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Formulating their future : transition to adulthood for students with profound disabilities

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# Formulating Their Future: Transition to Adulthood for Students with Profound Disabilities

A Dissertation submitted in partial satisfaction of the
requirements for the degree of Doctor of Education

in

Teaching and Learning

by

Krysti Robinson DeZonia

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The Dissertation of Krysti Robinson DeZonia is approved, and it is acceptable in quality and form for publication on microfilm:

Chair

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2008

# DEDICATION

This is dedicated to my mother, Thelma White Robinson, whose belief in me allowed me to believe in myself.  I love you, mom.

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| | |
|---|---|
| IDEA | Individuals with Disabilities Education Act. The law that outlines the rights and regulations for students with disabilities who require special education in the United States. |
| IEP | Individual Education Program. The IEP defines special education programs and services, and individual student goals, for persons receiving special education in public and private schools. |
| ITP | Individual Transition Plan. A document that is part of the IEP that defines student goals and services specifically related to preparing for life after graduation. |
| NCD | National Council on Disability. An independent federal agency that makes recommendations to the President and Congress on issues affecting persons with disabilities. |
| NELS | National Educational Longitudinal Study. Long term study that provides trend data about the experiences of students as they leave elementary school, progress through high school, and enter post-secondary institutions or the work force. |
| NICHCY | National Information Center for Children and Youth with Disabilities. NICHCY is a national center that provides information on disabilities and disability related issues, particularly those affecting children and youth. |
| NLTS | National Longitudinal Transition Study. A multi year study of the experiences of young people with disabilities after their graduation from school. |

# ACKNOWLEDGEMENTS

When I embarked on the journey that led to this dissertation, my eye was on the brass ring at the end of the ride. What I learned was that the process was much more valuable than the prize (you were right, Paula!). In my case, getting to this point entailed the help of not just a village but a small metropolis. There are many people I want to thank for their guidance, support, participation, and love.

My good fortune in having Alison Wishard Guerra as my chair is without measure. Alison, your positive words, hours and hours of plowing through long-winded drafts, and generous feedback kept me on track, energized, and confident that I might really be able to do this, and on time! I am so grateful to have had your support and guidance. I also want to thank Bud Mehan and Tom Humphries for their generous input despite crushingly busy schedules, and for the contributions they have made to their respective fields. Their work has focused the academic eye on critical issues in the lives of persons who fall outside the mainstream of society and is a gift to all of us who have had the opportunity to benefit from their knowledge. I would also like to thank Paula Levin, the best teacher I have ever had, or likely ever will have. While I lost some sleep as a result of the stretching of my brain, I am profoundly grateful to have had the opportunity to know you and work under your guidance.

Throughout this process, there were many people who set me on my feet and kept their hands firmly planted in my back to push me forward. They are my group of wonderful friends and colleagues. I would first like to thank Cheryl Kilmer for having the idea that I should really go ahead and pursue my doctorate instead of just talking about it all the time, and for giving me the freedom to make my dream a reality. We have seen many dreams come to fruition together, and I hope we will see many more. The teachers and administrators at my schools have uncomplainingly picked up the ball I dropped and for this, as well as your dedication to our vision, you have my gratitude. My wonderful "cherry slipper" cohort-Suzanne Stolz, Rachel Millstone, and Melissa Hertzig-propped me up when I needed it and were always there for me. You are simply the best! I have been blessed with many friends who acted as cheerleaders, counselors, and guides throughout this process. My GNO group-Paula Timmons, Helen Strachan, and Dede Quinn- has my thanks for the food, friendship, and determination to stay connected over these past 30 years. I'm sure I don't say it often enough, but I am so grateful for all of you! Sue Berrill, Patty Fuller, Nancy Rankin, Liz Wilson, and Diana Allen have, for 35 years, been my second family. I carry you with me wherever I go. My colleagues deserve special thanks for their willingness to talk and listen (and listen…and listen) throughout this process. I must thank Teresa Martin, Susan Parham (I miss you), Dave Tenny, Cheri Bene, Tracy Klaerich, and Jeff and Debbie Horne for their admirable restraint in never telling me to "shut-up" when they probably should have and for their belief in me. I would like to say things will be quieter now, but…..Also, my sisters Pam Rose and Linda McEwen. Nene, your a phone bill that must rival the national debt! Thanks for caring.

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# VITA

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Applied Research conducted on the happiness indices exhibited by children with autism and severe/profound delays. Publication pending.

Applied Research conducted on using personal narratives as a means to train paraprofessionals to have a humanistic viewpoint of students with profound and multiple disabilities.

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San Diego, California-2007

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North Dakota Provider Association
Minot, North Dakota-2006

Presenter: Strategies for Working with Students with Autism
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Presenter: Profound Disabilities: Using Stories to Change Paraprofessionals' Perspectives
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# ABSTRACT OF THE DISSERTATION

## Formulating Their Future: Transition to Adulthood for Students with Profound Disabilities

by

Krysti Robinson DeZonia

Doctor of Education in Teaching and Learning

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Alison Wishard Guerra, Chair

This study examines parent, teacher, and institutional formulations of adulthood for students with profound developmental disabilities. A comprehensive overview of post-school outcomes, transition practices, special education law, social constructions of adulthood and disability, and parent/teacher perspectives on adulthood for students with profound disabilities is provided. Using data collected from interviews with eight parent and teacher pairs, special education artifacts, and community resources, this study uncovers the similarities and differences in parent and teacher thinking regarding a student's adult life; the factors that influence the content of student Individual Education Plans (IEPs) and Individual Transition Plans (ITPs); and the role of culture, context and artifacts in the parent, teacher, and institutional formulations of adult life for this student population. This research provides new information about the factors that influence the formulations of the adult lives of students with profound disabilities. These factors included community and institutional perceptions of adulthood; the role of context in thinking and decision making; the influence of social and cultural expectations; and the disparity in the mental models that parents and teachers hold regarding their children/students with profound disability. The study reveals that parents, teachers, and institutions have different perspectives regarding the adult lives of individuals with profound disabilities. Parent thinking is focused on securing a fulfilling and nurturing future for their child and teacher thinking on active participation in a range of activities in institutional settings, while institutional formulations of adulthood revolve around work and independence. Parents are better able to envision an adult life for their child when provided life planning support. Teachers are more concerned with disability label than parents, and are more focused on the role of institutional settings in a student's adult life. IEP and ITP goals are more consistent with teacher perspectives regarding a student's adult future than with parent or institutional perspectives. Context emerged as one of the most significant factors that influenced parent and teacher thinking regarding a child/student's life after graduation. This study supports the critical need for establishing model transition programs and providing education to parents and teachers regarding the options available to individuals with profound disabilities when they reach adulthood. Implications for parents, teachers, and institutions are reviewed and recommendations for further research are provided.

# CHAPTER 1: INTRODUCTION

## Overview

During the past 10 years, there has been an increased research focus on transition services for special education students. This increased interest in transition is, in part, a result of several studies that detail poor post school outcomes for students who have received special education services during their public school years (Hughes & Eisenman, 1996; Kohler & Feld, 2003; Phelps & Hanley-Maxwell, 1997). These studies revealed that students with disabilities generally have a very difficult time adjusting to life as an adult. However, very little research has been conducted on persons with profound disabilities, their parents and teachers, and this study was initiated in order to gain further information about these individuals and their perspectives regarding adult life.

This study first provides an overview of the post-school outcomes for adults with a range of developmental disabilities, special education law, transition programs and practices, cultural constructions of adulthood and disability, and parent and teacher perspectives regarding adulthood for individuals with significant disabilities. To examine these issues, I designed a qualitative study employing parent and teacher interviews, review and analysis of special education artifacts, and information from newspapers and other community resources as data sources. The study was designed to uncover the factors that influence parent and teacher formulations of the adult life of students with profound disabilities and the Individual Education Programs (IEPs) and Individual Transition Plans (ITPs) designed for these students, as well as the role that context, culture, and artifacts play in the formulation of the adult lives of this student population.

## Background

Adults with developmental disabilities experience high rates of unemployment, substantial dependence on their parents, social isolation, and lack of involvement in their community (NCD, 2000; Wells, Sandefur, & Hogan., 2003). Overcrowded adult service agencies and limited vocational training programs add to the problem. Transition focused researchers found that federal, state, and local governments did not have coordinated policies and practices that were designed to maximize student learning during transition and, after graduation, in supported employment (Hughes & Eisenman, 1996). In general, students with learning disabilities and mild developmental disabilities fare better after graduation than those who have more severe disabilities, and are more often the target of research studies.

The cost of providing a free and appropriate education for all students with disabilities is high. The total estimated federal, state, and local spending on special education in 2000-2001 was close to $80 billion dollars, which represents about 20% of the overall budget for K-12 public education (Apple Education, 2006). The high cost of special education has resulted in a government and research focus on outcomes for students receiving these services. When outcomes are poor, as they are for students with developmental disabilities post-graduation, the practices and processes used to support and educate these students become a priority for researchers and funding agencies.

An additional reason for the importance of expanding the research-based literature related to students with severe disabilities is that the prevalence of this diagnosis is rapidly expanding. Specific to the State of California, there has been a significant increase in the numbers of students diagnosed with severe and profound disabilities, in particular individuals diagnosed with autism. Table 1. provides a summary of the percent of increase in persons diagnosed with severe disabilities between December of 1998 and December of 2002 in California (California Department of Developmental Services, 2003). An increase in numbers of individuals diagnosed with severe and profound disabilities results in the need to have more information for teacher training, student support, and cost effectiveness of special education programs serving students who are severely disabled.

Table 1.

**Increase in Persons Diagnosed With Severe and Profound Disabilities in California**

| Diagnosis | December-98 n | December-02 n | Percent Change |
|---|---|---|---|
| Autism | 10,360 | 20,377 | 96.69% |
| Mental Retardation | 108,563 | 130,722 | 20.41% |
| Cerebral Palsy | 28,529 | 33,071 | 15.92% |

Researchers and funding agencies are not the only stakeholders who impact the adult outcomes of students who have received special education services. Families of students with special needs, and the students themselves, expect that special education transition services will empower individuals by preparing them for meaningful adult lives (Szymanski, 1994). For some adults with disabilities, a meaningful life is defined as full inclusion in their community and opportunities to work, live, and recreate in a manner that is similar to that experienced by those who are not labeled as “disabled” (Cooney, 2002). For other adults with disabilities, often those with more severe disabilities, a meaningful life is defined for them by those who know them best, to include family members, friends, and teachers (Ferguson, 2000). This is necessary given these students' limited ability to communicate and understand the choices available to them. Oftentimes, a meaningful life for students with severe and profound disabilities is defined as having a safe place to live, being happy, and having constructive ways to fill one's free time (Hanley-Maxwell & Collett-Klingenberg, 1995).

The essence of a meaningful life, however defined, is always an individual matter. Examining and evaluating the transition practices, processes, and outcomes for students with disabilities is part of an overall process of preparing all students with disabilities to lead a meaningful life of their own choosing. In addition, understanding the perspectives of the various stakeholders, the current and historical context that surrounds decisions made about student transition to adulthood, and the artifacts that are used to support stakeholder decision making stakeholder will provide important information about how adult futures are formulated for students with profound disabilities.

## Theoretical Framework

This research was informed by three theoretical frameworks: schema theory, ecological systems theory, and distributed cognition theory. First introduced by R.C. Anderson in 1977, schema theory holds that people develop mental models regarding life based on their personal experiences and cultural constructions and that these mental models are organized in the form of schemas or connected pieces of information. In order to change a schema, new information must be introduced that is inconsistent with current knowledge. Schema theory is useful in understanding the thinking of the parents and teachers who participated in this study and in making comparisons between the mental models parents and teachers have regarding the adult lives of their children/students with profound disabilities.

Bronfenbrenner's ecological systems theory (1979) is a theoretical framework that will assist in unraveling the factors that influence or impact parent and teacher constructions of the adult lives of students with profound disabilities. Ecological systems theory examines the role that environment plays in human development. Within this theoretical framework, all of the environments in which we are situated are connected to each other, and these connections influence the learning and development we experience both as students and across the lifespan. The environment of students with profound disabilities includes not only their home and school, but their community and society. Each of these environments has rules and social norms that can have a significant impact in shaping thinking and human development. Additionally, persons with profound disability are subject to labeling and special education laws that have a bearing on how they are viewed within their environment and the types of opportunities afforded them as "special education" students.

The third theoretical framework that was applied to this study was that of distributed cognition. Developed by Ed Hutchins in the mid-1980s, distributed cognition emphasizes the ways in which knowledge is shared between members of a group and the role that artifacts play in the distribution of knowledge within the group (Cole & Engeström, 1993). The process of developing goals and plans for the adult life of persons with profound disability is a group process. Within this group, stakeholders bring to the table varying perspectives regarding what constitutes a preferred future for an individual with profound disability. These stakeholder perspectives are influenced, to greater and lesser degrees, by the artifacts used in special education. These artifacts include special education law, special education planning forms, student assessment tools, and school rules and procedures related to services provided to special education students. Knowledge is not contained solely within the head, but is influenced by the thinking of others and the tools they use. Distributed cognition theory will be useful in understanding how the institutional setting, its governing rules and artifacts, impact families and teachers as they come together to draft goals directed at the adult life of individuals with significant disabilities.

## Research Questions

The literature on transition to adulthood has concerned itself primarily with the outcomes and programs for students mild to severe developmental disabilities. Noticeably absent are the transition needs, plans, and processes for students who have profound and multiple disabilities. Also absent are the preferred adult outcomes for these students as envisioned by institutions, family members and professionals. Despite their multiple challenges, individuals with profound and multiple disabilities can, and will, transition to life as adults in communities that often have little understanding of their abilities and disabilities. Given this, the transition plans of students with profound and multiple disabilities should reflect an adult life that allows them personal fulfillment and to meet their maximum potential.

In the absence of a body of research designed to study the factors that influence the transition goals and adult outcomes for students with profound disabilities, the following questions beg attention:

What is the adult life envisioned for students with profound disabilities and what factors influence the process of constructing this envisioned life?

Part of this overarching question includes the following three sub-questions:

1. How do parents and teachers of transition-aged individuals with profound disabilities conceptualize their child/student's adult life?
2. What is the relationship between parent and teacher expectations, institutional practices, and the goals that are developed for transition aged students with profound disabilities for their lives after graduation from high school?
3. What roles do cultural understandings, context, and artifacts play in parent, teacher, and institutional formulations of adult life for students with profound disabilities?

The information gathered through these questions will provide researchers and practitioners the opportunity to positively affect practice and potentially improve the present and future life quality of students with profound disabilities and those who support them

# CHAPTER 2: LITERATURE REVIEW

This review of the literature defines profound disability, examines the concept of adulthood as it relates to persons with profound disability, and focuses specifically on three key components of the special education transition support process. The first is an overview of institutional practices as reflected in transition related legislation, including an assessment of what is currently happening in classrooms for students with developmental disabilities between the ages of 16 to 22 years. This portion of the review will provide information about the current and historical contexts that shape thinking regarding transition to adulthood for students with profound disabilities, to include the ways in which society constructs the meaning of disability and categorizes those labeled with disability. The second component of this review examines the postschool experiences and programs of students with disabilities while the third component looks at family, student, and teacher perspectives on the transition to adulthood. These two components offer insight into stakeholder perspectives and the environments in which decisions are made and enacted. Because the extent research has placed little focus on students with severe and profound disabilities, much of the literature reflects the needs and programs of students with more mild disabilities. As a result, attempts have been made to extend this literature to consider its application to students with profound disabilities, drawing on the few studies that have been conducted specific to this population whenever possible.

## Defining Profound Disability

Approximately seven million people in the United States are diagnosed with mental retardation (NICHCY, 2006). Of these, about six percent have a diagnosis of severe or profound mental retardation/developmental disability. Persons with profound disabilities have an IQ of less than 25 and require ongoing, extensive care and supervision in more than one major life activity in order to participate in integrated community settings (NICHCY, 2006). In addition, these individuals frequently have additional (multiple) disabilities including movement difficulties, sensory losses, and behavior problems.

The majority of children and adults with profound disabilities has little access to spoken language and instead rely on nonverbal, often idiosyncratic, behaviors as a means for expressing their wants and needs (Dennis, 2002). These behaviors can take the form of facial expressions, body movements, moving toward or away from something, or nonword sounds. Those who know these individuals best learn to interpret these behaviors and to recognize them as a form of communication (Bogdan & Taylor, 1989). Ascertaining the views of individuals with profound disabilities is highly inferential and it is often only possible to determine their immediate, as opposed to long-term, preferences.

Given the limited communicative repertoire of children and adults with profound disabilities, their Individual Education Programs (IEP) and Individual Transition Plans (ITP) are formulated on their behalf by a team of people consisting of, by law, the parents, student, special education teacher, general education teacher, and a representative of the local education agency (IDEA, 2004). This team is responsible for developing, reviewing, and revising goals and objectives designed to strengthen student needs and support student strengths. By the age of 16, goals related to transition to adulthood must be developed for students with disabilities. As a result, the adult lives of children with profound disabilities are formulated by a team of "others" who may have differing opinions about what constitutes a quality adult life for the individual (Cooney, 2002). These team members bring with them cultural and historical information that impacts the decisions they make on behalf of students with profound disabilities. Their knowledge about what is best for a student is co-constructed during team meetings and interactions with the student and is influenced by school practices, teacher training, and parent expectations as well as by the artifacts used to guide thinking during the goal setting process.

### *Social Constructions of Disability*

Disability research takes place within societies that hold particular ideological frameworks regarding persons with disability and their place within the society. An understanding of the social frameworks that underpin the study of disability is useful in designing research agendas, developing programs and setting policy for persons with disabilities, and in understanding the context in which research is conducted. Our society, both past and present, has had shifting ideologies regarding persons with disability. This section will explore three formulations of disability-two of which hold that disability is an individual pathology and two that view disability as a social pathology. These three formulations include a medical approach to disability; a rehabilitation approach to disability; and a sociological model that views the disability label as a consequence of how society is organized and the relationship of the individual to society.

#### *Medical Model of Disability*

The medical model of disability asserts that disability resides within the individual as a result of a physical condition or illness, bringing with it the need to attempt to cure or manage the illness through medical means (Rioux, 1996). The medical model of disability has had the greatest historical impact on the treatment of persons with significant disabilities, and has provided much of the impetus for the development of segregated programs and facilities for the care and treatment of the disabled. These institutions often became a warehouse for the profoundly disabled, who received sub-human treatment at the hands of the doctors and professionals responsible for their care and well-being (Blatt & Kaplan, 1974). The medical model, though less in favor today than earlier in the century, still persists in the continued existence of state hospitals for the intellectually disabled, the state and federal government focus on assessment and identification of disability label as a means for determining “treatment”, and the professionalization of the special education field.

### *Rehabilitative Model of Disability*

The second disability framework is the functional approach, or rehabilitative approach, to disability. In this framework, like in the medical model, disability is viewed as residing within the individual as a result of a condition or pathology, however this approach focuses on treatments that are directed at assisting people in becoming as socially functional as possible (Meyer, Peck, & Brown, 1991). Rehabilitation models and therapeutic interventions, as well as behavior modification, counseling, and vocational training, were the result of the functional approach to the “problem” of disability. Within these interventions, the goal is to assist the individual with a disability to acquire skills that will help them, to the extent possible, lead a live that approximates that lived by those without disabilities. The rehabilitative model is the one primarily employed in special education classrooms at the current time.

### *Sociological Model of Disability*

Unlike the medical or rehabilitative models, the sociological model of disability assumes that disability is not inherent to the individual but is, instead, inherent in the social structure. In this view of disability, it is society that needs to be fixed rather than the person with a disability label (Barnes, 1998; Rioux 1996). The sociological model of disability asserts that the politically and socially constructed environment has given rise to the need to label people with certain differences as disabled. Within this model, disability is viewed as part of the normal range of human conditions rather than an anomaly in need of fixing. Persons who adhere to the sociological model of disability view the inclusion of those with a disability label as the responsibility of the public, and they emphasize the need to “treat” society more so than the person labeled as disabled.

The sociological model of disability is traced back to the civil rights movement in the 1960s and is reflected in civil rights laws such as the Americans with Disabilities Act of 1990 which prohibits discrimination based on disability. The idea that disability is socially and institutionally constructed has, to date, had only a modest impact on the practices in our schools, which continue to espouse the idea that disability is situated within the child rather than within the institutional arrangements of the school. (Mehan, Mercer, & Rueda, 2002). The belief that disability is primarily a physiological fact impacts not only what happens in our classrooms but is also reflected in the attitudes and priorities of special education teachers and administrators. This belief affects the goals that are set for student adult life and the plans and priorities of the parents and teachers who design these goals.

### *Adulthood and Disability*

Attaining adulthood is a complex process that can be viewed from a variety of theoretical perspectives. These theories can be divided into three general categories: biological models; sociological models; and psychological models. A brief look at how adulthood is defined for the general population will offer support to the examination of transition to adulthood for individuals with profound disabilities.

#### *Biological Models of Adult Development*

Biological models are focused around the physical process of aging, both in mind and in body (Mott, 1999). Levinson et al. (1978) are cited as the frontrunners in biologically based research on adulthood. The research conducted by Levinson et al. states that adult life passes through various stages, each grouped into approximately 20 year cycles. This research proposes that adult life proceeds not randomly, but in a systematic alternation of stable and transitional periods. In order to move from one stage to another, each individual must complete certain tasks that are biologically driven within that developmental stage. These tasks include activities such as trying out adult roles in college or apprenticeships, having a career, getting married, and responsibility for a family.

There is a connection between the biological model and the transition planning model mandated for students with disabilities. The notion of completing certain tasks as a marker of adult status is echoed in the disabilities legislation. The National Dissemination

Center for Children with Disabilities (NICHCY, 2000) provides a definition of adulthood for students with disabilities and the intent of the disabilities legislation as follows:

> If students are to mature into independent, productive adults and become increasingly responsible for their actions and accomplishments, they need to acquire the skills that are of value in the world of adulthood. The Individuals with Disabilities Education Act (IDEA) acknowledges this and contains provisions meant to encourage student involvement and decision making. (NICHY Transition Summary 10, 1999, pg. 2)

In a biologically based model of adult development, acquisition of particular skills is critical to being classified as adult in our society. Given the severity of their disabilities, individuals with profound disabilities will likely have difficulty with many of the skills labeled as "adult", to include having careers, getting married and taking responsibility for a family. In addition, the team members who are responsible for selecting which "skills that are of value in the world of adulthood" may have differing opinions on what is important for a student to learn in preparation for graduation. Trying to reconcile these various opinions can lead to problems of control which might impact both a student's learning and post-graduation outcomes (Ferguson, Ferguson, & Jones, 1988; Hanley-Maxwell & Collet-Klingenberg, 1995).

### *Sociological Models of Adult Development*

The biologically based models of adulthood were primarily developed and tested on Caucasian, middle-class males, which led to the development of sociological based models of adulthood that attempted to apply these theories to minority groups (Price and Patton, 2003). These models stress the importance of the environments in which people live as a critical component in the formation of adult identity, as well as gender, ethnicity, and sexual orientation. From a sociological perspective, these factors are viewed as having substantial impact on how adulthood is defined and the path individuals take to reach adulthood.

The sociological perspective has its parallel in special education in that children from minority groups are disproportionately represented in special education classrooms, as are males (Smith et al., 1997). This would indicate that some individuals are labeled as disabled because the cultural knowledge or habitus they bring to the education setting has not prepared them to be viewed as “normal” in mainstream public school classrooms. With an IQ of less than 25 and substantial dependence in many areas of daily living, individuals with profound disability would likely be considered socially “disabled” regardless of their ethnicity, culture, gender, or environment. Thus, sociological models of adulthood do not offer a theory that would allow individuals with profound disability to be viewed as “adults” within most, if not all, modern social settings.

### *Psychological Models of Adult Development*

Unlike biological or sociological models of adult development, psychological models stress internal (psychosocial) as well as external (physical) changes in an individual that signal the onset of adulthood (Bridges, 1980). The key internal changes include assumption of changing roles and achievement of autonomy or sense of self. In addition, psychological models stress that periods of stability and transition are present throughout adulthood and that there is an ongoing struggle to achieve intimacy with others and to find personal identity.

The psychological model of adult development, perhaps more than the biological or sociological models, seems to exclude individuals with profound disabilities. Autonomy and the assumption of changing roles are challenging, if not impossible, for individuals who have multiple disabilities given their limited cognitive skills. According to Bogdan and Taylor (1989) intimacy, individuality, and social place are defined for persons with profound disability by those who know them best.

Ferguson (2000) echoes this finding in his examination of the problems inherent in defining adulthood for persons with profound disabilities. Ferguson notes:

> It is not so much that we do not see a "person" or a "real human being" when we encounter someone with so-called profound mental retardation. It is rather that we do not see any culture. We see no meaning to the behavior: there are words but no discourse; events but no story…The physiology seems to overwhelm the social. We see no religion, no politics, no racial awareness or class identity, no moral stance, no economy…Without such a cultural context, people with significant cognitive disabilities are neither the same as, nor different from the nondisabled population. (p. 7).

Ferguson further concluded that adult status for people with the most severe disabilities is, ultimately, constructed and interpreted by those who surround the individual, and he calls for a relational approach to understanding adulthood. "Disability is not the absence of self, it is the absence of other people" (p.8). Adulthood, for this population as viewed by Ferguson, will be attained through friendships and mutual supports.

### *Summary*

A review of the various theoretical models for understanding how adulthood is defined shows that persons with profound disabilities will likely not be able to acquire the skills and cognition commonly associated with adult roles. While individuals with profound disabilities may reach biological maturity, their cognitive and physiological limitations place them in jeopardy of being viewed as "eternal children". The adult lives of students with profound disabilities are formulated for them by the institutions (school, community) that surround them, their teachers and parents. Teachers and parents are, in turn, impacted by the mental models they bring to the planning process, the environment in which they are situated, and the distribution of cognition among members of the student planning team. During the Individual Education Plan (IEP) and Individual Transition Plan (ITP) development process, the influences of institution, teacher, and parent combine, resulting in goals and objectives that will define adult life for those who have profound disabilities. A review of institutional, parent, and teacher perspectives will provide insight into how these entities formulate adulthood for this population.

## Institutional Perspectives on Transition to Adulthood for Students with Profound Disabilities

### *Overview of Transition Policy and Legislation*

Our laws and policies are one of the means by which society can voice its perspectives regarding adulthood and students with profound disabilities. Between 1990 and 2004, the legislation passed by the federal government showed a clear commitment to addressing educational priorities regarding transition to adulthood for all students, and to charging schools with some of the responsibility for preparing children for life as an adult. This legislation was, in part, a response to reports such as A Nation At Risk that painted a gloomy picture of the results of American education. These and other reports created a national interest in the outcomes of the educational process. In a National Center on Education Outcomes report on education reform, Geenen et al. (1995) stated:

> Previously the domain of local schools, education reform became a priority issue for governors, Congress, and even the president. In order to avoid having to define and then monitor the exact ingredients of educational success, these policymakers emphasized the outcomes of education….there was greater awareness that monitoring the inputs into education…does not guarantee improvements in student outcomes. (p. 2)

Federal legislation since 1980 has mandated the ways in which schools and communities can ensure that learning takes place for all students, including those with disabilities, and that this learning prepares students for life after graduation. These mandates, in turn, influence how stakeholders view the adult lives of students with profound disabilities. The Goals 2000: Educate America Act (1993) established eight national education goals designed to provide a framework to measure student progress, support students, and define standards of excellence for U.S. schools (Paris, 1994). Goal six references the importance of preparing students for life after graduation, stating that students need to acquire the skills necessary to compete in a global economy. While students with disabilities are not specifically referenced in the goal language, this Act established a connection between school and work and in so doing placed the responsibility for learning at least some of the skills of adulthood on the public education system.

Specific to students with disabilities, The Individuals with Disabilities Education Act (IDEA) also set standards for education, assuring all students access to a free and appropriate public education. IDEA was authorized in 1990 and re-authorized in 1997 and 2004 and this act, like Goals 2000, specifically addressed life after graduation by requiring that students with disabilities have access to "…special education and related services designed to meet their unique needs and prepare them for employment and independent living." (IDEA, 34 CFR 300.29 (1)). The IDEA legislation mandated that transition plans be developed for special education students beginning at age 16, and defined transition services as outcome oriented with a focus that promotes movement from school to post-school activities in the areas of vocational training, employment, adult education, independent living, and community participation (IDEA, 2004).

For most students with disabilities, a large part of preparing for adulthood is learning vocational skills. The School to Work Opportunities Act (STWOA), enacted in 1994, authorized state funding directed at improving the work related skills of all students, including those with disabilities. STWOA programs must provide for specific activities for students that are designed to maximize their potential to engage in gainful employment, to include courses on career awareness; counseling; assistance in connecting school based learning with work based learning (employment skills and workplace mentoring); and instruction on work attitudes and other factors that enhance and sustain employability (Phelps & Hanley-Maxwell, 1997). Students involved in STWOA programs receive individualized programs, work experience, and ongoing evaluation as well as workplace mentoring. The School-to-Work Opportunities Act makes specific reference to students with disabilities and the importance of increasing their opportunities to access employment after graduation from special education based on personal interests and abilities.

As the focus on outcomes increased for students with and without disabilities, researchers began to scrutinize what was happening in classrooms across America (Wells, Sandefur, and Hogan, 2003; NCD, 2000; Hughes & Eisenman, 1996; Haring & Lovett, 1990). This research included an examination of curricula, teaching practices, and outcomes for transition aged students with developmental and other disabilities.

## School Programs and Curricula for Transition Aged Students with Disabilities

### *Special Education Transition Curriculum*

What happens in our schools and classrooms is a reflection of how institutions view the transition to adulthood for students with profound disabilities. A comprehensive research synthesis was completed by Hanley-Maxwell and Collet-Klingenberg (1995) with a specific focus on curricular practices in transition from school to the community for students with disabilities. Spanning a 15 year period from 1980 to 1995, this review examined models used to deliver transition services in classroom and community settings.

These researchers found that curriculum for transition-aged students with disabilities could be categorized under one of three basic models. These are the functional skill models which focus on independent living skills and vocational preparation; process models that are based on teaching students strategies for learning and problem solving; and academic skills models in which the curriculum centers on completing regular education requirements and compensatory or tutorial teaching strategies. Hanley-Maxwell and Collet-Klingenberg call for an interdisciplinary approach to transition planning and curriculum development, stressing the importance of involving students and families in curricular decision making and in choosing which curricular approach is most appropriate for a given individual. Involving students and families in curriculum development and transition planning will assure that cultural knowledge and understandings are an integral part of the goals set for transition aged students.

The Office of Special Education Programs (OSEP, 1996) specifically proposed an agenda for designing transition programs for children with severe disabilities. By soliciting responses from members of the special education services community, OSEP researchers developed a "…vision and conceptualization of an integrated lifestyle for individuals with severe disabilities" (p. 1).

OSEP's stated purpose in developing this mission was to improve educational outcomes for children, with "improvement" defined as leading an integrated lifestyle. OSEP researchers designated seven aspects that define an integrated lifestyle for children with severe disabilities, to include education; employment; social relationships; self-determination; recreation and leisure; neighborhood and community; and home. They further detailed each of these categories by developing indicators of an integrated lifestyle. For example, under the domain of employment, indicators include having employment experiences prior to graduation; engaging in real work in real workplace settings; working in locations that are integrated; receiving wages commensurate with individual skills; and communicating with peers at the workplace. To determine if these seven "best practice" domains are present in transition classrooms for students with severe disabilities, and might have an influence on teacher and school decision making, this literature review will next examine studies related to transition practices for this population.

### *Special Education Transition Practices*

Grigal, Neubert, and Moon (2001) note that there is little research about the school programs of students with significant disabilities between the ages of 18 to 21 years, and that the few studies that exist tend to focus on individual states rather than offering a national perspective. Grigal and colleagues examined 13 programs in post-secondary settings in the State of Maryland to determine the staffing patterns, program components, and assessment procedures employed by these schools. A questionnaire was used to conduct in-depth interviews with the teachers in these programs, and all interviews were held at the school site. The mean number of students served in each of these programs was 11.5 during the 1998-99 school years. The majority of the 13 programs studied had one special education teacher and one or two full time aides who worked with students. Most programs also had volunteer staff or interns who provided instruction to students in some capacity.

The program components in these classrooms included functional skill instruction, job training, assessment activities, social skills training, individual transition planning, and interagency collaboration. The authors considered these programs reflective of best practices identified in the literature pertaining to secondary special education and transition services. Community based instruction was also a critical component of the programs. This included teaching such activities as banking, shopping, restaurant skills, cooking skills, and using community facilities.

A second review of the educational practices for transition-aged children with mental retardation and significant disabilities was conducted by Neubert, Moon, and Grigal (2002). These researchers found that transition services for these students focused on community based instruction for vocational and independent living experiences. Neubert et al. (2002) concluded that students participate in a range of transition related activities which include functional skills acquisition, work, social and recreation activities, and accessing community resources. While not widely employed, individualized support approaches are also used in some transition programs. In this model, students and their support teams design individualized schedules of work, classroom instruction, and participation in activities designed to promote social skills. Neubert et al. note that this approach to curriculum design and delivery allows for a broader range of learning options that are not limited to what is available in “special programs”(p. 159). This individualized model would allow more latitude for incorporating the perspectives of various stakeholders in the goal planning and preferred outcomes for students with profound disabilities.

Zhang, Ivester, & Katsiyannis (2005) provide further insight into the transition practices in middle and high school special education programs. In a study involving 105 transition teachers and 37 transition personnel from South Carolina, Zhang et al. (2005) found that the majority of the schools offered a functional skills curriculum to students. This included teaching a school or community based work program, self help skills, and independent living skills. A significant number of the schools were identified as not providing adequate employment training based on best practice procedures. In addition, the schools that participated in the study offered little variety in terms of types of work experiences and almost no opportunity to participate in supported employment. In a little over half of the schools, the special education director or a transition coordinator was responsible for ensuring compliance with federal and state regulations. The addition of these individuals to the interdisciplinary student planning team would influence and potentially complicate the goal setting process by inserting federal and state perspectives on the critical skills a student needs to be prepared for adulthood. Although Zhang et al. found that special education teachers and parents were the most frequent participants at

ITP meetings, these researchers did not compare goal outcomes between meetings that were attended by special education directors or transition coordinators and those that were not.

### *Adult Services for Individuals with Developmental Disabilities*

When students with developmental disabilities graduate from special education programs at the age of 22 years, there are a number of adult services available for their support. These include competitive or supported employment, sheltered work, day activity programs, group homes, supported living, and even assistance in purchasing their own homes and starting their own businesses (ARC, 2002). Despite the range of services available, many are not accessed by or perhaps open to individuals with severe and profound disabilities. In a longitudinal study that examined the lives of 14 individuals with severe and profound disabilities one and three years after graduation, Frank et al. (1992) found that these young adults were placed exclusively in sheltered workshop settings earning between $.09 to $ .37 per hour or were unemployed and dependent on state support. Residential settings for this population were limited to group homes or family homes, and all individuals with disabilities were dependent on families, friends or special services for transportation and financial support.

One of the newer support systems designed to improve the adult outcomes for persons with developmental disabilities is self directed services, which are still in the pilot phase in California. In this service model, persons with disabilities receive direct funding that can be used to develop individualized residential, recreational, and employment opportunities (California Department of Developmental Services, 2007). In California, these dollars cannot be used to purchase services in group settings, which would include the workshops and group homes that research has shown are the primary settings accessed by adults with profound disabilities (Frank et al., 1992). It remains to be seen whether the lives of individuals with profound disabilities will change as a result of individualized funding, and whether this funding will make available a wider range of options for home, work, and recreation. It is also uncertain whether the advent of individualized funding will cause parents and student support teams to envision a life beyond group homes and sheltered workshops for persons with profound disabilities.

### *Summary*

This review of transition curriculum and programs for students with developmental and other disabilities reveals several similarities in the types of activities and training offered. In general, students with developmental disabilities in the age of transition (16 to 22 years old) receive instruction in vocational skills, typically at community-based job sites. These students are also learning functional skills to help foster greater independence as well as how to access their local community. Recreation/leisure/social skills are typically taught in transition classrooms and students receive a high level of individual support in order to benefit from instruction. The research literature paints a clear picture of what is happening in transition classrooms for children with a wide range of disabilities. It is less clear if these approaches to teaching and learning result in positive outcomes for these students after they graduate from school.

## Overview of Post-school Outcomes for Students with Disabilities

Two large scale studies examined the post-high school experiences of students with disabilities. The first of these, the National Educational Longitudinal Study of 1988 (NELS) provides information about the post-high school experiences of students with disabilities other than mental retardation while the second study, the National Longitudinal Transition Study of Special Education Students 1987-1991 (NLTS), included these young adults. Wells, Sandefur, and Hogan (2003) examined these studies to attempt to uncover the factors that most impact special education students as they transition to adulthood. Wells and colleagues found that disability and type of disability profoundly affect post high-school outcomes. In particular, individuals with mental retardation have poorer adult outcomes than those with physical or learning disabilities, in large part due to their higher need for individualized support across the lifespan. Wells et al. asserted "…Those who are mentally retarded and who have multiple disabilities are the most likely to become totally dependent on their families without taking on normative adult roles." (p. 816). These researchers believe that significant changes must be made to our current interventions before individuals with developmental disabilities can be fully integrated into a robust adult life.

In a second study conducted in 2000, The National Council on Disability (NCD) completed an analysis of the transition, post-secondary education, and employment outcomes between the years 1975 and 2000 for youth with a wide range of disabilities. Their conclusion of the general outcomes for this population revealed "…Americans with disabilities continued to lag well behind other Americans in many of the most basic aspects of life" (p. 27). In comparing the outcomes of young adults without disabilities with those who have disabilities of any kind, the NCD found the biggest gaps in the area of employment, with only three in ten people with disabilities of any kind employed full or part time after graduation versus eight in ten people without disabilities. Despite their finding that the data on the employment status of people with severe disabilities is sparse compared to the data on the larger population of persons with disabilities, NCD researchers asserted that young adults who have severe disabilities have a more difficult time finding and maintaining jobs than those with more moderate or mild disabilities.

In another follow-up study of special education graduates, Haring and Lovett (1990) surveyed 129 former special education students who had been out of school for five to seven years to determine their vocational and community adjustment. Those involved in the study represented a wide range of individuals with disabilities, with a little under half labeled learning disabled; approximately a quarter mildly mentally retarded; 15% moderately mentally retarded; and 14% severely/profoundly mentally retarded or multiply handicapped. The average age of those surveyed was 21 years and 64% of the respondents were male. Haring and Lovett's interview instrument examined numerous areas of adult life, including employment, residential status, social recreation activities and satisfaction, and parental perceptions. Either the individual, whenever possible, or those closest to the individual (parents or careproviders) completed the survey.

Haring and Lovett concluded that the lives led by the adults in their study were of poor quality in comparison to the general population. Those who were employed were working in subsidized employment settings with little opportunity for upward mobility.

This included employment in segregated sheltered workshops where individuals package or assemble items for a piece rate and work in semi-skilled jobs such as janitorial services, bussing tables, or litter abatement. A third of those interviewed were employed in community businesses or integrated settings and all of those surveyed received low wages. Most of these recent graduates were receiving no community services and 70% were still living with a parent, guardian or relative at age 21 years with no plans for living a more independent lifestyle. This compares to statistics that show only 47% of women and 56% of men aged 20-24 without disabilities still living with their parents (CCSD, 1996). Those with severe/profound and multiple disabilities were most likely to be employed in sheltered workshops or attending segregated adult day programs, living in a group home or institution or with parents, and dependent upon agency or relative provided transportation.

The outcomes for students with disabilities after graduation were also measured by Hughes and Eisenman (1996) who conducted an analysis of transition outcomes from 181 intervention studies written between 1970 and 1993. As part of their conceptual framework, Hughes and Eisenman developed a consensus list of 11 categories derived from literature across several fields, and used these categories as a lens through which to analyze the data. These categories are shown in Table 2.

Table 2.

**Eleven Categories of Transition Outcomes by Hughes and Eisenman**

| Category |
|---|
| 1. Social interaction |
| 2. Employment |
| 3. Community adjustment, competence, and independent living |
| 4. Self determination, autonomy, and personal choice |
| 5. Recreation and leisure |
| 6. Physical and material well-being |
| 7. Civic responsibility |
| 8. Psychological well-being |
| 9. Personal development and fulfillment |
| 10. Social acceptance, social status, and ecological fit |
| 11. Individual and social demographic factors |

Hughes and Eisenman found that outcomes in categories one through eight were the most frequently measured based on the literature they reviewed. Of the 457 outcomes reviewed, 147 addressed social interaction, 132 addressed employment, and 128 addressed community adjustment/competence/independent living. These three categories comprised 90% of the 457 total measures assessed across the studies reviewed. Hughes and Eisenman concluded in their meta-analysis that, while transition outcomes were routinely measured and addressed for categories one through eight, no targeted outcomes were found for categories nine through eleven. Although Hughes and Eisenman do not speculate regarding the absence of outcomes related to these areas, it may be that personal development, fulfillment, and social status are more subjective and therefore more difficult to measure. It is also possible that schools may not view personal and social goals as educational domains. For individuals with severe disabilities, however, personal development and social acceptance are often the factors of highest priority for leading a quality life as an adult (Halpern, 1993).

### *Summary*

A synthesis of this review of the postschool outcomes for students with disabilities reveals that, despite specialized transition supports and programs, young adults with disabilities are leading limited lives as compared to those without disabilities. Unemployment among persons with disabilities is between 50 to 75% as compared to only 7% among persons who are not disabled (Gajar, Goodman, & McAfee, 1993). Students with disabilities have a more difficult time finding employment and, when employed, tend to work in lower-paying jobs with few opportunities for advancement. Although many students with disabilities are being taught skills designed to promote independent living, 70% of individuals with disabilities are still dependent upon family members seven years after graduation as opposed to 47-56% of young adults without disabilities (Haring and Lovett, 1990). Those with the most severe disabilities have poorer outcomes than those with more mild disabilities, with few opportunities for meaningful work, varied and integrated social opportunities, community access, or upward social and economic mobility.

It is unlikely that, if asked, either the individuals with disabilities or their families envisioned lives such as those detailed in the literature reviewed. Examining the perspectives of families, students with disabilities, and their teachers regarding the transition to adulthood may shed light on desired outcomes and, when juxtaposed with actual outcomes, provide important information on directions for research and the ways in which transition and special education students and programs are influenced by the voices of the primary stakeholders.

## Family and Teacher Perspectives on the Transition to Adulthood

The desires and needs of families, and to a lesser degree students with developmental disabilities and their teachers, have been the focus of several transition studies over the past two decades. These studies have examined family, student, and teacher desires for the future (Chambers et al., 2004; Cooney, 2002); the skills that are important to master prior to graduation (Hamre-Nietupski et al., 1992; Hanley-Maxwell et al., 1994); and how the transition process affects families (Ferguson et al., 1988, 1996; Ferguson, 2000; Hanley-Maxwell & Collet-Klingenberg, 1995). In all of these studies, parents and other relatives of developmentally disabled students and teachers were interviewed, along with, when feasible, the developmentally disabled students themselves.

The desired adult outcomes parents harbor for their children with disabilities vary based on the severity of an individual's special needs. Hamre-Nietupski, Nietupski, and Strathe (1992) interviewed the parents of 68 students with moderate to profound disabilities to determine what outcomes they felt were important for their child after graduation from special education programs. For parents whose children were moderately disabled, paid work and living independently from the family were primary indicators of successful adulthood. Those parents whose children were more severely disabled believed friendships and the development of social relationships were more important than academics or vocational goals for the future happiness of their children. This conclusion was supported by Chambers (2004) whose research on families of children with developmental disabilities revealed, in addition to primary concerns about work and residential living options, parents were “extremely” or “very” concerned about their family members’ social life after high school (p. 85). Based on the work of Hamre-Nietupski et al. and Chambers, parents’ primary concerns regarding adult life for their family member with disabilities involve work, living situation, and social life.

Students, parents, and professionals often have differing perspectives regarding desired student outcomes for life after graduation from special education. Cooney (2002) is one of the few researchers to compare and contrast the perspectives of these three groups related to transition to adulthood. Cooney collected data in the form of in-depth interviews, participant observation, and reviews of documents such as Individual Education Programs (I.E.P.) and Individual Transition Plans (I.T.P.). He interviewed parents, special education teachers and adult service professionals, and nine students labeled “severely disabled” who were able to answer his questions regarding their visions of life as an adult. It is important to note that the ability to accurately communicate about something as abstract as a desired future is typically not within the scope of persons who are severely disabled. Although this fact clouds the definition behind the disability label of the young adults Cooney interviewed, their perceptions are nonetheless helpful in understanding how students who have developmental disabilities conceptualize their lives as adults.

Cooney stated that the students he interviewed spoke of their future in optimistic terms, expressing a desire to get a job, live on their own away from their family, and make new friends. Conversely, parents' goals for these young adults were primarily safety oriented, but included a wish that their offspring with disabilities has the ability to use his or her strengths to achieve a sense of fulfillment and make a contribution to their community.

Cooney also interviewed 15 special education teachers and adult service providers who were involved in the transition services for the students in the study. Unlike either parents or students, the professionals in Cooney's study used disability as the primary means for conceptualizing an adult life for their students. One teacher stated "It's not uncommon for people that are mentally retarded to have a life that is more limited and we have to pretty much comply with what their limitations are" (p. 431). The limitations imposed by an individual's disability, rather than the desires of the student or family, were often the basis for professionals' decision making regarding skills of importance for transition to adulthood. Most of the professionals in Cooney's study were skeptical about students' ability to achieve personal goals due to limited resources and supports available to adults with developmental disabilities. Cooney concluded that transition to a desired future as an adult was "more of a promise than a reality" for the nine students with severe disabilities and families he studied (p. 426). Cooney's findings are significant in that they provide critical insight into the social and personal construction of adulthood from the perspectives of those most invested in the outcomes of transition education for students with severe disabilities.

The work done by Hanley-Maxwell, Whitney-Thomas, and Pogoloff (1995) and Hanley-Maxwell and Collet-Klingengerg (1995) supports the finding that there is a mismatch between the outcomes valued by parents and students with disabilities and those valued by professionals. Hanley-Maxwell et al. conducted a study of 14 families whose children with developmental disabilities were undergoing the transition to adulthood. The children of these families had a range of diagnoses from mild to profound developmental disability, with two families having children with profound disabilities. When asked to define transition, the parents interviewed by Hanley-Maxwell et al. frequently discussed work related outcomes. However, when asked to discuss transition in relation to their desires and hopes for their children, parents spoke of residential and social outcomes. Parents in this study described a "threefold vision" for their child's future which included "a safe, happy residential situation; included strong social networks; and involved the constructive filling of the child's free time" (p. 7).

In a subsequent and related review of the literature on transition to adulthood, Hanley-Maxwell and Collet-Klingenberg (1995) noted that preferred adult outcomes for families whose children have developmental disabilities reflect personal needs and desires while the outcomes described by professionals are focused on the existing services available to adults. This can result in adult outcomes that are not desired by the family or the individual with a disability and may be one of the underlying factors in the poor prognosis for adulthood already discussed in this review. Hanley-Maxwell and Collet-Klingenberg also suggest that our current educational system values the acquisition of certain kinds of knowledge (usually academic versus practical or social) as the key to successful adult life. Educators who adopt this ideology may push students with disabilities into an academic or work focused transition curriculum, viewing the outcomes desired by individuals and families as of little value. Hanley-Maxwell and Collet-Klingenberg assert that "…currently practicing educators are not taught to think in systems and total life perspectives. Without these perspectives, identifying critical adult skills is virtually impossible" (p. 59). Without specific training on the desires of families and individuals with disabilities regarding adult life, educators will likely continue to promote goals that do little to prepare their students for a self determined lifestyle. This lack of teacher training, in turn, could result in continued poor outcomes for young adults with developmental disabilities.

While families and students with developmental disabilities may know what they desire for the future, they are hampered by inadequate knowledge about the type and scope of services available after graduation from public school special education programs. Using questionnaires to obtain results from 16 family members of students with significant disabilities, Chambers (2004) found that families often lack knowledge about what services and supports are available to adults with developmental disabilities within their community. These students and families have had little opportunity to meet others who have successfully made the transition to adulthood, and schools often fail to provide families information about adult service systems until shortly before graduation. As a result, parents and students dream of a future that may not be possible, particularly if the student requires high levels of support in order to function within the home, community, or workplace. Adult programs often have long waiting lists for admission and are based on a group, rather than individual, system of service provision. The limitations and absence of entitlements inherent in the adult service system make even the simple dream of working, making new friends, and having a place of their own impossibility for some individuals with developmental disabilities.

Not only are families ill-informed about the adult services available to their children with disabilities, they also find that transition to adulthood is as much a family transition as an individual transition. Ferguson, Ferguson, and Jones (1988) examined the social construction of transitions within the family and the role that culture and history plays in these transitions. The results of this ethnographic study involving 15 Caucasian families from a range of socioeconomic backgrounds showed that parents undergo three distinct types of transitions when their child with a developmental disability leaves high school behind. Ferguson et al. categorized these transitions as bureaucratic, family life, and adult status. For most parents, the process of transition was about control: theirs or the professionals. Ferguson et al. also uncovered a distinct difference between the relationships parents had with public school special education professionals and the ones they experienced with adult service providers. Parents interviewed spoke of feelings of surrender to professionals, abandonment by professionals, and a sense that they as parents were forced to act as professionals in order to gain needed supports for their children.

The lives of the families interviewed by Ferguson et al. changed radically when their adult children were no longer in a formal school setting for a fixed number of hours but instead were working part time jobs at odd times during the day or week. One mother lamented, “It makes our whole life so much more hectic than it was, trying to arrange our life around her schedule while before, when she was in school, things were so much more predictable.” (p. 183). Many family life changes that occur around the time of a child’s transition to adulthood were interpreted as a new burden by family members in this study.

Ferguson et al. found that the adult status of children post-high school was an ill-defined concept for the parents they interviewed.

While some families defined adulthood by using cultural markers such as moving away from home, turning 21, or getting a job, most families expressed that the adult status of their children was not something they could either grant or withhold. Ferguson et al. further noted that the focus of parents during their child's transition to adulthood "…often became translated from a "child-or- adult" question to a "parent control-or-professional control" question." (p. 185). The struggle for control may be a second factor that accounts for the poor adult outcomes experienced by young adults with developmental disabilities and may have a significant impact on how, or if, family, teacher, or institutional perspectives are co-constructed and ultimately shape the goals and futures of these students..

*Summary*

The research conducted regarding the perspectives of students, families, and professionals and the transition to adulthood for students with disabilities shows that transition does not happen just to students when they leave formal schooling. Instead, transition is very much a family matter. For transitioning students, adulthood as constructed in the United States includes such features as a job, friends, and a place to call your own. For families, adulthood is about safety, self-fulfillment, separation and control. For the professionals who support students before and after they leave public school classrooms, transition is about available adult programs and encouraging students and families to let go of dreams that do not fit the realities of a limited service system. Still, most students with developmental disabilities do reach the age of 22 and leave behind public school special education supports; their parents will, at some point, be unable to guide their future; and, undoubtedly, service providers will continue to struggle with limited funding and programs to designed to meet the needs of adults with profound disabilities. These research findings support the need to understand more about how stakeholders co-construct adulthood for individuals with profound disabilities and what factors influence this construction.

## Conclusion of Literature Review

Although the federal government has recognized some of the needs and problems inherent in the transition to adulthood for students with disabilities through the enactment of legislation, the adult lives experienced by many of these students continue to be characterized by dependence, economic instability, and isolation. Special education transition programs are engaged in offering work, social, and independent living skills training to students with disabilities, but these skills are either not adequately mastered by the time students leave public school or are not adequate to lead a full and self determined adult life. The lives that families envision for their children with disabilities, and the lives the children envision, are often at odds with each other, professionals, and what is available through a limited adult service system. In addition, special education and adult professionals primarily use disability, rather than individual desires, as a framework for planning transition goals and curricula for students with disabilities. Due to the documented need for teamwork on the part of all stakeholders in order to maximize successful outcomes, this conflict between family, student, and professional views of desirable transition goals may be one of the primary factors accounting for the poor quality of life led by many adults with developmental disabilities (Cooney, 2002; Hanley-Maxwell & Collett-Klingenberg, 1995).

Those with the most severe disabilities have the poorest prognosis for leading a high quality adult life. There is a paucity of research focused specifically on desired outcomes and best practice transition procedures for this population, particularly young adults with profound disabilities. The little research that has been conducted indicates that the families of individuals with profound disabilities envision a future that includes a safe home, friends, and meaningful activities (Cooney, 2002). This vision on the part of families is in contrast to both special education and adult programs that focus on vocational training, independent living, and academic skills as the best means for preparing students with developmental disabilities for adulthood. Given the increase in numbers of students diagnosed with severe disabilities, the high costs for educating these students and the need to assure that dollars spent result in meaningful outcomes, the disparity in the ideologies of the primary stakeholders, and what we know about the development and social construction of meaning relative to disability, it is critical that researchers increase their focus on studying transition practices, influences and outcomes for students with profound disabilities. In addition, understanding the relationships between stakeholder constructions of adulthood, current and historical contexts that lead to decisions regarding educating students with profound disabilities, and the artifacts that are used to guide decision making will provide insight that could be critical in maximizing the potential for positive adult outcomes for these students.

The literature on transition to adulthood has concerned itself primarily with the outcomes and programs for students mild to severe developmental disabilities.

Noticeably absent are the transition needs, plans, and processes for students who have profound and multiple disabilities. Also absent are the preferred adult outcomes for these students as envisioned by institutions, family members and professionals. Despite their multiple challenges, individuals with profound and multiple disabilities can, and will, transition to life as adults in communities that often have little understanding of their abilities and disabilities. Given this, the transition plans of students with profound and multiple disabilities should reflect an adult life that allows them personal fulfillment and to meet their maximum potential.

The literature reviewed in this chapter was selected in order to provide the background information and framework needed to examine the research questions. An understanding of the cultural and historical context in which parents, teachers, and institutions make decisions and set policy regarding the adult lives of individuals with profound disabilities is important in determining the factors that influence decision-making, a primary goal of this study. Ecological systems theory informs us that environment plays a significant role in human development (Bronfenbrenner, 1979). Reviewing the literature regarding current practices and policies related to the provision of special education transition services for students with profound disabilities offers insight into the potential environmental influences at play for parents, teachers, and students. A knowledge of the available literature on the mental models of parents and teachers regarding adult life for their children/students sets the stage for uncovering the adult life schemas of the parent and teacher study participants. Finally, special education laws and forms are artifacts that play a potentially significant role in how knowledge is distributed across the stakeholders who have the responsibility of envisioning and setting goals for the adult lives of students with profound disabilities

# CHAPTER 3: RESEARCH METHODS

High school graduation is a time when many critical life decisions are made, when one’s future is envisioned and concrete steps are taken to actualize the vision, and when some future paths are rejected while others are embraced. These life decisions can include attendance at college or continuing education programs; decisions about where and with whom to live; decisions about marriage and family; and decisions about work or future career. Some young adults approaching graduation rely heavily on family influences, while others take a radically different path from that chosen by parents.

The transition from school to adult life for persons with profound disabilities shares much in common with the transition experienced by young adults without disabilities, but differs in one critical way: what happens to individuals with profound disabilities is determined largely by others. Family members, special education teachers, therapists, and school administrators decide what the future will hold when schooling ends. Research that examines the post-school lives of persons with profound disabilities paints a grim picture of dependency, isolation, and stigmatization (Haring and Lovett, 1990; National Council on Disability, 2000; Wells, Sandefur, and Hogan, 2003). It is unlikely that the teams of people charged with envisioning future lives for students with profound disabilities intended these outcomes.

This study was initiated based on my concerns about the life quality of adults with profound disabilities, a population I have worked with for the past 25 years. My anecdotal experiences with young adults as well as parents led me to believe that what parents say they want for their child, and what actually happens to their child, is often widely divergent. For at least 16 years, and often longer if their child’s disability was identified at birth, parents whose children are in the transition years have participated in annual Individual Education Program planning to identify goals that are critical for their child's present and future life. For the final seven years of their child's special education schooling, parents have also participated in designing Individual Transition Plans (ITPs) to specifically address life after graduation. By law, parents must approve an IEP and ITP before the goals contained in these documents can be taught to their child. Given this, how is it possible that their child's adult life is not what they envisioned? Clearly, factors are at play that influence the final outcomes experienced by students with profound disabilities. This study seeks to understand these factors in the hope of improving the life quality of adults with profound disabilities.

## Positionality

Mertens (2005) stresses the importance of researcher clarification regarding personal closeness to the topic and values. As mentioned earlier, I have worked with students with profound disabilities for the past 25 years, both as a teacher and the administrator of programs for children and adults with this diagnosis. I currently operate two nonpublic (school district funded) schools that serve 17 school districts. Approximately 60% of the students at my schools, and a similar percentage of the adults at my adult day training program, meet the definition of "profoundly disabled". I have had the unique opportunity to compare the services offered to both children and adults with profound disabilities and to talk with many parents over the years about their fears and hopes for their children upon graduation from special education.

As the parent of a young adult who has profound and multiple disabilities, I have personally experienced the roles of parent, teacher and special education administrator. I bring to this study knowledge of the service system, protocols, paperwork and terminologies used in the field, as well as an understanding of the global needs of individuals with profound disabilities. I believe that my experiences as a parent and an educator may increase the likelihood that I bring pre-conceived notions to bear on my data analysis and conclusions. I hope that an awareness of this has helped me to avoid misreading data or failing to see emerging theories or patterns that may not be part of my current mental model.

### *Positionality as a School Director*

Throughout my career, I have worked extensively with parents and teachers of students with profound disabilities. In general, parents are poorly informed about the continuum of supports and services available to their children once they reach adulthood (Kraemer, B. & Blacher, J., 2001). The parents I have met have expressed dismay and dissatisfaction about the quality and variety of adult support programs, as well as about the availability of space within existing programs. Upon entering adulthood, individuals with significant disabilities and their families lose entitlement to a wide range of services, to include specialized therapeutic supports such as speech, occupational, and physical therapy that they have viewed as critical to their child's ability to maintain current skills or acquire new skills. Parents worry about their child's health, safety, and life quality after they leave behind the rich teacher/student ratios and access to specialists provided by the special education service system. Many parents state that they feel powerless and "beaten down" by the complex system of adult services. Part of my job over the past years has been to develop transition and adult programs in response to the feedback received from parents regarding their wishes for their child's adult life.

I have also had extensive experience working with, and training, special education and adult day program teachers and paraprofessionals. In classrooms across the county, both public and private, there are shared problems related to teacher recruitment and retention. In many private and public school programs, the turnover rate for staff and teachers serving persons with profound disabilities is an average of 1-1.5 years (Washburn-Moses, 2005). Low rates of pay and low unemployment rates keep this problem at the forefront for most programs. It is difficult to recruit qualified teachers to work with students who have profound disabilities. In the county where I reside, there is such a severe shortage of teachers with moderate-severe teaching credentials that the local department of education issues on-the-spot provisional credentials to applicants who have a bachelor's degree in any field; can pass a basic education skills test; are made an offer of employment by a private or public school; and are willing to enroll in a special education training program within one year. This means that, oftentimes, people with no experience or formal training are the professionals responsible for designing student goals and supporting the transition to adulthood of students with the highest level of need.

In my personal experience, most teachers work a few years with students with profound disabilities and then "move up" to students who are more capable or to non-teaching positions within the school. Teachers with whom I have spoken express dissatisfaction with the ever-increasing paperwork and accountability measures to which they have been subjected. Many perceive a lack of awareness on the part of their administration regarding the day-to-day challenges of working with students with profound medical, developmental, and behavioral needs. They talk of "burn-out" and "red-tape". I have participated in hundreds of IEP teams over the years and observed that completing the paperwork, and deferring to the voice of the administrator, often seems to be the priority of the meeting, and that the *process* of writing and approving goals typically takes precedence over thoughtful, detailed and personalized discussion about a student's present and future needs.

### *Positionality as a Parent*

In January of 2007, my son graduated from public school special education services and entered the world of "adult services" for persons with profound disabilities. This has afforded me the unique opportunity to perceive the educational system from both a parent and a professional perspective, and to personally undergo the process of envisioning and developing goals directed at my son's adult life. As a result of my training and insider status, I have been able to put into place the goals and programs my son needed during his transition years and to construct a support system for his adult life based on his personal strengths rather than existing services. Most families are not this fortunate. Lacking the social capital, resources, and information necessary to plan and institute a highly individualized and supported adult life for their children, many parents express that they feel they are at the mercy of a system that is not structured to meet their child's unique needs, either immediately upon graduation or across the lifespan.

## Participant Selection

### *Access to Subjects*

The overall procedure I used in subject selection involved stratified nonrandom sampling. The cases I selected to study were all members of a particular subgroup of "parent of a child aged 16-22 with a profound disability" or "teacher of a child aged 16-22 with profound disability" living and working within the county in which I reside. Within this subgroup, my selections were made using several criteria which differed depending on whether a teacher/parent attended the private school I direct or a public school program. In total, 16 teachers and parents participated in this study.

### *Public School Participants*

For participants involved in public school special education programs, I used snowball or chain sampling. My participant selection was based on referrals made by colleagues. I asked directors of special education within specific school districts to give me the name(s) of teachers who work with transition aged students who have profound disabilities whom they believed would be willing to participate in my study (study was first described to the director). School districts, and special education directors, were selected based on proximity to where I work and live as well as my familiarity/historical working relationship with the director.

I first selected 6 school districts whose students attend my private school. These students' placement is funded by these school districts, and students are referred by the district, typically, because the students have either significant behavioral problems or parents who have initiated litigation against the school for perceived wrongdoings relative to their child's special education services (often, both factors apply to all students). I chose these 6 districts based on a number of factors: my familiarity and history with the special education directors of the districts; my intuitive sense of which directors would most likely be amenable to helping me with my research project; and those directors with whom I had the longest work history.

My initial phone call to the special education directors of these six districts was fairly informal. After some initial casual conversation, I provided them with a brief overview of my research which included the fact that I wished to interview teachers who have students aged 16-22 with profound disabilities and talk with them about the adult life they envision for one or more of their students. I stated that, in addition to a willingness to be interviewed, these teachers would also need to assist me in contacting the parent of a student in their classroom who met the criteria (profound disability, aged 16-22) for study inclusion, informing the parent of the general intent of my study, and providing me with the contact information for interested parents.

With these criteria in mind, special education directors from four of the six districts immediately agreed and gave me the names of 1-3 teachers within their district. The directors from these four districts also indicated that they had the authority to grant permission for me to access teachers at their school site. The special education directors at the two remaining districts were more hesitant about helping with my study and deferred decision making to another party. I told these directors that several other schools had agreed to participate and that I would contact them if I needed additional participants. They indicated a willingness to work with me further, however I chose to eliminate their districts from the study in the interest of time.

I received a list of 6 teacher names from the 4 districts. Ultimately, 3 teachers from 3 of the districts were eliminated because none of their students have profound disabilities. The remaining 3 teachers agreed to participate in the study. After completing these interviews, an additional teacher was eliminated from the study because the parent he identified decided not to participate. Table 3. provides demographic information about the 2 public school special education teachers who were interviewed for this study.

The special education teachers who agreed to participate in the study provided me with the names and contact information of 2 parents (one from each of their classrooms). Both parents had a special needs child still living in the family home. I contacted these parents by telephone, explained the nature of my study and what their participation would entail, and arranged a time for the interview. Table 4. provides demographic information about the two public school special education parents who were interviewed for this study.

Table 3.

**Demographic Information for Public School Teacher Participants**

| Name | Experience | Education | Class |
|---|---|---|---|
| Teacher Dave | 29 years teaching severely disabled<br>3 years special education administrator | BA Social Science<br>Masters –Administration<br>Single subject credential<br>Moderate-severe credential | 12 students<br>3 full time aides<br>3 part time aides |
| Teacher Jeff | 18 years teaching severely disabled<br>5 years as aide for learning handicapped | BA Liberal Studies<br>Masters-Special Education<br>Multiple subjects credential<br>Moderate-severe credential | 12 students<br>4 full time aides |

Table 4.

**Demographic Information for Public School Parent Participants**

| Name | Age | Race | SES | Marital Status | Child Name | Age | Child's Diagnosis |
|---|---|---|---|---|---|---|---|
| Parent Martha | 61 | White | Lower Middle Class | Married | Taylor | 21 | Down's Syndrome<br>Profound Retardation |
| Parent Russel | 54 | Middle Class |  | Divorced | Justin | 19 | Profound Retardation<br>Cerebral Palsy<br>Blind |

## *Private School Participants*

### *Description of School*

The private school participants were all selected from the nonpublic, nonprofit school that I founded and also direct (convenience sampling). This school is part of a larger organization that provides residential, respite, adult day program, camp, and transportation services to approximately 500 children and adults with developmental disabilities and their families. The school is located in a light industrial area in a suburban city about 50 minutes away from a major metropolitan area. The city has a large population of military families and transients, being located next to a large military base.

A total of 62 students attended the school at the time of my research. Students range in age from 6-22 years. About half of the students live in their family homes while the remaining students live in small group homes within the community. Approximately 90% of the students are diagnosed as autistic, and 60% of the total student population falls within the severe-profound range of intellectual and developmental functioning. Students are bussed to the school from 17 school districts across the county, some riding the school bus over 2 hours each way. Students are referred to the school by their home school district, typically because their problem behaviors (aggression, property destruction, self abuse, dangerous behavior) cannot be managed on a comprehensive school site or at another nonpublic school setting. About half of the students have been unsuccessful not only in public school settings, but also in other private settings.

School districts pay the costs of educating the children which are high given the severity of the students' special needs. All students have a 1:1 instructional aide, and there is a certified teacher for approximately every 12 students. In addition, the school has therapists, a director, and a behavior specialist who support staff and students as well as providing students monthly access to psychological, psychiatric, and assistive technology consultants. The school curriculum is highly structured and individualized, with each student receiving a specially designed daily program of instruction.

About 70% of the total staff of the school has at least two years of college, and approximately the same percentage has at least 2 years of experience in the field. The average turnover for this school is less than the norm, with most staff staying about 3 years before leaving or changing jobs. Staff range in age from 20 years through about 58 years of age. Most of the staff at the school are in their 20's or early 30's. None of the certified teachers at this school are considered "highly qualified" by the State Department of Education. All are experienced in the field upon hire, and all of them are currently taking college coursework to complete their clear credentials in moderate-severe disabilities. Of the 6 special education teachers from this school who participated in this study, four previously worked at the school as 1:1 instructional aides and were promoted to the position of certified teacher.

As the director and founder of the school, I designed the majority of the training programs that all school staff receives upon hire. As a result, some of my philosophy regarding quality of life and quality standards for educating special needs students is embedded in the training that all of the staff at this school receives, both upon hire and on an ongoing basis through inservice training. In the school year immediately preceding the study (the 2006-07 school year) I functioned as the onsite director of this school because I was unable to hire a qualified school director. Unlike previous years, this meant that I had high levels of direct, daily contact with all of the staff at the school, but particularly the certified teachers, just prior to conducting research at the site. The certified teachers are very familiar with my topic of study, and we have had many group and individual discussions about the need for better transition services for students with significant disabilities. At the time of the interviews (July-October, 2007), I had hired a new school director but was still maintaining an office at the school site, although my daily interactions with certified teachers diminished somewhat significantly from the previous months.

### *Description of Private School Participants*

To select participants from the private school setting, I used convenience sampling as well as extreme cases sampling measures. I first met individually with each of the six certified teachers at the school, explained my study, and asked if they would be willing to be interviewed. All teachers agreed to participate. I took special precaution to inform each teacher that participation was not necessary and that I would not take offense if an individual decided not to participate. All certified teachers indicated an enthusiasm for participation, expressing eagerness at having an opportunity to discuss their perspectives regarding particular students. Table 5. shows the demographic information for the certified teacher participants at this school.

Table 5.

**Demographic Information for Private School Teacher Participants**

| Name | Experience | Education | Class Size |
|---|---|---|---|
| Teacher Allegria | 7 years teaching English abroad | BA History | 11 |
| | 3 years teaching severely disabled | Ma in Education (in process) | |
| | 1 year teaching at this school | Moderate/severe credential | |
| Teacher Luis | 1 year Biology teacher | BA Biology | 12 |
| | 8 years teaching physically disabled | Physical handicaps credential | |
| | 16 years special ed. Administrator | Moderate/severe credential | |
| | 5 years teaching severely disabled | | |
| | 1 year teaching at this school | | |
| Teacher Tracy | 4 years 1:1 aide at this school | BA English | 11 |
| | 2 years teaching at this school | Moderate/severe credential (in process) | |
| Teacher Ingrid | 10 years teaching learning disabled | BA Education | 4 |
| | 6 years as 1:1 aide at this school | Moderate/Severe cresential (in process) | |

Table 5. (continued)

**Demographic Information for Private School Teacher Participants**

| Name | Experience | Education | Class Size |
|---|---|---|---|
| Teacher Teresa | 3 years as aide for severely disabled | BA Liberal Studies | 10 |
| | 1 year as 1:1 aide at this school | Multiple subjects credential | |
| | 3 months as teacher at this school | Moderate/severe credential (in process) | |
| Teacher Roxie | 2 years at 1:1 aide at this school | BA Communication Disorders | 10 |
| | 1 year as teacher at this school | Moderate/severe credential (in process) | |

My next step was to select those students at the school who were the *most profoundly disabled* and were also between the ages of 16-22 years. "Profound disability" was defined by my knowledge of student ability levels as well as test scores and diagnosis from student files. I then grouped these students under their appropriate certified teacher. There are six certified teachers at the school and each one has between 10-12 students in his/her class. I did not want to interview any certified teacher more than one time because of my focus on distributed cognition and desire to compare understandings between teachers, between parents, and between teachers and parents. Within any given classroom, there was an average of three students who have very profound disability (IQ scores of less than 20; developmentally at a toddler level or lower). I started with the parent of the most profoundly disabled student in each classroom and telephoned them to query their interest in participating in the study. I then moved along in this manner until I had six parent participants whose children are in six different classrooms. In every classroom, the parent with the *most profoundly disabled* child agreed to participate. Table 6. shows a list of parent participants from this school.

Table 6.

**Demographic Information for Private School Parent Participants**

| Name | Age | Race | Marital Status | Child Name | Child Age | Child Diagnosis |
|---|---|---|---|---|---|---|
| Parent Shelly | 43 | White | Married | Rob | 16 | Profound autism |
| Parent Blanca | 42 | Latino | Single | Linda | 20 | Profound autism |
| Parent Helen | 62 | White | Married | Pam | 16 | Cerebral palsy |
| Parent Patty | 39 | White | Married | Nancy | 18 | Profound autism |
| Parent Paula | 26 | Latino | Divorced | Aaron | 20 | Profound autism |
| Parent Denise | 43 | White | Married | Jack | 17 | Profound autism |

## Data Collection

A triangulated approach was taken to data collection to ensure credibility of the data. Data was collected from five primary sources: Interviews with parents and teachers; examination of student IEP and ITP documents prepared by students' interdisciplinary teams; examination of institutional documents to include the forms used to conduct and write IEPs and ITPs, diagnostic tools, and state and federal laws related to transition for this student population; an online newspaper blog related to a student with profound disability; and field notes. Pilot testing was conducted as a means for refining interview questions and formats for gaining information that was directly related to my research questions. I viewed my role in the data collection process as that of an insider-facilitator whose primary focus was to help parents and teachers work their way through the maze of their thoughts about a child/student's adult future and the factors that influenced their thinking. As a facilitator, my role was to guide but not influence the thinking of the participants.

### *Pilot Testing*

I believed that, during the course of interviewing parents and teachers of students with profound disabilities, I might ask them to consider factors which might be new to them. My interview required these participants to envision a desired adult life for their students/children 15 years after graduation from special education. I speculated that, in some cases, there may be parts of life that parents or teachers have given little consideration relative to their child or student, such as personal relationships or spiritual/religious life. It was important to me that participants think deeply about their child/student in relation to several life areas that I have identified as critical to life quality based on the literature. I conducted a pilot study to examine which of two methods- interview questions or the use of a graphic to elicit information- produced the richest source of detail and thinking on the part of the participant.

I chose two teachers and two parents at the private school where I am an administrator as the participants in the pilot interview. In order to preserve my primary participant candidates for the study, I asked two parents whose children have less severe disabilities to complete the interview. Two teachers who were later part of the study served as the teacher participants. Appendix A lists the interview questions used for this pilot, which were the same questions used for the study. I found that I was able to elicit in -depth responses to all questions except the question regarding the adult future the teacher/parent envisioned for the student. In order to gain greater information, I added a graphic representation of nine significant life categories to the final interview process (see Appendix B). The categories I selected for the graphic were based on life quality literature as well as my own knowledge regarding the services and supports available to, or desired by, adults with significant disabilities.

### *Teacher Interviews*

Teacher interviews were all conducted at the private or public school in which the teachers were employed. The teachers that were interviewed in the public school setting chose to conduct the interview in their classroom after their students had left for home. The private school teachers were interviewed in an office both during and after school hours. Interviews lasted from 45 minutes to over an hour, depending upon the respondent. Interviews were audiotaped and later transcribed for future coding.

The protocol for the interview was slightly different from one teacher to the next based on my knowledge of the teacher. I had never met the public school teachers prior to the interview, but I discovered that one of these teachers had served many of the residents of the agency where I work and knew one of the co-founders of the agency. This discovery put the interview on immediate, comfortable footing. With the second, unfamiliar public school teacher, I started the interview by explaining my positionality, first as an educator and second as a parent. All teachers reviewed and signed IRB approved permission documents prior to starting the interview. Throughout the interviews, there were times when teachers would ask questions or reminisce about former or current students. This lent a conversational nature to the interviews, and the participants and I engaged in information sharing throughout the interview process. The private school teachers and I have worked together on a daily basis, and my interviews with them were less conversational, perhaps because of our daily opportunities to meet and share information. During all interviews, I asked for clarification or expansion of a thought when needed.

All teachers used the graphic to assist in answering the question regarding their envisionment of a student's adult future 15 years after graduation from special education services. For this question, which was at the core of my research, my goal was to elicit a very rich and detailed description of the respondent's thoughts, goals, and wishes. I started by simply asking them to describe how they envisioned the student's adult life when he/she was 35 years old. Several teachers asked if I wanted them to describe the life they *thought* the student would have or the life they *wished* the student would have (this was not a question asked by any of the parent participants). When teachers asked this, I simply repeated the original question. After the teacher answered the original question, I presented the nine category graphic and asked them if the graphic prompted them to want to say anything further. Every teacher had more to say once shown the graphic, despite the fact that each was told that it was not necessary to say more on the subject as a result of seeing the graphic prompt.

### *Parent Interviews*

Parent interviews were conducted in a variety of locations depending on the preference of the parent. Four of the eight parents were interviewed in the parents' homes; one at her child's public school; two at their child's private school; and one at a coffee shop in his home community. In all but one instance, their child was not present during the interview. Parent Paula's son, Aaron, arrived home mid-way through the interview which caused only a brief disruption in the process. The study proposal was reviewed with each parent and permission forms were signed prior to the start of the interview. Parent interviews were audio taped for future coding.

Of the eight parents who participated in the interviews, I was unfamiliar with two; acquainted with five through participation in their child's IEP; and moderately familiar with one whose child has attended my school for several years. Unlike with the teachers, I started my interview with parents by first stressing my positionality as a parent followed by my administrator/teacher role. We discussed the fact that my son's transition to adulthood led to my interest in this study. I provided a brief verbal description of my son to parents who had never met him. This strategy seemed to put parents instantly at ease and allowed for a comfortable interview climate. As with the teachers, the interview often involved sideline conversations or exchange of information. Most parent interviews were completed in about one hour’s time.

Parents were asked the same interview questions as teachers (see Appendix A) and were also offered the opportunity to use the graphic (see Appendix B) to provide additional information about their envisionment of their child’s adult life. Unlike the teachers, parents required the graphic prompt in order to give detailed descriptions of the adult life they envisioned for their child. At the close of my parent interviews, I asked each parent if he/she was interested in learning more about the existing adult service continuum. All parents were interested. I informed parents that I would offer a parent training at my school on this subject in the spring of 2008.

### *Transcription Procedures*

Parent and teacher interviews were audiotaped using a portable mini-tape recorder. I personally transcribed twelve of the sixteen interviews, typing each word verbatim into a Microsoft Word document. These twelve interviews were transcribed within 72 hours of the original interview to promote accuracy. Four of the interviews were transcribed by my school’s administrative assistant. I found it was necessary to compare these transcripts to the original tape because information was sometimes inconsistent with my recollection of the interview. This was primarily due to the transcriber’s lack of familiarity with the subject matter and the terms used in the field. As a result, I made a large number of corrections to the transcripts prepared by my assistant in order to render them more faithful to the original interview data. Each participant’s transcript was placed in a separate Microsoft Word folder and labeled with the participant’s name as a means for data storage. Access to these folders is password protected to assure confidentiality. The original tapes were placed in a locked cabinet in my office for safe keeping.

### *Document Reviews*

#### *IEP and ITP Document Reviews*

At the onset of each interview, parents were asked to sign a consent that would allow me to access copies of their child's IEP and ITP documents. All parents agreed to allow me access to these documents. Student IEP and ITPs provide demographic information about each student; list current education plan goals and benchmarks; provide statements of needed transition services; and have a checklist of potential post-high school goals that are marked by the team at the time of the student's annual meeting. My interest in reviewing these documents was to compare the content of the goals and plans written during the IEP and ITP meeting with the goals and plans voiced by teachers and parents. I was also interested in these forms as cultural and historical artifacts that might impact, or potentially limit, the thinking of teachers and parents. During my interview with parents and teachers, I questioned the influence that the IEP and ITP process has on their thinking regarding a child's adult life. I was interested in determining if the teacher or parent's voice was more heavily represented in the goals and plans that comprise these documents.

#### *Federal and State Regulations*

Much of what occurs in special education classrooms is a result of laws that have been enacted to assure that special needs students have access to a publicly funded and appropriate education. These laws function as artifacts that contain the collective cultural and historical knowledge of our society regarding the "best" ways to educate and prepare special needs students for their adult futures. For this study, I reviewed the language specific to transition services contained in the Individuals with Disabilities Education Act (IDEA 2004) and the California Code of Regulations, Title 5. IDEA 2004 reflects federal government regulations while Title 5 is specific to California. Both Title 5 and IDEA 2004 regulations detail the process, content, and focus of student IEP and ITP documents. I collected and reviewed the key provisions on transition to determine the extent of the influence of these laws on parent and teacher thinking, as well as to gather information about cultural influences that may be impacting IEP or transition goals.

### *Community Comment on Profound Disability*

While the literature contains numerous studies on the cultural construction of disability, no information exists detailing the community perspective regarding persons with profound disability (McDermott & Varenne, 1995; Ingstaad & Whyte, 1995). Because this study sought, in part, to determine the roles that cultural understandings of profound disability play in parent and teacher constructions of a student's adult life, I felt it was important to determine how the community in which this study was situated viewed profound disability. Gaining an understanding of the community's perspectives regarding profound disability would allow me to determine if the community perspective is present in parent, teacher, and institutional constructions for the students in this study. As a means for uncovering the perspective of the "common" citizen regarding persons with profound disability, I reviewed community comments posted to an online blog in response to a newspaper article about a student with profound disability. The student who was the subject of the newspaper article was a former student at the private school I direct. This student's profile is similar to that of the other students whose parents and teachers participated in this study, and he lives in the same community as the study participants. The posted community responses were coded for content which was then compared to parent, teacher, and institutional perspectives regarding students with profound disability.

### *Field Notes*

Field notes were collected to assist in providing thick description of the data and in making transparent my thinking related to data analysis. Field notes were both descriptive and reflective, providing a written record of observations as well as my thoughts and reactions throughout the data collection and reduction process. Upon the completion of each interview, after leaving the parent or teacher, I immediately recorded thoughts, impressions, questions or other data regarding the interview onto the end of each tape. I transcribed these notes along with the interviews and stored them in the participant's individual electronic folders for later review. I also collected field notes as I was transcribing tapes. I found that listening to the tapes gave rise to further questions, ideas that required investigation, and possible connections or influences between participants and artifacts. These notes were kept in a single book and were a significant part of the iterative process of data analysis.

## Data Analysis

I used a cross-case, constant-comparison, inductive analysis method for making meaning of the data and kept a journal to document my thinking throughout data analysis. Data collection and analysis overlapped as each interview was transcribed and field notes were collected. Often, a second interview would cause me to return to a first interview to add new notes or ideas that emerged throughout this process. The coding and categorization of my data was guided by my research questions and my theoretical frameworks of schema theory, ecological systems theory, and distributed cognition. Distributed cognition theory directed my focus to individual knowledge, interests and concerns and how these are shared by the social actors in my study, constrained by artifacts, and influenced by cultural values and expectations. Schema theory directed my attention to the mental models of the study participants as well as the artifacts reviewed for the study. Ecological systems theory made me alert to the rules and norms surrounding individuals with profound disabilities that shape parent, teacher, and social thinking. These theoretical frameworks, combined with my research questions, caused me to analyze my data with a narrowed purpose and as a result I focused on only the portions of the data that were pertinent to these concerns.

To assure the quality of my data, I employed several methods that are listed in Table 7.

Table 7.

**Methods Used to Assure Quality of the Data and Findings**

| Procedure | Method used |
|---|---|
| Dependability audit | Data analysis journal |
| | Collecting evidence from various sources (triangulation) |
| | Collaborative checks of data analysis procedures and findings with other professionals |
| | Focused effort to make transparent the process |

Table 7. (continued)

**Methods to Assure Quality of the Data and Findings**

| Procedure | Method Used |
|---|---|
| Credibility audit | Ongoing and intensive engagement with the data |
| | Peer debriefing |
| | Negative case analysis |
| | Triangulation |
| Confirmability audit | Description of how data is related to original sources |
| | Journal and field notes |

### *Data Reduction*

Data was analyzed using the grounded theory or constant comparative method (Mertens, 2005). This involved an iterative process of asking questions of the data in order to generate theories and to relate theories to each other. As theories emerged, I used theoretical sampling, seeking text that fit with emerging theory as well as text that disconfirmed emerging theory. Throughout this process, I continued asking questions of the data. Through the use of systematic coding procedures, I was able to identify and develop theories that explain relationships (or the absence of relationships) between teachers, parents, and institutions. Use of this methodology ensured that findings were grounded in the data collected. The coding process made use of the system developed by Glaser and Strauss (1967) for grounded theory data analysis, involving three primary steps to include open coding, axial coding, and selective coding.

### *First Level: Open Coding*

The purpose of open coding is to name and categorize the data (Glaser & Strauss, 1967). During this first step in data analysis, I used the sentence as my unit of analysis. I developed a list of codes based on the interview questions so that I could easily group teacher and parent responses by code during the second level of analysis.

I then reviewed each sentence of the transcribed interviews, as well as the documents, and applied these codes. At this level, there were a total of 21 codes applied to the data. After all relevant data was coded, I cut and pasted all similarly coded sentences into individual documents, creating separate documents for each coded category. I was careful to label sentences as “parent”, “teacher”, or “document”, and to reference individual names for later comparison. My next step was to review each of these documents and summarize as well as code the main content of the sentences. Table 8. provides an example of summaries that were drawn from a parent interview response to the question “Does anything worry you about your child’s adult life?”

Table 8.

**Example of Coded Sentence Summary (Parent Respondent)**

| Sentence | Summary |
|---|---|
| "Her physical handicaps worry me, not because they will get worse but I don't want somebody stuffing her in a wheelchair because it's easier." | PCONCERN*: Worried that caregiver will do the "easy" thing instead of the right thing in relation to physical needs. |
| "I'm just paranoid of her not having a life, of the whole young life we've worked so hard for her to have going for naught." | PCONCERN*: Worried she won't continue the lifestyle parents have provided for her. |

*Note: "P" indicates that this response is a parent response. CONCERN is the code applied to sentences indicating a worry or perceived constraint.*

*Second Level: Axial Coding*

During axial coding, connections were sought between categories of coded data. It is during this coding level that theories emerge and are verified based on patterns in the data. To locate patterns I examined frequency; searched for omissions; noted similarities and differences in the data; sought co-occurrence of ideas and corroboration between informants and documents; and looked for patterns in sequences of text (LeCompte and Schensul, 1999). Previous codes were combined and collapsed to form new category codes. During this level of coding, I compared parent to parent responses, teacher to teacher responses, and parent to teacher responses. I also compared the coded data from document reviews to parent and teacher responses.

### *Third Level: Selective Coding*

Selective coding represents the final step in the data reduction process. During selective coding, primary themes or paradigms emerge and are related to coded categories to determine if they fit and are grounded in the data. Frequently, this involved a return to first or second levels of coding as part of the iterative process. Selective coding makes meaning of the data and its relationship to the research questions and theories integral to the study. During this level of coding I generated theories related to parent and teacher constructions of profound disability; the relationship between parent/teacher thinking and IEP/ITP goals; and the roles of cultural understandings, context, and artifacts in parent, teacher, and institutional formulations of adult life for students with profound disabilities.

# CHAPTER 4: PARENT AND TEACHER CONSTRUCTS OF ADULT LIFE

The purpose of this portion of the study was to provide an overview of how parents and teachers of transition aged individuals with profound disabilities conceptualize their child/student's adult life and to determine the factors that influence these envisionments. The interview questions to which parents and teachers responded were designed to gather general information about their thoughts regarding adulthood and persons with profound disabilities as well as information specific to their child/student. The results of this portion of the study revealed that parents and teachers believe adult life is difficult for persons who have significant disabilities. Their ideas about what it means to be an adult are inconsistent with the abilities of their children/students. For many parents and teachers, this translates to a view of their child/student as "eternal children".

Parents and teachers admit they have little knowledge regarding adulthood for persons with significant disabilities and the adult service continuum. Despite this, both parents and teachers have definite ideas about the adult life they would like to see their child or student lead. The focus of parent thinking regarding their child's adult life is on happiness, security, and life quality. Teachers, on the other hand, are focused on institutionalized services and their student's ability to access and fit into these services. In order to think beyond generalities regarding their child's adult life, parents need guidance and support. The findings in this portion of the study highlight the need for training for both parents and teachers in adult services available to students with profound disabilities, the importance of understanding what influences parent and teacher thinking, and the need to provide parents with life planning supports.

## Parent and Teacher Constructions of Adulthood for Children/Students

### *Parent and Teacher Definitions of Adulthood*

When asked to define an "adult", both teachers and parents used terms implying skills and abilities that, with the exception of adults being over age 18, are likely unattainable by individuals with profound disabilities. Adults, according to the participants of this study, are independent and responsible. They work at jobs that allow them to be self supporting and they make a contribution to society. Adults understand life's priorities and have the abilities they need to make reasonable decisions. They are mentally and emotionally mature and can effectively manage the basic components of daily living.

> So to be an independent, full fledged adult I think you'd have to have all the abilities to make daily decisions that are healthy and as wise as they possibly can be.
> *Teacher Teresa*

> I guess I kinda relate adulthood to somebody who can completely make decisions on their own-rational decisions; who can support themselves and possibly family and make decisions based on "this is the most responsible thing to do."
> *Parent Sue*

Dependency on others for the most basic of needs (eating, mobility, self care) is a pervasive feature of the label "profoundly disabled" as is mental and emotional immaturity (NICHCY, 2006). Persons with profound disability typically lack an understanding of the need to conform to social norms. They have difficulty comprehending complex ideas and lack many of the necessary skills to work at jobs that pay a self supporting wage. Based on the descriptions of an "adult" provided by the participants of this study, individuals with profound disability will never be socially regarded in the same light as other "adults". Despite this, parents and teachers envisioned an adult life for their children and students that included some of the cultural markers of adulthood, working and making a contribution to society being the most frequently cited.

When thinking of adulthood in relation to students with profound disability, about half of the parents and teachers discussed how caregivers and others should behave rather than how the student/child should behave once he has reached adulthood. Teacher Jeff's thinking typifies the responses regarding how "adulthood" is often conferred on students with profound disabilities through the thinking and behavior of those who care for them:

> Although the majority of my students have limited intellectual capacity by society's standards, I still think of adulthood [for my students] as an attitude thing from the point of view of the caregivers. I think you can affect the personality and the capability of the person you are working with by the attitude you have toward them.

### *Parent Beliefs Regarding Adult Life for Persons with Significant Disabilities*

When asked what they believe adult life is like for people with profound disabilities, 75% of the parent participants either do not know anything about adult life (two parents) or had a negative opinion about life quality for this adult population (four parents). The remaining 25 % (two parents) had a positive outlook, but this was primarily because they used their own frame of reference in determining what constitutes a "good" adult life. These parents believed that, because these children are free from the stresses that non-disabled adults face, their lives are uncomplicated and therefore "happier" than the lives of most typical adults.

The remaining six parents had a negative perspective about adulthood for persons with significant disabilities. These parents viewed adult life for this population as “hard”; “sad”; “scary”; and of poor quality. They believed that their children are not understood by others in the general community and that this results in isolation, a lack of empathy, and a lack of opportunities.

> I think in fact they are pretty oblivious to the stresses and strains that us typically developing humans have and live with, although I do see that he gets anxious and nervous. But I don’t think it’s that he worries about money or worries about where his next meal is coming from. I think that they can be pretty happy.
> *Parent Paula*

> For the majority of them? I don’t think they have much quality of life, the majority, cause I think it takes a really special family to provide all those needs and a lot of times the kids go to places or have workers that really don’t connect with them emotionally and if they don’t connect emotionally, they really don’t grow either. It’s just sort of you know, feed me, wash me, wipe me, just basic. Like how we care for a plant. Do you know what I mean?
> *Parent Denise*

Parent beliefs regarding adult life for persons with significant disabilities is influenced by their avowed lack of knowledge about adult services and the worries they have regarding who will care for their child and how their child will be treated by persons outside the family. All parents in the study indicated they knew little to nothing about adult service supports and options. Their primary concern was that, when the parent dies, no one will love or care as deeply about their child as they do. This is closely tied to parent beliefs that adults are frequently warehoused and offered little or inadequate support in environments void of stimulation. Parents also worry about social isolation and the potential for their child to be the victim of physical or financial abuse. These factors combine to paint a grim mental model of the future lives of their children.

> I worry about safety.  I worry a lot a lot about the transition.  She's needed a 1:1 for most of her educational years and once she transitions into adulthood, the fear that I have is that she might need that 1:1 support and she's not gonna have it and the behaviors will escalate and we will go through a really ugly time.  That part worries me a lot. I can tell you that the whole experience has been nothing but fight for Linda.
> *Parent Blanca*

*Teacher Beliefs Regarding Adult Life for Persons with Significant Disabilities*

More teachers than parents have a negative perspective regarding adult life for persons with significant disabilities.  Of the eight teacher participants, only one thought adult life is positive for this student population while the other seven had negative beliefs that parallel those expressed by parents.  The one teacher participant who believed adults with significant disabilities have a positive life to look forward to believed this for the same reasons as the parents who expressed a positive outlook: that the student is free from worries about money, taxes, and the small and large challenges that face most adults.

> Actually, I kind of in a way envy people who have profound disabilities.  I don't see them burdened with what other people think about the because their self conscious level really isn't there, so on that aspect I feel like they have a higher quality of life than most of us do.  They are not going to sleep at night going over a list of things they didn't do and responsibilities they didn't complete.
> *Teacher Roxie*

The remaining seven teachers used terms similar to those used by parents to describe adult life for students with profound disabilities.  All of these seven teachers expressed the belief that adult life is "hard", largely due to a perception that having profound disabilities is stigmatizing and  there are limited opportunities and placements for these students across their adult lifespan.  Teachers, like parents, believed adults are often lonely and sad, and that adults with profound disabilities get overlooked and warehoused. Both parents and teachers used the term “scary” to sum up the prospect of being an adult with profound disabilities.

> Very difficult, very difficult. Because they are seen by people in society as being different… If they are profoundly disabled, it’s difficult to even take care of their own personal needs. If they are not capable of it, they always have to have another person there to take care of their own personal needs. And sometimes that can be embarrassing as an adult.
> *Teacher Luis*

Teachers are also influenced by their lack of knowledge about adult services and their concerns. Despite their education and responsibility for teaching students on the brink of adulthood and developing student IEP and ITP goals, teachers professed little knowledge about adult services and adult life for students with profound disabilities. Two of the eight teachers said they know almost nothing while the remaining six admitted knowing only a little. Teacher descriptions of adulthood for this student population were focused on “programs”, which were frequently not further defined. Those teachers who mentioned details about services talked exclusively of work programs (“sheltered workshops”) and group homes. Most teachers believed there are an inadequate number of programs for students with profound disabilities. No teachers commented on circles of support, individualized services, micro-enterprise, supported living or other new service continuums more recently available to this student population.

> I think, in reality, I’m transitioning them out of public school rather than transitioning them into adult life. I think I probably know more than the average citizen does, but probably not that much more.
> *Teacher Jeff*

Teacher concerns paralleled those expressed by parents, but differed in that they were more focused on institutional influences on adult life quality. Teachers worry that there is inadequate funding and that, without family support, the service system will warehouse adults with profound disabilities. They are concerned that negative student behaviors will preclude students from participation in many adult programs. Like parents, teachers worry about the potential for abuse and neglect. They also are concerned that, when parents can no longer advocate for their children and educational entitlements end, students will experience inadequate supports and poor life quality.

> If she doesn't have those advocates-people who are looking out for her best interests- then she could end up with the adult life I envision: bleak and waiting for her time to expire.
> *Teacher Roxie*

## Parent Descriptions of their Children and Their Child's Adult Life

### *Parent Descriptions of their Children*

> She just doesn't say anything. She's kind of just, you know, she kind of just walks around all day. It's hard to identify who she is, what makes her happy or sad. We can't really do anything but just care for her right now, and even trying something new is just futile. I mean, I don't think there's any point in thinking at the end of the month that anything's going to be different…They're the hardest people in the world to love if you don't just love them, you know? They don't give much. They're selfish.
> *Parent Patty* in response to *Tell me about your daughter*.

When asked to describe their child, all parents' initial responses fell within four primary categories: personality or positive attributes of their child; child's disability, to include the impact of the disability on the parent and the family; child preferences/likes; and child's negative or problem behaviors. A total of 75% of the parent responses to the request to “Tell me about your child” fell within these four categories. Other responses that were less frequently noted were comments about their child’s skills or skill deficits, the parent’s feelings toward the child, and the current or historical services the child has required or receives. Most parents first described their child’s personality or positive attributes using terms that were more subjective than objective. This typically included descriptions such as “loving”, “affectionate”, “a great person”, “sweet”, and “funny”.

> He’s tall and big and handsome now. His [negative] behaviors are all but gone. He still does some of the pinching and stuff but I haven’t seen him head butt in a long, long time. He’s a very affectionate person. He’s a great human being. He’s a handsome boy. I just adore him-I adore him.
> *Parent Paula*

All of the parents have attributed positive traits to their child, but for most this was not their initial way of thinking about, or describing, their child. Typically, a profile of disability was the descriptor that first emerged when parents were asked to describe their child.

When discussing their child’s disability, all parents started their talk with the moment of diagnosis and the series of experiences they had surrounding the discovery that their child has profound disabilities. Included in this discussion was parents’ struggle to locate and receive support services, both for themselves and for their child. Despite the fact that the children of the parent participants were 16-22 years old, and parents have had many years to cope with the realities of having a child with a significant disability, parents were still very focused on the early years and the impact of their child’s diagnosis. For many, this impact continues to have personal and social ramifications that they view as negative rather than positive.

> When I first had Pam, I went through a grieving. You grieve for the child you are never gonna have. And you pull yourself together and you get past it and then you start working. But some people, unfortunately, never get past the grieving. It's so sad, so sad. There is potential in everybody.
> *Parent Helen*

> You sometimes feel like there's a mountain around you. Once people see you are a special needs family, they kind of bounce off. Shock is a strong word, but sometimes that's how it feels. I think people are afraid of what to do or what not to do.
> *Parent Russel*

Child preferences and likes were also a commonly used parent descriptor of their children. Parents in this study stated that their children prefer very structured routines in familiar settings surrounded by people they know and like. Their child's day, when at home, was typically very routine from one day to the next. Children engage in a small number of preferred activities when they are not engaged in eating or self care. These varied depending on the child, but all children had activities that the parents believed bring them pleasure, and parents were not concerned about how functional or age appropriate these activities are. These activities included watching preschool programs such as Sesame Street and Dora the Explorer; rifling the pages of books; playing with strings; wandering aimlessly about the house; hearing parents make "goofy" noises (eg.clucking like a chicken); and sifting sand through their fingers. Parents described these "likes" with humor and enjoyment, and they were held forth as part of what makes their child unique and, in the eyes of the parent, loveable.

> If we ask Rob to do a chore like help me with the garbage or anything, he's always willing to do it. I mean if you can tear him away from his books. It doesn't matter what book it is-an atlas; I think Dad's physics book was out last night. He's not really reading it but he's thumbing through every single page. If there's a picture, he's looking at it. I'll laugh if he comes out with Newton's laws or something. That's Rob

> in a nutshell… When I really look at him and you get past the aggression, I know that he just wants so much to be happy and please us and just kind of fit in.
> *Parent Sue*

Their child's problem behaviors were also a primary focus of parents when thinking about, and describing, their child. This is not surprising given that six of the eight parent participants in the study have children who pose significant threats to the safety of parents and siblings. Their child's behavior limits not only the child and the range of people and activities he can safely access, but also limits the life of the parent and the rest of the family. Despite this, parents perceived of their child's behavior as more difficult for the child than the family. Parents expressed the belief that their child's problem behavior is something the child would not, under other conditions, choose to have, and parents believed they are learning from the challenges their child faces each day.

> I love her very much and she's taught me a lot of lessons in life. I think about how everything is a struggle for her, you know? Things that most people take for granted like dressing-everything seems to be a struggle. It has taught me how not to give up in life and my own challenges in life. I look at her and think everything is a struggle, and when I have a rough day I think about Linda and it helps me move on.
> *Parent Blanca*

> He does get frustrated. He has a hard time finding the words to describe what he wants and that brings out a lot of aggression; and he has hormones raging all over the place and sometimes it just surges. So sometimes you just have to watch out cause you don't know what's gonna upset him. He'll kick or hit or things like that-very vocal, very noisy. Not conversational, but trying to tell you his basic wants and needs… I think he's as frustrated with the aggression as we are.
> *Parent Sue*

### *Parent Envisionment of Child's Adult Life*

Parents were asked to describe the adult life they see, or would like to see, their child leading 15 years hence. After they gave their initial response, parents were shown a chart with nine pictures, arranged in a circular fashion, that represent the primary areas of life, including where one lives; friendships/relationships; work/volunteerism; community time/connections; religious/spiritual life; family; health/fitness; recreation/leisure; and new skills/experiences one may have as an adult (see Appendix B). Parents were invited to make additional comments if any of the categories sparked their thinking about how they envision their child's life at 35 years of age.

All parents' first responses fell exclusively within the friendship/relationships; family; and residential categories. Parents also discussed other wishes that could be defined as life quality envisionments. Parents want their children to have personal fulfillment and comfort; to be as productive and independent as possible; to be with people who love them; and to be part of life, not just an observer. Parents who have strong religious beliefs (three of eight parents) felt that their child will be healed or otherwise taken care of through God's intervention. Most parents, however, simply discussed their desire that their child has a place in the world where he is respected, happy, and loved.

> I would just like her to become part of the world, you know?
> *Parent Patty*
>
> I know that our son would be happy if there was something planned for him every day and it was relatively fun. He would be fine and happy.
> *Parent Sue*
>
> I sometimes feel there is more of Justin trapped inside that never gets to be seen. I'm hoping that I get to see more of Justin <when he is an adult>.
> *Parent Russel*

> I want to shoot for the moon even if I only hit a star.
> *Parent Helen*

Where and with whom their child will live was a primary concern for parents when thinking of their child's adult life. This life category, more than any other, was a focus of the talk of all the parents who participated in the study. Of the eight parents, six want to have their child live at home as long as possible. Only one of these six parents had a concrete plan for what will happen when he can no longer care for his child (family members have committed to care for his son). The remaining five parents hoped that someone will come forward from their families or that, over time, they will find a suitable living arrangement for their child. Two of the eight parents plan to place their child in a group home as an adult. These parents indicated a desire to continue to have their child live with them in adulthood but cited the difficulty of maintaining their child within the family home as their primary reason for considering group home placement.

> I have a lot of pressure to put Jack in a home. They [friends and family] see I have no life. I'm a highly educated real estate broker and I've had opportunity like you can't even imagine but I'm like," Sorry, Jack is the most important thing in my life." you know, and that is kind of a bummer. Not for me, but for other people…In my head I have to think positive about it [residential placement], that's where I put it, but the truth is I'm miserable and I wish that he could stay with me forever, and his behaviors weren't so severe, and I could treat him more like an adult than a baby.
> *Parent Denise*

> It's doing him a disservice to not put him in an independent place where possibly relatives, his brother, could visit him and that way he's ready for whatever happens and he knows that he's going to be taken care of…This is one of my questions- is he gonna miss us? How long will he want to be away from us and how gradual will that transition be? Sometimes I think it will break his heart to be away from us, and sometimes I don't think that at all.
> *Parent Sue*

### *Changes in Parent Thinking When Provided Support*

The families in this study did not have a concrete picture of a day to day adult life for their child. None of the parents interviewed detailed a "typical" day for their child that involved a specific list of planned activities. These parents were, instead, thinking of and wishing for "happy" lives for their children but they did not operationalize what activities, supports, and daily occupations were necessary to bring about the results they envisioned. Parents discussed the need for structured activities, but did not provide a list of what these activities entail, where they should take place, or who will provide them. Parent thinking could be characterized as idealized rather than concrete and purposeful. The terms parents used to describe their child's adult life were subjective in nature and conceptually ambiguous. This included the use of terms such as "happy", "fulfilled", and "being part of the world", "comfortable" and "productive".

When shown the picture chart containing nine life categories (Appendix B), parents became more concrete in their thinking, listing recreational and leisure activities they felt are an important part of their child's life; places and people their child would enjoy; possible jobs their child might do with support; and specific services they believe their child will need. This finding highlights the need and the benefit of offering futures planning to families. When provided with a structure that helped guide their thinking, families were able to give detailed descriptions of the adult lives they wish for their children. These descriptions can be used as a basis for writing goals and objectives that will better prepare the child to lead the adult life their families envision. It is likely that offering parents guidance in the form of futures planning prior to designing IEP and ITP and ITP objectives will result in better adult outcomes for these students.

Despite their lack of concrete plans for the day to day adult life of their children, most parents believed that the life they envision for their child is achievable, and all parents believed that their child would, if able, desire an adult life similar to what their parents have envisioned. Parents cited a decline in their health or their child's health as the primary factors that might interfere with the adult life they hope to see for their child.

*Influences on Parent Thinking About Child's Adult Life*

Parent thinking related to the adult life of their child is influenced by both internal and external factors with a greater number of parents citing internal influences (eight parents) than external influences (two parents). Table 9. lists the factors parents believe have exerted the greatest influence on their thinking regarding their child's adult life.

Table 9.

**Factors that Influence Parent Thinking Regarding Child's Adult Life**

| Internal | External |
|---|---|
| Religious beliefs | What they read |
| Personal expectations | Knowledge of child's likes/dislikes |
| Family/cultural norms | Information from tests (medical) |
| Worries/concerns | Experiences with support agencies |
| Feelings toward the child | Society's reactions to child |
| Parent's ability to cope | Comparisons to "typical" children |
| Parent belief that he/she is the best possible caregiver. | Talking with other parents/teachers |
| Belief that the system isn't trustworthy | |

When envisioning an adult life for their child, parents based their thinking on their direct, daily experiences with their child and their perceptions of his abilities, likes, and dislikes. These beliefs were influenced by concerns/worries that are grounded in experiences parents have had with community members, teachers, and other disability support organizations. Parents believe that no one will love and care for their child as they do, and that this will negatively impact their child's adult life quality. This belief often had a cultural basis originating from the parent's own upbringing or religious/spiritual convictions.

> Family are the best people to care for someone. In my family, nothing is more important than family.
> *Parent Russel*

> My daughter is my everything. She doesn't even have to say anything and I know. I just pray that I can outlive her or go home to the Lord with her, because life would be really rough for my daughter without me.
> *Parent Blanca*

Although parents did not cite it as a factor, it is likely that their stated lack of knowledge about adult services and supports also influenced what they want, and more often what they do not want, for their child as an adult. Although they have not personally experienced having their child in an institutional setting, parents fear that their children will be neglected by careproviders and offered little to no opportunity for future growth and learning. The source of these fears is not known, but may be influenced by media reports and the state of services prior to the passage of laws that regulate quality of care for adults with disabilities in licensed facilities. One parent used an analogy drawn from a movie to describe what she believed life in a group home might be like for her child.

> [People say] “You know he’s going to have to go somewhere. He can’t be with you forever” and I’m thinking like, crazy sanitarium where he’s locked in his cell every night and every one’s running around in white shirts. <u>One Flew Over the Cuckoo’s Nest</u>, that’s where they want you to put your son.
> *Parent Denise*

## Teacher Descriptions of their Student and Their Student’s Adult Life

### *Teacher Descriptions of Their Students*

When asked to describe their student, teachers’ initial responses fell within three primary categories: description of disability; negative behaviors; and skills the student either exhibits or needs to acquire. This differed from parent descriptions of the student in that personality and child preferences, while mentioned by some teachers, were not the main focus of the teachers’ talk. A full 100% of the teachers described their student based on his disability and 63% (five of eight teachers) based on student skills and negative behavior. Other descriptors used less frequently by teachers included student age, personality, physical appearance, and student preferences/likes/strengths. Positive descriptions of students were generally skill based and focused on what a student had learned during his or her time with the teacher.

Most teachers first described their student by disability, which included ability level. Their discussion of students had a more impersonal tone, with fewer emotion laden words than those used by parents. Teacher focus was not on disability label but on the resulting “level of functioning” and learning profile of the student. This focus is consistent with the teachers’ primary responsibilities for helping students acquire functional skills and appropriate social behavior.

> He understands verbal directions; he has trouble speaking in sentences. He uses one word answers and communicates what he likes or dislikes by gesturing or getting what he wants. He used to touch the kids a lot or grab them, but over the past year he's improved in keeping his hands off the other kids. He likes to play sports; listen to music- Elmo and Sesame Street. He likes to go places, but he also likes to lick his fingers a lot and other things like that.
> *Teacher Dave*

Detailed descriptions of student skills were a frequent response of teachers when asked to describe their student. The skills, or lack of skills, most often discussed were those related to daily living (eating; self care; household chores), communication abilities, and functional academics (e.g. understanding of money; recognition of own name out of a field of two-three names). Given that teachers are charged with the responsibility of helping students learn concrete concepts and behaviors, this way of thinking about the student is consistent with both teacher training and job duties.

Like parents, teachers discussed negative student behaviors when asked to describe their student. Eight of the ten students whose teachers and parents participated in this study have significant behavior problems which could cause harm to the teachers or other students, so this focus on negative behavior is consistent with teacher concerns. About half of the teachers expressed a positive belief that their student would, over time, "outgrow" or successfully reduce their problem behavior. The other half stated concerns about how these behaviors will impact student options after graduation. Teachers frequently analyzed their role in behavior support and discussed programs and strategies they were using related to student behavior.

> Sometimes he will hit us, and it's a little unpredictable so that's not fun. He also is very prompt dependent. That's an issue. Sometimes I wonder if it's more an aide issue, because

> he is such a slow processor that I think we prompt him sometimes before he gets a chance to get it out.
> *Teacher Tracy*

> He has autism and he has a lot of [difficult] behaviors. They tend to be task avoidance behaviors but they are fairly aggressive…He is fairly noncompliant, but he loves his aides who work in there, and he does have that ability to care about the people around him. I think, given time, he can grow out of a lot of this stuff.
> *Teacher Teresa*

Unlike parents, teachers did not express the idea that student behaviors are something out of the control of the student. Teachers, instead, often discussed the function the behavior serves (e.g. avoiding tasks) and details regarding the observable actions the student takes when engaging in the behavior (e.g. hitting; licking fingers). Where parents were most descriptive when discussing their discovery of their child's disability and its impact on the family, teachers were most descriptive regarding student behavior, often giving detailed accounts of incidents that had occurred years before. Despite this focus, 75% (six of eight) of the teachers ended their discussion of details about student behavior on a positive or hopeful note that included comments on student progress toward more appropriate behavior.

> He used to have severe aggression. He's been here for over seven years and he was super aggressive; he was the most aggressive kid I had ever seen at that point. I remember I had to go to the doctor the first day he started with us. We were all black and blue and bitten. He tried to keep us away from him; he wanted to be left alone. He has come a very, very long way.
> *Teacher Ingrid*

*Teacher Envisionment of Student's Adult Life*

Like the parents, teachers were asked to comment on the adult life they envision for their student 15 years after graduation. After their initial response to the question, teachers were shown the same chart that was provided to parents and were given an opportunity to further expand their comments (Appendix B). Unlike parents, teachers had little to add once shown the chart. Their comments about adult life for their student were generally holistic in nature. Teachers discussed residential life; involvement with family and friends; daily adult educational or work programs; and social and recreation activities they envisioned for their student. Using the nine category chart as a means for grouping responses, teachers' responses were spread across eight of the nine categories. The only category that was not part of the teachers' envisionment of a student's adult life was that of spirituality/religion.

Regarding students' residential life once reaching adulthood, six of the eight teachers envisioned their students living in a group home setting (75%) while two teachers, based on their knowledge of the parents' wishes, saw their student living in the family home as an adult. This is in direct opposition to parent envisionments for the same students, with 75% of parents believing their child will still live at home or with family members 15 years after graduation. Parent reasons for wanting to keep their child at home were based on their fears and concerns about treatment their children might receive in a residential setting. Teachers, however, saw a positive impact that residential placement could have on students when they reach adulthood. Teachers believed that group homes will offer students a wider circle of support, will promote independence and new skill acquisition, and will provide structure and stimulation they believe these students require across the lifespan.

> What I would like to see is her living in a group home environment. I know that the family is involved with Nancy but I also know that it is a hardship with the medical issues and these problems that she

> has. So I would like to see her in an environment that is designed to work with her and to help her through her life. Where she could be a part of some kind of community or social circle that is familiar to her, meaning with people who have disabilities as profound as she does. That she could contribute somehow and be able to be with them and live a life with them.
> *Teacher Roxie*

As with the parents, teacher beliefs about the positive benefits of residential placement were not based on an avowed knowledge of the adult service system. When questioned about their knowledge of adult services, 75% of teachers (six of eight teachers) stated they know only “a little” and the remaining 25% (two of eight teachers) stated they know “nothing” about adult services. In addition, all but one of the teachers questioned believed that adult life will be “hard”, “scary” or otherwise a negative experience for their students. This is inconsistent with the positive experiences they believe their students will have if placed in a group home setting.

Teacher thinking regarding residential placement may be based, as two teachers suggested, on their knowledge of the difficulties families have in maintaining these students in the home environment and their concerns about the families’ ability to continue to support students as parents age. Four teachers expressed the belief that parents view these students as “eternal children” and that this inhibits the student’s future potential for growth, therefore residential placement was seen as a positive step toward independence.

> I don’t have that emotional connection-I mean I care about them but I’m not their mom-I can look at what this person’s strengths are and where they need to go to have as independent a life as they possibly can. It tends to be that the parents are so concentrated on “my little boy” or “my little girl”.
> *Teacher Teresa*

> I could see her going to a group home or some sort of institution where she wouldn't be getting what she was used to and it would be different when it had to be shared with other people. She wouldn't be getting the 1:1 attention. Hopefully, she [would be] able to lead as much of an adult life as possible. She wouldn't be dependent.
> *Teacher Luis*

Most teachers (six of eight teachers) did not believe their students will work once they graduate from public school. The remaining two of eight teachers envisioned their students working in a structured setting with high levels of support from a job coach and performing tasks that are routine and viewed by the student as positive or motivating. Instead of work, most teachers discussed the types of activities they believe are important for students to participate in once they are adults. Table 10. provides a list of these activities based on the responses of the six teachers who stated they do not believe their students will work upon reaching adulthood.

Table 10.

**Teacher Envisionment of Student Activities in Adulthood**

| Name | Summary of envisionment |
|---|---|
| Teacher Teresa/Student Jack | Time with family; Friendships with familiar people; Leisure activities; Time in community; Chores that are useful at home |
| Teacher Jeff/Student Justin | Friendships with familiar people; time around non-disabled people (for stimulation it provides); attend a day program; maintain current abilities/no new skill acquisition; |

Table 10. (continued)

**Teacher Envisionment of Student Activities in Adulthood**

| Name | Summary of envisionment |
|---|---|
| | activities that will keep him involved and stimulated. |
| Teacher Ingrid/Student Aaron | Structured day at a day program; involvement in household chores; time alone; opportunity for participation in a variety of activities |
| Teacher Luis/Student Pam | Being actively involved in a range of activities; time in the community; learning daily living skills; recreational activities; socializing with peers and others |
| Teacher Roxie/Student Nancy | Time in the community; relationships with familiar people; recreation and leisure activities; no new skill acquisition; time with others who have disabilities. |
| Teacher Dave/Student Taylor | Structured day at a day program; time to socialize; recreation/leisure |

A summary of Table 10. reveals that teachers were primarily concerned that their students remain active as adults. While the definition of active involvement varied from one student to the next, teachers generally viewed it as spending time in the community;

learning or completing functional tasks that are useful in a home setting; spending time engaged in recreation/leisure activities; and doing activities that maintain current skill levels. Half of the teachers who did not believe their students will work specifically envisioned their students in a structured adult day program setting.

All but one of the teachers interviewed felt time spent with friends and family is important for their students when they reach adulthood. Five teachers specifically mentioned the importance of friendships with students who are also profoundly disabled while three teachers stressed the importance of time around people who are familiar with the student. Given the physical, behavioral, and communicative difficulties experienced by people with profound disabilities, initiating and maintaining friendships can present a particular challenge. "Friendships" were variously defined by teachers as time spent around people who are familiar with the student; time with people who will engage the student in activities; and time with people who enjoy the same activities as the student.

> One of the things in a group home, they have more friends. When they are in a program like [ABCD], they have recreation and leisure as part of the program, which is good… He is very social, so he would like to do things like that.
> *Teacher Dave*
>
> It would certainly be nice if he were involved in friends and relationships. In Justin's case a friendship would involve a certain amount of extension from another person. He's not going to get on the phone or introduce himself to new people or advocate for himself other than through his own attitude. I think that would go a long way in keeping the personality he has, because you don't mind assisting someone who is pleasant.
> *Teacher Jeff*
>
> I think his friendships will be minimal, but will definitely be the people he comes into daily contact with.
> *Teacher Teresa*

While all parents believed their children would agree with the adult life they have envisioned for them, only 37% of the teachers involved in this study (three of eight teachers) believed students would share their viewpoint regarding the student's adult life. Four of the eight teachers (50%) stated that they were sure the student would disagree with them but were unconcerned about this factor, commenting that what the student might want is not what the teacher believes is best for the student. One teacher stated he "didn't know" whether his student would agree or disagree with the teacher's vision for the student's adult life.

> I hope he's not having to earn a squeeze toy for the rest of his life. But, I think if he could, he would rather just "stim" [self stimulate] and be in his own world. He would definitely just look at his books and his globe and stumble around on the computer and stuff… I think he would just be all about what feels good to him.
> *Teacher Tracy*

> I think if Jack had his choice he'd stay at home. He loves his family. He would spend his time probably destroying a lot of things. When he gets upset, he destroys property, and I think his family loves him so much they have a hard time deciding when to step in. I don't think staying at home would be a good choice for him. I think having separation is probably very healthy for both of them. I think it will actually foster a better relationship between them because when they did see him they would be very excited to see him. They [parents] would be in a safer environment and I think it would be better for both of them. So I don't think he'd envision the same life as I do.
> *Teacher Teresa*

### *Influences on Teacher Thinking about Student's Adult Life*

When asked what influences their thinking regarding their students' adult lives teachers, like parents, listed a number of internal and external factors. Unlike parents, all teachers cited more external influences on their thinking than internal influences.

Table 11. lists the factors teachers believe have exerted the greatest influence on their thinking regarding their student's adult life.

Table 11.

**Factors that Influence Teacher Thinking Regarding Student's Adult Life**

| Internal | External |
|---|---|
| Personal/Professional experiences | Adult options available to the student |
| Student potential | Student abilities |
| Beliefs about what will help the student in adult life | Resources available to the teacher |
| Intuition/Personal Beliefs | Adult life cultural expectations |
|  | Student likes/dislikes |
| Relationship with family | Teacher's training/education |
| Concerns | Feedback from mentors/colleagues |
|  | Time available for student learning |
|  | Student progress on IEP goals |
|  | Culture/expectations of the workplace |

While both teachers and parents based their thinking about a student's adult life on their direct, daily experiences with the child as well as on their concerns or worries, teacher thinking was additionally influenced by factors that are somewhat external to their day to day knowledge of, and interactions with, their students. Teachers cited the influence of their education, their colleagues and mentors, formalized student assessment (IEP progress), workplace culture, and their limited knowledge of the existing service continuum as major factors that shape their thinking. Teachers' also use their general, personal and professional experiences with other students with profound disabilities to guide their thinking about what might be "possible" for an individual student. In addition, the current continuum of adult services is cited as a factor that influences teacher thinking, despite the fact that most teachers stated they know little or nothing about what adult services are available to their students.

Although six of the eight teachers stated that they do not maintain contact with their students after they graduate from public school, all teachers expressed a number of concerns about their students' adult lives and cited these concerns as an influence on their thinking. Teachers worry about limited funding for adult services; student behavior problems continuing into adulthood; that students will be "warehoused" and vulnerable to abuse; that students will lose skills they have acquired in school; and that student life quality will decline if they do not have families to advocate for them.

> People think there's this wonderful place for these people. There isn't a place. And when there was, it wasn't a place you wanted to be. People may not want to pay taxes to fund a good life for people who have profound disabilities. So there's my fear.
> *Teacher Jeff*

> My worry is that this rosy idea I have [about adult life for students with profound disabilities] doesn't exist for most people. They would say, what does he **do?** Then, buzz, they put him in a bed over there, check his pulse once in a while, my fear is he ends up in a hospital setting.
> *Teacher Jeff*

> [Rob's] behavior [is a concern]. It doesn't help him get along or make people like him. His staff here love him; we look beyond that at [School], but other people, if he's the only one with behavior who lives in the house, I wouldn't like for him to be the only one who doesn't get the extra cookie or things like that.

*Teacher Tracy*

## Discussion of Findings on Parent/Teacher Adult Life Envisionments

The purpose of this portion of the study was to determine how parents and teachers of transition aged individuals with profound disabilities conceptualize their child/student's adult life and to determine the factors that influence these envisionments. Based on a review of interviews, field notes, and documents (student IEP/ITP forms), four primary findings emerged. The first of these findings was that parents and teachers have different formulations of a student's adult life, and these differences in thinking were based largely on the mental models held by parents and teachers relative to what constitutes an attainable and desired life for the student. The second finding was that parents and teachers lack knowledge about adult services available to students with profound disabilities, and this lack of knowledge impacts the priorities that parents and teachers have for a student's life as an adult. The third finding was that parent and teacher thinking is influenced by different factors, with parents more influenced by internal factors and teachers by external factors. The forth and final finding of this portion of the study was that parents need support in order to formulate an adult life for their child that can be operationalized into concrete goals and objectives. Without this support, parent thinking is generally idealized as opposed to concrete and purposeful. These four findings contribute to the discussion regarding the potential causes for the poor adult outcomes experienced by students with profound disabilities.

### *Differences in Parent and Teacher Formulations of Student Adult Life*

Parents and teachers differed in their opinions regarding what constitutes an attainable life of quality for students with profound disability once they reach adulthood. These differences in opinion were primarily a result of the differing relationships that teachers and parents have with a student as well as differences in the priorities of parents and teachers . The parents in this study stated that personal fulfillment and comfort, being productive and as independent as possible, being surrounded by people who love them, and being an active participant in life were their greatest priorities for the adult lives of their children. Unlike the parents, the thinking of the teachers in this study was more focused on student participation in planned activities within institutionalized settings such as residential and adult day programs. While teachers acknowledged the importance of supportive relationships in the lives of their students once they reach adulthood, teachers were less concerned about emotional attachment than parents, viewing student relationships as primarily consisting of time spent with peers and familiar staff.

Schema theory informs us that the mental models we have regarding a given situation are often context specific and are based on individual experiences (Widmayer, 2008). The context in which parents know their child is one that is focused on providing emotional and physical support as well as a perceived responsibility for the child's safety and well-being across the lifespan. The mental models of parents would therefore direct their attention to adult outcomes involving relationships, safety, love, and personal relationships. On the other hand, the context in which teachers know the child is one that is institutionalized and has a concentration on skill acquisition and remediation in an attempt to help the child acquire abilities that will help him lead a more "normal" life. In the classroom context, teachers are aware of the financial and staffing limitations imposed on special education classrooms and the ways that these limitations impact the attainment of student goals. The mental models of teachers are grounded in the context of the institution, resulting in a primary focus on student participation in institutionalized settings once the student reaches adulthood.

Residential placement once a student reaches adulthood was a primary topic of discussion for both teachers and parents and another area in which they evidenced differences in thinking. Most of the parents in this study have decided to keep their child at home as long as possible. Their rationale for this decision was based on their fears about how their child will be treated by others outside the family and by their conviction that no one can love their child as they do. The decision to place a severely disabled young adult in a residential setting is difficult for parents, particularly when they largely view their sons and daughters as eternal children. Parents who abandon their children are considered bad parents within most societies, and there is likely a significant measure of guilt experienced by many parents when they finally choose a place their child in a home that does not contain family members or trusted friends. In most states there is a lack of residential programs for persons with profound disabilities, and the consequence of this is that parents have few choices and must often settle for a residence they do not consider ideal. With proper life planning well in advance of a child's entry into adulthood, parents would have the opportunity to explore their options and become familiar with available programs. With repeated observations over time and an opportunity to come to know residential providers, parent fears and guilt might be alleviated. When the time comes to place their child in a residence, parents who have had the advantage of planning and preparation may be able to view this transition as a positive step toward adult life rather than a tragic necessity.

Unlike the parents in this study, most of the teachers viewed residential placement as a reasonable and desirable next step for students with profound disabilities after they graduate from school. Teachers were not as concerned about students being loved as they were about students being actively involved in a range of supported activities. Teachers feared inactivity more than they feared an absence of affection in the adult lives of students with profound disabilities. Although teachers worry about student safety and life quality, these worries have not impacted teacher beliefs that moving out of the family home is often necessary in order for students to continue to move forward in life. Many of the teachers in this study stated that families "baby" their severely disabled children and expressed the belief that leaving the family home would open new opportunities for student learning and maturation. Transition teachers could play an important role in helping reduce family fears regarding residential placement of their children by helping families become more knowledgeable about residential licensing regulations, facilities, and supports. Unfortunately, the teachers in this study admitted to having little knowledge about the adult services available to individuals with profound disabilities. If teachers are to offer families the critical supports they need to prepare for their child's transition to adult life, teacher training programs and school districts must provide more education to teachers regarding the adult services available to their students after graduation.

Parents and teachers also think differently about their responsibility to act and plan in ways that represent what the student would want could he/she participate in designing goals for an adult life. When parents envisioned an adult life for their child, they stated they believed they were representing the wishes and desires of the child. Conversely, most teachers (five of eight) did not think that the adult life they envisioned for the student was one the student would want to lead. Teachers perceived the students as eternal children and, given this, believed they needed to plan an adult life that would be "best" for the student as opposed to a life the student himself would want. While parents worry about their child's safety and vulnerability, they nevertheless stated that a happy life should be based on the child's definition of happiness. Children need others to make their decisions for them, while adults have the leeway to decide what constitutes a fulfilling life. In this regard, parents more than teachers saw their children as capable of filling an adult role after graduation from special education.

The finding that parents and teachers have different mental models about what is important for students with significant disabilities once they reach adulthood is supported by the literature. Hamre-Nietupski, Nietupski, and Strathe (1992) found that friendships, residential life, and social relationships were the primary focus of parent thinking regarding the adult life of their severely disabled children, while Chambers (2004) additionally found that work was an important facet of life for some families whose children have severe disabilities. The literature also supports the finding that parents and professionals differ in their desires for the adult lives of students with moderate-severe disabilities. While parents are focused on safety, student ability to maximize their personal strengths, and students making a contribution once they reached adulthood, professionals are primarily focused on the resources available to students after graduation and the limitations imposed on a student by his disability (Cooney, 2004). Differences in parent and teacher thinking likely plays a large part in the poor outcomes experienced by students with profound disabilities. Given that teachers and parents are responsible for planning the adult life of students, and parents are the most consistent influence in the adult life of an individual with profound disabilities, lack of consensus regarding a student's adult future could negatively impact futures planning as well as the establishment of goals designed to prepare a student for adult life.

### *Parent and Teacher Lack Knowledge of Adult Services*

This portion of the study revealed that both parents and teachers lack knowledge about adult services that are available to a student after graduation from special education. Without this knowledge, parents and teachers make their decisions based on a number of internal and external factors as well as on vague worries and concerns they have developed over time. This study revealed that all of the parent participants and most of the teacher participants stated they know "almost nothing" or "nothing" about the adult service continuum for students with significant disabilities.

This lack of knowledge influences both teacher and parent mental models. Instead of making decisions based on available supports, the thinking of the parents in this study was guided by their concerns, their beliefs regarding their child's likes/dislikes, and their personally conceived ideas regarding what constitutes a life of quality. Teacher thinking was also guided by their concerns/worries as well as the influence of their workplace, colleagues, personal experiences with persons with profound disabilities and the standards in their field which focus on "normalization", independence, and active participation as the hallmarks of an adult life of quality for this population. A lack of knowledge about the services and supports available for students with profound disabilities once they reach adulthood results in parents and teachers making decisions based on insufficient information and subjective opinions. In order to have an attainable dream for these students, both parents and teachers first need to know what is possible. Parent and teacher lack of knowledge regarding adult services may account, in part, for the poor adult outcomes experienced by persons with profound disability who rely on parents and teachers to define their adult lives.

### *Influences on Parent and Teacher Thinking About Adulthood*

In addition to having different mental models regarding the desired adult life for a student with profound disabilities, parent and teacher thinking was influenced by different sources. This finding is supported both by parent and teacher statements as well as the literature which reveals that parents are influenced by personal desires and teachers by available services regarding their wishes for a child/student's adult life (Hanley-Maxwell & Collet-Klingenberg, 1995). The sources that influence parent and teacher thinking account, in part, for the differences in their envisionment for a student's adult life. In this study, parents stated that their thinking was influenced primarily by internal factors. These factors included religious beliefs, personal expectations, family/cultural norms, feelings toward the child, parent's ability to cope, and parent misgivings regarding the service system.

The influences on teacher thinking regarding a student's adult life, on the other hand, were primarily external and included teacher knowledge regarding available adult options for the student (limited), student abilities, resources available to the teacher, cultural expectations, teacher’s training/education, feedback from colleagues, time available for student learning, and student progress on IEP goals. Some influences were shared by both parents and teachers. These included cultural norms, perceptions regarding a student’s likes and abilities, and personal experiences with support agencies and community members. An understanding of what influences parent and teacher thinking is useful for designing training programs directed at maximizing the chances of student success upon reaching adulthood as well as in conceiving of strategies to promote teamwork and joint consensus between parents and teachers. This is important because there is a greater likelihood that students will experience higher levels of success after graduation if all of the members of the student’s planning team understand each other’s priorities, goals, and motivations.

### *Need for Parent Support with Life Planning*

One of the notable findings of this portion of the study was that parents were unable to voice concrete, observable and measurable goals for their child’s adult life. Without support in the form of a guide or mentor to prompt their thinking, parents’ envisionment of their child’s adult life was typically idealistic and only partially conceived. The parents in this study described their child’s adult life using terms that were subjective and difficult to measure or operationalize (e.g. “happy”; “fulfilled”). When the parents were provided with a graphic guide to prompt their thinking, their statements became more specific and easier to translate into measurable goals and objectives as well as action plans concerning their child’s adult future. Conversely, the teachers in this study did not require this guide in order to think holistically and concretely about their student’s future. This may be because one of the teacher’s primary duties is to identify goals and objectives in a range of life areas as part of the process of writing student IEP and ITP goals.

A parent’s inability to express her wishes for her child in terms that can be converted into goals and action plans may account for the finding (later in this study) that the teacher has the greatest influence on the goals and objectives established for students for their life before and after graduation. Since parents have the primary responsibility for supporting adults with profound disability across the lifespan, and teachers are making most of the decisions regarding the goals that are established for a student’s adult life, then it is likely that many of these goals will not be consistent with the life a student will actually lead after graduation. In order to maximize student success in adulthood, the transition plan and individual student goals must largely reflect the wishes of the people who will be most involved in supporting the student across the lifespan-typically the student’s parents. This finding substantiates the critical need to provide life planning support to parents prior to team meetings to design transition goals and objectives. Ensuring that family wishes are reflected in student goals will help to increase the chances that students will lead a high quality adult life.

# CHAPTER 5: FACTORS THAT INFLUENCE STUDENT GOALS

This portion of the study was designed to examine the relationship between parent and teacher expectations, institutional practices, and the goals that are developed for transition-aged students with profound disabilities. Each year that students receive special education services, Individual Education Plans (IEPs) are written. These plans contain goals and measurable objectives directed at helping the student acquire skills and abilities their interdisciplinary team has deemed important for the student. When the student turns 16, an Individualized Transition Plan (ITP) is added to the IEP. Typically, the ITP is designed by the same interdisciplinary team that designed the IEP, including family members, teacher, school administrator, the student, therapists, and other involved parties. The purpose of the ITP is to define the skills and supports a student will likely need after graduation from special education and to set goals to help the student attain desired outcomes.

Based on the findings in Chapter 4, it is evident that parents and teachers think differently regarding the adult lives of students with profound disabilities. Given that parents and teachers are part of the interdisciplinary team that designs student IEP and ITP goals, this portion of the study sought to understand the impact of parents, teachers, and other factors on the design of student goals. The findings revealed that teacher thinking was more frequently reflected in the content of IEP goals than parent thinking. In addition, a little more than a third (39%) of the IEP goals reflected the classroom routine rather than parent or teacher thinking. Teacher thinking also predominated the ITP goals that were written for students with profound disabilities. The findings presented in Chapter 5 reveal the influence of the institution on the goals and plans made for students with profound disabilities as they prepare to transition to adult life.

## Factors that Impact Student IEP Goals

### *Content of IEP Goals*

> What I have found is that my goals are not the same as the parent's. For example Aaron's mom. She insists upon goals for counting and reading and it's not gonna happen. He's 20 years old and it's not gonna happen. She doesn't want to give up on it, so we put those goals back [into the IEP]. I want to honor her, and maybe those goals can happen. It's unfortunate because it takes time away from other skills I want to teach him. She agreed to those goals, but it's the time. We only have 6 hours a day and we've got lunch and toileting and stuff like that that takes time from actual instruction. Also, staff ask why are we doing these goals when he isn't making progress?
> *Teacher Teresa*

A review of the IEP goals for seven of the eight students in this study revealed that a total of 45 goals were targeted. The IEP and ITP goals for student number eight (Justin) were not available for review. The IEP goals for the seven students were categorized under 12 primary skill areas which included behavior management; communication; self help; socialization; vocational; community use; time on task; working as part of a group; functional academics; gross motor; leisure/recreation; and independence. Table 12. provides an overview of the skills that comprise each of these 12 goal categories.

Table 12.

**Definitions of IEP Goal Categories**

| Goal Category | Definition |
|---|---|
| Self Help | grooming; toileting; hygiene; dressing |
| Functional Academics | numbers; recognizing community signs; matching; sorting; name recognition; writing/typing; identifying common items and their use; money skills |
| Social Skills | greetings; interactions with others; identifying others |
| Behavior | strategies to reduce or eliminate behavior that is dangerous to self or others, socially stimagitizing (e.g. hand flapping) or interferes with learning/daily activities |
| Independence | working without the need for teacher/aide assistance or redirection |
| Time on Task | attending to an activity for a set number of continuous minutes (3-10 on average) without engaging in off-task behavior. |
| Group Work | working in cooperation with peers or in proximity to peers without the need for continuous teacher/aide assistance |

Table 12. (continued)

**Definitions of IEP Goal Categories**

| Goal Category | Definition |
|---|---|
| Communication | expressive and receptive communication skills; usually involves pointing to pictures to communicate wants/needs; using a pre-recorded message device to communicate wants/needs; using gestures (e.g. pointing) to communicate wants/needs; increasing number of words used or understood |
| Vocational | cleaning tasks; folding; sorting; delivering items; recycling; shredding documents; packaging; making copies for which students receive a vocational training wage |
| Community Use | accessing stores, restaurants, parks, recreation areas, city/government facilities, libraries, and other community resources |
| Gross Motor | exercise; physical therapy goals; mobility goals |
| Leisure/Recreation | sports; games; hobbies; music therapy; constructive use of free time |

Table 12. shows that IEP goals for the students in this study were spread across several life categories. The focus of these IEP goals is consistent with the literature which states that transition aged students with profound disabilities are engaged learning functional rather than academic skills (OSEP, 1996; Grigal, Neubert, & Moon, 2001).

*Relationship between Parent/Teacher Thinking and IEP Goals*

Parent and teacher envisionments of a student's adult life were compared to the 12 goal categories to determine which goals were representative of parent thinking, which goals were representative of teacher thinking; which goals contained shared parent and teacher thinking; and which goals had no relationship to either parent or teacher statements about their thoughts specific to a child's life as an adult. Figure 1 shows the result of this comparison.

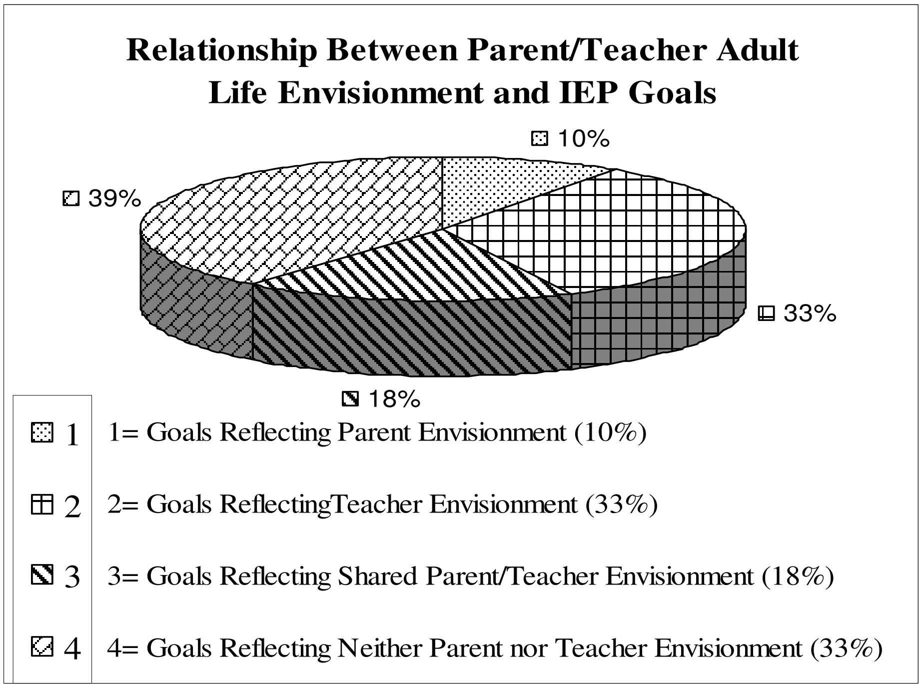

Figure 1. Relationship between IEP goals and parent/teacher envisionment of student adult life (n=45 IEP goals divided into 12 categories)

Figure 1. reveals that a little more than half (61%) of the IEP goals written for the students who participated in this study contained language that was consistent with parent and teacher envisionments of a student's adult life. Teacher envisionment of a student's adult life was more reflected in the goals that were written. For the 61% of the goals that contained parent or teacher adult life envisionment, 42% had language that echoed teacher thinking while only 19% mirrored parent thinking. This is consistent with the literature which supports the fact that there is often a mismatch between teacher and parent thinking relative to the adult lives of students with significant disabilities (Cooney, 2002; Hanley-Maxwell, Whitney-Thomas, & Pogoloff, 1995; Hanley-Maxwell & Collet-Klingengerg, 1995).

The data in Figure 1 also shows that fully 39% of the IEP goals established for the students in this study did not reflect either parent or teacher statements about their envisionments of the child's life as an adult, as reported in interviews. These IEP goals fell within the categories of self help skills; communication; time on task; working as part of a group; functional academics; and working without the need for 1:1 support. Further investigation was necessary in order to determine the factors related to the 39% of the goals labeled as not representative of parent or teacher adult life envisionments for their child/student.

### *Relationship between IEP Goals and Parent/Teacher Short-Term Goals*

In an attempt to uncover what might have influenced the 39% of the IEP goals that were not directly related to parent or teacher envisionments of a child's adult life, I conducted a second comparison, this time matching the 12 IEP goal categories and 45 IEP goals to parent/teacher statements regarding their short-term (rather than adult life) goals for students. At the time they were interviewed, a short-term goal was defined for parents and teachers as the most important goals they have for the student from the present until the time the student graduates from public school (between 1-6 years for the students in this study). Figure 2 shows the results of a comparison between IEP goal categories and parent/teacher short term goals for their child/student.

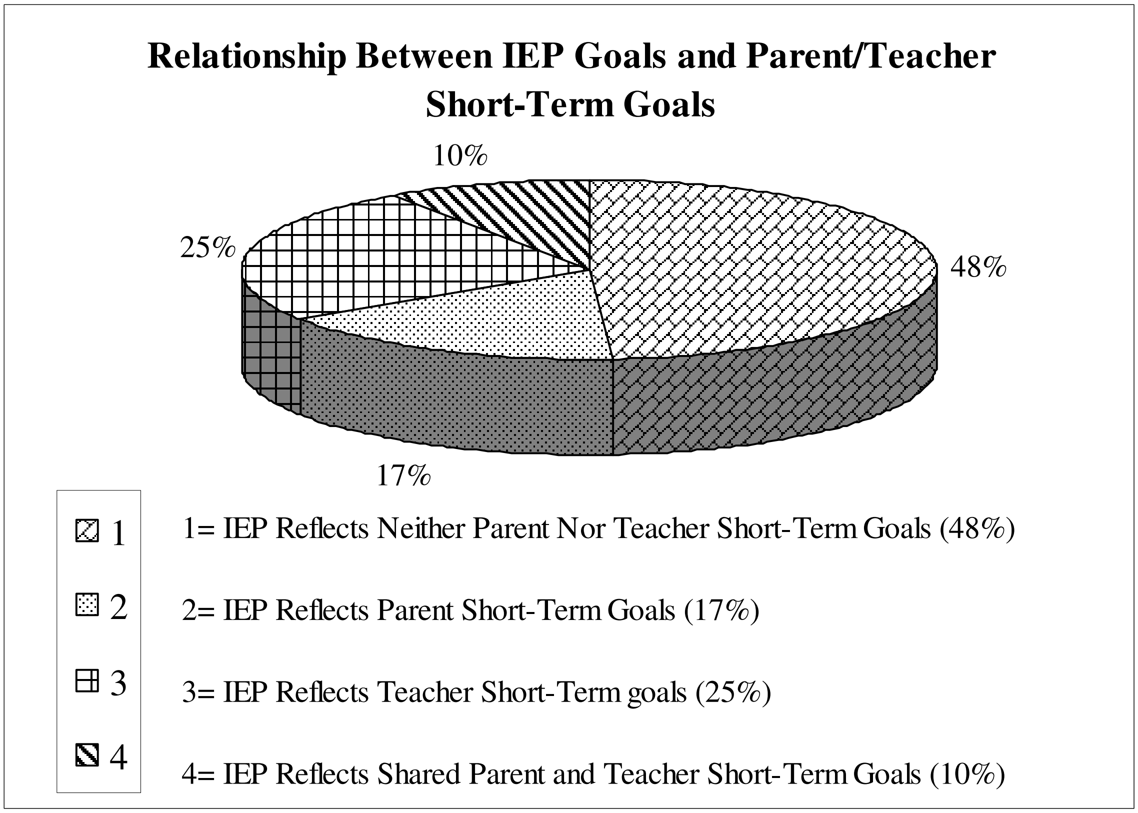

Figure 2. Relationship between IEP goals and parent/teacher short term goals for students (n=45 IEP goals divided into 12 categories)

Figure 2. reveals that parents' and teachers' short term goals for their student were contained in a little over half (51%) of students' IEP goals. As with envisionments of students' adult lives, teacher thinking was more frequently found within the content of IEP goals than parent thinking, with teacher goal priorities reflected in 35% of the goals and parent goal priorities in 21% of the goals. The 49% of the short term goals that were

not consistent either parent or teacher thinking fell within the IEP goal categories of self help; vocational; time on task; working as part of a group; leisure skills; and independence.

In a review of the literature on transition to adulthood, Hanley-Maxwell and Collet-Klingenberg (1995) noted that preferred adult outcomes for families whose children have developmental disabilities reflect personal needs and desires while the outcomes described by professionals are focused on the existing services available to adults. An examination of the findings in this portion of the study revealed that parent and teacher short term goals had even less of a relationship to IEP goals than did parent/teacher adult life envisionments, with 61% of the IEP goals consistent with parent/teacher adult life envisionment and 51% of the goals consistent with parent/teacher short term goals. This review of parent and teacher short term goals did not produce a reason why 39% of the IEP goals did not contain language that was reflective of parent or teacher interview statements regarding their priorities for their child/student. This resulted in a need to conduct further assessment which included an examination of students' daily activities in order to determine if there was a connection between activities and IEP goals.

### *Relationship between IEP Goals and Students' Daily Activities*

In a further effort to uncover the factors related to the content of the IEP goals that are written for students with profound disabilities, I examined the activities that parents and teachers reported their children/students were engaged in on a daily basis. Using the same 12 goal categories and 45 goals used for the previous two comparisons, I collated daily student activities into their corresponding goal categories. Table 13. shows the results of this comparison.

Table 13.

**Comparison between IEP Goals, School Activities, Home Activities, and School/Home Activities**

| IEP goal category | Nancy | Jack | Aaron | Pam | Rob | Linda | Taylor |
|---|---|---|---|---|---|---|---|
| Behavior | X | X | X | X | X | X | |
| | S | S | S | S | B | S | |
| Communication | X | X | | X | X | X | |
| | S | S | | S | B | S | |
| Self Help | X | | | X | | X | X |
| | S | H | | S | | S | S |
| Social Skills | | | X | | | X | |
| | | | S | | | S | |
| Vocational | | | | | X | | X |
| | | | | | S | | S |
| Community Use | X | | | | | | X |
| | S | | B | B | | B | S |
| Time on Task | X | X | X | X | | | |
| | S | S | S | S | | | |
| Group Work | | X | X | | X | X | |
| | | S | S | | S | S | |
| Functional Academics | | X | X | X | X | X | |
| | | S | S | S | S | S | |
| Gross Motor | | | X | X | X | X | |
| | | | B | B | B | S | |
| Work without 1:1 | | | X | | | | |
| | | | S | | | | |
| Leisure/Recreation | X | | | | | | |
| | S | B | B | B | B | B | H |
| Independence | X | X | X | X | X | | |
| | S | S | S | S | S | | |

X= student has a goal in this category
H= category reflects home activities
S= category reflects school activities
B= category reflects both home and school activities

Table 13 reveals that, of the 45 IEP goals written for students in this study, 40 of the goals (89%) were targeted in categories that reflected activities conducted by the school while the remaining 5 goals (11%) were targeted in categories that reflected activities conducted both at home and at school. Student focus of time at home fell largely in the leisure/recreation and community use domains. Although students communicate, exhibit problem behavior, and engage in self help skills within the home setting, these skills were not listed as related to IEP goals unless parents indicated that they “worked on” these skills in the home setting. For the purpose of this study, I defined “worked on” based on parent statements during their interview that they purposefully attempted to help their child gain new skills or modify existing skills within the home setting.

Generally, parents in this study were not engaged in helping their child learn new skills in the home environment. Instead, they typically spent their time with their special needs child involved in activities the child finds pleasurable or performing caregiver functions that are a necessary part of daily living (helping child with eating and dressing). Many parents stated that they feel they should be working on helping their child learn new skills in the home setting, but cited the difficulty of being both a teacher and a parent as a reason why their expectations of new skill acquisition are not a focus of their home life.

> Like I said before, I probably should have him do more as far as make his own bed and be more independent. And I tell myself that every day, you know, don’t hold the toothbrush. But I have to make sure he gets every single tooth, you know?
> *Parent Sue*

> Well I'm just terrible cause all I do is just baby him. (laughter) I'm sure some mothers are like "yeah we do this and this". Me, I'm just like, okay if you can imagine Jack 6' [tall], 17 [years old] sitting on my lap and hugging me. Okay this is Jack, sits on my lap on the couch and hugs me and wants to watch TV and likes to move my face like to be next to his. You know how can you give that up?
> *Parent Denise*

A comparison of IEP goals and student activities in home/school settings clearly indicated that the majority (89%) of the IEP goals of the students in this study were grounded in the activities provided within the school environment. Given this, it would follow that the IEPs of the students in this study are preparing them to be more functional within the school setting rather than the home or community setting. Although teachers can discuss the skills they believe are important for a student in adulthood, the majority of the skills that teachers are working on with their students are those which have a direct connection to the classroom. While some of these skills are likely useful at home and in the community, they are not the skills that teachers or parents have identified as important to a student's life as an adult. Although a small percentage of the IEP goals also addressed activities in the home (11%), this analysis strongly supports the notion that teacher and institutional priorities are a major focus of the IEP goals designed for students.

### *Discussion of Factors that Influence IEP Goals*

Federal legislation related to special education (IDEA 2004) specifically states that schools must provide students with disabilities "…special education and related services designed to meet their unique needs and prepare them for employment and independent living." (IDEA, 34 CFR 300.29 (1)) The results of this portion of this study revealed that, while about half (51-61%) of student IEP goals were a reflection of a student’s unique needs as assessed by parents and teachers, the remainder of the IEP goals designed for students were based on the activities and curricula that are part of their school day. The activities provided to students with profound disabilities in this study were consistent with the literature that shows that transition aged special education students participate in a range of vocational, self help, independent living, and community based skills training during their school hours (OSEP, 1996; Grigal, Neubert, & Moon ,2001; Neubert, Moon, & Grigal (2002). Zhang., Ivester, & Katsiyannis, 2005).

The notion that institutional priorities are a primary influence on student activities, and that teachers and institutional personnel have the primary voice in deciding student priorities, is not new. Mehan, Hertweck, and Meihls (1986) provided compelling evidence that schools and institutional practices have a profound impact on student identities and decisions that are made about and for students. In their book *Handicapping the Handicapped: Decision Making in Students’ Educational Careers*, these authors provided evidence that supports the findings in this study that, in a school setting, the voice of the institution overshadows the voice of the parent who, presumably, best knows the student. The finding that student IEP goals are substantively based on the priorities of the classroom and school provides critical new information for the study of special education students with significant disabilities. This single finding may account, in large part, for the poor outcomes experienced by special needs students once they reach adulthood (Hughes & Eisenman, 1996; Kohler & Feld, 2003; Phelps & Hanley-Maxwell, 1997). If a significant portion of a student’s time in special education classrooms is focused on making the student more functional within the school setting it is likely that, once out of the school setting, students will not have the skills and support systems they need to lead a successful and individually determined adult life.

## Factors That Influence Student ITP Goals

### *Student ITP Goals, Parent and Teacher Expectations, and Institutional Practices.*

IDEA legislation defines transition services as outcome oriented with a focus that promotes movement from school to post-school activities in the areas of vocational training, employment, adult education, independent living, and community participation (IDEA, 2004). The Individual Transition Plan (ITP), which is part of a student IEP once he or she reaches the age of 16, is specifically designed to assess and set goals in those areas that are designated as “post school” or pertinent to a student’s adult life. Like the IEP, the ITP for students with profound disabilities is designed by a team comprised of the student’s parent, teacher, school administrator, and any consultants or therapists who are involved with the student within the school setting. In Southern California school districts, where this study was conducted, a form is used for transition planning and goal writing (see Appendix C). This form categorizes measurable post-secondary goals into five primary domains: Instruction; Community Experiences; Employment/PostSchool Living; Daily Living Skills and/or Vocational Assessment (if appropriate); and Interagency Responsibilities/Linkages. The ITP form is designed such that a statement of needed transition services must be written for each of the five domains and activities must be designed to correspond to each statement.

Transition plans were available for seven of the eight students whose parents and teachers participated in this study. Table 14. shows the transition goals established for the seven students in each of the domains on the ITP form.

Table 14.

**Student Individual Transition Plans (ITP)**

| Student | Instruction | Community | Employment | Daily Living Skills |
|---|---|---|---|---|
| Taylor | To use communication skills in activities at home, school, and community | To be exposed to a variety of community settings with family and friends | To work at a job site as a team member | To increase his independence independence in eating, dressing, and self care |
| Linda | Increase time on task when working as part of a group | Experience a variety of community settings | Experience a variety of vocational opportunities | Decrease tantrum and refusal behaviors |
| Nancy | Decrease maladaptive behavior | Increase ability to behave appropriately In the community | Increase time on task for up to three minutes | Increase ability to take care |
| Aaron | Increase ability to work in small group settings | Display appropriate social skills in public | Decrease maladaptive behaviors | Increase time on task |

Table 14. (continued)

**Student Individual Transition Plans (ITP)**

| Student | Instruction | Community | Employment | Daily Living Skills |
|---|---|---|---|---|
| Aaron | Increase ability to work in small group settings | Display appropriate social skills while in public | Decrease problem behaviors | Increase time on task |
| Rob | Decrease escape motivated behavior | Behave appropriately in a variety of public settings | Participate in group activities without 1:1 instruction | Use picture schedule to improve independent skills in self help/ADL |
| Pam | Improve expressive communication skills | Display socially appropriate behavior | Stay on task for up to 5 minutes without prompting | Increase independent self care skills |

The ITP goals for the seven students were compared to the adult futures envisioned by both parents and teachers to determine the relationships between these goals and parent/teacher perspectives. Figure 3. shows the results of this comparison.

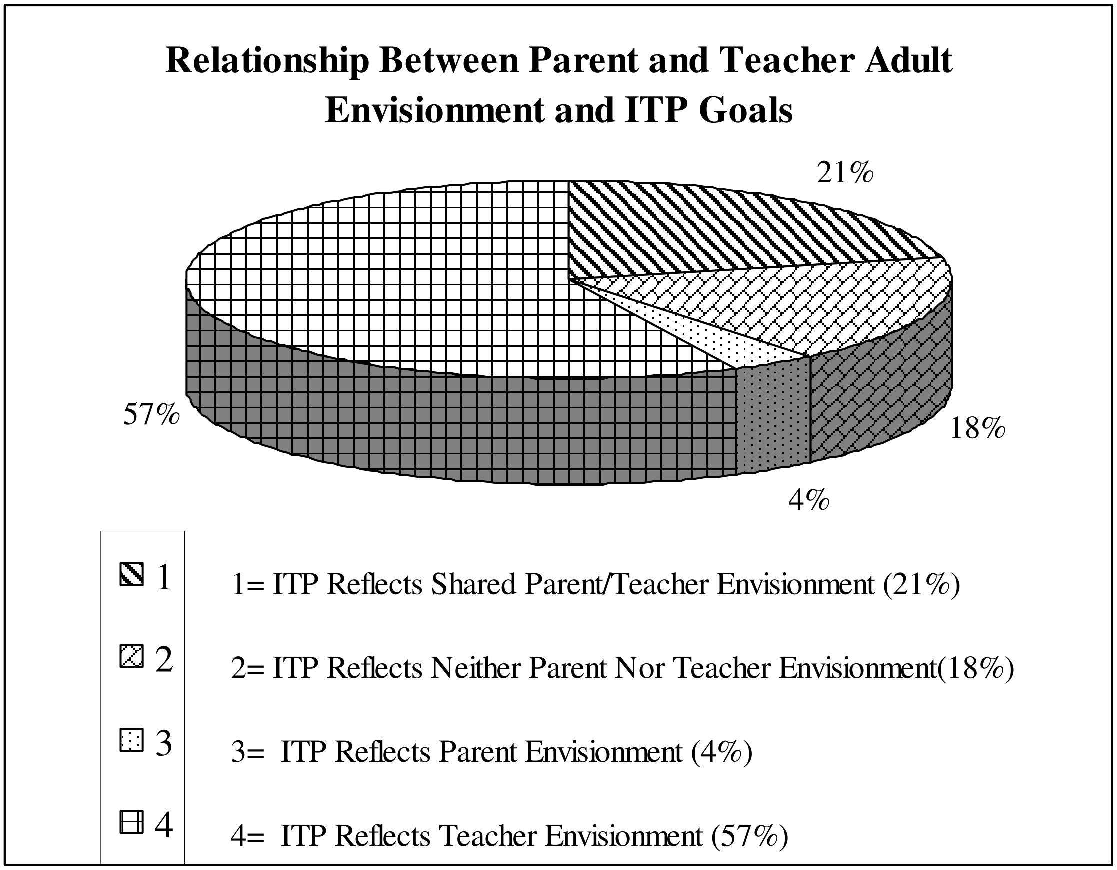

Figure 3. Relationship between ITP goals and parent/teacher adult life envisionment for students with profound disabilities (n=28 ITP goals)

A review of the results of the comparison between ITP goals and parent/teacher statements about desired adult futures for their children or students shows that a little over half (67.5%) of the 28 goals are consistent with teacher thinking (57% plus half of 21%) while a lesser percentage are consistent with parent thinking (28.5%). This supports the previous findings that revealed teacher long-term thinking has the greater influence on IEP goals that are set for the students. Since the ITP document is part of the

IEP, the connection between these two findings shows that teacher influence extends to, and predominates, all goals that are set for a transition aged student with profound disabilities. This finding does not, however, account for the 18% of the ITP goals that are not a reflection of parent or teacher envisionments of a student's adult life.

An examination of the ITP goals that do not reflect parent or teacher statements about their thinking shows that most goals (3 of 5 total) fell within the "Employment/Post School" domain, while one goal was in the "Instruction" domain and one goal in the "Daily Living Skills" domain. These goals in the "Instruction" and "Daily Living Skills" domains were both part of Student Taylor's ITP. A review of his mother's long term goals for Taylor reveals that she stated, "I don't know that he's capable of too many skills." (Interview, Parent Martha). In addition, Parent Martha's first response to the question "Tell me about the adult life you envision for Taylor when he is 35 years old" was that he would do what he wants (eat and play); live at home; and engage in preferred leisure activities. These are all skills Taylor currently displays. This insight into Parent Martha's thinking would explain why ITP goals for new learning (Instruction) or increased independence (Daily Living Skills) are not a priority for this parent.

Unlike his mother, Taylor's teacher is more focused on Taylor's skill deficits.

> He understands verbal directions; he has trouble speaking in sentences.
> He uses one word answers and communicates what he likes or dislikes
> by gesturing or getting what he wants.
> *Teacher Dave*

While Teacher Dave does not discuss Taylor's current needs in the area of daily living skills during his interview, a review of the field notes shows that Taylor requires physical assistance for eating, dressing, and toileting. Based on the information gathered from the interview and field notes, it appears that Taylor's ITP goals in the areas of Instruction and Daily Living Skills are not grounded in parent or teacher long-term thinking but instead are reflective of his teacher's focus on Taylor's skill deficits. This is consistent with the literature which confirms that the limitations imposed by an individual's disability, more than the desires of the student or family, are often the basis for professionals' decision making regarding skills of importance for transition to adulthood (Cooney, 2002).

The remaining three ITP goals that were inconsistent with parent or teacher adult envisionments for their student fell within the Employment/Post School domain for students Jack and Linda. A review of the parent interviews for these two students reveals that neither parent feels work is a priority for their child post-graduation.

> I really don't see him going into a community situation and working. He would need something where it's just really structured. Cause out in the community things happen that aren't expected. Jack does not like unexpected things. Forget it.
> *Parent Denise*

> As far as the community, because she is social and likes being around people, she likes that a lot- that she can participate. Just get her out more. I don't want her and I to feel isolated. Being able to go shopping and to the beach and things like that. As far as recreation, that's the tool that I would like to see Linda….you know going swimming, being around other kids, social times… Other than that, that covers the primary things.
> *Parent Blanca*

Even when shown a chart with vocational/volunteerism as a possible adult option, Parent Blanca makes no comment about her daughter working when she reaches adulthood.. Parent Denise believes that Jack would be unable to work because the community setting is too inconsistent for someone like her son who requires a very structured and predictable day in order to be comfortable in his environment. Like Jack's mother, Jack's teacher expresses doubt about employment as a preferred future goal for him. Linda's teacher, on the other hand, can envision Linda working in a sheltered setting .

> I don't know if vocationally Jack will reach that point where he can work in any type of facility, but I do see him being more participatory in his home life, doing more work about the house.
> *Teacher Teresa*

> What I see for Linda is working at a place like [School thrift shop] where she can greet people who come in, help at the store, and do certain little tasks and at the end of the day she cleans up her section and goes home.
> *Teacher Allegria*

A potential explanation for why vocational goals were established for these two students when their parents and one of their teachers do not believe work is a feasible option for the students' adult lives may lie in the form used to complete the ITP goal writing process. The ITP form is consistent with Nemeth, Cook, O'Connor & Klock's (2004) definition of a "cognitive artifact" in that it is an object such as a schedule, worksheet, or list that is "used to mediate collective work " ( p.728). Cognitive artifacts, and forms in particular, represent a portion of the collective wisdom of a particular domain and present it in a manner that is streamlined and concise. Nemeth et. al assert that the study of human objects is a necessary part of understanding people and their actions given that objects are a reflection of the group as an entity. Cognitive artifacts like the ITP form are created, reworked, adopted, and rejected based on changes in stakeholder and societal thinking and, given this, could be said to represent a "voice" in the ITP decision making process. It is possible that the "voice" of the ITP form, which maintains that ITP goals should be established for students in the employment domain, provides the reason why work goals would be designed for students despite the fact that their parents and teachers do not believe that employment is a viable adult outcome for the student.

### *Discussion of Factors that Influence Student ITP Goals*

The process of creating and establishing ITP goals is a group venture. By law, ITP goals should be individualized and focused around a particular student's desired adult future. The adult future of students with profound disabilities is envisioned for them by their families, teachers and, as the findings of this portion of the study revealed, the institutions that are designed to support students as they prepare for their future after graduation from special education programs. These institutions, in turn, are representative of the broader society's viewpoint regarding what constitutes "adult life" for persons within the community. The principles that underlie distributed cognition theory may assist in gaining a deeper understanding of the factors that influence the IEP and ITP goals for students with profound disabilities.

Distributed cognition theory asserts that an individual's knowledge, interests, and concerns are formed in interactions, constrained by available materials (artifacts), and influenced by cultural values and expectations. Instead of existing solely within the individual, knowledge is instead distributed across individuals (Solomon, 1993). During the process of constructing IEP and ITP goals for students with profound disabilities, the stakeholders bring with them ideas that are grounded in their experiences, expectations, and social influences. Figure 4. presents a representation of the ways in which multiple factors combine to influence thinking and decision making within a group of stakeholders when they meet to conceive and design IEP and ITP goals for a student.

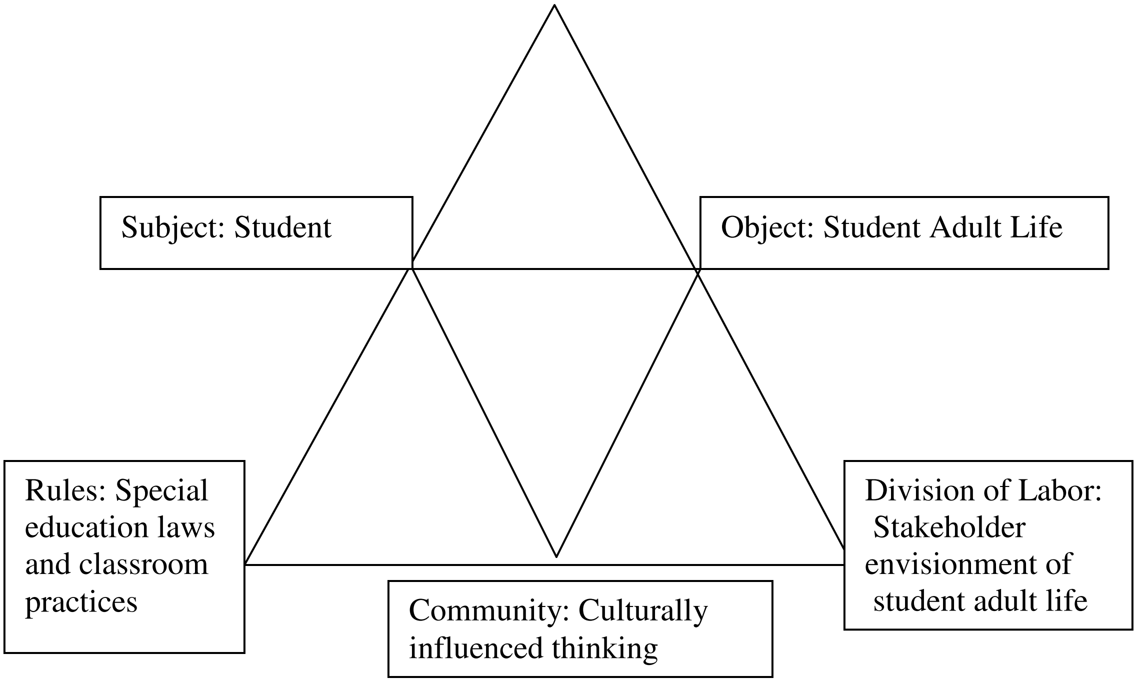

Figure 4. Graphic representation of the distribution of cognition and influences among stakeholders who design IEP and ITP goals for students with profound disabilities (Figure adapted from Cole & Engeström, 1993).

Using Figure 4. as a means for unpacking the findings of this portion of the study, we see that each stakeholder who participates in drafting IEP and ITP goals for a student with profound disabilities is influenced by similar factors (community; division of labor; rules; artifacts; their knowledge of the student; and their perspectives regarding what constitutes “adult life”). This study revealed that institutional and, by extension, teacher understandings were more frequently reflected in both IEP and ITP goals designed for students with profound disabilities. Community or cultural understandings influence, and are influenced by, the laws and artifacts that govern special education practices. When it is time to divide the labor of drafting IEP and ITP goals, the voice of the parent appears to be only a murmur. The literature shows that most students with profound disabilities will remain dependent on their families well into adulthood (Haring & Lovett, 1990) and that adult outcomes are poor for this student population (Hughes & Eisenman, 1996; Kohler & Feld, 2003; Phelps & Hanley-Maxwell, 1997). It is unlikely that adult outcomes will improve for students with profound disabilities until the envisionments and perspectives of parent stakeholders are a substantive influence within the distribution of cognition among IEP/ITP development team members.

# CHAPTER 6: CULTURAL UNDERSTANDINGS, CONTEXT, AND ARTIFACTS

The parents, teachers, and students who were a part of this study are situated in a specific context surrounded by a society that has preconceived notions regarding persons with disability and their place within that society. Special education and disabilities-related laws dictate the structure of many of the programs and supports offered to students with profound disabilities, their teachers and families and contain information about social expectations regarding adulthood and persons with disabilities. The forms used to guide special education decision-making are artifacts that have the potential to influence the thinking of stakeholders as they come together to envision and design an adult life for students with profound disabilities.

The results of this portion of the study revealed that society's understandings of persons with significant disability are often not grounded in fact or personal experience. Instead, people in the community harbor misunderstandings about persons with profound disability and, generally, have a negative perspective regarding the potential for persons with significant disabilities to make a contribution that is valued by their society. This perspective on the part of community members has had a potential influence on the thinking of both parents and teachers, who view adult life as difficult, scary, and hard for their children/students. The socio-cultural understandings that surround persons with profound disability represent a barrier to their full acceptance within their society, and this barrier confronts both parents and teachers as they attempt to envision an adult life for their child/student.

In addition to the influence of society's understandings regarding their children or students, parent and teacher thinking is impacted by the context in which they are situated. The findings in this chapter revealed that context is one of the most significant factors that influence parent and teacher envisionments of a child's adult life. Parents know the child in a context that involves familial love and support, caregiving, interdependency, and a perceived life-long responsibility to support the child with a disability. Teachers know their student in an institutionalized context, and teacher thinking is heavily influenced by the structure, rules, and practices of their schools and classrooms. When asked to envision an adult life for their child, parents are focused on replicating the home environment. They want their child to be loved, safe, happy, and accepted for who he is. Teachers, on the other hand, envision an adult life that is an extension of the school environment, with teacher thinking focused on active participation in other institutionalized settings (group homes; adult day programs), continued remediation of perceived student deficits, and the principles of normalization.

The final portion of this chapter reviews the impact that artifacts, specifically the ITP form used as a framework to plan student goals directed at adult life, may have on shaping parent and teacher thinking regarding a child or student's adult life.

The message contained in the special education laws is that adults in our society, regardless of the severity of their disability, should work; be independent both personally, socially and financially; and should be maximally integrated into their communities. These expectations are inconsistent with the abilities of most persons with profound disability. This inconsistency has the potential to result in attempts on the part of both parents and teachers to strive for adult outcomes for students and children that may be impossible to attain.

The artifact used to design goals for student adult life, the ITP form, reflects special education laws in its structure and mandates to ITP development team members. The findings of this study uncovered an inconsistency between parent thinking regarding their child's adult life, teacher thinking, and institutional perspectives. This inconsistency may be one of the primary causes of poor adult outcomes for students with profound disabilities. The participants in this study are coping with this inconsistency by ignoring the social/institutional perspective as defined in laws and represented in special education forms in favor of using their own definitions of adult life when drafting student ITP goals. As was noted earlier in this study, teacher thinking regarding a student's adult life is more consistently reflected in student IEP/ITP goals than is parent thinking. Institutional perspectives on what adult life should be like for students with profound disabilities, and the special education forms used to guide parent/teacher decision making regarding post-school adult life for students, has had little influence on the goals that the parents, teachers, and other team members involved in this study have written.

## Cultural Understandings of Persons with Profound Disability

This section of Chapter 6 will explore the role that social and cultural understandings play in parent and teacher formulations of the adult lives of students with profound disabilities. For the purposes of this study, culture is understood as defined by McDermott and Varenne (1995) with a particular focus on the expectations, rules, and perceptions of society regarding persons with profound disabilities.

> If there is anything people do naturally, it is that they live
> culturally, in groups, with goals, rules, expectations, abstractions and
> untold complexities…People use established cultural forms to define
> what they should work on, work for, in what way, and with what
> consequences…
> (McDermott & Varenne, p. 331)

The data used to uncover social expectations, rules, and perceptions included special education laws, particularly those directed at transition to adulthood for students with profound disability, and a case study in public comment regarding a student with profound disability who is part of the community in which this study was conducted. The information from these data sources was compared to parent and teacher conceptualizations of their child/student's adult life to determine if there was a relationship between parent and teacher thinking and the cultural understandings of profound disability held by the broader community.

Although the literature has addressed social and cultural perceptions of disability, information about the general public's viewpoint regarding persons with profound and multiple disabilities is noticeably absent. As a means for understanding the constructions of profound disability held by the members of the community in which this study was conducted, I chose to complete a case study of public comment regarding a student named Benny who has profound disabilities and, until recently, lived in the same community as six of the eight students whose parents and teachers participated in this study. Benny's biographical profile is very similar to that of most of the students in this study. Unlike them, Benny's parents have chosen to place him in a special school on the East Coast in the hope that it will help him reduce his significant behavioral problems. For the purposes of this study, Benny represents the "everyman" of students who have profound disabilities as well as severe behavioral disorders. An understanding of community members' perspectives regarding Benny might offer insight into their general thoughts about all persons with profound disabilities.

The findings of this portion of the study revealed that the general community has a number of misperceptions regarding persons with profound disabilities. Public misperceptions were often manifested as fear, anger, pity, and resentment toward persons like Benny. These public sentiments are a likely source of parent and teacher worries described by the participants of this study regarding the adult lives of their children and students with profound disabilities and a factor that influences the adult lives they envision for their children or students. These findings highlight the critical need for community education regarding persons with profound disabilities.

A review of special education laws, specifically IDEA 2004 and the California Code of Regulations (Title 5), disclosed the fact that in our society there is an expectation that all adults, regardless of level of disability, will work and strive to achieve personal and financial independence once they reach adulthood. This expectation is reflected in the special education artifacts used to guide parent and teacher thinking when drafting IEP and ITP goals for students with profound disability. This expectation is also inconsistent with the abilities of many adults with profound disability and with the adult life envisionments of the parents and teachers who participated in this study, and may be a significant factor in the poor adult outcomes experienced by individuals with profound disability.

# Benny: A Case Study in Public Perceptions of Profound Disability

*Background Information*

In August, 2007, a large, metropolitan newspaper in the community in which this study was conducted printed a story regarding Benny and his family and invited public opinion, which was posted on an online message board forum. The story focused on the struggle Benny and his family have undergone as a result of the severity of his behavioral and developmental needs and the high costs his California school district is paying to support Benny in a special program located in Massachusetts. Benny was described in the article as follows:

> Benny has been in therapy since he was a toddler. He can't talk and has worn diapers all his life. When he was 3, he underwent eight hours of surgery to remove a brain tumor the size of a walnut…Benny was on special diets and taken vitamin supplements, and he has been prescribed a long list of drugs over the years, such as Thorazine, Haldol, and Depakote. He also has participated in countless medical trials and endured numerous procedures. (Gao, 2007)

The article detailed the myriad services and supports the family has tried in an effort to educate Benny and control his significant behavioral problems as well as the fact that the Massachusetts program has cost his district more than $270,000 for one school year. In addition to the high cost of his placement in this residential school, there was controversy over the Massachusetts school's use of electric shock for managing Benny's aggressive and self abusive behavior. In the article, Benny's parents stated that he has improved significantly in his new placement, with his dangerous behaviors having decreased from 2,000 incidents per month to an average of 30 over the past two years. It was necessary for Benny's parents to sue the school district in order to secure payment for his placement at the Massachusetts program. His family continues to reside in California and visits him on a regular schedule.

A total of 124 public opinion responses were posted on the newspaper's message board after this article was published. These responses were used as a source of data for determining social/cultural understandings regarding persons with profound disability in the community in which this study was conducted. Of the 124 responses, 31 were eliminated as a data source due to content that was not relevant (e.g. "Doesn't anyone believe taxpayers have special needs?"). The remaining 93 responses were coded, resulting in 182 codes. These codes were then grouped under the following categories:

1. Descriptions of individuals with PD (37 coded responses)
2. Expectations of individuals with PD (13 coded responses)
3. Education of individuals with PD (22 coded responses)
4. "Problems" associated with individuals with PD (21 coded responses)
5. Potential solutions to "problems" associated with individuals with PD (15 coded responses)
6. Who is responsible for individuals with profound disabilities (PD) (54 coded responses)
7. Other (20 coded responses)

*Descriptions of Individuals with Profound Disabilities*

All of the comments regarding persons with profound disabilities posted by readers of this article viewed these individuals as objects of pity or otherwise problematic to society. Profoundly disabled children were perceived as suffering and in need of help; troubling; damaged; not educable; eternal children; and, in a limited number of comments, potentially dangerous to society. Parents who have children with profound disabilities were viewed as having had "bad luck" and were sometimes seen as victims of their child's disability.

> Then again, if we don't help this kid out now, what happens when he gets older if he didn't get any help? He possibly could be more of a danger to society if we do nothing now, maybe even hurt or injure (or worse) someone else, then what would we say?
> *Posted by Sitting on the john on 8/27/2007 at 10:04 a.m.*

> Thank God that my children are normal and healthy and that they can function without the help of an institution. I am blessed.
> *Posted by salsera1 on 8/27/2007 at 1:23 p.m.*

### *Expectations of Individuals with Profound Disabilities*

The persons who posted comments coded as "societal expectations" of persons with profound disabilities generally felt that these individuals have little they can contribute to their community. The consensus of opinion was that profoundly disabled children have little potential in life; cannot be educated; cannot function in society and, in an extreme case, don't deserve high levels of individual support at the expense of the taxpayer. In two cases, persons who posted comments stated that they believed profoundly disabled students deserve a chance at a good life and that there is reason to remain hopeful about their future ability to lead a somewhat "normal" life.

> …If you would have read the posts, you would have seen that this individual is at a three year old level at 14. There is no future in society. Only more institutions for the rest of his life. The advanced age of the parents should have called for testing of the fetus at an early stage.
> *Posted by gerwierdo on 8/27/2007 at 10:29 a.m.*

### *Education of Individuals with Profound Disabilities*

About half of those who commented on education and students with profound disabilities were parents of children with special needs. These parents consistently used a "war" metaphor to describe their experiences with the school system relative to special education services. Parents described fighting to get services; battling to help their child receive an appropriate education; and struggling against the special education service system. Some community members believed that profoundly disabled children don't belong in schools and are not educable, asserting that schools are merely taking care of this student population. Several who posted messages believed the system needs change and that schools and states shouldn't be "stuck" with paying the high costs associated with students like Benny.

> …This child-person cannot be helped according to the article. I'm sure there are many more like him. I will never see $700,000 [total cost for 2 years of Benny's Massachusetts based education] yet I have to pay for this…What happens when he turns 21? Into an institution? I have seen a child in a wheelchair with a full time nurse at a local school. This child cannot hold his head up or communicate yet is in the school?
> *Posted by sheila on 8/27/2007 at 9:01 a.m.*

*Problems Associated with Individuals with Profound Disabilities*

Many community members perceived of individuals with profound disabilities as creating a problem for society, with 61% of those who commented in this category believing that nondisabled students are suffering as a result of the funding that is being directed at special education programs in our schools. There was general agreement, among those who posted comments to this article, that there is too much money spent on special education services, with one person stating that he feels society is being "ripped off" when their tax dollars are used for serving profoundly disabled students.

> The whole thing just set me off. How do we as a society go about fixing this? The Feds have rammed this huge mandate [to serve special education students] onto the local level, folks with special needs kids hold the system hostage, and the general children's population gets left out in the cold. The percentage of funding that is spent on special education vs. the number of kids who benefit is very skewed. There are kids with their own personal sign language interpreters in the classroom, kids with their own personal aides of one kind or another in the classroom, etc.
> *Posted by vgieseke on 8/28/2007 at 5:08 p.m.*

### *Potential Solutions to Problems Associated with Individuals with Profound Disabilities*

Virtually all of the people who posted comments regarding solutions to perceived problems associated with individuals with profound disabilities advocated for either institutionalization or fetal testing (presumably to avoid the birth of individuals with profound disabilities). Of the 15 comments coded as potential solutions, seven advocated for institutionalization while six suggested fetal testing. One individual proposed that it was worthwhile to spend whatever money was necessary in order to keep others in society safe from the potentially dangerous behavior of some people who have profound disabilities. A second individual suggested removing supports of any kind.

> Wow, lot of money to throw down the toilet on someone who probably won't even be able to pick up trash for a career.
> It might be insensitive, but how much money are we going to waste on these people? Just leave the kid at home in front of a TV until he dies an early death due to his condition. As far as pulling heart strings about what parents have to endure, it isn't the responsibility of the rest of us to ease their burden. Life isn't fair; they rolled the dice of life and lost. No amount of money thrown at the problem will change this.
> *Posted by billpetterson on 8/27/2007 at 2:34 p.m.*

*Who Is Responsible for Individuals with Profound Disabilities*

A little over half (58%) of those who posted comments to the article about Benny expressed opinions about who is ultimately responsible for supporting individuals with profound disabilities. Sentiments regarding who has the ultimate responsibility for this population were split between three categories, with some people believing parents have the moral and financial responsibility for supporting their special needs children (46%); some believing society has a responsibility (28%); and the remainder believing society is not responsible (26%). Those who believed society has a responsibility toward this special needs population generally perceived this as a moral as well as a financial obligation. Those who felt society does not have a responsibility toward students with profound disabilities believed that our social priority should be on students without disabilities who are perceived as having more to contribute to the community. Most people, however, felt that parents should assume the majority of the financial costs of a child with profound disability across the lifespan as well as have the responsibility for resolving the "problems" that many citizens asserted are associated with being profoundly disabled.

> We need to end laws that mandate this. It's unfortunate that "Benny" is such a handful, but he needs to be his parent's problem, not mine. I'm being bled dry by taxes. I have my own bills to pay.
> *Posted by stidge on 8/27/2007 at 9:51 a.m.*
>
> Unless this child disappears, there will come a time where his parents will be gone from this earth and he will be alone to fend for himself. You either pay for him now to get as much help as possible, and hopefully be able to get into a supervised living situation or you pay for him later when he's in our welfare system, possibly homeless, possibly dangerous…
> *Posted by AJJay on 8/27/2007 at 10:06 a.m.*

### *Other Comments Regarding Individuals with Profound Disabilities*

Twenty of the 182 coded responses were categorized as “other comments”. These comments grouped within three primary themes: It is not possible to understand the needs of parents or profoundly disabled children unless you have personal experience with them; solutions to the “problem” presented by profoundly disabled children are the responsibility of trained professionals; and parents of children with profound disabilities need society’s help in order to care for them.

> It’s THIRD WORLD COUNTRIES that just throw these types of kids to the streets or sticks them in god awful orphanages to die a slow death. It’s pathetic that some of you have that THIRD WORLD mentality and just want to throw anyone who doesn’t meet your standards to the streets. Thank God there are decent people in this country that actually care about their fellow citizens that are physically and mentally unable to care for themselves.
> *Posted by sav on 8/27/2007 at 10:08 a.m.*

### *Discussion of Case Study*

While caution should be exercised in assuming that the persons who posted comments to the article about Benny Walker are representative of the community in which this study was conducted, their comments offer a degree of insight into how a portion of the community views persons with profound disabilities and their place within our society. The cultural understandings of profound disability expressed by those who posted comments are that people who have these disabilities are to be pitied for their lack of “normalcy” and perceived “suffering”. Profound disability was discussed in tragic terms, with many people thanking God that their own children are not profoundly disabled.

In opposition to this, research has shown that many families are able to adjust to the birth of a child with mental retardation and maintain a positive and hopeful attitude toward the future (Kearney & Griffin, 2001). Despite their worries about the adult life awaiting their children or students, the parents and teachers in this study were all able to enumerate many valued and positive attributes of their disabled family member/student. The comments of the people who posted messages in response to this article provided justification for the concerns expressed by the parents and teachers in this study. Despite this, parents and teachers have not been so influenced by negative public perceptions that they cannot still dream about a high quality adult life for their child or student.

It is possible that the diversity between community thinking, the lived experiences of parents whose children have profound disability, and the literature can be attributed to the general community's lack of knowledge about, and personal relationships with, individuals who have profound disabilities and their families. The segregation of this student population in special classrooms and state funded residential settings helps to remove them from the public eye, reducing opportunities for the general community to develop cultural understandings that persons with profound disability have something of value to offer society.

Based on this review of public opinion postings, there was little expectation that profoundly disabled individuals have much potential in life, with many people stating that this special needs population has no place within our schools. The cultural understandings of those who posted public opinion supported the idea that individuals with profound disabilities should live in segregated, institutional settings. This finding was consistent with teacher statements that living in group homes and attending adult day programs are desired adult outcomes for persons with profound disabilities but inconsistent with most parents’ determination that their children should live with family members as long as possible. Many of the public opinion postings contained strong language regarding the belief that it is the parent’s, rather than the taxpayer’s, responsibility to care for individuals with profound disability across the lifespan. While most of the parents in this study cited family norms and expectations as the reasons why they believed their child should live at home until parents can no longer care for them, it is conceivable that the sentiments of the general community may be a factor that influences parent thinking in this regard.

In general, those who posted opinions made no comments indicating a familiarity with the current, community based continuum of services for persons with profound disability and laws that have mandated deinstitutionalization. Some persons within the community were angry about the costs of supporting students with profound disabilities and believed that “normal” children are being cheated out of their educational rights as a result. It is possible that this anger and lack of knowledge on the part of some members of the general community has negatively impacted both parent and teacher thinking regarding the adult lives they envision for their children and students with profound disabilities and is a contributing factor to the reasons why parents and teachers view adult life as “hard”, “sad”, or “scary” for persons with profound disability. The fact that the community sees little potential for those with significant special needs may also limit parent and teacher thinking regarding roles that an adult with profound disabilities might occupy within their local community.

## Special Education Law and Cultural Understandings of People with Profound Disabilities

Both the state of California and the federal government have passed laws pertaining to special education services, and preparation for transition to adulthood, for students with significant disabilities. Within California, Education Code-Part 30 of the California Code of Regulations (Title 5) is the legislation that governs special education services. For the federal government, the Individuals with Disabilities Education Improvement Act of 2004 (H.R. 1350) addresses individualized education programs and educational placements for special education students. These laws can be viewed as a collective representation of society's cultural/historical understandings and expectations relative to transition education and adult life for those who have profound disabilities.

A review of federal and state special education laws disclosed the fact that, in our society, there is an expectation that adults will work, be independent, and will function as much as possible in a manner that approximates that of "normal" citizens. This expectation is inconsistent with the abilities of most persons with profound disabilities. The teachers in this study expressed opinions that supported the viewpoints contained in federal and state special education laws, particularly the perception that one of the goals of special education is the concept of normalization. Parents, on the other hand, want their child to maximize their potential and engage in activities that make them happy. They are less vested in the "normalcy" of their child's adult life than they are in their child's satisfaction with adult life.

### *California Code of Regulations (Title 5)*

Chapter 4.5, Article 2, sections 56460-56463 of the California Code of Regulations specifically addresses transition services for special education students. A close examination of this portion of the law revealed that certain beliefs and suggested actions relative to special education students are contained within the language of the law. As a means for uncovering these beliefs, the sentences that comprise the law were examined in order to unpack the social and cultural understandings that underlie the legal text. The information contained in this section of Title 5 was grouped under three primary categories: expectations of special education graduates; institutionalization of special education; and other regulations.

### *Expectations of Special Education Graduates*

> The Legislature finds and declares all of the following:
> That while the passage of the Education for All Handicapped Children Act of 1975 (Public Law 94-142) and the California Master Plan for Special Education have resulted in improved educational services for individuals with exceptional needs; this has not translated into paid employment opportunities or maximum integration into our heterogeneous communities for individuals with exceptional needs.
> *Title 5- 56460(a)*

This portion of the text that comprises Title 5 regulation states that there is a belief that passage of laws can improve education for students with special needs. This belief is grounded in historical fact in that students with severe disabilities were not able to access publicly funded education until it was mandated by law. Prior to laws being passed, parents of special needs children banded together to educate their children as best they could (ARC, 2008). This history may be an influence on the current thinking on the part of some members of the community that parents should bear the financial and lifespan support responsibility for special needs students.

This section of Title 5 regulation also states the expectation that special needs children will graduate from school and enter into paid employment as well as integration into the community. The expectation that all adults will engage in work can be problematic for individuals with profound disabilities and their parents when significant mental and/or physical limitations make paid work an unlikely option for these children after adulthood. Given that "paid worker" is a social role that is valued by our "heterogeneous communities", it may be difficult for those who have profound disabilities to achieve "maximum integration" in the devalued role of non-worker. The *expectation* of work and integration may be a factor in the poor outcomes for people with profound disability that are reflected in the literature.

> The goal of transition services is planned movement from secondary education to adult life that provides opportunities which maximize economic and social independence in the least restrictive environment for individuals with exceptional needs. Planning for transition from school to postsecondary environments should begin in the school system well before the student leaves the system.
> *Title 5-56460(e)*

Here, the Title 5 regulations move forward in defining expectations about adult life for special needs students by adding "economic independence" to the list. Given their lack of the physical and/or mental capacity to earn wages that will provide for even basic subsistence, the vast majority of persons with profound disabilities will not achieve economic independence. In light of this, the financial needs of these individuals once they reach adulthood have historically been the responsibility of either their families through trusts or other financial assistance or the general society through welfare and disability benefits. Studies examining the economic resources of adults with profound disabilities reveal that most of these individuals will rely on taxpayer dollars for their support across the lifespan (Wells, Sandefur, & Hogan, 2003; NCD, 2000; Haring & Lovett, 1990). The need to rely on taxpayer dollars for their subsistence is another factor that reinforces the cultural perception that those who have profound disabilities require institutional involvement and are unable to occupy valued adult roles within the community. A new movement in the field of services to adults with disabilities involves assisting these individuals in establishing micro-enterprises that will provide income after graduation from school. If it proves effective, this support strategy may help to improve the adult outcomes and opportunities for community acceptance for those who have profound disabilities.

### *Institutionalization of Special Education*

> That there is no formalized process that bridges the gap between the security and structure of school and the complexity of service options and resources available for individuals with exceptional needs in the adult community.
> *Title 5- 56460(b)*

The desire for a formalized process results in the need to create a defined set of procedures in order to take a particular action, in this case help a child move from school to adult life. The stated need for a formalized process reinforces the perception that institutionalization is necessary in the lives of persons with special needs. The language of this portion of the law also reinforces the idea that school is secure (safe) and structured (organized) while adult services are complex (difficult). When "secure and structured" are juxtaposed with "complex", it sets the stage for the thought that adult life might be "hard" for children with special needs. This thought was echoed by the parents and teachers in this study.

> That there is insufficient coordination between educators, adult service providers, potential employers, and families and students in order to effectively plan and implement a successful transition for students to the adult world of paid employment and social independence. That because of insufficient vocational training throughout the middle and secondary school years, and effective interagency coordination and involvement of potential employers in a planning process, the majority of options available for individuals with exceptional needs in the adult community are programs that support dependence rather than independence.
> *Title 5-56460(c)(d)*

This portion of the Title 5 regulations clearly states that a successful transition necessitates a coordination of efforts between professionals (educators; adult service providers), the community (employers) and families/students, reinforcing the idea that success requires the involvement of institutions. This institutionalized structure of special education serves to highlight the differences between “normal” students, who make their decisions about adult life primarily at the microsystem level (self and family), and special needs students who are perceived to require involvement from the macrosystem level of society (school and community) (Bronfenbrenner, 1979). This section of the legislation again stresses the expectation that “adult” means paid employment while adding the expectation that it also means “social independence”. The law further implies that independence is preferable to dependence. Persons with profound disability are, by virtue of their significant developmental needs, destined to be interdependent across their lifespan. The idea that adults must be independent reinforces the perception that those with profound disabilities will remain eternal children, incapable of being considered as adults within their communities.

### *Other Regulations*

The remainder of the Title 5 legislation related to transition to adulthood for students with disabilities (sections 56461-56463) defines the services that will be made available by the state to support teachers, students, and parents in facilitating special needs student transition to adult life. This includes the development of materials, curriculum, and handbooks for teacher and parent training; defining the roles of various agencies in the transition process; establishment of model transition programs; development of work skills and other training programs; and the collection of data on program efficacy. In essence, this portion of the Title 5 legislation defines the "formalized process" set forth in section 56460(b).

### *Individuals with Disabilities Education Improvement Act of 2004 (H.R. 1350)*

The Individuals with Disabilities Education Improvement Act (IDEA) was enacted to ensure that children with disabilities have access to a free and "appropriate" public education. The language contained in this legislation, like that in the California Education Code-Title 5, provides insight into social and cultural understandings regarding persons with significant disability. Specific to transition aged students with disabilities, Sections 601 and 602 of IDEA address the purposes of special education services and the definitions of transition services as well as individual education programs for those who have special needs. McDermott and Varenne's ( 1995) definition of culture as the goals, rules, and expectations that define what people should "work on and work for" was used as a guide for examining the cultural and historical understandings within the text of IDEA 2004. (p. 331). The information in this portion of

IDEA 2004 was grouped under two categories: expectations of special education graduates and expectations of special education planning teams.

### *Expectations of Special Education Graduates*

> The purposes of this title are (1)(A) to ensure that all children with disabilities have available to them a free and appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living.
> *H.R. 1350, Section 601 (d)(1)(A)*

The language within this section of IDEA implies that, in order to be appropriate, education for special needs students should prepare them for further education, employment and independent living once they reach adulthood. As was noted previously in the review of California special education law, this expectation is inconsistent with the limitations that their disability imposes on students who are profoundly disabled. These students, while certainly able to benefit from education across their lifespan, will likely not engage in employment to the degree that their earnings will make them self sufficient and will be unable to live independent of assistance. The expectation that special needs individuals will, someday, be independent workers creates a tension for parents and teachers who are charged with conceptualizing and planning for adult life for those who have profound disabilities. It is possible that, in an effort to meet these cultural expectations, the focus of student IEP and ITP goals will be inconsistent with the abilities and interests of children with profound disabilities and their families. If this is the case, we are preparing these students for a life they will likely not lead, resulting in perceived poor outcomes due to the mismatch between social expectations and students' lived lives once adulthood is reached.

> The term “transition services” means a coordinated set of activities
> for a child with a disability that- (A) is designed to be within a
> results-oriented process, that is focused on improving the
> academic and functional achievement of the child with a
> disability to facilitate the child’s movement from school to post-school activities, including post-secondary education, vocational
> education, integrated employment (including supported
> employment), continuing and adult education, adult services,
> independent living, or community participation.
> H.R. 1350, Section 602 (34)(A)

Within this portion of the law, there is a clearly stated expectation that delivering transition services to special needs students will yield “results” and “improvement” for the student in several culturally determined areas of life (employment, education, adult services, independent living, and community participation). Improvement requires a change from the status quo. If the social expectation is that individuals with profound disability will change in a substantive way such that they are viewed as successful in a range of areas of life, an inability to evidence this change could be perceived as “failure” by those who hold such expectations. The literature that details poor outcomes for students with profound disabilities may, instead, be reporting on these students’ failure to meet social expectations regarding the “results” expected from those who have reached adulthood.

### *Expectations of Special Education Planning Teams*

> [The term “transition services” means a coordinated set of activities
> for a child with a disability that] (B) is based on the individual child’s
> strengths, preferences, and interests; and (C) includes instruction,
> related services, community experiences; the development of
> employment other post-school living objectives, and when appropriate,
> acquisition of daily living skills and functional vocational evaluation.
> *H.R. 1350-Section 602 (34)(B)(C)*

An understanding of the strengths, interests, and preferences of students with profound disabilities is typically based on the perceptions of those who know them best, to include the understandings held by teachers and family members. The literature on this student population reveals that parents and teachers often have divergent viewpoints regarding the needs, abilities, and potential of individuals with profound disabilities (Cooney, 2002). The result of divergent viewpoints on the part of parents and teachers could be that the instruction, related experiences, and community experiences provided to children with profound disabilities may be inconsistent with either parent or teacher perceptions. This inconsistency, much like social expectations that people with profound disabilities will work and become independent, may be a factor in the perceived poor adult outcomes for this student population.

### *Discussion of Special Education Laws*

The message contained in the special education laws reviewed in this section is that adults in our society, regardless of the severity of their disability, should work; be independent both personally, socially and financially; and should be maximally integrated into their communities. A failure on the part of an individual with profound disabilities to meet these expectations may serve to further reinforce social perceptions that those who have these disabilities are unable to make a contribution of value to humanity.

The laws related to educating and preparing special needs students for the transition to adult life send a clear message regarding society's expectations of these students once they reach adulthood. These expectations center on the need to work and be financially and personally independent. In addition, the laws reflect the perception that special needs students require an extensive system of institutional supports in order to achieve desired adult outcomes. These laws relate to the concept of “normalization” which asserts that persons with mental retardation should strive to lead lives that approximate, as closely as possible, the lives led by the general society. Failure to meet these social expectations may result in devaluation of special needs individuals. This devaluation of people with profound disabilities has been a historical fact as evidenced by the segregation, mistreatment, and institutionalization this population has suffered (Blatt, 1974).

While the purpose of state and federal special education law is, in part, to correct the wrongs done to persons with significant disabilities, the language of the laws continues to send a message that society expects persons with profound disability to meet a set of social expectations that may be outside of the ability of many of those who are profoundly disabled. Although substantial progress has been made in recent decades regarding making a place within our community for persons with significant disabilities, their devaluation will likely continue until the general society is able to accept those with profound disabilities as valuable in their own right.

### *Relationship between Cultural Understandings and Parent and Teacher Envisionments of Student Adult Life*

An examination of public laws directed at transition to adulthood for students with disabilities and of a case study of public opinion regarding a student with profound disabilities provides insight into the social/cultural understandings and expectations of individuals with profound disabilities. The results of this examination were compared to parent and teacher envisionments of the adult life of their child/student with profound disabilities to determine if social/cultural constructions of this student population were a factor in parent and teacher thinking. Table 15. provides a summary of parent, teacher, and cultural expectations of individuals with profound disability once they reach adulthood as revealed in the data sources used for this study. The parent and teacher summaries in Table 15. are representative of the statements of the majority of the respondents and do not include conceptualizations expressed by participants who were in the minority.

Table 15.

**Comparison of Parent, Teacher, and Social/Cultural Conceptions of Adult Life for Students with Profound Disabilities**

| Parent conceptions | Teacher conceptions | Social/cultural conceptions |
|---|---|---|
| Adult life will be hard; scary ; of poor quality for their children; parents know what is best for their child | Adult life will be difficult or negative due to stigmatization; lack of skills; inadequate programs | Adult service system is complex; preparation for adult life requires involvement from institutions |
| Child will have personal fulfillment and be involved in “structured” activities (not otherwise defined) | Students will be actively involved in functional tasks; spend time in the community, engage in leisure activities | Adults will work and live independently within the community |

Table 15. (continued)

**Comparison of Parent, Teacher, and Social/Cultural Conceptions of Adult Life for Students with Profound Disabilities**

| Parent Conceptions | Teacher Conceptions | Social/Cultural Conceptions |
|---|---|---|
| Child will live with family or loved one | Student will live in a community based residential setting | Adults will be financially, personally, and socially independent or institutionalized in segregated settings |
| Child will not work as an adult | Student will not work as an adult | Adults work in independent or supported settings in the community |
| Child will have friendships/relationships with people who care about them | Student will have opportunities to spend time with friends and family or people familiar with the student | Not reflected in data reviewed. |
| Child will be part of life, not an observer | Student will attend a structured adult day program | Adults will achieve maximum integration in our communities; people with profound disabilities have little to offer society |

Analysis of the comparison between parent, teacher, and social/cultural perceptions regarding adult life for individuals with significant disabilities reveals several discrepancies. While families are focused on “life quality” pastimes that will result in personal fulfillment for their child, teacher focus is on active engagement in structured activities conducted within adult service settings. Both parent and teacher perspectives are in direct opposition to social/cultural viewpoints which assert that adults should be independent and self sufficient. Although most parents and teachers in this study believed their child/student will not work after graduation from publicly funded education, the community conception of adulthood is that all adults work and are financially self supporting.

Friendships and relationships with family members, peers, and those who know the student with profound disabilities are a primary focus of parent and teacher expectations for a student’s life as an adult. The general public, and the laws drafted to formulate educational supports and strategies for transition to adulthood, do not indicate an understanding of the importance of social relationships on individual life quality for students with significant disabilities. While parents want their adult children to lead a valued life within the general community, many people within that community feel that persons with profound disability have little to offer society. Teachers believe that adults with profound disabilities will require structured, adult day services in order to participate within their communities, and social/cultural perspectives concur with this viewpoint by institutionalizing the system of adult supports. The result of this is that, rather than leading individually determined lives with the support of family members and other loved ones, persons with significant disability will typically spend their lifespan in institutionalized settings that have rules and supports based on sociocultural norms and ideals.

Although the laws designed to educate and support students with disabilities use language that states adults should work and live independently, the system of supports for adults with significant disabilities has not historically promoted independence (Zhang, Ivester, & Katsiyannis, 2005). Instead, current adult services rely on a bevy of professionals and paraprofessionals, curricula and intervention strategies to provide adult supports to persons with profound disabilities, perpetuating the institutionalization of this population. Within the last decade, several states have made self determination and individualized supports available to adults with significant disabilities. This new model seeks to replace institutionalized service systems with funding that will allow individuals to design and lead lives of their own choosing (Kennedy, 1996). It remains to be seen whether this new approach to supports for individuals with profound disabilities leads to the happy and fulfilling lives their families so fervently hope will characterize adulthood for their children.

## Context and Parent/Teacher Formulations of Student Adult Life

Transition aged children with profound disabilities are typically educated within institutionalized settings both before and after their graduation from publicly funded special education. Part of the institutional process involves labeling students as a method for determining the types of curricula and supports they will need in order to achieve goals and show progress within the educational setting. While many professionals may view labels as a necessary means of providing the best possible education for students with disabilities, these labels can also serve to limit the expectations and potential of those who are labeled (Lovett, 1996). Being one who is labeled can be viewed as part of the context in which an individual with significant disabilities is situated.

Context also involves the setting, actions, and people within the environment of a person with profound disabilities. Gleason (1993) extends the definition of context to include "the ongoing set of relationships in an interaction which makes up an event….and the set of explicit and implicit conditions and relations which influence the course of the interaction." (p. 165) Viewed from this perspective, the activities in which students with profound disabilities are involved, the actions and expectations of the people who surround them, and the goals that are set for these students are part of the context in which they are situated. For the purposes of this study, an understanding of the influence of context on the parent and teacher envisionments of a student's adult life will be gained through a review of data collected from diagnostic tools used to label this student population and a review of the goals and activities provided to students with profound disability in the home and school setting.

This portion of the study revealed that context plays a significant role in parent and teacher formulations of a student's adult life. When discussing a child's adult life, both the parents and teachers in this study sought to extend the context in which they know the child. Parents were intent on replicating the home environment for their children when they become adults and on assuring that their child will be loved, safe, and have opportunities to engage in activities he/she enjoys. Teachers, on the other hand, were most concerned about the activities that are part of the school environment and assuring that students have access to a wide range of supervised and structured activities when they reach adulthood. Teachers, more than parents, were influenced by student labels and institutional formulations of disability. The focus of the teachers in this study, when asked to describe their student, was primarily on student level of functioning, skills and skill deficits. Parents were less concerned with labels and more focused on student strengths.

### *Definitions of Intellectual Disability Used to Label Individuals*

#### *American Association of Mental Retardation (2002) Definitions*

The American Association of Mental Retardation (AAMR) defines mental retardation as a significant limitation in intellectual as well as behavioral functioning that originates before the age of 18 (AAMR, 2002). When applying the label of "mental retardation" to an individual, five assumptions are cited as critical:

> 1. Limitations in present functioning must be considered within the context of community environments typical of the individual's age peers and culture.
> 2. Valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor and behavioral factors.
> 3. Within an individual, limitations often co-exist with strengths.
> 4. An important purpose of describing limitations is to develop a profile of needed supports.
> 5. With appropriate personalized supports over a sustained period, the life functioning of the person with mental retardation will generally improve.
>
> *Pomona Project, p. 2*

An examination of the AAMR criteria for applying the label of mentally retarded to an individual reveals that the context within which the individual lives plays a role in deciding whether his/her current functioning is limited. While some people when placed in a different context may not be viewed as mentally retarded, this is not the case for those who have profound disabilities. Given this, one could expect that persons with a "profoundly disabled" label will be viewed as limited within the context of the general society of nondisabled persons. The AAMR critical assumptions imply that it is necessary to understand a person's limitations in order to decide what types of supports the individual needs in life. While acknowledging that limitations often co-exist with strengths, limitations are the focus of the AAMR definition.

The AAMR definition also states that the provision of personalized supports over time should yield "improvement" or change for the better for the person receiving supports. An individual with a label of profound disability who fails to "improve" may be viewed by the general public as unworthy of continued support. In addition, within the AAMR labeling system, there is the implication that persons with mental retardation *should* be labeled so society can offer them supports to help *promote* a change from who they essentially are to someone society would prefer them to be. The idea that persons with profound disability should be changed speaks to the devalued role they currently hold within society and the difficulty they will likely have in finding a place within the society. It may be that the current focus on work and independence for persons with disabilities is an attempt to find a socially valued role that these individuals can occupy, thereby promoting their intrinsic worth to their society.

### *DSM IV Diagnostic Criteria for Mental Retardation*

The Diagnostic and Statistics Manual (DSM) is the artifact used by the American Psychiatric Association to label an individual as mentally retarded. According to the DSM, a person is labeled mentally retarded if, prior to the age of 18, he/she possesses:

> A. Significantly sub average intellectual functioning; an IQ of approximately 70 or below on an individually administered IQ test (for infants, a clinical judgment of significantly

> sub average intellectual functioning)
>
> B. Concurrent deficits or impairments in present adaptive functioning (i.e. the person's effectiveness in meeting the standards expected for his or her age by his or her own cultural group) in at least two of the following areas: communication; self-care; home living; social/interpersonal skills; use of community resources; self direction; functional academic skills; work, leisure, health and safety.
> *Pomona Project, p. 2*

The DSM diagnostic criteria have a primary focus on limitations and deficits. The labeling technique employed by those who use the DSM as their standard assigns mental retardation to those individuals who score below a certain level on a standardized test. In this way, "not normal" people can be sorted into a separate category from those who are viewed as "normal". In addition to a test score, individuals must fail to meet 2 prescribed standards of effectiveness in the way they speak, live, socialize, negotiate their community, work, recreate, or direct their lives. The general community, therefore, would expect that a person labeled mentally retarded using the DSM criteria will be less intelligent and less capable in negotiating daily life than people who do not have this label. This promotes the expectation that people with this label will require education and residential placements that are different from those accessed by people without this label, reinforcing the need for "special" programs, supports, activities, and other institutional contexts.

### *International Statistical Classification of Diseases and Related Health Problems (ICD 10)*

The World Health Organization, which developed the ICD 10, defines intellectual disability as falling within four primary classifications, ranging from mild to profound. This organization's label for profound intellectual disability states:

> Profound intellectual disability: Severely limited understanding; Immobility or restricted mobility; Incontinence: requires constant supervision; IQ less than 20; usually organic etiology.
> *Pomona Group, p. 3*

Similar to the DSM criteria, the ICD 10 focuses on limitations and standardized test scores to identify persons as profoundly intellectually disabled. The expectations of those without a disability label, when confronted with a person labeled "profoundly disabled" according to the ICD 10, would be that the individual could not be left alone; will likely not understand what is happening around them; may require diapers regardless of age; and will likely always have the label because it is part of their physical make up (organic etiology). In any given context, those without disabilities would be predisposed to focus on the limitations of the labeled individual and to structure the environment based on these perceived limitations. The focus on limitations has historically resulted in people with profound disabilities being deprived of opportunities to be a part of classrooms and communities typically inhabited by "normal" people.

### *Discussion of Context and Disability Labels*

Having the label of "intellectually disabled" is part of the context that surrounds those who have profound disability. This label, whether conferred using AAMR, DSM, or ICD 10 criteria, focuses the attention of others on the limitations of the person who has the label. This focus on limitations creates a perception that "normal" settings and ways of learning and living will not be suitable for those with intellectual disability. As a result, society has created a continuum of segregated and institutionalized services for this population. The culturally accepted belief that people labeled as "not normal" need separate and specially configured services may have an influence on what parents and teachers believe is feasible for their children and students with profound disabilities once they reach adulthood. At worst, parents and teachers will fail to consider life options for people with profound disabilities that fall outside of traditional, institutional settings. A belief that only “special” systems can support an adult with significant disabilities may serve to limit the opportunities that are afforded to this population.

The alternatives to labeling a person involve individualized life planning strategies. Individuals who, for whatever reason, are unable to function successfully within a school, home, or community setting would be the subjects of the life plan. Using a life planning strategy rather than a labeling strategy, persons who are involved in the life of the individual would come together to discuss goals and design action plans to help achieve goals. In a special education setting, these action plans would become IEP and ITP goals and the teacher would be part of the team that supports the student in meeting his or her goals. Outside of the special education setting, life plans and action plans could help individuals, their families, and other stakeholders stay focused on what is most important to the life quality of the individual. The development of life plans and related action plans could be accomplished without the need for disability labels and with the support of a single trained mentor or life coach. Using a life planning approach to support individuals currently labeled with mental retardation could significantly reduce the need for a range of institutionalized services and, as a result, allow more funding to flow directly to the individual who is the subject of the life plan. It is also likely that increased funding and highly individualized life planning supports would improve outcomes for individuals who currently have disability labels.

### *Context and Classrooms for Students with Profound Disability*

A review of the literature on the structure of transition programs for students with significant disabilities reveals that students placed in these classrooms are typically not fully integrated with nondisabled students (Zhang., Ivester, & Katsiyannis, 2005; Neubert, Moon, & Grigal , 2002; Grigal, Neubert, & Moon, 2001). Instead, students with profound disabilities are usually placed in a Special Day Class with others who are also labeled as disabled and are taught by a certified special education teacher and supported by special education classroom aides. The focus of instruction in most special education transition classrooms is on the acquisition of vocational skills; functional living skills; self help skills; and community use. In addition to the teacher and classroom aides, most transition classrooms are also supported by a transition specialist, designated school administrator, or program specialist. These persons, in addition to the student and family, typically comprise the team of people who design student IEP and ITP goals.

The classrooms attended by the students whose parents and teachers participated in this study are very similar to those reviewed in the literature. Six of the eight students were in a segregated, private, special education school and the remaining two students attended class on an integrated public school campus but were located in a segregated special day classroom. There was one special education teacher for every 10-12 students, regardless of school. In the private school, each student has his or her own paraprofessional aide who supported them across the school day in all activities. The two students in the public school classroom had access to aide support that was shared across 2-3 students. All schools provided students a wide range of other supports provided by professional level staff, to include access to behavior specialists; speech/occupational/physical therapists; psychologists; and school administrators.

The activities of the students whose parents and teachers participated in this study revolved around their individual education program (IEP) and individual transition program (ITP) goals as well as other activities provided by the schools in the areas of self help skills; community access; vocational training; social skills; leisure/recreation skills; and independent living skills. As was noted elsewhere in this study, approximately 2/3 of the activities the students engaged in during their school day were a reflection of teacher or institutional formulations. The context in which these students are educated was one that supported the notion that “special” students need “special’ teachers in “special” classrooms following a “special” curriculum. Teachers in these settings were fully aware of the disability labels of their students, and the goals they set for their students were focused on student limitations or “needs” and on remediation. Within the classroom context, teachers in this study perceived their responsibility as one in which they are charged with keeping the student safe and assisting students in meeting goals and acquiring new skills that have been formulated by the student’s interdisciplinary team.

The context of the classrooms of the students whose parents and teachers participated in this study is consistent with an institutional perspective regarding the needs and structure of special education services. Several studies have shown that the current institutionalized structure for educating students with significant disabilities produces poor adult outcomes (Wells, Sandefur, & Hogan, 2003; NCD, 2000; Gajar, Goodman, & McAfee, 1993; Haring & Lovett, 1990). An alternative to the current segregated and institutionalized special education settings involves mainstreaming students with disabilities by placing them in regular education classrooms with extra supports, as needed. While mainstreaming has been a successful strategy for many special needs students, it is not feasible for the students whose parents and teachers were involved in this study due to the aggressive and abusive nature of the students' problem behaviors. An alternative for students with significant behaviors would be to provide high levels of short-term behavioral support using research-based intervention strategies. When student behaviors have been reduced to safe levels, or eliminated, students could then be mainstreamed into regular education classrooms.

### *Context and Home Settings for Students with Profound Disability*

All of the students whose parents and teachers participated in this study live in their family home and have siblings without disabilities who also reside in the home. While the literature does not describe the typical activities and supports individuals with profound disabilities access in their family homes, the parents who participated in this study provided this information. In summary, the students with profound disability who were the focus of this study spend their time away from school engaged in a range of recreational, leisure, and family activities. Parents reported that students spend time watching t.v. or videos; engaging in preferred, often self stimulatory behavior (rifling the pages of books; rocking; playing with strings; etc.); joining the family for meals or outings; playing ball, swimming, or other recreational activities; going to community or family functions; and spending time socializing with family members or family friends. Parents reported that their children spend social time exclusively with immediate or extended family, or with paid workers, some of whom are viewed by parents as extended members of the family.

Most (63%) of the parents in this study were not focused on teaching their child new skills, although several parents expressed that they felt this is something they probably should be doing. Three of the eight parents stated that they try to work on communication and appropriate behavior in the home setting. The home setting, as described by parents, is a context that is child centered and supportive of individual interests and needs. All of the parents in this study indicated that they have modified their lifestyles to accommodate the special needs of their children with disabilities. When describing their child, parents first discussed the impact of learning their child had a disability and the nature of their child's disability, but did not focus on their child's label to the degree observed when teachers describe their students.

While parents considered the other IEP team members a source of support, they do not reproduce the institutional, classroom activities in their home settings. Their children are not segregated from the rest of the family, but are instead perceived as an important part of the family unit. All of the parents in this study discussed their affection for their children and their desire that their children lead happy and fulfilling lives as adults. Parent thinking was not primarily focused on their child's limitations or a desire to change their children. The exception to this was a wish on the part of parents that their children's dangerous behavior would decrease. Parents described a happy life for their child as the opportunity to engage in preferred activities; spend time and live with people who care for them; receive the personal supports they need in order to be safe and healthy; and have a wide range of social and community based experiences. This desire is similar to that of other parents of children with significant disabilities (Chambers, 2004; Cooney, 2002; Hamre-Nietupski, Nietupski, & Strathe, 1992).

### *Discussion: The Role of Context in Parent and Teacher Formulations of Adult Life for Individuals with Profound Disabilities*

In this study, context was a significant influence in parent and teacher formulations of the adult lives of their children/students with profound disabilities. The influence of student labels and institutional formulations were reflected in teacher conceptions that students will spend their adult lives in segregated residential placements and adult service continuums for individuals with special needs. Teacher focus was consistent with the context in which they are situated, and their goal is that students will acquire new skills or remediate areas of need/perceived limitations. The skills that were the focus of teacher expectations for students' adult lives were similar to the skills that have been identified by institutions as important for this population to acquire: vocational skills; independent living skills; self help skills to promote personal independence; and skills that will improve student social and leisure access. Teacher formulations of student adult life included participation in a range of activities with the support of professionals and paraprofessionals who are trained to work with this population. This is consistent with teacher focus for students within the classroom context. Although teachers acknowledged the importance of relationships in the adult lives of their students, they viewed these relationships as primarily between people who are familiar with the student and others who have significant disabilities. While parents wished for a happy and fulfilling life for their child once they reach adulthood, teachers spoke of an active and structured life within a system of institutionalized supports.

The parents in this study were influenced by the context in which they know their child best-that of a family home where a child with profound disability is surrounded by people who love and accept him. Families were not focused on skill acquisition to the degree that teachers in this study were, but instead desired that their children lead fulfilling and high quality lives. Unlike teachers, families did not operationalize their priorities for their children into discrete and measurable goals. Instead, the families in this study spoke in emotion laden generalities about the adult lives they desire for their children. When provided with structured supports (such as life planning assistance), families were able to become more concrete in describing the details of the adult life they wish for their children. Families placed importance on the life areas that stem from the context they share with their children. They want to see their children continue to live with people who care for them and engage in activities that promote personal well being. Families believed that they, more than professionals, know what is best for their child. The majority of the families in this study (six of eight) did not want their child to live in a segregated, institutionalized setting. Like teachers, they sought to extend the context in which the child is currently situated into the child's future adult life.

## Artifacts and Their Impact on Parent/Teacher Formulations of Student Adult Life

The Individual Transition Plan (ITP) form is the principal artifact used to assist parents, teachers, and other stakeholders in the design of transition goals for students with profound disabilities and is specifically used to address desired post-graduation outcomes for students in special education. While each school district may have a slightly different form for transition goal planning, the form examined for this study was the one used by the school district in which six of the eight student study participants attend school (see Appendix C). The ITP form meets the definition of a cognitive artifact in that it is a "highly encoded representation about what matters in a domain." (Nemeth, Cook, O'Connor & Klock, 2004). Examination of the ITP form assisted in uncovering the social and cultural perceptions regarding "what matters" in the lives of special education students as they prepare to transition to adulthood.

The goal of this portion of the study was to determine if there was a relationship between the language and directives on the ITP form and the adult futures envisioned by the parents and teachers in this study. The ITP form contains a mandate that team members must set at least one measurable transition goal in the life areas of training, employment and education with the option of also establishing goals regarding independent living. Despite this mandate, the parents and teachers who participated in this study did not establish goals in each of these areas, particularly the employment area. The findings of this section of the study were that the ITP form was not a significant impact on the thinking of the parents and teachers in this study regarding the adult life of their child/student.

### *Overview of the ITP Form*

The ITP form that stakeholders used to design transition goals for the students in this study was divided into five sections: general information; graduation plan; post-high school outcomes; measurable post-secondary goals; and transition services/activities. Each section of the form provided a set of directions for how that section was to be completed. As an addendum to the form, teachers had access to sample post-secondary goals and activities that might be appropriate for special education students. The data that follows is a summary of each of the five sections of the ITP form, a discussion of the potential implications of the language contained in the form, and an assessment of how this language might impact the thinking of the parents and teachers who participated in this study.

### *General Information Section of the ITP Form*

The general information section of the ITP form is designed to gather information about student preferences and goals after leaving high school, student needs, and the results of vocational and transition related assessments. This portion of the ITP form stresses the importance of student input and participation in the design of ITP goals. When students have profound disabilities, their ability to provide input in the design of post-high school goals is limited.  Most students with profound disability indicate preferences using body language, sounds, and behavior, so it is likely that student preferences/interests would be drawn from parent, teacher, and team perspectives regarding the meaning of students' nonverbal communication (Dennis, 2002).  This portion of the ITP form illustrated the institutional (school) reliance on standardized tests as a means for information gathering and decision making.  The ITP form lists a specific requirement that transition aged students receive vocational evaluations,, reinforcing the social and cultural perception that students with disabilities should engage in work after graduation from high school.

### *Graduation Plan Section of the ITP Form*

This portion of the ITP form is used to determine if students are diploma bound or will be working to achieve a certificate of completion. Graduation plan language on the form contains the expectation that some students in special education will receive a high school diploma while others will receive a certificate of completion.  A review of this section revealed that a certificate of completion is an indication that a student completed an alternate or modified curriculum. All students with profound disabilities will exit special education with a certificate of completion, and the majority will enter sheltered workshops or activity centers where the vocational opportunities they are offered will result in participation in repetitive or menial work for extremely low wages (less than $.50/hour) (Frank, Sitlington, & Carson, 1992; Haring & Lovett, 1990). In light of this, a certificate of completion is affording most adults with profound disabilities the opportunity to participate in an institutionalized setting that offers little chance for a self determined lifestyle.

*Post-High School Outcomes Section of the ITP Form*

The ITP form offers a limited selection of post-high school outcomes from which team members can make selections. Table 16. shows the outcome categories and choices as they are listed on the ITP form.

Table 16.

**ITP Form Post-High School Outcome Categories and Choices**

| Categories | Choices offered |
|---|---|
| EDUCATION | ☐ Four year college<br>☐ Trade/Tech School<br>☐ Community College<br>☐ None due to post-high school employment<br>☐ Adult Education<br>☐ Job Corps |

Table 16. (Continued)

**ITP Form Post-High School Outcome Categories and Choices**

| Categories | Choices offered |
|---|---|
| EMPLOYMENT | ☐ Unsubsidized full-time employment<br>☐ Supported employment<br>☐ None due to post-high school education/training<br>☐ Work Activity Program<br>☐ Volunteer Work<br>☐ Unsubsidized part-time employment |
| INDEPENDENT LIVING | ☐ Independent residence<br>☐ Semi-independent/supervised<br>☐ Family/Relatives residence<br>☐ Residential care facility<br>☐ Transportation<br>☐ Health Care<br>☐ Family Support<br>☐ Supplemental Security Income (SSI)<br>☐ Socialization<br>☐ Social Security Disability Insurance |

The ITP form, like other artifacts, mediates not only our actions but also our perceptions (Norman, 1991). In this portion of the form, parent and teacher attention is directed toward education, employment, and independent living as the principle outcome areas for a student's adult life. Choices within these outcome areas are limited, which may in turn limit the thinking of the stakeholders completing the form. For example, in the area of employment, micro-enterprise is not listed as a potential outcome. In the area of independent living, home owner is not a choice. In states that provide individulalized funding for adults with profound disabilities, the establishment of micro-enterprises as a vocational option and home ownership are viable outcomes. These examples illustrate the ways in which the ITP form currently used in California for persons with profound disabilities might limit their adult outcomes by limiting the options presented to the stakeholders who complete the form.

### *Measurable Post-Secondary Goals Section of the ITP Form*

This section of the ITP form is an extension of the post-high school outcomes section. ITP team members are directed to state what the student hopes to achieve after leaving high school, based on assessments, in the areas of education, employment, training, and independent living (if appropriate). The form further contains language mandating that goals must be written in the areas of education, employment, training, and independent living (optional). The goals drafted in this section of the ITP are to take into account student preferences, interests, and strengths, as gleaned through formal assessment and student input.

The ITP form requirement that a student must have post-secondary goals in the outcome areas of training, employment and education, further demonstrates that these life areas are those that, from a socio-cultural perspective, "matter" for persons with disabilities. Those outcomes that address life areas related to independent living, or other areas not listed on the form, are not required but are suggested if appropriate to the desires, needs, and interests of the student. The absence of a mandate to establish goals in areas not listed on the form could result in ITP team member devaluation of these non-mandated areas of life. The consequence of this might be that areas of adult life that team members consider vital to the life quality of a student, for example friendships or social activities, might be excluded from the planning process or dismissed as not important.

### *Transition Services/Activities Section of the ITP Form*

This final section of the ITP form is designed to assign the persons responsible for tracking and supporting student progress in the areas of education, employment, training, and independent living and to document the results of student instruction in these goal areas. Transition services and activities are focused on student achievement of specified goals. In keeping with the other portions of the ITP form, this section further reifies the social-cultural perception that education, training, employment, and independent living are outcomes that “matter” for students with disabilities.

### *Role of Artifacts* in *Parent and Teacher Formulations of Adult Life for Individuals with Profound Disabilities*

Parents and teachers, as well as other stakeholders, designed a total of 28 ITP goals for the students who were part of this study. The distribution of these 28 goals across various instructional categories is shown in Table 17.

Table 17.

**Distribution of ITP Goals across Instructional Categories**

| ITP goal category | Number of goals in category |
|---|---|
| Reduce negative behavior | 11 |
| Communication | 2 |
| Community use | 2 |
| Vocational | 3 |
| Self Care | 5 |
| Time on task | 4 |
| Other | 1 |

The ITP form contains a requirement that at least one goal must be set in each of the categories of Employment, Education, and Training. The ITP form also indicates that, if appropriate, goals may be established in the Independent Living category. The ITP goals of the students who were part of this study did not meet the criteria established in the ITP form. Table 18. provides a comparison of ITP form goal categories and how student goals were, or were not, aligned with these categories.

Table 18.

**Comparison of ITP Form Goal Categories and Student ITP Goals**

| Student | Employment | Education | Training | Independent Living | Other |
|---|---|---|---|---|---|
| Taylor | 1 goal | 0 | 1 goal | 1 goal | 1 goal |
| Nancy | 0 | 0 | 0 | 1 goal | 2 goals |
| Jack | 2 goals | 0 | 0 | 1 goal | 1 goal |
| Aaron | 0 | 0 | 0 | 0 | 4 goals |
| Linda | 1 goal | 0 | 1 goal | 0 | 2 goals |
| Rob | 0 | 0 | 0 | 1 goal | 3 goals |
| Pam | 0 | 0 | 0 | 1 goal | 3 goals |

Note. Training goals are those that specified training in the goal language. For example, the one goal listed under the "training" category for student Linda stated that she will receive training in accessing a variety of community resources.

An examination of Table 18. reveals that 11 of 28 goals (39%) established for the students in this study as part of the ITP process fell within the categories required on the ITP form (education; employment, training, independent living). The majority (61%) of the students' ITP goals were in categories ("Other") not reflected on the ITP form. The student goals categorized as "Other" were designed to decrease or eliminate maladaptive behavior; improve expressive or receptive communication skills; or increase the amount of time a student is focused on a task. Although the ITP form does not reference behavior, communication, or attention to task as skills of importance when considering the transition to adulthood, the parents and teachers in this study nevertheless included these goals in the students' transition plans.

### *Discussion of the Role of Artifacts in Parent/Teacher Adult Life Envisionments*

Based on the results of this study, the ITP form was not a primary influence on parent and teacher thinking. The majority of the ITP goals designed for students did not fall within the designated areas of employment, education, training, or independent living. Instead, parents, teachers, and other stakeholders who participated in designing student ITP goals based their decisions on individual student needs, and established goals in the areas of communication, behavior, and attention to task. Although the ITP form mandates that goals must be written for students in particular domains, this mandate did not impact the team that designed ITP goals for the students in this study. Despite this, the ITP form has the potential to limit the choices made by ITP planning teams due to the language used in the form and the limited options presented on the form. As a cognitive artifact designed with the purpose of facilitating decision making on the part of a group, the ITP form misses the mark relative to the students with profound disabilities who were part of this study. Instead of providing a guide to operationalize parent, teacher, and stakeholder formulations of the adult lives of students with profound disabilities, in this study the ITP form served instead as a guide for decision making based on institutional and social constructions of adulthood.

In order to better reflect the needs of students such as those in this study, the ITP form could be reconfigured so that it offers choices based on a wider range of life skill categories. This reconfiguration would then serve to guide team-member thinking away from a narrow range of adult options (work, education, training, independent living) and toward a more holistic perspective regarding the adult life of students with profound disabilities. It is likely that such a revision of the ITP form would result in transition goals that are more individualized to the needs and desired futures of students with profound disabilities. The potential consequence of designing more individualized goals is improved adult outcomes for this student population

# CHAPTER 7: DIFFERENT WAYS OF KNOWING: CONCLUSIONS AND IMPLICATIONS

This study was conducted in an effort to gain an understanding of the adult lives that parents and teachers envision for students with profound disabilities and to determine the factors that influence the construction of these envisionments. Consistent with the literature in this field, teacher and parent participants had conflicting ideas regarding adult life for children with profound disabilities (Chambers, 2004; Cooney, 2002; Hanley-Maxwell & Collet-Klingengerg, 1995; Hanley-Maxwell, Whitney-Thomas, & Pogoloff, 1995). This study provided new information about the factors that influence the formulations of the adult lives of students with profound disabilities. These factors included community and institutional perceptions of adulthood; the role of context in thinking and decision making; the influence of social and cultural expectations; and the disparity in the mental models that parents and teachers hold regarding their children/students with profound disability.

The parents and teachers in this study were influenced by these factors to greater and lesser degrees, largely dependent on cultural and contextual frameworks. While parents sought to reproduce the home context in their child's adult life, teachers were focused on reproducing the institutional and classroom context in which they know the student. Cultural influences also played a significant role in the thinking of the parents and teachers in this study, with parents most influenced by internal sources such as their knowledge of the child and their familial norms, and teachers most influenced by institutional perspectives regarding adulthood and special needs students. In this section I will present a discussion of the factors that, based on the findings of this study, have influenced parent, teacher, and institutional constructions of adult life for students with profound disabilities, as well as the implications of this study for families, teachers, and schools. Suggestions for future research are also presented.

## Influences on Institutional Construction of Adult Life:
## Culture, Expectation, and Reification

Our schools and institutional artifacts reify the idea that disability is a personal fact as opposed to a social construction. The field of services to persons with disabilities is highly professionalized, and socially we have come to believe that specially trained people must be involved with “special needs” people. The professionalization of disability services serves as a yet another rationale for the segregation of those with disabilities from those who are not so labeled, providing more reasons for the average person to avoid those with significant disabilities. Western society elaborates the cultural construction of disability through its laws, institutional procedures, diagnostic criteria, welfare systems, professional specializations, and business interests (Ingstad & Whyte, 1995). Concepts of personhood, identity and value are impacted by these cultural constructions. When a person’s worth is measured by what he or she can or cannot do, having a disability serves to diminish them in the eyes of their community. If, however, persons were considered in terms of their relationships to others, society might adopt a different perspective.

Social constructivism offers some insight into what it means to be a person with a disability within society. Social constructivism holds that those aspects of life that a society perceives as “reality” are constructed and maintained in social interactions (Berger & Luckmann, 1966). People tend to distance themselves from those they devalue- to label and segregate them from the rest of society. This has been the historical reality for persons with significant disabilities. Segregation reduces the opportunity for natural relationships, and a new understanding, to develop between people who view themselves as fundamentally different from each other. The result is that persons with profound disability often rely on paid workers to fill the roles of friend, companion, and helpmate.

Our schools and political institutions are social systems, and the activities of these social systems are motivated by many needs and shaped by the social context (Wertheim, 2008). Research has shown that schools are vested in the medical model of perceiving disability as a condition of the individual rather than reflective of social perspectives (Mehan, Mercer & Rueda, 2000). Our society, as well as the participants in this study, tends to define adults as persons who are independent both personally and financially; have the ability to make reasonable decisions; and are capable of contributing to society. This perspective regarding adulthood is reflected in special education law and special education artifacts used to write transition goals for students with disabilities. These artifacts and laws reinforce the cultural importance of work and independent living for adults within our society. Individuals with profound disabilities who are unable to fill the role of worker or independent adult are, consequently, viewed by many as eternal children. In this study, teachers were comfortable envisioning a future for a student with severe disabilities despite a belief that the student would prefer a different future. Viewing adults with profound disabilities as eternal children provides a justification for a society's failure to treat those who have profound disabilities with the dignity and respect afforded to most adults in our society.

Schools and educational institutions can play a role in improving the adult outcomes experienced by people with profound disability by leading a reform effort directed at supporting students in becoming active members of their local community. One way this can be achieved is to move the educational setting of students away from segregated classrooms and into the community in which they will soon become a member. Generally, we tend to fear the unknown, and this fear is evident in the comments of the community members whose statements were examined in this study. Individuals like these community members believe that those who have profound disabilities represent a potential threat to society. The antidote to fear is knowledge. As persons with profound disability become active members of their local communities, and move out of segregated settings, it is to be hoped that fear will be replaced by an understanding that all people have something of value to offer others. In the case of those with profound disability, this value may be as simple as offering opportunities for others without profound disability to experience interdependence, emotional attachment, and relationships without an agenda.

### *Implications of this Study for Institutions*

Schools and other special education institutions, theorists, and researchers can play a significant role in shifting social thinking away from a focus on disability toward a focus on the personhood and innate value of those who have profound disability. This will not be an easy task. Even our most basic understanding of what it means to be disabled within our society is not a shared schema (Rioux, 1996). Historically, institutions have been grounded in the medical and rehabilitative models relative to students with disability labels. Although research is increasingly focusing its attention on other ways of viewing disability within our society, the schemas of the teachers and institutions that were examined in this study remain grounded in these medical/rehabilitative perspectives. This study provides some justification for recommending a shift in personal, social, and institutional thinking such that the social construction of disability plays a greater part in our understanding of what it means to have a disability label in our society.

Given the significant differences between persons with profound disability and others in our society (even those with more mild disabilities), it is difficult to argue that their disability is not, indeed, a medical fact rather than a social construction. Certainly, persons with profound disability have medical, neurological, and sensory differences not present in most persons within our society. These differences cannot be cured or significantly rehabilitated. Society did not “construct” the neurological and medical challenges faced by those with profound disability. When we meet a person who cannot speak, point, control his body or in any conventional way share his personhood with us, we have difficulty perceiving that personhood. We make assumptions that, perhaps, there is no personhood, at least as our culture has led us to understand the term. Where, then, is the rationale for encouraging teachers, parents, institutions, and the general public to adopt a social constructivist viewpoint regarding profound disability?

The argument lies in the historical outcomes that have resulted from our focus on a medical model of disability. This model has, in the past, led to segregation, abuse, instutionalization, and isolation for those who have profound disabilities. While our current rehabilitative perspective is perhaps more humanistic in nature, it is nonetheless producing poor adult outcomes, and poor life quality, for persons with profound disability. I suggest here that a knowledge of the theories surrounding the social construction of disability, when applied to those with the most significant disabilities, may result in an understanding on the part of society that beneath the profound medical and neurological manifestations of disability resides a person who is more like than unlike the general society. In the case of those with profound disability, society has constructed not the presence of a disability but how we are to respond to the person with a profound disability and the opportunities we should afford the person with a profound disability. At its foundation, social constructivist theories of disability begin with the premise that all persons have civil rights to a place of belonging within the society-all persons have something of value to offer.

A shift in thinking away from a medical model of disability to a social constructivist model may focus public attention on our common humanity and our moral and ethical responsibility to accept others despite their differences. This shift would then provide the groundwork for a new way of educating students and preparing them for their adult lives that is directed at fostering interdependence rather than dependence; helping students with profound disabilities connect with their community; and supporting students with profound disabilities in the assumption of socially valued roles after graduation. While the institutional focus on employment and independence is, perhaps, one means for helping students with disabilities gain the respect and acceptance of their community, there is a need for a broader range of post high school options that will meet the needs of those with very significant disabilities. For these individuals, work and independence is an unlikely adult outcome. Recognizing this, schools could better prepare students with profound disability for their adult lives by helping them form social relationships with people within their home community; educating the general community on the humanity and personhood of persons with profound disability so that these relationships have a chance to flourish; and helping students develop a range of interests that will connect them to others with similar interests (for example an appreciation of music, sports, or other mainstream activities). The result of our efforts at educating students with profound disability should be that we are preparing them for a life worth living. Few would argue that a life worth living must involve the presence of people who value us, enjoy our company, and are not paid to be part of our lives.

There is an additional need for a shift in the messages contained within our institutional artifacts and laws which currently reify the idea that professionalization and institutionalization is necessary in the lives of persons with profound disabilities. These artifacts could be modified to be more person-centered and reflective of the importance of leading a self determined life. The funding for adult services for persons with disabilities is based on a group model and, like the special education artifacts, must change to an individualized service model in order to maximize adult outcomes for students with profound disabilities. This is presently happening in many states with some success. Finally, institutions must acknowledge the importance of the voice of the family in constructing formulations for the adult lives of students with special needs. The family will be the primary source of support to the student across his/her lifespan. Attaining parity between family expectations and institutional formulations will likely lead to improved adult outcomes, and happier lives, for persons with profound disability.

## Influences on Parent Constructions of Adult Life:

## Context, Culture and Heuristics

Schema theory is useful in gaining an understanding of the thinking of the parents who participated in this study regarding their child’s adult life. Schema theory holds that a society has rules and scripts that they use to interpret the world (Widmayer, 2008). People will persist in their way of thinking until they learn new information that causes them to change their mental models. It is likely that parent thinking regarding the adult life they find acceptable for their children with profound disabilities will remain grounded in fear and the child’s home context until parents have direct and positive knowledge about, and experience with, adult services and supports. Our schemas are used not only to interpret a current circumstance but to predict future situations. In order to predict a future life that is meaningful and fulfilling for their children, parents must be provided with substantive information and the opportunity to see and experience adult service models.

The mental models of the parents in this study relative to the adult lives of their children were primarily grounded in the context in which they know their child; their cultural orientation; their intuitive sense of what is “right”; and their schemas regarding adulthood and persons with significant disabilities. When envisioning an adult life for their child, parents based their thinking on their direct, daily experiences with their child and their perceptions of his abilities, likes and dislikes. Parents wanted their children, upon reaching adulthood, to have personal fulfillment and comfort, to be as productive as possible, to be with people who love them, and to engage in activities that maximize the child’s strengths. These envisionments for the adult life of their child were in opposition to institutional formulations of adulthood in which all adults are expected to work and be financially and personally independent. Instead of incorporating these instutional and social constructions of adulthood into their mental models, the parent participants relied instead on internal influences in their decision making about their child's adult life. These internal influences included religious beliefs; family and cultural norms; their feelings toward the child; their perceptions of their ability as parents to support their child emotionally and functionally; and their beliefs about the quality and activities of the adult service system.

As demonstrated through their interviews, parent worries and concerns impacted much of their thinking regarding the adult lives they do, and do not, want for their child. Instead of being based on an actual knowledge of the supports available to adults with profound disabilities, parent thinking regarding their child's adult life revolved around a mental model that portrays adulthood as difficult, stigmatizing, isolated, and stagnant. This way of thinking was grounded in part on society's historical practice of warehousing and institutionalizing persons with significant disabilities as well as media portrayals of this population (Blatt & Kaplan, 1974). Without knowledge of the programs and services that could be accessed to support their children once they reach adulthood, and without mentorship, the parents in this study were unable to operationalize their wishes for their child's future. When given guidance in the form of an artifact to help organize their thinking around multiple life domains, parents were able to be more specific in their envisionments of the adult life they would like to see their child lead. This finding supported the notion that parents need assistance in life planning and goal setting prior to participating in ITP team meetings.

Although the initial impact of having a child with a severe disability was still very much present in the stories parents told about their child, the focus of the parent participants in this study was not primarily on their child's disability. Instead, these families have found intrinsic value in knowing and living with a person who has a profound disability. In the case of the parents in this study, familiarity with an individual with significant disabilities bred not contempt but acceptance and appreciation for the many ways in which knowing a child with profound disabilities has enhanced their lives. Finding a means for sharing this appreciation with the general public is one method that could be used to help increase the public's knowledge about, and acceptance of, persons with significant disabilities. One means for doing this is to share humanizing stories about individuals with profound disabilities that focus on the ways in which these individuals can enhance the lives of those without disabilities (Ferguson, 2000). The adult life quality of persons with profound disabilities could be significantly enhanced through educating the general public on the intrinsic value inherent in having relationships with persons who differ significantly from what is viewed by the public as "normal".

It is likely that, in order for parents to develop new schemas on which to base their thinking regarding their child's adult life, they will need to be exposed to adult support programs that offer them insight into the adult lives of people with profound disabilities who are not living in the family home. While more knowledge about adult services may not outweigh the influence of context and culture in parent thinking, an understanding of the options available to their child in adulthood would broaden the alternatives open to families when they make plans for the adult life of their child. With more choice comes the opportunity for more detailed and individualized life plans for young adults with severe disabilities and the potential for better life quality outcomes as a result.

### *Implications of this Study for Families*

The findings from this study provide support for the need to develop a system for informing families about the adult services available to their children so that they can make informed decisions about their child's future. Parents need detailed information about types, content, eligibility, and continuum of services offered by programs within their community. They also need information about new individualized adult support models that may not yet be available within their local community. For the parents in this study, fear and worry played a significant role in their mental models of their child's adult life. Increasing parent knowledge about adult service models and options would not only have the potential increase the choices available to their child when he reaches adulthood, but might also could play a significant role in empowering parents through reducing their fear and increasing their practical knowledge base. This empowerment would be advantageous to parents who, according to the literature, will be the primary support system for their child across the lifespan (Wells, Sandefur, & Hogan, 2003).

In addition to information, parents need help turning their vague ideas about their child's adulthood into concrete action plans. Life planning assistance is a critical step in this process. Life planning involves mentoring parents and the use of artifacts and tools to guide parent thinking along holistic lines relative to life outcomes. During the process of developing a life plan, families are guided to think across multiple life domains and are provided information about best practices and new adult support models.

A life plan is developed based on the results of the planning meeting, and action plans are designed to assure that life plans are operationalized. These action plans can then serve as the foundation of individual student transition goals. Currently, most parents participate in the development of transition goals without the benefit of having first written a life plan for their child. As a result, and as revealed in the findings of this study, parents' goals for their child's adult life are often a reflection of institutional priorities rather than parent priorities. Schools, adult service providers, and social service agencies must join forces in educating parents well in advance of a child's graduation from school. Institutions can support this process by mandating life planning prior to the development of individual transition plans for students with disabilities, and by increasing the funding dedicated to parent training.

## Influences on Teacher Constructions of Adult Life:

## Context, Disability, and Positivism

As with parent thinking, schema theory is also useful in understanding the thinking of teachers regarding the adult lives of their students with profound disabilities. The mental models of the teachers in this study were heavily influenced by the disability labels and resulting "level of functioning" of their students. Teachers voiced little awareness of the possibility that society might, at least in part, play some role in the construction of disability and in the application of this label to certain persons within the society. The teachers in this study saw the "problem" of disability at an individual level, residing within the student. Teacher participants viewed their job as one involving remediation and helping a student to function as closely as possible in the manner in which nondisabled persons of the same age might function. The schools in which the teachers worked supported this schema, and the artifacts the teachers used to design student goals directed teacher thinking toward a focus on student levels of performance, change in levels of performance, and teacher/institutional responsibility to facilitate the acquisition of skills that will foster independence. As a result, teacher decision making and thinking was focused on changing the individual, an extremely challenging task given the pervasive nature of the disabilities of the students in this study.

An alternate method to focusing energies on attempting to change people with disabilities so that they can be more like the "normal" population lies in the theory of social role valorization (SRV) (Wolfensberger, 2000). In this theoretical model, the goal of educating persons with significant disabilities is to help them attain socially valued roles which may, as a result, increase their perceived value to and acceptance within society. For example, home owner and business owner are socially valued roles. Newly emerging SRV supports for persons with disabilities include assistance in purchasing homes using federally funded loans and Medicare dollars and in starting home-based or small businesses, dubbed "microenterprise development".

Those who speak against the functionality of social role valorization principles argue that educators who teach students using these principles are preparing students to occupy valued roles within an unequal society-something of an exercise in futility (Oliver, 1999). Those in favor of social role valorization principles counter-argue that, in transforming the lives of persons with profound disability, we also transform the society in which they live (Wolfensberger, 1999). The review of literature in this study revealed that our current methods for educating students with profound disabilities are yielding poor adult outcomes. Educating teachers in methods for helping children attain socially valued roles is one strategy that may achieve two needs identified in this study: the need to improve student outcomes and the need to find a place of belonging for students with profound disabilities within the broader society. Our current educational and adult support systems have failed to produce the substantive social change needed in order for persons with profound disabilities to be valued by much of society. It is possible that educating students using the principles inherent in social role valorization might help change social perspectives and, as a result, improve life quality for adults with profound disabilities.

When envisioning an adult life for their students, teacher participants based their thinking primarily on external influences which included their (limited) knowledge of the adult options available to the student; their perceptions of student functioning and need; their training and education; time constraints and available resources; and the culture and expectations of their workplace. The teachers in this study envisioned their students with profound disabilities leading lives that are heavily influenced and supported by existing institutions. This included teacher beliefs that their students will live in group homes; be primarily involved with family, careproviders, and persons with disabilities similar to those of the student; attend adult day programs; and participate in a range of social and leisure activities within an institutionalized system supported by trained professionals/paraprofessionals. New adult service models for individuals with profound disability, which are not yet widely available in the state where this study was conducted, are moving away from institutional models toward individualized services, which research has shown results in better adult outcomes for students with disabilities (Perlmutter & Monty, 1997; Realon, Favell & Lowerre, 1990). In order to support students and families, and to help maximize adult outcomes for students, teachers need to receive ongoing training in best practice procedures related to adulthood and students with profound disabilities.

The teachers in this study, like the parent participants, sought to extend the context in which they know the child into the child's life as an adult. The goals teachers had for the adult life of their students with profound disabilities were based on remediation of perceived deficits and the concept of normalization. A majority of the transition goals established for students with profound disabilities reflected the school setting, with a focus on helping students increase time and attention to task, eliminate problem behaviors, and become more independent in activities of daily living. The IEPs established for the students in this study were, in large part, designed to assist the student in being more functional within the school setting instead of the home, community, or adult service setting. This is noteworthy given that students will spend only a few years in a school setting while the majority of their lives will be spent in home, community, or adult service settings. With student learning focused on the skills needed to be successful at school, it is likely that, once out of the school setting, students will not have the tools they need to lead successful lives as adults.

### *Implications of this Study for Teachers*

Knowledge about the adult service continuum and best practice models is as important for teachers, particularly those teaching transition aged students, as it is for parents. The teachers in this study admitted that they have little knowledge about the adult services available to their students after graduation. This can be rectified through better education in college and university settings and in on the job seminars and training relative to the adult service system. Like parents, teachers need to not only read about but also see model adult programs for students with profound disabilities. Teachers additionally need education in how to support parents in developing life plans for their children. A closer collaboration between parents and teachers would help to bridge their current disparity in thinking regarding adulthood for students with profound disabilities, and would likely improve the adult outcomes experienced by students with profound disabilities. Since parents will be the most consistent source of support for their children across the lifespan, teachers must view parents as viable partners in the planning and goal setting process.

This study revealed that teachers are grounded in a medical model regarding disability, viewing disability as a problem that exists at the level of the individual. In addition to receiving training on adult services and model adult programs, teachers also need opportunities to explore that notion that disability might be a social construct and, as such, there might be new and different means for educating and supporting those who have significant disabilities. As new models such as microenterprise and individualized funding take hold on a national level, teachers will naturally learn about alternative methods for helping persons with profound disabilities lead individually determined lives. Teacher training programs are another means for providing opportunities for educators to modify their current weltanschauung and, possibly, assist in developing new curricula and support methods that will enhance the adult lives of those with profound disabilities.

## Suggestions for Further Research

Historically, there has been a lack of research interest relative to persons with profound disability (Watson, 1996). Greater research interest is warranted regarding this population given the significant increase in numbers of children diagnosed with autism, the high levels of funding required to deliver special education services, the percentage of education resources devoted to special education students, and the poor adult outcomes reflected in the literature (California Department of Developmental Services, 2003). The following suggestions are designed to provide information to future researchers who may be interested in studying transition related issues for students with profound disability.

Research needs to be conducted on best practice transition support processes for students with profound disabilities, their families and teachers. Model transition programs need to be developed, researched, and the information disseminated. In addition, there is a critical need for further research on social roles that can be effectively assumed by persons with profound disability and on how teachers and parents can best prepare students to occupy these social roles. Related to this is a need for disseminating positive, person-centered information about the potential of persons with profound disability. Such information needs to be shared with the research community, parents, teachers and the general society. We must find an effective way to connect research to practice to society if we are to assist in improving the lives of persons with significant disabilities.

Life planning services have emerged in this study as a significant, potential solution to the poor outcomes experienced by adults with profound disabilities. Research is needed on the best methods for developing and integrating individualized life plans into special education goal setting processes, to include methods for training teachers and other personnel in supporting parents in developing life plans for their transition-aged children. Special education reform is needed so that student ITPs mandate life planning before goals can be drafted. Researchers can take part in this reform by examining new models for transition plan development, assessing process, and conducting research on the relationship between life planning and adult outcomes for students with profound disabilities.

This study was conducted with parents and teachers who are primarily middle class, White, English speakers. Future researchers should consider replicating this study with socio-economic and cultural minorities to determine if the priorities of these populations and their institutional experiences are consistent with the findings of this study. In addition, this is a small study (n=16). Replication with a much larger sample size is needed in order to determine if the findings are reflective of a broader segment of the population.

## Final Thoughts

I undertook this study because my career and personal life has been heavily influenced, and enriched, by the time I have spent with persons who have profound disability, their families and teachers. In the 20 years I have spent as both a special education professional and a parent of a young man with profound disabilities, I have seen a number of positive changes. I remain optimistic that we are heading in the right direction. Like the participants in my study, I hope for more but need help to find the solutions. Parent researchers like Ann and Rud Turnbull, Philip and Diane Ferguson, Eva Feder Kittay, and Linda Ware have been a source of inspiration and made invaluable contributions to the moral and ethical issues surrounding persons with profound disability. These researchers, and others who are dedicated to studying this minority population, have given us a road to follow-a means for developing "different ways of knowing" those who have profound disability. Persons with profound disability are without a voice. It falls to those of us who know and care for them to provide that voice. By helping persons with profound disability gain entitlement to dignity and social acceptance, we move them one step closer to a life of quality within our society. In so doing, we help society build new ways of understanding what it means to be "human". This, perhaps, defines our task as parents, practitioners, and researchers.

> The fundamental law of human beings is interdependence. A person is
> a person through other persons. *Bishop Desmond Tutu*

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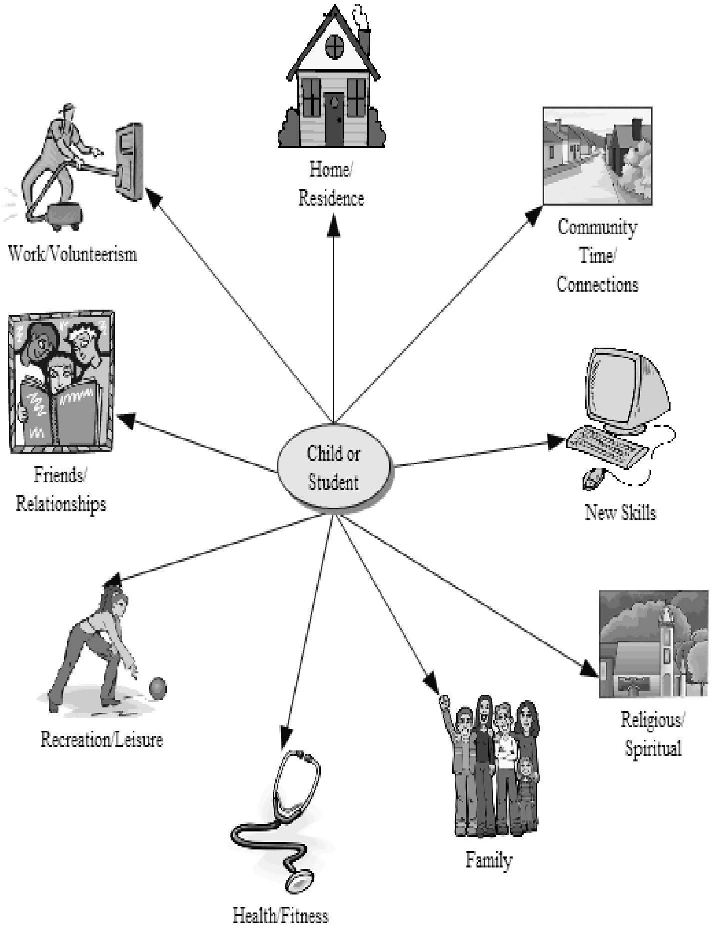
## APPENDIX A: Parent and Teacher Interview Questions

1. I don't know <student> as well as you do. Tell me about him/her.
2. Based on your personal thinking and beliefs, what is an "adult"?
3. What do you believe adult life is like for individuals with profound disabilities?
4. Tell me about the adult life you envision for <student>?
    a. <Note first response>.
    b. Take a look at this graphic that shows life categories. Is there anything else you would say based on looking at this?
5. Do you think this adult life is the one <student> would envision for him/herself? What makes you think this?
6. Do you have any concerns you about <student's> adult life?
7. What do you look forward to about <student's> adult life?
8. How does <student> spend an average weekday? How about an average weekend?
9. What do you think the school is doing to prepare <student> for his/her adult life?
10. Tell me about anything the parents (or you as a parent) are doing to prepare <student> for his/her adult life?
11. How do you think the goals you have developed for <student> in his/her IEP and ITP are related to his/her adult life?
12. What are the most important goals you have for <student> between now and graduation?
13. What has caused you to believe that the future you envision for your child/student is the "right" or "best" one for him/her?
14. What is your understanding of the current adult programs/services/supports available to people with profound disabilities in our community?
15. Do you believe there is anything that might interfere with the future you envision for <student>?
16. Do you believe the IEP/ITP team goal development process has influenced the adult life you envision for <student>?
17. Tell me about anything you believe has influenced the construction you have of <student's> adult life?
18. Is there anything else you would like to tell me?

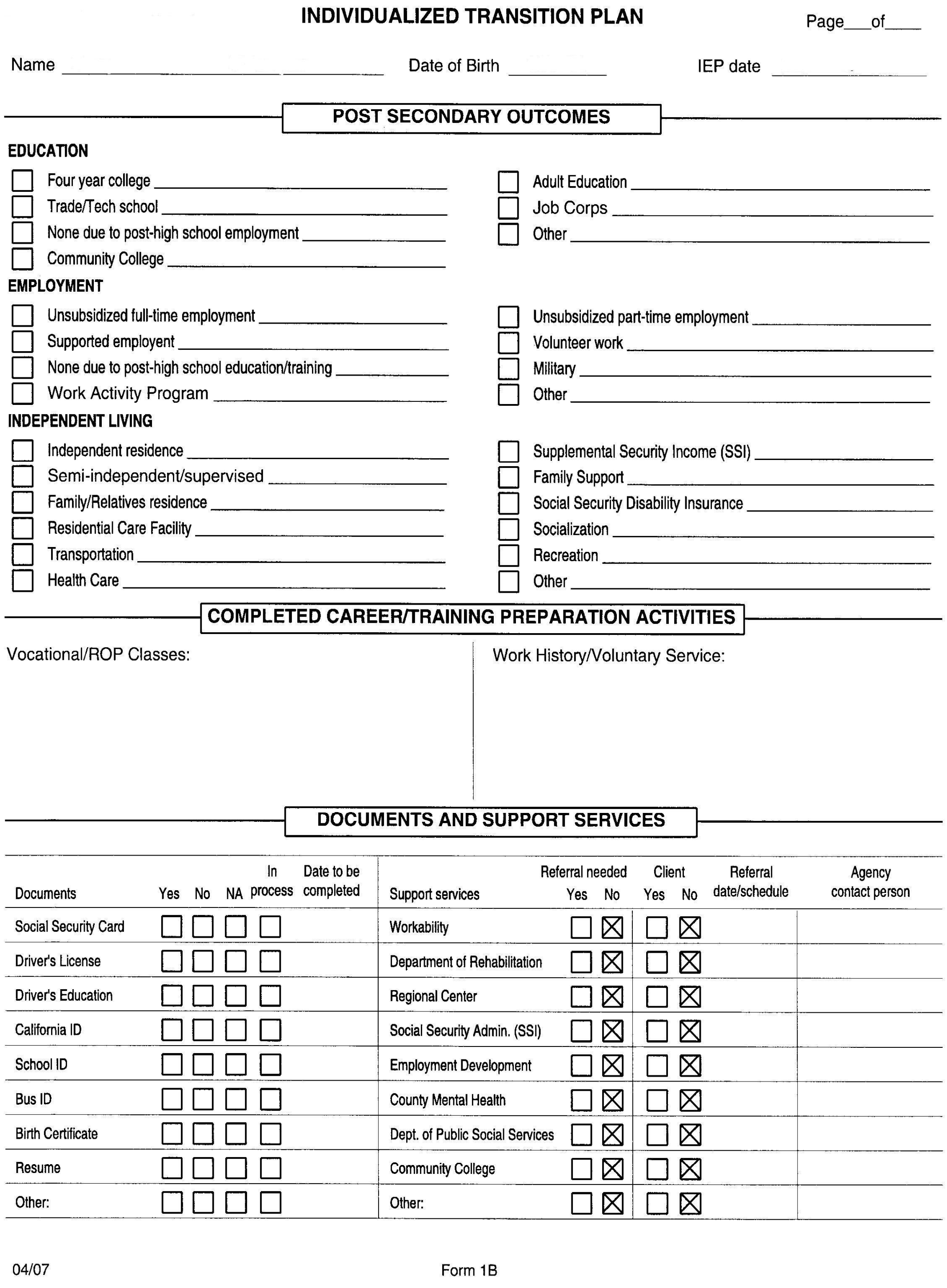
**Teachers Only**: What training or education have you received specific to designing ITP's for students with profound disabilities? What training or education have you received specific to futures planning for students with profound disabilities?

# APPENDIX B: Interview Chart

Formulating Their Future
DeZonia IRB
Parent/Teacher Interview Graphic
February 14, 2007
16.4



# APPENDIX C: Individual Transition Plan Form



## INDIVIDUALIZED TRANSITION PLAN

Page___of____

Name ______________________ Date of Birth __________ IEP date ________________

### POST SECONDARY OUTCOMES

**EDUCATION**

☐ Four year college ______________________
☐ Trade/Tech school ______________________
☐ None due to post-high school employment ____________
☐ Community College ______________________
☐ Adult Education ______________________
☐ Job Corps ______________________
☐ Other ______________________

**EMPLOYMENT**

☐ Unsubsidized full-time employment ______________
☐ Supported employent ______________________
☐ None due to post-high school education/training __________
☐ Work Activity Program ______________________
☐ Unsubsidized part-time employment ______________
☐ Volunteer work ______________________
☐ Military ______________________
☐ Other ______________________

**INDEPENDENT LIVING**

☐ Independent residence ______________________
☐ Semi-independent/supervised ______________________
☐ Family/Relatives residence ______________________
☐ Residential Care Facility ______________________
☐ Transportation ______________________
☐ Health Care ______________________
☐ Supplemental Security Income (SSI) ______________
☐ Family Support ______________________
☐ Social Security Disability Insurance ______________
☐ Socialization ______________________
☐ Recreation ______________________
☐ Other ______________________

### COMPLETED CAREER/TRAINING PREPARATION ACTIVITIES

Vocational/ROP Classes:

Work History/Voluntary Service:

### DOCUMENTS AND SUPPORT SERVICES

| Documents | Yes | No | NA | In process | Date to be completed | Support services | Referral needed Yes | Referral needed No | Client Yes | Client No | Referral date/schedule | Agency contact person |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Social Security Card | ☐ | ☐ | ☐ | ☐ | | Workability | ☐ | ☒ | ☐ | ☒ | | |
| Driver's License | ☐ | ☐ | ☐ | ☐ | | Department of Rehabilitation | ☐ | ☒ | ☐ | ☒ | | |
| Driver's Education | ☐ | ☐ | ☐ | ☐ | | Regional Center | ☐ | ☒ | ☐ | ☒ | | |
| California ID | ☐ | ☐ | ☐ | ☐ | | Social Security Admin. (SSI) | ☐ | ☒ | ☐ | ☒ | | |
| School ID | ☐ | ☐ | ☐ | ☐ | | Employment Development | ☐ | ☒ | ☐ | ☒ | | |
| Bus ID | ☐ | ☐ | ☐ | ☐ | | County Mental Health | ☐ | ☒ | ☐ | ☒ | | |
| Birth Certificate | ☐ | ☐ | ☐ | ☐ | | Dept. of Public Social Services | ☐ | ☒ | ☐ | ☒ | | |
| Resume | ☐ | ☐ | ☐ | ☐ | | Community College | ☐ | ☒ | ☐ | ☒ | | |
| Other: | ☐ | ☐ | ☐ | ☐ | | Other: | ☐ | ☒ | ☐ | ☒ | | |

04/07

Form 1B