprised of three elements: "First, that the others are present so that they can be tolerated; second, that those who are becoming tolerant understand the opinions, practices, or behavior of those they learn to tolerate; and third, that this recognition leads to respect" (p. 49).

Tierney (1993) contended that the inevitable presence of difference means that we all have to be comfortable with building communities of difference.

> I am suggesting that we build the idea of community around the concept of diversity, for communities generally suggest commonality. Such communities, however, have inevitably silenced those of us on the borders. Instead, we need to develop the notion of difference and engage in dialogues across border zones. Differences are confusing, even threatening, because we are forced to confront ideas and lives that may bring in to question our own commonly held assumptions and beliefs, but I am suggesting that dialogues of difference also enable us to respond to the current challenges in education . . . . We are united in a community and culture through mutual desire to understand one another's differences, and from those differences to forge alliances that, in effect, create a new organizational culture (p. 77).

Overarching Themes

My task at the outset of this research project was to conduct a systematic, critical review of the literature encompassing the transition movement, including the perceptions of researchers, theorists, policy analysts, practitioners and persons with disabilities, and as well, carry out a narrative analysis of the perspectives of change agents, reconstructing these into some holistic understanding of society's relationship with persons with disabilities. In the process, I have realized deeply that, as Bill said, "Everything doesn't fit into a neat little box." However, several themes emerged across both the narrative and document analyses in my study. These may be grouped conceptually into the three overarching themes of *voice, interdependence, and inclusion.*

Voice

Similar to the theme presented by Skrtic and Sailor (1996), *voice* is represented in the literature and narratives in the shift from a focus on individual deficits to individual preferences and choices, person-centered planning, self determination, and the newer shift in adult services toward consumer-centered planning. It is also evident in the shift from "fixing" persons with disabilities, and instead, teaching others around them how to support and interact with them.

Interdependence

Interdependence is represented throughout the literature and narratives through the importance of relationships, social support networks, and the work on deconstructing and changing attitudes toward increasing tolerance and appreciating diversity.

An unexpected outcome of my research was the recognition of the importance of various relationships for the participants I interviewed, as well as the pattern of

relationships as a central theme present throughout the document analysis. At least two different kinds of relationships were significant in the lives of participants: with persons or people with disabilities, and with mentors. The document analysis included multiple examples of the significance of relationships and building social support networks as a central theme in the K-12 literature (e.g, Strully & Strully, 1985; Forest, 1988; Grenot-Scheyer, 1994; Meyer, 1998; Jorgensen, 1998), in transition (e.g., Steczak, et.al, 1987) and in work environments (e.g., Park, Chadsey-Rusch, & Storey, 1998).

Additionally, as noted, over the previous two decades there has been a movement from dependence, to independence, to interdependence (especially apparent in the low incidence literature) ... akin to the paradigmatic shifts delineated by Bellamy (1997), from protection [dependence] to preparation [independence] to participation [interdependence]. Kim and Turnbull (2004) provided an applied example, recommending the merger of two practices to better address the complexity of transition planning for the adolescent with disabilities: person-centered planning (from the transition literature), and family-centered planning (from the early childhood special education literature), into "person-family interdependent planning" (p. 53). This merger would bring to bear multiple interventions and the collective enterprise of concerned individuals on the challenges inherent to transition ...and in my analysis, are representative of the general trend toward increased collaboration and interdependence across various persons, roles, groups reflected in the literature. The benefit of shared expertise, an outcome of increased collaboration between general and special education teachers was something on which Dr. Tobin also commented.

> Romie: They [general educators] know about curriculum, and special ed knows about strategies. And you know ... at that high school conference they were

> talking about differentiated instruction. Where do you think that came from? That's our bag! Teachers are realizing that a lot of the strategies that special ed has used for a lot of years, are really good for a much broader range of kids in general ed. They are recognizing that kids learn through lots of different modalities and intelligences, such as doing multi-sensory reading strategies...[it used to be that] if you didn't learn how to read one way, then you were left out of the loop. Now they're trying to figure out how to help kids who have missed pieces in their phonemic awareness and ... decoding skills... they're up into secondary school now, and they're still not reading. They're figuring out how to catch those kids up, and I think they gave up on them, a lot before.

Interdependence is further reflected in the shift from modernist to pluralist thinking in larger society.

Inclusion

The final overarching theme, also encompassing these first two, is *inclusion*; corroborating what Skrtic and Sailor (1996) proposed, that "far more than a new special education movement, [*inclusion* represents] the new culture logic that corresponds to the emerging historical conditions of the 21st century" (p. 143).

The implications of these overarching themes are diverse. However, they may be reduced to "one steady trend toward progressive inclusion", first articulated nearly two decades ago by Lipsky and Gartner (1997, p.110), with various implications for service delivery across the life span of individuals, as articulated in the following example.

The development of social support networks and multiple personal and professional relationships are undoubtedly an integral component. In fact, the experience of relationships is critical for developing understanding, accepting and appreciating individual differences. My study adds to the evidence already amassed that without children being educated together, they will typically not develop these kinds of relationships -- that change minds and attitudes and teach compassion and caring; and these are the kind of relationships that ultimately will transform society's relationship

with persons with disabilities. As noted, years of "disability" or "ability awareness" activities as an-add on failed...and part-time mainstreaming precludes the perception of class membership (Schnorr, 1990). Recall Strully and Strully's (1985) comment about their daughter Shawntell's relationship with her friend, Tanya ...

> It will be relationships such as this (Tanya and Shawntell's) that will ensure that Shawntell will be an active member of her community and it will be relationships, not attitudinal gimmicks (e.g., large puppets and blindfolds), that will create change in typical children such as Tanya (p. 224).

Yet as Turner and Louis noted, it is not enough for children to just be physically present in the same classroom or cafeteria. For relationships to develop and diversity to be appreciated, educators and other adults need to work to bring to the surface the layers of prejudice toward differences embedded in student attitudes, curricula and society, and explicitly address them; they need to promote collaboration and cooperation and teach component interpersonal skills, value and facilitate "friendship as an educational goal", and create classrooms and school cultures that value diversity and actively promote inclusion.

The challenges presented by poverty are even more complex. Yet, at a fundamental level, the association between poverty and disability represents a logical outcome of the general devaluing and neglect of persons with disabilities. Changing schools in the aforementioned ways are a start, as new generations of citizens grow up potentially caring about quality of life for *everyone* in their communities. The most hopeful trend in adult services is the shift David described as the trend toward "consumer –based" adult services. These are reflective of building networks of support around an individual, personalizing the services to address his or her specific needs, and valuing his or her voice: preferences and personhood. This shift requires that agencies collaborate

and coordinate, in spite of the paucity of resources currently available to them; it also requires that varied citizens and citizen groups increase their demand for such services-strategically, through multiple local, state, and national political venues. These are the activities that will contribute over time to increased awareness and allocation of services, in kind, changing more minds and attitudes... and societal transformation.

Rather, then, than generating an orderly theory, I have instead arrived at some understandings of what contributes to transformation of society's relationship with persons with disabilities; something which may be conceptualized in an integral model of inclusion; incorporating tenets of both Bellamy's (1997) *Braid of Progress* and Wilber's (2000) *Model of Integral Consciousness*, that is, that the quadrants are dynamic, and interactive; that change in any one area influences change in the others, and that addressing each of the quadrants is important for impacting and sustaining change.

Table 5- *Idealized Model of Integral Inclusion*

Upper-Left Quadrant	Upper-Right Quadrant
"I"	"IT"
Interior-Individual= ***Voice***	Exterior-Individual= ***Voice + Interdependence***
Intentional	**Behavioral**
Self determination, empowerment, developing voice...choices and preferences...developing whole person, character, emotional intelligence, inter and intra personal skills, academic and intellectual abilities, spiritual development, physical development...	Attention to pedagogy, co-creation of knowledge, classrooms and schools as communities. Explicit instruction in differences; contextual learning and career education. Collaboration between special and general ed teachers and learners is valued and dynamic...emphasis is on interdependence...social networks are supported...friendship and relationships are valued and facilitated; instruction is differentiated based on the preferences and needs of individual students, resulting in fluid and flexible grouping for instruction... reciprocity and equality and joy are the norm...
Lower -Left Quadrant	**Lower-Right Quadrant**
"WE"= ***Voices + Interdependence + Inclusion***	"ITS"= ***Integral Inclusion***
Interior-Collective	Exterior-Collective
Cultural	**Social (Systems)**
Teaching character development, morals; building inclusive schools and communities. Everyone matters, everyone belongs, and it's all related. Everything is accessible to everyone, interdependence is valued... as is community participation and creation; schools are diverse communities of learners where knowledge is co-created by teachers and learners engaged in the process of deconstructing and constructing new knowledge together.	Adhocratic schools based on meeting the needs of all students and faculty- special education as a separate system is eliminated, rather it is integrated into responsive education for all; this leads to responsive societies ... interdependence ... schools are linked with other human service agencies, health, mental and physical, social services, recreation, and adult service agencies ... early intervention is addressed; poverty is eliminated...

Conceptualized in this way, inclusion represents an integral model, which incorporates all of Wilber's five dimensions, so may be said to be integral, or "second tier". As more people reach Kegan's *autonomous* and *integral* levels of consciousness, this will help to shift the collective consciousness toward *stage* changes, and inclusion

will become more manifest as the accepted culture. Perhaps then we will actually enter into Lipsky and Gartner's era of "full community membership". Bellamy's last paradigmatic shift might better be described as "from preparation to partial participation"; the next will be "from partial participation to full participation". Though they share common words, the leap they imply might be measured in light years.

Vision for Youth with Disabilities

In this last section, I turn to the various ways my participants articulated their vision for youth with disabilities, including improving transition and life quality. In the first excerpt, David spoke of issues germane to Wilber's upper-right quadrant (the "Exterior-Individual" or "Behavioral"), reflecting a partial solution.

> David: I hope that part of the vision is being able to maintain high expectations and high standards for all kids. I don't think I want lose that as part of the vision. I think that is a good part of the vision. It's messy as hell, too. I mean, not all kids are faring well in that I think part of the vision has to begin to look at investments in evaluation and research to better understand some of the impediments in those systems and work through them. I think continuing to keep high expectations and hold people accountable and things like that is not bad- I think that doing a couple of those things would help to shape a lot different future.

Susan articulated a desire to "resume where we left off eight years ago"; before the standards and assessment movement subsumed the national focus from less dominant competing priorities.

> Susan: I wish that we could resume where we left off eight years ago. Ensuring that, or promoting, good jobs for people, and creating the availability of quality post-school resources so that kids could live in decent places, and have friends. ….[Youth] need to be living in safe and caring environments where they can be productive and follow their dreams and be as self-empowered as they want to be. That would be my dream. That young people with disabilities and young people in poverty would have opportunities to achieve their goals, be engaged in work that they loved, have enough money so they could do things that they wanted to with their friends, and feel like they were included in the community.

Like David's preceding comment, in the following response, Romie focused on one quadrant, the upper-left.

> Romie: The kinds of things that I think are going to advance [society's relationship with persons with disabilities] are the kinds of things that promote [individual] interests and preferences. And if planning begins with the student's interests and preferences, their course of study is going to look different; the experiences that they have are going to look different. I hope that special ed, like IDEA and the Rehabilitation amendments, get stronger...[and are driven by individual preferences and needs], as opposed to what's available.

Later, David reiterated his vision for a "consumer- focused model" of adult services.

> On the one side, I do believe that we have a lot of positive things going on, that really kind of center the question of services and supports around the individual. From the standpoint of the individual and families driving the game.... I believe in the principles and values of self-determination, self-directed behavior. Voucher for the consumer; I'm not talking about educational vouchers; but being able to direct your resources and your destiny. And have a say in it; an actual voice...is probably part of a vision that's coming...I think that's important ...it's going to be messy, but I think if you start putting the resources in the hands of those affected, to direct and drive certain types of training and employment supports-community living supports, you're going to see a bit of a shift in attitude toward those people, and, although quality control's going to be like hell to pay here.

And he referred to a notion articulated by Bellamy (1996), a change strategy contained in the Braid of Progress.

> David: People by word of mouth, families by word of mouth, begin to learn about who's good, and who's not, and that may change the whole quality tenor of public service and community service. And they also direct an evolution of new types of services that meet needs. I think that's part of that vision.

Bill's response was the most succinct: "Attack poverty." While Michael's vision was integral: "My vision for youth with disabilities is that they become anything they want, and people acknowledge them because they become anything they want, not that they become anything they want *with a disability*." I couldn't have said it better.

Study Limitations and Future Research Directions

This study has several implicit limitations, the most salient of which are discussed here. First, while care was taken to purposively sample the literature across the time period selected, and across low and high incidence themes, given the sheer volume of the literature from 1984 – 2003, and the scope of the topic (disability and transition related theoretical pieces, essays, program evaluations, policy analyses, empirical works and invited commentaries), it is possible that the pieces selected for analysis here, and therefore the themes developed, are not representative of the larger literature base. As well, there are numerous ways I might have approached the document analysis. Because of the volume and complexity of the works included, I was able to identify patterns over time and compare and contrast prominent themes across the general education, low and high incidence literature. Another researcher might select a single disability label, for example, and do an exhaustive analysis of the literature related to that label over time. The possibilities are as multifarious as the research process itself. Another researcher might explore the federal policies related to transition for youth with disabilities and conduct and in depth and critical policy analysis of these, something I was unable to do in this project.

Second, I have discussed some of the challenges I faced when interviewing experts in chapter 3, such as the limited amount of contact time I had with them, their projection of public selves, and the implications of our relative positions all affecting the quality of data I was able to collect. A related challenge was my relative inexperience in conducting in depth interviews; I learned a lot in the process. For example, although I was careful to ensure a semi-structured interview format through the use of an interview

guide, and open-ended questions, at times I interrupted informants' train of thought and essentially "hijacked" the direction of the interview. In the future, I would train myself to become more comfortable with pauses that naturally ensue in an interview context, and thus gain access to more of the informants' voice, and less of my own. Also, while the participants included here provide one picture of issues related to transition and in general, society's relationship with persons with disabilities, it would be valuable to repeat this research with other elite informants, and additionally, with students with and without disabilities engaged in the transition process, and in the struggle toward inclusion; as well, their families and teachers.

The third, and perhaps most important, criticism of my work has to do with the challenge inherent in attempting to combine the methodologies associated with narrative analysis and historical document review. Given the amount of hard work each entails, there is the risk that neither has been adequately conducted. However, in the combination of the two, hopefully the richness each has brought to bear on the other makes up to some extent for what has been lost by not focusing on one or the other exclusively.

Conclusion

Something akin to the notion of "integral inclusion" truly contains the potential for societal transformation, for *all* of us, deconstructing and eliminating the layers of prejudice toward disability [and other marginalized groups], changing conditions that contribute to poverty, and moving us all forward. Inclusive education *is* about social equity, social justice, and ultimately emancipation, after all. My research adds to the growing body of evidence that we can't achieve inclusive communities and societies without it. And, in the end, I think Bill was right. It is all about "reliance on a receptive

community". The situation will not change; until we indeed "fix the society that views them as broken".

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APPENDIX A: REFERENCES USED IN THE DOCUMENT ANALYSIS

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APPENDIX B: INTRODUCTION TO STUDY FOR POTENTIAL PARTICIPANTS

Study Title: Transition from School to Post-School Environments for Youth with Disabilities:

A Critical Analysis

P.I. *Dr. Brian Cobb, Colorado State University*
Co-P.I. *Ms. Morgen Alwell, Colorado State University*

Date

Dear

As part of my dissertation research, I am planning to conduct interviews with a small number of local or nationally recognized transition experts. These people [will name them] have suggested your name as someone who may be interested in participating in this study. Let me describe the study to you, so that you may consider it.

The purpose of my study is to critically examine the transition movement for youth with disabilities, how change has happened over time; in the context of the process of transformation in society's (United States) relationship with persons with disabilities.

During a one-two hour interview, I will be interested to learn: some information about your life's work, and what drew you in to special education/transition work; your perspective of the current status of persons with disabilities, particularly for those of transition age; critical events or activities you think may have contributed or led to this; what you feel contributes to/impedes progress or transformation; and what vision you may have for the future for persons with disabilities. I will also be interested in any recommendations you may have for important documents for me to include in my research—or other important potential interviewees.

I am attaching a copy of my curriculum vitae so that you have some idea of my background.

If you are interested, I would arrange to come to interview you at a place and time convenient for you. The initial interview will be one-two hours in length, and I will follow up within a month or so with a second phone contact, to clarify points made in the first, and to give you an opportunity to restate anything you wish. You will also have the choice of whether you would like to participate anonymously.

Thank you so much for your consideration of this project. I look forward to hearing from you.

Sincerely,

Morgen Alwell, Research Associate
9 Education Building
Colorado State University
Fort Collins, CO 80535
970-491-6284
malwell@cahs.colostate.edu

APPENDIX C: INFORMED CONSENT

COLORADO STATE UNIVERSITY

INFORMED CONSENT TO PARTICIPATE IN A RESEARCH PROJECT

TITLE OF PROJECT:
Transition from School to Post-School Environments for Youth with Disabilities: A Critical Analysis

NAME OF PRINCIPAL INVESTIGATOR: *Brian Cobb, Ph.D.*
NAME OF CO-INVESTIGATOR: *Morgen Alwell*
CONTACT NAME AND PHONE NUMBER FOR QUESTIONS/PROBLEMS:
Brian Cobb 970-491-6835; Morgen Alwell 970-491-6284

PURPOSE OF THE RESEARCH:

The purpose of this research study is to understand the process of transformation of society's relationship with persons with disabilities through a critical and holistic examination of the transition movement. The proposed study has three guiding questions:

> *1.) Considering the transition of youth with disabilities from school to young adulthood, how have issues of inclusion and emancipation of these youth been framed, conceptualized, and critiqued in the scholarly literature, by key researchers, scholars, change agents, institutions, and by persons with disabilities themselves?*
> *2.) Are there patterns in these "discursive constructions" (i.e., the research and other literature, and the perspectives of persons with disabilities and advocates) over time?*
> *3.) How does an alternative analysis of the transition movement increase our understanding of the transformation in society's relationship with persons with disabilities? (This study will complement a more traditional meta-analysis of the same body of literature being conducted by the What Works in Transition Project at Colorado State University, by examining the "bigger picture" in transition: the social climate, contexts, policies and underlying theories contributing to [or preventing] systemic change.)*

To explore these questions, two primary data sources have been selected; a set of empirical and theoretical works, and the personal narratives of participants, experts, and change agents.

PROCEDURES/METHODS TO BE USED:

The research will involve two interviews; the first will be face-face and one-two hours in length; the second a telephone follow-up conversation. Your permission will be requested to audio tape the interview; tapes will be destroyed after they have been transcribed; record of transcriptions will be kept in a locked file cabinet in the P.I.'s office for the required three year period.

RISKS INHERENT IN THE PROCEDURES:

There are no known risks, with the exception of potential loss of confidentiality. However, several safeguards are being employed to avoid this (please see Confidentiality section, below).

While it is not possible to identify all potential risks in research procedures, but the researchers have taken reasonable safeguards to minimize any known and potential, but unknown, risks.

BENEFITS:

There are no known benefits for participation in this study. However, we hope that participants will have the opportunity to be recognized for their contributions to the transition movement for youth with

disabilities (if they choose); and have the opportunity to reflect on their personal and professional histories and contributions as change agents.

CONFIDENTIALITY:

To avoid loss of confidentiality, we will take several precautions to ensure privacy for those participants wishing to remain anonymous. We will keep all documents and notes on file in hard copy format, in a locked file cabinet in Brian Cobb's office, shredding any notes that identify participants wishing to remain anonymous, and deleting these files from our computers, upon completion of the study. Near completion of data analysis, we will send sections of our analysis with contextual information for you to review, and allow you to edit material that you feel compromises your confidentiality (if you wish to remain anonymous) or if you would like to restate responses. We will incorporate your suggestions until you feel comfortable, or omit the selection.

LIABILITY:

The Colorado Governmental Immunity Act determines and may limit Colorado State University's legal responsibility if an injury happens because of this study. Claims against the University must be filed within 180 days of the injury.

Questions about participants' rights may be directed to Celia S. Walker at (970) 491-1563.

PARTICIPATION:

Your participation in this research is voluntary. If you decide to participate in the study, you may withdraw your consent and stop participating at any time without penalty or loss of benefits to which you are otherwise entitled.

Your signature acknowledges that you have read the information stated and willingly sign this consent form. Your signature also acknowledges that you have received, on the date signed, a copy of this document containing _2_ pages.

_____
Participant name (printed)

_____ _____
Participant signature Date

_____ _____
Witness to signature (project staff) Date

ANONYMITY: Please sign one of the following statements (you may change your mind at a later date).

I *do* wish to remain anonymous in this study.

_____ _____
Participant signature Date

I *do not* wish to remain anonymous in this study.

_____ _____
Participant signature Date