

INTELLECTUAL DISABILITIES AND MEANINGFUL LIVES:
A STUDY OF POLICY AND CHANGE
DISSERTATION

by

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DEDICATION

To the memory of my Mom and Dad, whose love, devotion, and support gave me the confidence to try anything. You both are always in my heart.

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ABSTRACT

Political advocacy was combined with disabilities studies to describe the policies in place for transition services, and what is actually happening in regards to bridging the school and community for our students with intellectual and/or developmental disabilities. The study is an examination of the similarities and differences in public policies, laws, and procedures among the 1st, 25th, and 50th states as ranked by the United Cerebral Palsy Organization (Bragdon, 2012), and documents findings informing policy makers as to the effects of their policies by recounting the real-life experience of a family with a son who has intellectual and developmental disabilities as he transitions into his community. Special educators follow the sanctions of the Individuals with Disabilities Act (IDEA), and policy makers have worked to enact legislation for The Americans with Disability Act (ADA) to provide a continuum of support for those with disabilities. State agencies were created to provide services for those with disabilities, as sanctioned in The Americans with Disability Act. However, Texas, has long waiting lists for this support, and a very complex system to navigate to the appropriate list. Texas is ranked 50th of the 51 US states, including the District of Columbia, in the services offered adults with disabilities (Bragdon, 2012). Every year, United Cerebral Palsy (UCP), an international advocacy group, produces an annual ranking of how well state Medicaid programs serve Americans with all disabilities, including those with intellectual and developmental disabilities. Medicaid is the critical safety net that provides financial,

healthcare security, and community supports and is considered to be our moral responsibility for those of our citizens with intellectual and developmental disabilities because “it is the duty of a civil society such as ours to aid these individuals, who are often the most vulnerable members of society” (Bragdon, 2012, p.1). This study discloses what the top states have done to support their individuals with disabilities. Policy makers have access to what is working well and examples to use to improve the services offered in Texas.

CHAPTER I

Introduction

“...There may be times when we are powerless to prevent injustice, but there must never be a time when we fail to protest...”

--Elie Wiesel (1984, p. 86)

Graduation from high school is an occasion for celebration. My daughter's graduation from high school meant we were about to enter into a new and wonderful phase in both of our lives. She was headed for college, and I was about to become an empty nester. My daughter was about to have experiences that would be both wonderful and challenging in a way that could not be provided during high school or living under my protective roof. No more yellow school bus, no more PTA meetings, and no more parent teacher conferences. I experienced so many emotions at that time. I was happy, sad, and excited for my daughter, and fearful all at once. This is perhaps not an unusual experience for a parent. Many of my daughter's peers and their families report experiencing much the same thing. Reflecting back, this phase in our lives proved to be a wonderful time of growth and learning for all of us.

While my experience highlights the joys associated with high school completion, the lived experiences of parents of children with severe intellectual or developmental disabilities can be quite different. When the yellow school bus stops coming for students who received special education services, there are usually no celebrations for what is to come. The joys associated with high school completion seem to be replaced with fear and worry about what is ahead and how to provide for a child with special needs. The

fear of “what ifs” enter in: What if I am not able to qualify for agency support to help me take care of my child? What if something happens to me, who will care for my child? How will I be able to continue to provide a purposeful and meaningful life for her? She, with the support of her teachers, worked so hard in school to grow and develop skills to become as independent as possible, and now what? How will I continue to help her grow and not become stagnant? She had such full days at school and, now, what is there for her? In a complicated world, having an intellectual disability means support is needed to accomplish the daily living tasks that so many of us take for granted.

Background to the Study

As the transition coordinator for students who receive special education services in a public school district in Central Texas, it is my job to help families and their children with disabilities transition from preschool to adulthood. Together with the help of the student, when they are able, their family, and our faculty and staff, we plan and set goals that will enable our students to live as independently as possible and have purposeful and meaningful lives, even after they leave the public school system. I hear parents daily speaking of the fears and challenges they face when the yellow school bus stops coming.

My interest in this topic developed from my commitment to students I serve who have been identified as having intellectual and/or developmental disabilities, and to their families. As transition coordinator, I feel as though I have done my job when I see families leave school with a plan in place that provides for their young adult with disabilities to continue living his or her life with purpose and meaning and as much independence as possible.

Transition, as stated in the Individuals with Disabilities Education Act (IDEA), is a

results-oriented process that requires special education program leaders to focus on the specific needs of each student to enable successful integration into his or her communities. IDEA (2004), as outlined in the Code of Federal Regulations (CFR), defines transition services as:

a coordinated set of activities for a student with a disability that is designed 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 training, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation.

(34 CFR § 300.43)

A way to better understand the process of transition is to imagine special education transition services as the framework of a bridge that connects a student's school opportunities and experiences on one side to community-based opportunities and life experiences on the other side. Students receiving special education services, and their educators, with a pragmatic emphasis on life outcomes, consciously work to link the two sides.

There is quite an array of information regarding transition practices available to those interested (Blalock, Patton, Kohler, & Bassett, 2008). The area of transition includes everything from transition law, transition practices, accountability, students with learning disabilities transitioning into colleges and universities, emotionally disturbed students entering the workforce, students with autism in school and work, and more (Wright, 2011). There has been progress, especially in the idea of shifting the focus from

what the student with disabilities cannot do, to what the student can do, turning disabilities into capabilities (IDEA-B, 2004). The emphasis in the law concerning transition for students with intellectual and/or developmental disabilities (ID/DD) is to enable purposeful meaningful lives for them within their communities.

The focus for transition coordinators, therefore, is on the four life domains of transition: (1) social, recreation, and leisure; (2) adult living; (3) lifelong learning; and (4) employment. These four domains are said to encompass the whole person and, when addressed in tandem, can provide a purposeful and meaningful life (Halpren, 1985; Transition Inventory Manual, 2002), as students transition into their community. The need for community integration is vital for students with intellectual and/or developmental disabilities; otherwise the effect is minimal employment rates and decreased participation in everyday life activities (Dolyniuk, Kamens, Corman, DiNardo, Totaro, & Rockoff, 2002).

Statement of the Problem

Special educators follow the sanctions of the Individuals with Disabilities Act (IDEA), and policy makers have worked to enact legislation for The Americans with Disability Act (ADA) to provide a continuum of support for those with disabilities. State agencies were created to provide services for those with disabilities, as sanctioned in The Americans with Disability Act. However, in Texas, we have long waiting lists for this support, and a very complex system to navigate to the appropriate list. Texas is ranked 50th of the 51 US states, including the District of Columbia, in the services offered adults with disabilities (Bragdon, 2012). For the third year in a row, service agency budgets are being cut. So many already over-extended agencies are being asked to do more with less

(From an agency director, personal communication, November 9, 2011).

Every year, United Cerebral Palsy (UCP), an international advocacy group, produces an annual ranking of how well state Medicaid programs serve Americans with all disabilities, including those with intellectual and developmental disabilities. Medicaid is the critical safety net that provides financial, healthcare security, and community supports to individuals with intellectual and developmental disabilities so that their autonomy, quality of life, and community participation can be better realized, and the four life domains of transition -- social, recreation, and leisure; adult living; lifelong learning; and employment -- can be addressed. Medicaid is considered to be our moral responsibility for those of our citizens with intellectual and developmental disabilities because “it is the duty of a civil society such as ours to aid these individuals, who are often the most vulnerable members of society” (Bragdon, 2012, p.1). Some states do better than others in having the political will to enact the Medicaid policies necessary to achieve better outcomes for their citizens with intellectual and developmental disabilities.

The first annual ranking of how well state Medicaid programs were serving Americans with intellectual and developmental disabilities was published in 2006 (Bragdon, 2012). Since then, Texas has remained at the bottom of the list, without much change.

Significance of the Study

My specific objectives for this study are:

- To describe the policy in place for transition services from birth through age 22 in the public school, and what is actually happening in regards to bridging school and community for our students with intellectual and/or

developmental disabilities;

- To examine the similarities and differences in public policies, laws, and procedures among the 1st, 25th, and 50th states as ranked by the United Cerebral Palsy Organization's publication, *A Case for Inclusion* (Bragdon, 2012); and
- To inform Texas policy makers as to the effects of their policies, by recounting the real life experiences of a family with a student who has intellectual and developmental disabilities.

Pierangelo & Giuliani (2004) believed that the quality of life for individuals with disabilities is contingent upon not only the level of training and support they receive prior to their exiting the public school, it is also contingent upon the connection to the appropriate community resources upon graduation. It is imperative to identify the needs and barriers impeding disabled youth and their families from connecting with the appropriate support systems and formulating a plan of action to secure the necessary supports.

After a Texas family's son graduated from high school they expressed great frustration while trying to navigate the agency system in order to access Medicaid programs for their son with intellectual disabilities. Mom said, "the school brought us to the top of the Grand Canyon and left us there for the agencies to take over. Only instead of a smooth hand-off we were led to the edge where we are left teetering in the wind and about to fall into the abyss" (D. J., personal communication, August 3, 2011).

Definition of Terms

Special education occurs in the context of contentious, confusing expectations, and definitions. The resulting terminology, the language of disability, takes on meanings that stir emotions and may confuse or cause disruption in the discussion (Bently, 2005). In this section, special education policy and practice are defined as they relate to this study, which will enhance the reader's understanding of the issues at stake. Unless otherwise cited, all definitions are found in the Code of Federal Regulations, Title 34 (CFR, 2004).

Individuals with Disabilities Education Act of 2004: Formerly named the Individuals with Disabilities Education Act of 1997 (IDEA 1997). The IDEA mandates special education programs for children and youth aged 0-22. This law has four subchapters, referred to as Parts A, B, C, D. Part A refers to the general provisions of the law. Part B refers to programs and services for school-aged children. Part C provides an outline of programs for infants and toddlers from birth through age three, and part D focuses on technical assistance, grants, and additional implementation requirements and activities.

Special Education: Special Education is specifically designed instruction, offered at no cost, to meet the unique needs of a child with a disability. This includes specialized instruction conducted in a classroom, in the home, in hospitals, in institutions, or in other settings, and includes instruction in physical education. The term takes into account related services as determined by a child's individual education program (34 CFR § 300.39).

Individualized Education Plan (IEP): Once an individual is eligible for special education and related services, school districts are obligated to develop an IEP. An IEP

is a written statement of the program for a child with a disability that is developed, reviewed, and revised in a team-meeting format. The IEP specifies the individual educational needs of the child and what specific special education and related services are necessary to meet those needs (34 CFR § 300.22).

Developmental Disability: The developmental Disabilities Assistance Bill of Rights Act of 2000, defines developmental disability of an individual five years of age or older that is attributable to a mental or physical impairment or a combination of mental and physical impairments. Developmental disability is manifested prior to age twenty-two and is likely to continue indefinitely. These disabilities result in functional limitations in three or more of the following areas of life activities: self-care; receptive or expressive language; mobility; self-direction; capacity of independent living and economic self-sufficiency. Developmental disabilities are also reflected in an individual's need for a combination and sequence of special, interdisciplinary, or generic services, supports or other assistance that are of lifelong or extended duration and that are individually planned and coordinated (Developmental Disabilities Assistance Bill of Rights Act, 2000).

Intellectual Disability: Intellectual disability is a below-average cognitive ability with three (3) characteristics: intelligent quotient (or I.Q.) is between 70-75 or below, significant limitations in adaptive behaviors (the ability to adapt and carry on everyday life activities such as self-care, socializing, communicating, etc.), and the onset of the disability occurs before age 18. Intelligence refers to general mental capability and involves the ability to reason, plan, solve problems, think abstractly, comprehend complex ideas, learn quickly, and learn from experience (34 CFR § 300.7).

Transition Services: Transition services are a coordinated set of activities conducted by and IEP team for a student with a disability that is designed within a results-oriented process, which 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 training, integrated employment, including supported employment, continuing and adult education, adult services, independent living, or community participation (34 CFR § 300.43).

Termination of Special Education: Special Education services are ended once a student completes high school requirements for a diploma, or reaches the age of 22 (34 CFR § 300.534).

Medicaid: Medicaid was created by the Social Security Amendments of 1965, and was created as an entitlement program that is a joint federal and state project to help states provide medical coverage for low-income families and other categorically-related individuals who meet eligibility requirements. Candidates include the blind, aged, disabled and pregnant women. In essence, Medicaid serves as the nation's primary source of health insurance coverage for low-income populations. Each state administers its own Medicaid program, establishes its own eligibility standards, determines the scope and types of services it will cover, and sets the rate of payment. Benefits vary from state to state, and because someone qualifies for Medicaid in one state, it does not mean they will qualify in other states (U.S. Social Security Administration, Office of Retirement and Disability Policy, 2011).

Format of This Research

This dissertation is organized in 5 main chapters. Chapter 1 provides an introduction to the topic, background of the study, statement of the problem, significance of the study, research inquiry, and definition of terms. Chapter 2 includes a literature review of the historical and legal aspects of special education, the transition process, state-by-state provisions for adults with disabilities, advocacy research and critical disabilities studies. Chapter 3 describes the theoretical framework, an overview of the research design and method of the study, data collection and management procedures, and the procedures used in the analysis of the data. Chapter 4 focuses on the findings the data provided, and Chapter 5 provides the conclusions drawn from the study, the implications for policy making and practice, and a discussion of additional areas of study as suggested by the research.

Chapter Summary

As stated earlier, the goal of my research is:

- to describe the policy in place for transition services from birth through age 22 in the public school, and what is actually happening in regards to bridging school and community for our students with intellectual and/or developmental disabilities;
- To examine the similarities and differences in public policies, laws, and procedures among the 1st, 25th, and 50th states as ranked by the United Cerebral Palsy Organization's publication, *A Case for Inclusion* (Bragdon, 2012); and

- inform Texas policy makers as to the effects of their policies by recounting the real life experiences of a family with a student who has intellectual and developmental disabilities.

This study emerged from the recognition of a lack of information, and opportunities for transition services in the area of graduation from school to integration into the community for students with intellectual and/or developmental disabilities. The focus of this research is on the policies and practice of the state of Texas and the provisions these policies provide for our adults with disabilities as compared to the policies now in practice in other states. What is working and what is needed to improve these practices.

CHAPTER II

Review of Related Literature

Since the mid eighties, there has been a plethora of literature published relating to the transition of high school students receiving special education services to their life after graduation. There are resources detailing the history, models of, and best practice of transition services in the public schools. There is now a growing body of literature regarding the post-school outcomes for adults with disabilities. However, there is little research regarding how students with intellectual and/or developmental disabilities and their families access their community to bridge the gap that connects the student's school opportunities and experiences, on one side, and the community-based opportunities and life experiences on the other.

This chapter provides an overview of special education, giving weight to the literature pertaining to special education transition services for students with disabilities. This literature review delves into the historical and current context of transition practices in special education. Facts about special education, and transition outcomes, the experiences in and beyond the school setting have been obtained from the federally-funded National Longitudinal Studies (NTLS 2, 2005), the Government Accountability Office (GAO) 2012 report to the House of Representatives on Education and the Workforce for students with disabilities, and the United Cerebral Palsy Organization's publication (Bragdon, 2006 - 2012)

This review also addresses advocacy research, with special attention paid to how the constructs of this theory apply to and blend with the theory of critical disabilities

studies; as well as discussion of how the context of these theories in the specific setting of special education transition allow for better understanding.

Special Education

The civil rights movement and the ensuing landmark case, *Brown v. Board of Education* (1954) called attention to the types of discrimination and social injustices that were predominant in our country at that time (Yell, 2005). The case overturned the 1896 decision from *Plessy v. Ferguson* that sanctioned “separate but equal,” which ignored the fact that the school facilities for persons of color were inferior to those intended for Whites.

The civil rights movement was a catalyst that exposed the marginalization of individuals with disabilities on a national level. The attention generated by civil rights groups that petitioned for human and civil rights for people of color also influenced the organization of advocacy groups to demand a federal examination of the civil rights of citizens with intellectual and/or developmental disabilities (Yell, 2005). As recently as 1970, most students with disabilities were excluded from public schools and were either educated at home or institutionalized.

Change is difficult and takes time to develop. Every effort to improve the conditions that brought about the Civil Rights movement took years to change the every day life of those involved. In the 1950s and 60s, the Federal government, with the strong push from advocacy groups such as the Association for Retarded Citizens (ARC), began to develop and validate practices for children with disabilities and their families (2012), and the push continues today.

The Federal government has a long history of response to the push from advocates

for citizens with disabilities (Ed.gov, 2012). The more notable responses include key legislation that supported improved programs and services as early as 1959, for example, the Public Law 86-158, which helped train leaders to educate children with mental retardation; and Public Law 87-715, enacted in 1961, which supported the production and distribution of films for training teachers to reach their handicapped students. In addition, in 1965, legislation known as the Elementary and Secondary Education Act and the State Schools Act was passed (PL 89-313) which provided states with direct grant assistance to help educate children with disabilities.

With a push from parent advocacy groups, by 1968, the federal government had supported training for more than 30,000 special education teachers and related specialists; captioned films viewed by more than 3 million persons who were deaf; and provided education for children with disabilities in preschools and elementary, secondary, and state-operated schools across the country (Ed. Gov, 2012).

However, in the early 70s, American schools educated only one in five children with disabilities, and many states had laws excluding certain students, including children who were deaf, blind, emotionally disturbed, or mentally retarded. As civil rights groups were advocating for the rights of people of color, disability advocacy groups vied for legal action against state boards of education that denied children with disabilities access to public education.

Significant cases that set the precedence for subsequent rights to education were the *Pennsylvania Association for Retarded Citizens v. Commonwealth of Pennsylvania* (1972) and *Mills v. Board of Education of the District of Columbia* (1972). In 1975, the issues in these cases led to the passage of Public Law 94-142, the Education for All

Handicapped Children Act (EHCEA) (Yell, 2005).

Before the enactment of Public Law 94-142, EHCEA, the future for many individuals with disabilities was dim. Too many citizens lived in state institutions for persons with mental retardation or mental illness. In 1967, state institutions were home for more than 200,000 persons with significant disabilities. Many of these facilities provided minimal food, clothing, and shelter (Ed.Gov, 2012). Too often, citizens with severe disabilities were merely accommodated, rather than assessed, educated and rehabilitated.

Included in the archived history of special education by the federal government is found the story of “Allan.” Allan was left as an infant on the steps of a state institution in the late 1940s. By age 35, he had become blind through self-abuse while sitting in the corner of the institution rocking back and forth and humming to himself. In the late 1970s, after passage of Public Law 94-142, Allan was assessed properly for the first time and found to be of average intelligence, and that he had learned his self-deprecating behavior from observing others in the institution. The institution then began through special programs now provided to teach Allan, although a major portion of his life was lost because of a lack of appropriate interventions and assessments (2012).

Allan’s story was repeated in the lives of tens of thousands of individuals with disabilities who lacked the support of laws such as Public Law 94-142 (Yell, 2005). Until the passage of such laws, most families were not provided the opportunity to be involved in the planning or placement decisions regarding their children with disabilities. The resources were not available to enable children with significant disabilities to live at home and receive an education within their own communities.

EHCEA, PL 94-142 proved to be the cornerstone of special education, requiring public schools to provide a free and appropriate public education (FAPE) to students with a wide range of disabilities, including physical handicaps, mental retardation, speech, vision and language problems, emotional and behavioral problems, and other learning disorders (Learning RX, 2012). Data collected in the mid 70s and 80s revealed that post school outcomes for students with disabilities were a cause of great concern. The data reflected 40% to 90% unemployment rates for students with disabilities after exiting from high school (Halpren, 1985). Policy makers determined from the data that special education teachers should consider and be concerned with what happens when their students graduate from their schools (Halpren, 1985).

In 1990, EHCEA was updated and renamed the Individuals with Disabilities Education Act (IDEA). IDEA has since been reauthorized. In 2004, the act was renamed the Individuals with Disabilities Education Improvement Act, still called IDEA.

Transition

In 1984, Madeleine Will authored the first Federal Transition Initiative. Madeleine at the time served as the Assistant Secretary to the Director of the Office of Special Education and Rehabilitative Services (OSERS) (Lehman, Clark, Bullis, Rinkin, & Castellanos, 2002). This initiative spelled out the services needed to facilitate the transition from school to work for students with disabilities. Funding was provided to create demonstration models, research, evaluation, and reporting of findings.

Based on these findings, two models of transition practices were proposed, one by Will (1984) and the other by Andrew Halpern (1985). Will's model emphasized employment as the key outcome. Halpern's model emphasized community adjustment,

which consisted of three components: employment, residential adjustment, and establishment of social and interpersonal networks, as well as how to achieve success in these domains by emphasizing the importance of empowering youth to make their own decisions and establish their own goals (Yell, 2005).

Also in 1984, the Carl D. Perkins Vocation and Applied Technology Act (P.L. 101-392) passed. This act provided funding for schools to provide the related services needed to enable students with disabilities to successfully complete vocational training and participate in career development (Lehman, et al., 2002).

With all of the advances that transition practices were making, two significant limitations occurred. The 1986 legislation session did not mandate transition services, and there was no funding made available for the previous projects. However small, the transition practices in place proved to be successful for the students receiving these services (Halpern, 1993). With this knowledge, the reauthorization of the Individuals with Disabilities Education Act (IDEA, 1990) mandated the continuation of transition practices, which was carried over into the reauthorization of IDEA (2004). In essence, the belief that individuals with disabilities should enjoy a better quality of life began to impact practice and policy (Yell, 2005).

Transition as a service moved from being an afterthought and an incidental feature of an IEP to an integral component of a student's educational program. Transition-focused special education shifted the focus from disability deficit or categorical services to an approach grounded in consideration of individual student choices and post-secondary needs in a variety of domains (Kohler & Field, 2003).

The section of IDEA (2004) that is relevant to this research is Part B. Part B

mandates for all students with disabilities to be provided a free and appropriate public education, and defines special education as “specifically designed instruction, at no cost to the parents, to meet the unique needs of a child with a disability, including instruction in a classroom, in the home, in hospitals, in institutions, and in other settings, and instruction in physical education” (34 CFR § 300.26). Also included is a transition component to ensure that educators are taking into consideration the future needs of their students with disabilities (Yell, 2005).

Transition is to be systematic and instructional, providing an Individual Education Plan (IEP) that not only considers the individual needs of the student, but the student’s strengths, preferences, and interests. The IEP must also consider the future endeavors of students with disabilities and their integration into their communities after leaving the public school system (IDEA, 2004).

Part B requires that IEPs address how the educational program will improve the academic, developmental, and functional needs of the student and will facilitate transition to post-school activities, including postsecondary education. These services are to begin no later than the student’s 16th birthday, or earlier if appropriate, and be updated annually thereafter. The IEP must include appropriate measurable postsecondary goals based upon age-appropriate transition assessments, related training, education, employment, and, where appropriate, independent living skills, and the transition services needed to assist the student in reaching these goals (IDEA, 2004).

Before the transition mandate, the move from school to adult life for a student with a disability was determined by the student’s disability, the family, and the agency resources that were available at the time. The resources that were most typical of the pre-

transition era included state-run sheltered workshops apart from families, or centers that provided day care for persons with severe intellectual disabilities (ARC, 2012).

Pursuant to state and federal law, special education services provided in public schools will be available only to entitled students ages 3-21. At which time, they age out of the public school system and officially graduate. Graduation terminates a student's entitlement to services. A student receiving special education services who is 21 years of age on September 1 of a school year is entitled for services through the end of that school year. This is in accordance with the Texas Education Code (TEC), §§29.003 (1996). For individuals with developmental disabilities and their families, graduation from high school, means an end to any support.

For many adults with developmental disabilities, the majority of their social activities, their living situations, and learning continued only within the context of their own families or within a sheltered setting apart from their own home community (deFur, 2003). Transition for youths with disabilities has been referred to as the “transition cliff” (Podmostko, 2007); because of the shift in eligibility for adult services verses the entitlement of special education services in the public schools.

Eligibility vs Entitlement

It is important to understand the difference between eligibility and entitlement programs. The Individuals with Disabilities Education Improvement Act of 2004 (IDEA) assured that all children with a disability were entitled to a free, appropriate public education, designed to meet their unique needs. When high school ends, after graduation, these entitlements no longer apply. When citizens with disabilities seek out the support of government programs and services, these programs operate under another law—the

Rehabilitation Act of 1973. This law requires applicants to meet certain criteria in order to be eligible, not entitled, for services.

Rehabilitation Act

One of the most important pieces of legislation during the 1970s was the Rehabilitation Act of 1973. Section 504 of this act, put in almost as an afterthought, made it illegal for any federal agency, public university, defense or other federal contractor, or any other institution that received federal funding to discriminate against anyone solely on the basis of disability. The language of Section 504 was the same as that of the Civil Rights Act of 1964. At the time, the Nixon administration and disability activists thought the Rehabilitation Act was just a funding bill (Howe & Fernald, 2010). No one debated Section 504, or seemed particularly concerned with civil rights protection. Disability activists soon realized what had happened, as did the Ford Administration. The Department of Health, Education, and Welfare (HEW) estimated that compliance with Section 504 could cost billions of dollars. This stalled the issuance of the final regulations.

The new secretary of HEW in the Carter Administration, Joseph Califano, assigned a group of lawyers to rewrite the Section 504 regulations (Howe & Fernald, 2010). Disability activists descended on Califano, holding a candlelight vigil at his house asking him not to rewrite the regulations. Four years after the law had been passed, Califano gave in to the protests; the advocates won and the regulations were signed without change.

Section 504 requires that qualified individuals, those who are eligible because of their disabilities will not be excluded from, denied access to, or be subjected to

discrimination under any program or activity that receives federal financial assistance. Section 504 has promoted the development of disability support services in colleges and universities, and has driven the federal government to write disability employment policies and is enforced through the Office for Civil Rights (OCR).

Transition in Texas' Schools

Today in the state of Texas, transition is an enigma for educators, in that the results may not be seen right away. As is so often the case in education, teachers may not see the results of their efforts with and for a student until years later, when they hear what that young adult is doing to be a productive citizen in his or her community. The process, though, is a very community-oriented plan that involves the students, families, teachers, and any other support people in the students' lives. This assures teachers that after all of their work, when the student leaves the safety net of special education, the student has a community of support and a plan for success that helps to facilitate a purposeful and meaningful life.

Transition practices required by IDEA today have been founded in the results of evolving research investigating which elements produce improved post-school outcomes (Blalock, & Patton, 2008). The research is also becoming more accessible, in that researchers are helping teachers and district leaders understand how to use the information to improve their practice (Dell'Angela, 2010).

When it comes to improving the teacher's use of the transition tools, it is not the quantity of data that counts, but how the information is used (Dell'Angela, 2010). Using the information from transition training, teachers are able to observe the change in their students when they understand the purpose of their education and are a part of developing

a plan for their future (Wehman, 2006). When the students have buy-in to their own education they work harder to achieve their own desired results. This changes the context for teachers for the whole process, the time invested, and the extra work that is needed to fulfill the intent of the law (Wehman, 2006).

Everything we do in special education evolved from legislative code. Recently, the Texas House, passed a bill that required transition services to begin at the age of fourteen, instead of the current requirement, at age sixteen (Tx-SB 1788, 82 Cong. 2011). The goal of this change in transition planning is to ensure that students gain the skills and services needed to succeed in life (Flanagan, 2002).

IDEA (2004) recognizes that transition practices can better prepare students with disabilities to enter the workplace, continue to learn, be as independent as possible, and contribute to their community. In the development of a student's Individual Education Plan (IEP), teachers must take into consideration what the student wants to do when he or she leaves high school. Post-school activities include post-secondary education, vocational training, integrated employment, and independent living. These must be a documented, coordinated set of activities that proves the school has taken into account student preferences, interests, and include instruction, community experiences, employment objectives, and daily living skills (IDEA, 2004).

Research based on the objectives of IDEA (Halpren, 1985; Transition Inventory Manual, 2002) suggests that transition planning focus on four life domains whenever the planning with students takes place. These four domains are: (1) social, recreation, and leisure, (2) adult living, (3) lifelong learning, and (4) employment. Transition from school to adult life for any student is a complex process involving many people,

decisions, and activities. It is all the more complex for students with disabilities, and therefore, requires much time. Now that the mandate is to provide transition services to students who have reached the age of 14, middle school special education teachers have to fulfill the new legislation for their students.

The law leaves much room for school districts to design how they will carry out the IDEA mandate of transition services (Test, Mazzotti, Mustian, Fowler, Kortering, & Kohler, 2009). As long as they are able to show that the state required twelve-point checklist (see Appendix A) is being addressed in very specific ways, school districts are considered in compliance with the law. The checklist involves assuring that the students have been provided a transition plan that includes the student's input along with the parent's input on plans for the future. The district must show that the student has a plan in place that verifies there is a coordinated set of activities (IDEA, 2004) to enable the student to reach his or her dreams and that if an outside agency will be needed to support the student when they graduate from high school, the agency is to be invited to meet with the student.

There is evidence that transition services statewide are making a difference for our students receiving special education services (GAO, 2012). One such report, *The Texas Effectiveness Study; Post School Experiences* (2006), summarizes the educational and post-school experiences of twenty former high school students, ten of whom received special education services while attending high school. Of these ten individuals, four report that one year after high school they were receiving assistance from a state agency as well as partial support from Medicaid. Five of the students work. Only one is attending a post-secondary education program. Two of the ten participants in this case

study are active in their community or volunteer with community organizations.

National Studies on Transition

On the national level, transition practices are documented through a national longitudinal transition study (2005). This study was prepared for the Office of Special Education Programs of the U.S. Department of Education (OSEP). The National Longitudinal Transition Study–2 (NLTS2) was the second study of its kind, lasting ten years and generating information on the experiences and achievements of youth with disabilities in multiple domains during their secondary school years, and in their transition to young adulthood.

The first study (NLTS 1, 1987-1993) examined the schooling experiences, disability characteristics, and academic achievements of a nationally-representative sample of secondary students with disabilities. NLTS 1 focused on the experiences of more than 8,000 students aged fifteen to twenty-one as they transitioned from secondary school to early adulthood (Wittenburg & Maag, 2002). One important finding of the report was that the type of disability significantly influenced post-school outcomes for students who received special education, as evidenced by the fact that some groups had more success in the areas of post-secondary transition than others (Wittenburg & Maag, 2002). Blackorby and Wagner (1996) summarized the NLTS 1 data and found that students with intellectual disabilities and/or developmental disabilities had lower rates of accessing their communities, whether it be through employment, volunteerism, living, or social settings, the four life domains that provide for purposeful and meaningful lives.

In 2000, a second NLTS study (NLTS 2) was commissioned. This study involved more than 11,000 youth who were ages 13 through 16 who received special education

services in grade 7 or above on December 1, 2000. The NLTS 2 focused on 28% of youth with disabilities who were out of secondary school and ages 15 through 19 when they were interviewed. The findings presented the characteristics of out-of-school youth with disabilities, their experiences in the post-secondary education, employment, independence, and social domains in their first two years out of high school.

The key findings were that two years after exiting high school, $\frac{3}{4}$ of youth with disabilities are still living with their parents, and $\frac{1}{3}$ have not found a way to become engaged in their communities (Wagner, Newman, Cameto, Garza, & Levine, 2005). The validity of this report is important to this research in that it shows outcomes for high school graduates who received special education services and the National Longitudinal Study will continue to describe the experiences of youth with disabilities as they age and investigate the programs and experiences during their transition years that are associated with positive results in young adulthood (Wagner, Newman, Cameto, Garza, & Levine, 2005).

The United States Government Accountability Office (GAO) conducted a very telling study. This report is specifically presented to the Ranking Member Committee on Education and the Workforce, and House of Representatives on students with disabilities and how they transition from high school (2012). This study looked at the multiple federal agencies and how their funding supports students with disabilities as they transition from school to community.

The GAO found that students with disabilities face many challenges when trying to access services that may assist them as they transition from high school into their communities (GAO, 2012). Eligible students with disabilities are entitled to transition

planning services during high school, but after leaving high school, to receive services that facilitate their transition, they must apply as adults and establish eligibility for programs administered by multiple federal agencies. Students may face delays in services and end up on waitlists if these programs are full. In addition, while improvements have been made, parents and students still report that it is difficult to navigate the system of agency providers, and for providers to coordinate services across different programs.

GAO also noted a lack of sufficient information or awareness of the full range of service options available after high school on the part of students with disabilities, parents, and service providers (GAO, 2012). The Department of Education, Health and Human Services, Labor, and the Social Security Administration coordinate transition activities to some degree, but their coordination has limitations and they do not assess the effectiveness of their efforts (GAO, 2012). The conclusions that developed out of this research is that the current federal approach to assisting students with disabilities in their transition to their communities necessitates that students and their parents navigate multiple programs and service systems to piece together the supports the students need to achieve maximum independence in adulthood. Under this complex structure, information dissemination and service coordination are essential.

Without receiving accurate and timely information about available services, students may miss opportunities to access needed services that could mean the difference between achieving an optimal level of independence and longer reliance on public assistance to meet their basic needs (GAO, 2012). Coordination barriers need to be broken down, only then can agency providers systematically address the persistent

transition challenges and improve outcomes for students with disabilities. Assessment of agency provider effectiveness is also an important addition to the improvements that need to occur.

There are four agencies that have the primary responsibility for administering the Federal programs that can provide services to transition-age youth with disabilities. The four are: (1) Education Rehabilitation Services Administration, which funds vocational rehabilitation programs; (2) The Department of Labor, which is a comprehensive workforce investment system; (3) The Social Security Administration which provides cash benefits to qualifying individuals with disabilities; and (4) Health and Human Services Centers, which manages Medicare and Medicaid services. Within the Medicaid program, states provide home and community-based services to individuals with certain types of disabilities who might otherwise be cared for in institutional settings. Because Medicaid usually does not cover home and community-based services, states must obtain a waiver to provide these services. These waivers vary by state, are individualized, and may include different services by state (GAO, 2012).

Recommendations from the GAO include improving transition services through enhanced coordination among the multiple Federal programs and the Commissioner of the Social Security Administration, directing the appropriate program offices to work collaboratively to develop a federal interagency transition strategy that includes compatible policies, methods to increase awareness of the providers and their services, and ways to assess the effectiveness of the Federal coordination efforts (Moran, 2012).

The Difference a Few Words Make

The term Mental Retardation was wiped from all federal health, education, and labor laws and replaced with “intellectual disability” as part of a 2010 measure designed to foster sensitivity toward Americans living with such disabilities (Sweet, 2010). The legislation forcing the change is known as Rosa’s Law and was signed into law by President Obama on October 5th, 2010. The law is named for Rosa Marcellino, age 9, who has Down Syndrome and worked to force these changes. President Obama said that “Now this may seem to some people like a minor change, but I think Rosa’s brother Nick put it best, he said, ‘What you call people is how you treat them. If we change the words, then maybe it will be the start of a new attitude towards people with disabilities.’ That’s a lot of wisdom from Nick” (Sweet, 2010).

Quality of Life

Halpern (1993) proposed that education and employment are the primary indicators of quality of life. He used his meta-analysis to develop three domains that measure a person’s quality of life: (1) physical and mental well-being, (2) performance in adult roles and through completion of adult tasks, and (3) personal fulfillment. Quality of life as a measureable experience began to be factored into the post-school planning for individuals with disabilities. In the early ‘90s, placement in sheltered workshops and vocational centers began to be considered an antiquated way of measuring community integration and employment opportunities for individuals with intellectual and/or developmental disabilities.

Halpern’s (1993) analysis of quality of life asserted that supported employment in the community offered greater opportunities for other forms of community integration

when compared to sheltered employment. Quality of life was most evident for individuals who had access to community employment when considerations were provided for our citizens with disabilities to live as independently as possible with purpose and meaning (Transition Inventory Manual, 2002).

The Case for Inclusion

Each year, since 2006, United Cerebral Palsy (UCP), an international advocacy group, produces an annual ranking of how well state Medicaid programs serve Americans with all disabilities, including those with intellectual and developmental disabilities. Medicaid is the critical safety net that provides financial, healthcare security, and community supports to individuals with intellectual and developmental disabilities so that their autonomy, quality of life, and community participation can be better realized, and the four life domains of transition; social, recreation, and leisure; adult living; lifelong learning; and employment can be addressed.

Nationwide, Medicaid serves more than 530,000 individuals with intellectual and/or developmental disabilities, spending over \$27.4 billion, or more than \$52,000.00 per person per year. Although this is a small portion of the number of individuals enrolled overall in Medicaid, Americans with disabilities are some of the most vulnerable Medicaid recipients (Bragdon, 2006). Individuals with intellectual and/or developmental disabilities make up just 1.3% of all Medicaid recipients, but 9.5% of Medicaid spending. Despite these figures, too often this population is not considered in the discussions about Medicaid funding (Bragdon, 2006).

Like all Americans, individuals with intellectual and/or developmental disabilities deserve to live in the community and experience a quality, meaningful life (Lakin & Larson, 1999). Medicaid can play a crucial role in making that a reality (Bragdon, 2006).

The Case for Inclusion study (Bragdon, 2006) involves a three-part effort:

(1) Nationwide scan of state Medicaid programs which includes a compilation of data about each state, its Medicaid program, its Medicaid-funded services to individuals with intellectual and/or developmental disabilities and key outcomes, and interviews with key Medicaid and disability experts across the country; (2) a ranking of all states, with further research of top-performing states through a weighted scoring methodology, identifying top-performing states, and further analysis of how and why certain states best support individuals with intellectual and/or developmental disabilities through Medicaid; and (3) Creation of state-specific improvement plans for United Cerebral Palsy affiliates which empowers local advocates with a state improvement plan containing clear, meaningful steps as to how they can replicate success within their own state.

The Case for Inclusion report for 2012 added enhancements to the above three-part effort. The United Cerebral Palsy Organization published all of their subsequent reports to enable policymakers, advocates, and voters to have access to each state's performance data on Medicaid funding for individuals with intellectual and/or developmental disabilities.

The 2012 report broadened its focus on quality assurance measures by rewarding states that participate in the National Core Indicators (NCI). NCI is the voluntary effort by public developmental disabilities agencies to measure and track their own performance. The core indicators are standard measures used across states to assess the

outcomes of services provided. There are five broad categories and more than 100 data measures within these categories.

In the 2006 report, the main findings from the state rankings revealed that (1) too many Americans with intellectual and/or developmental disabilities are still not living in the community; (2) too much funding for individuals with intellectual and/or developmental disabilities is directed at large institutions rather than community-based services; (3) quality assurance efforts are too few; (4) too many working-age individuals may not be engaging in meaningful activities as evidenced by low competitive employment participation; (5) many states are not helping individuals transition from Medicaid to work; and (6) too few states prioritize self-directed services as evidenced by providing significant personal assistance funding (Bragdon, 2006).

An additional finding of interest was that it is not just about the money (Bragdon, 2006). While funding levels are critical, increased spending alone does not guarantee higher quality of service, neither do high tax burdens buy better results, and it is not about which political party is in control of the governor's office and the state legislature high and low rankings cut across party lines. There is a high correlation to a state's high ranking when a state prioritizes community inclusion with its funding (Bragdon, 2006).

The results of the state rankings in 2006 placed New Hampshire at number 1 for Medicaid policies and practices. Tennessee is the mid-point, and Texas comes in last at number 51 (Bragdon, 2006). To comprehensively determine the top-performing states, a weighted scoring methodology was developed. Thirty key outcome measures were selected and individually scored in ten major equally weighted categories on a 100-point scale.

In 2006, key facts about the top ten states were very diversified. They were geographically varied, politically diverse, had both high and low tax burdens, had high and low socio-economic standings, and had both large and small Medicaid programs (Bragdon, 2006).

The Case for Inclusion 2012 (Bragdon), included four key aspects of a high functioning Medicaid program (The University of Minnesota's Research and Training Center, 2005). The promise of access to and support for integrated community lives and roles for persons with intellectual and/or developmental disabilities is clearly expressed in national legislative, judicial, administrative and other sources that make four basic commitments: (1) people with disabilities will live in and participate in their communities: promoting independence; (2) people with disabilities will have satisfying lives and valued social roles: promoting productivity; (3) people with disabilities will have sufficient access to needed support and control over that support, so that the assistance they receive contributes to lifestyles they desire: keeping families together and reaching those in need; and (4) people will be safe and healthy in the environments in which they live: tracking quality and safety.

The results of the state rankings for 2012 placed Arizona at number 1, Louisiana moved to number 25, and Texas moved up one point to number 50 (Bragdon, 2012). Louisiana improved 19 places since the 2007 report because the percentage of individuals and resources dedicated to community services over institutions rose. And Louisiana had a large drop in the percentage of individuals served in large institutions.

Use of The Case for Inclusion helps advocates and policymakers understand how their states perform overall in serving individuals with intellectual and/or developmental

disabilities. It clearly states what services and outcomes need attention and improvement in their state, and what top performing states are doing differently (Bragdon, 2012).

Advocacy Research and Critical Disabilities Studies

In this qualitative study, I used advocacy research as my theoretical framework, supported by the literature of critical disabilities studies. Advocacy research is a type of descriptive policy research carried out by people who are deeply concerned about certain social problems (Marshall, 1998). Through this study, I explored one particular social problem in order to heighten public awareness of it and to provide a catalyst for policy proposals and other action to mitigate the problem in question (Marshall, 1998).

Among the studies reviewed, Tweedie (2006) explained advocacy research as generally understood as a process that aims to bring about change in public policy or practice. Public policy can be generally defined as a system of laws, regulatory measures, courses of action, and funding priorities concerning a given topic brought to the forefront by a state representative (Kilpatrick, 2000). Advocacy research is concerned with achieving equity and social justice through empowerment of disadvantaged, marginalized people, so that they can participate more directly in the decision-making processes that affect their rights and their lives.

According to Neuman (2000), advocacy research arose from the works of Marx, Adorno, Marcuse, Habermas, and Freire (as cited in Creswell, 2003). Advocacy research should be intertwined with politics. Specific issues need to be addressed that speak to important social issues, such as empowerment, inequality, and oppression. The bottom line in advocacy research is to create a political debate and discussion so that change will occur (Creswell, 2003).

Advocacy research creates space or opportunities for those affected by the issues to advocate on their own behalf (Tweedie, 2006). However, in this case, the citizens in this study may not be able to participate freely and directly in their own self-advocacy. They are young adults with severe intellectual disabilities who are often non-verbal, and for lack of a better term, locked inside their bodies. Those with severe intellectual and developmental disabilities will always need someone to advocate for them, support them, and provide for them.

Civic participation is the essence of democracy. The First Amendment to the United States Constitution makes provision for the freedoms of speech and association. The ability of any citizen to advocate for the common good is unique in our history. In describing early America, Alexis de Tocqueville (1985) wrote:

As soon as several of the inhabitants of the U.S. have taken up an opinion or a feeling which they wish to promote in the world, they look out for mutual assistance; and as soon as they have found one another out, they combine. From that moment they are no longer isolated men, but a power seen from afar, whose actions serve for an example and whose language is listened to. Nothing, in my opinion, is more deserving of our attention than the intellectual and moral associations of Americans. If men are to remain civilized or to become more so, the art of associating together must grow and improve in the same ratio in which the equality of conditions is increased.

(de Tocqueville, 1835)

The success of major social movements throughout the last two hundred years have

been the result of dedicated advocates and effective advocacy research (Johnson, 2006). Most social change started out as an advocacy activity, but ended with major lobbying efforts to change or enact laws for the common good.

A Special Interest Group

In 1999, a special interest group of the American Educational Research Association initiated a growing movement in educational research, theory and practice, called Disability Studies in Education (AERA, 1999). The mission of the Disability Studies in Education Special Interest Group is to promote the understanding of disability from a social model perspective drawing on social, cultural, historical, discursive, philosophical, literary, aesthetic, artistic, and other traditions to challenge medical, scientific, and psychological models of disability as they relate to education (SIG # 143, from AERA, 1999). The members of this special interest group defined critical disability studies as an “emerging interdisciplinary field of scholarship that critically examines issues related to the dynamic inter-plays between disability and various aspects of culture and society” (Gabel, 2004, p.1). This type of study unites critical inquiry and political advocacy.

In order to qualify as critical inquiry, a study needs to meet three criteria: it must be explanatory, practical, and normative (Bohman, 2012). According to Max Horkheimer (as cited in Bohman, 2012), critical inquiry must explain what is wrong with the current social reality, identify who can change it, and provide both clear norms for criticism and achievable practical goals for transformation. Uniting critical inquiry with advocacy research may help identify and provide the opportunity to make clear the public policy priorities which can be used to educate the public and policy makers, thereby improving on the public policy making for, in this case, individuals with intellectual and/or

developmental disabilities.

Research can be a powerful advocacy tool because it provides policy makers with accurate facts and figures. Policy makers do not come up with laws in a vacuum (Bass, Arons, Guinane, & Carter, 2007). When presented with the facts and figures, policy makers may no longer be able to ignore an issue. This research can not only be used by lawmakers to gain support for their position, it may provide concrete tools to convene around and mobilize new and improved ways to support our citizens with intellectual and /or developmental disabilities.

Partners in Policy Making

Founded in 1987 in Minnesota, by the Governor's Council on Developmental Disabilities, Partners in Policy Making (Partners In Policy, 2007) is one of the more forward-thinking ventures of the Governor's council. Partners In Policy is a leadership-training program for adults with disabilities and parents of young children with developmental disabilities. The program has two goals: to teach best practices in disabilities, and to develop the competencies of influencing public officials.

State Partners programs have been implemented in 46 states since 1987 (Partners In Policy, 2007). More than 13,000 people have graduated from the Partners In Policy training programs and are part of a growing national and international network of community leaders serving on policy-making committees, commissions, and boards at all levels of government.

Partners in Policy Making (2007) was the first training venture in the curriculum of the Governor's Council, in 1987. It has since expanded to meet current needs with courses that can be completed in three to eight hours online, titled Partners in Time,

Partners in Education making your Case, Partners in Employment, and Partners in Living.

In Texas, The Governor's Council on Developmental Disabilities mission is to "create change so that each individual is able to be fully included in their own communities and exercise control over their own lives" (Texas Council for Developmental Disabilities, 2004). This year, the Council has published a state plan, including goals and objectives through the year 2016. These goals include working with the Texas Education Agency to improve the services children with disabilities receive in school districts across Texas, and to look into how services can improve as these children transition into their community (Texas Council for Developmental Disabilities, 2012).

Advocacy and Legislation

The civil rights movement and related legislation inspired parents' efforts to work to change their schools and communities for their sons and daughters with disabilities (Yell, 2005). However, parents also understood that societal change and the elimination of prejudice would take time. Essentially, attitudes cannot be legislated, and education is needed for any reform. The noted educator, Paulo Freire (1970) promoted education as a means to transform society for the better. Freire wrote:

Education either functions as an instrument which is used to facilitate the integration of generations into the logic of the present system and bring about conformity to it, or it becomes 'the practice of freedom,' the means by which men and women deal critically and creatively with reality and discover how to participate in the transformation of their world. (p. 72)

Advocates for disability rights, have continued their efforts to affect change in

society by engaging in what the sociopolitical theorist Max Weber (1968) called social action. Weber's social action theory is summarized in his own words: "We can [through social action] accomplish something which is never attainable in the natural sciences, namely the subjective understanding of the action of the component individuals" (pp. 24-25). Hanna Arendt (1998), a noted political writer and contemporary of Weber, stated

Action would be an unnecessary luxury, a capricious interference with general laws and behavior, if men were endlessly reproducible repetitions of the same model, whose nature or essence was the same for all and as predictable as the nature or essence of any other thing. (p. 8)

It is through education and social action that advocates hope to change the policies of lawmakers to improve the services provided to those with intellectual and/or developmental disabilities in our schools, communities, society, and the world.

Chapter Summary

Special education services have been improving since the mid-1900s. The Individuals with Disabilities Education Improvement Act (2004) mandates transition services for all students with disabilities. These services are designed to prepare students for life beyond school and in the community. The literature suggests that there needs to be better communication among families, schools, and providers in order to bridge the transition from the school into the community for individuals with intellectual and/or developmental disabilities. Texas policymakers need to understand the provisions that Medicaid can make to improve the lives of our citizens with disabilities in order to improve the provision of our state services.

CHAPTER III

Method of Research

The job of an intellectual does not consist in molding the political will of others. It is a matter of performing analyses in his or her own fields, of interrogating anew the evidence and the postulates, of shaking up habits, way of acting and thinking, of dispelling commonplace beliefs, of taking a new measure of rules and institutions... it is a matter of participating in the formation of a political will, where the intellectual is called to perform a role as a citizen.

Source: Foucault, M. (1984) in an interview with *L'Espresso*

The purpose of this study is to describe the policy in place for transition services from birth through age 22 in the public school, and what is actually happening in regards to bridging school and community for our students with intellectual and/or developmental disabilities. I examined the similarities and differences in public policies, laws, and procedures among the 1st, 25th, and 50th states, as ranked by the United Cerebral Palsy Organization (Bragdon, 2012), and in order to inform Texas policy makers as to the effects of their policies by recounting the experiences of a family with a student who has intellectual and developmental disabilities.

In this qualitative study, I used advocacy research supported by the literature and theory of critical disabilities studies. The use of qualitative research in policy analysis was necessary in order to identify the factors that contribute to or inhibit effective

implementation of policies (Yanow, 2000), and to provide policymaking bodies with the rationale for inclusion of socially-informed directives in their policies (Giroux, 1992).

Encouraged by Moses and Gair's (2004) discourse regarding researchers' abilities and desires to transcend ideological perspectives when conducting research involving policymaking, I was drawn to this study informed by my own professional experience and intuition. Staying true to the qualitative nature of this study, I did not assume independence from any ideology, but rather attempted to fully examine and represent multiple perspectives involved (Krathwohl, 1988).

Peshkin (1990) acknowledged that the subjectivity of researchers is an inevitable and natural occurrence, but that they should strive for objectivity. Moreover, the ways in which personal or professional interests and subjectivity influence data collection and analysis depends upon the researcher's acknowledgement of this subjectivity and candid recognition of its impact. Such information should be clearly indicated in the study results (Peshkin). In this study, any subjective biases have been identified and documented in this section.

My main task was to introduce dialogue into the current conversation of policy with the purpose of identifying sources leading to understanding successful practices that may provide the impetus for change and a more feasible system for citizens with intellectual and/or developmental disabilities when accessing agency support in Texas.

Advocacy research is a type of descriptive policy research, carried out by people who are deeply concerned about certain social problems (Marshall, 1998). The methods involved in conducting advocacy research supported by critical disabilities studies included a combination of extensive document analysis, interviews, a focus group, and

observations. To solidify the research, I kept a study journal of reflections from the observations, the data findings and evidence from the documents and interviews.

The document analysis included, but was not limited to, state expenditures per capita in Medicaid, how monies are allocated and budgeted, and the programs these afford. This analysis also included relevant public school transition program policies and services. These documents were all publicly accessible. The interviews, which were unstructured and open-ended, and in which I took interview notes (Creswell, 2003), were with individual state legislative advocacy supporters involved in the decisions for state expenditure for Medicaid in Arizona, Louisiana, and Texas, and a parent with a young adult with intellectual and developmental disabilities who is currently navigating the system in Texas.

I conducted interviews with state agency administrators who have the task of disseminating the funding allocated for Medicaid by their policy-makers. A focus group made up of area transition coordinators from central Texas public schools also provided valuable information.

In light of the increased attention to transition for students with disabilities and after reviewing the literature related to advocacy research, I felt that an account of the contexts of special education transition services was needed. It also became clear to me that the results from this inquiry may aid policy makers in identifying effective resources for our citizens with disabilities as they move from school into the community. A rich narrative garnered of the experiences of a family currently navigating the resources available made for a compelling portrait. As indicated by Seidman (2006), the portrayal

of human experience through narrative is a powerful way of understanding a particular issue or event.

A qualitative research design provided the means for making clear the events that occur when a citizen with intellectual and/or developmental disabilities transitions from high school into his or her community. Supporting a purposeful and meaningful life for citizens with disabilities with an emphasis on policy provided the context within which to study the structure, activation and potential of services provided for by our policymakers.

Patton (2002) listed several key characteristics of qualitative research. It should occur in the real world, be immersed in the details, be data driven with thick rich description. A qualitative approach is appropriate for programs concerned with individualized outcomes. The use of a combination of interviews, documents analysis and observations provided the opportunity for me to be immersed in the details, and gain an understanding of how policy makers are informed for their vote.

Data Collection and Analysis

Data analysis is the process of making sense out of the data. Making sense of data, for me, involved consolidating, reducing, and interpreting what people said, using the documents collected, and immersing myself in the data. After the data collection began, analysis of the data became a side-by-side process. There was a constant shift between reading, reflecting, and analysis. The use of qualitative research necessitates that the researcher continuously move between the data and its meaning (Merriam, 2009).

Organizing and making meaning of the data collected was an iterative process; a continual flow of gathering, analyzing, and gathering more. The process provided the means to make informed decisions and gain discovery by bringing results closer to the

surface with each iteration. From the beginning I kept a journal of field notes that chronicled my own reflections, thinking, perceptions and understandings. This became an integral part of the research process.

Triangulation

Every method has its limitations, and multiple methods are usually needed. Triangulation, as a long-standing rule strengthens a study by combining methods (Patton, 2002) and provides a more detailed and balanced picture of the study. Denzin, (2006) identified this type of triangulation as methodological triangulation, which involves using more than one method to gather data, such as interviews, observations, questionnaires, and documents. Triangulation calls for reporting multiple perspectives rather than seeking a particular truth (Patton, 2002). The perspectives of policymakers, disability advocates, agency administrators, school transition coordinators, and a parent provided these multiple perspectives.

Selection

The documents and the interviewees included were selected based on their ability to illuminate the historical and current aspects of the transition process for persons with intellectual and/or developmental disabilities as they work to access life in their communities after graduation from high school. Interviewee selection was guided by the perspectives needed for this study to ensure representation of the different stakeholder groups associated with policymaking and the ramifications of certain policies as they relate to our citizens with disabilities. The process to determine the right person to interview involved some trial and error on my part. I found that those behind the scenes of policy making were really the ones in the know and the actual up front decision

makers referred me to advocates and aides for the more in-depth answers to my questions.

Analytical Procedure

Inductive analytical procedure involves a back and forth movement within the data until all relevant data is evaluated. The relevance for me was when I had a clear understanding of the data and could apply and interpret the inferences made in context of the research. Identifying text that fulfills the research interests and forming emergent ideation is another layer of this analysis. This was accomplished by gleaning significance through multiple readings, pulling out key words, statements, and recurrent patterns, and comparing and synthesizing insights gained (Wertz, et al., 2011). Checking, revising, and refining my understandings throughout the research process proved to be critical and this was logged in my research journal.

Interviews

Based upon the review of literature and my experience, a set of interview questions was developed (see Appendices C, D, and E). Due to the nature of qualitative research, it was never the intent to use these questions as a strict interview protocol, but more as a guide to assist in thorough coverage of several different areas with the informants in a relatively short amount of time (Creswell, 2003). Allowing the answers to my questions, drive the conversation for a clearer understanding provided the freedom to have understanding and clarity.

Seidman (2006) divided the process of interviewing into the following three parts: determining the pathway or direction, soliciting details, and interpreting meaning. These guidelines provided the framework for organizing the questions included in the interview

protocols for this study. The goal is to have the participant reconstruct his or her experience with the topic under study (Seidman, 2006). Each of the interview protocols were reviewed with an outside colleague to edit for clarity and understanding.

Focus Group

Data was also collected through a focus group, which lasted 90 minutes and was conducted in the conference room of one of the local school districts. The focus group was guided by predetermined questions (see Appendix D). The group comprised of six local school districts transition coordinators.

Interview Sessions

Each individual interview lasted approximately one-hour. These were conducted either through long distance calls or in person at the interviewees preferred location. Each interviewee was contacted an additional time to review my writing and interpretation of our interview as a way to check for accuracy or for more clarification.

I transcribed each interview, which provided me opportunity for further understanding and clarity. Reducing the text involved using coding to mark areas of interest. Analyzing and interpreting the data by crafting a profile of an interviewee's experience gave me a starting point to report the findings (Seidman, 2006).

A variety of artifacts were reviewed. This included, but was not limited to locating the data for the States of Texas, Arizona, and Louisiana on their expenditures of Medicaid and how the spending was allocated by state. Studying the six years of publications from the United Cerebral Palsy Organization's *The Case for Inclusion* report (2006, 2007, 2008, 2009, 2010, 2011, & 2012), as well as the United States Government Accountability Office's report, *Students with Disabilities* (2012). Additional and helpful

data also came from the Office of Special Education Programs, U.S. Department of Education's *National Longitudinal Transition Study* (2005).

Assurance of Confidentiality

Participant confidentiality was ensured both verbally and via written agreement. Pseudonyms were used in this study to protect the identity of participants, individual agency providers and specific locations.

Validity

Miles and Huberman (1994) contended that validity in a qualitative study can be measured by asking, "Do the findings of the study make sense? Are they credible to the people we study and to our readers? Do we have an authentic portrait of what we are looking at?" (p. 278). Relevance may be determined through the following questions: How content rich and meaningful are the details? Does the content make sense, seem convincing, and maintain a vicarious presence for the reader? Is the account comprehensive and representative of the content? Is triangulation achieved? Are areas of uncertainty defined? Did the original interviewees consider the results to be accurate (Miles and Huberman, 1994)?

The final state of the analysis sought the experiences of how one family transitioned their son with intellectual and developmental disabilities into their community. Narratives of experience were developed with an emphasis on the key themes relative to my research.

Chapter Summary

The purpose of this study was to describe the policies in place for transition services from birth through age 22 in the public school, and what is actually happening in

regards to bridging school and community for our students with intellectual and/or developmental disabilities. I examined the similarities and differences in public policies, laws, and procedures among the 1st, 25th, and 50th states, as ranked by the United Cerebral Palsy Organization's publication (Bragdon, 2012), with the intention of informing Texas policy makers as to the effects their policies are having on people by using as a representative, and recounting the real life experiences of a family with a student who has intellectual and developmental disabilities transitioning from school to their community.

In this qualitative study, I used advocacy research, supported by the literature of critical disabilities studies. Explanations of the data collection and analyses were included here as well as the use of triangulation to enhance the validity of this study. Data gathered from this study may be of benefit to practitioners and policymakers in order to enhance transition outcomes for students with intellectual and/or developmental disabilities who requires extensive planning and have complex service needs.

CHAPTER IV

Findings

In this study I described the policies in place for transition services, and what is actually happening in regards to bridging the school and community for our students with intellectual and/or developmental disabilities. I examined the similarities and differences in public policies, laws, and procedures among the 1st, 25th, and 50th states as ranked by the United Cerebral Palsy Organization (Bragdon, 2012). I documented my work informing policy makers as to the effects of their policies by recounting the real-life experience of a family with a son who has intellectual and developmental disabilities as he transitions into his community.

Transition

The Individuals with Disabilities Education Act (IDEA, 1990, 2004) mandates that every school district in every state, address the transition needs of our students with disabilities. This includes school diagnosticians conducting individual assessments that focus on the students' strengths, preferences, and needs, in order to develop a plan that carries individual students from school to post-school activities. The purpose for these transition services, according to the IDEA, is to address how our students will continue to have purposeful and meaningful lives after they leave the special education programs the schools offer and transition into their communities (Yell, 2005)

The Individual with Disabilities Education Acts' mandated that (IDEA, 1990, 2004) school districts appoint staff designated to oversee the transition process (Yell, 2005). Responsibilities for the designated transition staff were developed and have

evolved over the past twenty years to meet increased expectations for the transition process, as IDEA (2004) was reauthorized and the associated laws and policies were amended (see Appendix A). Today, although many larger districts have transition personnel on staff, in the current Texas legislative session there is a bill on the docket (HB 617) that calls for the Education Commissioner to require all school districts in Texas to name an individual designated to oversee effective transition planning and services.

Focus Group

Transition coordinators from area school districts agreed to come together to be a part of my research, when asked to participate in an hour-long focus group. The session actually ran much longer because of the lively discussion the questions sparked. The focus group was comprised of six transition coordinators from Central Texas school districts, four women and two men. The districts they represent vary in size and population. Three districts are small enough that they have only one high school campus. One district has three high schools, another has five, and the largest in our group has six high schools. Although the transition coordinator's job descriptions may vary, the responsibility for following the full extent of the law for transition falls on each coordinator.

The Questions

This section presents the questions I asked and a summary of the responses I got from the focus group (see Appendix D). There was, for the most part, agreement on the answers, as noted.

The first question I asked of the transition coordinators was what they felt their responsibility was toward the post-school outcomes for their students. The consensus that they felt their responsibility was to provide was appropriate vocational assessments for our students, assessments that would enable them to not only place students in the appropriate setting while receiving Special Education Services, but to provide the most accurate information to their families about how to access the outside agency services that will support the student in making a successful transition into their community. To provide training for families to understand what Medicaid can and will do for them and how to access the various programs they may need.

They felt that transition training needs to be provided to the special education teachers. As one transition coordinator said, “Training teachers to boost their students’ independence levels is so crucial for their success when they leave us by building self advocacy and self determination skills which provide our students with the crucial tools they can use for life.” There was a tremendous sense of responsibility expressed by each of the transition coordinators for their students in order to help them engage in their communities whether they go on to post-secondary education, employment or both. The transition coordinators agreed that the goal was to know that their students are living active and productive lives and not just going home to sit on the couch.

I asked what was working well in the school transition programs. Without hesitation, one coordinator said, “the very fact that we are providing transition for our students is very powerful for their futures” and “that teachers as a whole are having to be concerned with what happens to their students when they leave their class stresses the importance of the transition process.” Another said, “we have come a long way in

figuring out how to provide appropriate assessments for our students.” All agreed that they now have some pretty effective tools at the school level to help address the transition needs. For example, the Transition Decision Making Matrix was discussed. This matrix charts the functioning level of each student and draws attention to the four life domains of transition: (1) social, recreation, and leisure, (2) lifelong living, (3) lifelong learning, and (4) employment. Another tool is the Person Centered Planning process. The Person Centered Plan is a way to provide open discussion for students to express his or her dreams and hopes for their future and to create an action plan to help them accomplish these goals.

More discussion regarding the more prevalent opportunities to network with other transition coordinators through newly formed transition organizations and conferences. The support from the Regional Education Service Center (Region XIII) provides regularly scheduled networking meetings, which creates natural ways to collaborate, understand, and develop best practices for serving the students.

Several coordinators praised the legislators for passing legislation that requires schools in Texas to begin transition services at the age of fourteen instead of sixteen (SB 1788). “The earlier we are able to provide transition services the better.”

I asked about the coordinators’ frustrations. This generated a lot of passionate responses. The main issue for the coordinators was their frustration in working with outside agencies providing the support through Medicaid funding when students graduate: as one coordinator said, “they talk such a good talk, they say they are there to serve our students, yet they very rarely come to the schools to talk to our students or their parents.” Another chimed in; “The system is difficult for us to navigate, how are parents

supposed to understand the different agencies when they make it so complicated to even hear about their services?” A common response was that there are so many agencies out there that take Medicaid funding, yet “none of them coordinate their efforts with the other agencies. And it is very difficult to even understand what the different agencies provide and how to access their services if you can’t figure out how it would benefit you.”

They talked about the change in support from public school to community. Educators provide job development, training, coaching, and support. When students graduate, the agencies are supposed to provide a continuum of services so that these young adults with disabilities can keep their jobs and continue to learn lifelong vocational skills. However, as the agencies deal with continual budget cuts, which cause a shortage of staff and a shortage of supports that can be offered. All had experiences with the students who graduated with a job yet lost the job later because they were not able to handle a new problem and had no support to help them with the issue. They also all talked about parents who have had to quit their own jobs because they had to spend so much time trying to get services for their sons or daughters with disabilities.

For each of the past five years, this group of transition coordinators, and I, plan and execute a Central Texas Transition Fair. We invite all of these support agencies, different Medicaid service providers for parents and students to come together and visit face to face to start the conversation about who will do what when students have graduated from school and need the support of these agencies. This past year we had over 70 different providers just for our area.

The transition coordinators in the focus group brought up the Transition Fair and how we all leave with pamphlets and information from each of the different agencies and

businesses and try to make sense of what they do. They said how overwhelming it is when they have a better understanding of the system than the parents. One coordinator said that, “it has to be so overwhelming to our families!” She continued; “Parents get mad and blame us for the lack of support because we are the only ones they can go to. The agencies are not meeting their needs and they are not listening, so they come back to us with a lot of anger.”

I asked the participants to share their greatest need from the school, as opposed to the agencies, regarding transition. The most prevalent response was concern over the lack of support from administrators, their lack of understanding of what transition is and how it should be implemented on campus. Each focus group participant brought up the lack of time allowed for training all of those involved in the transition process, including teachers, campus special education case managers, para-educators, and support service personnel.

All expressed concern regarding budget cuts across the state of Texas that have resulted in a reduction in staff and the expectation that they have to provide more with less. Almost by definition, anyone who works in this area already gives “above and beyond,” said one participant, and now they are expected to stretch even more. There was concern expressed that “people may leave the profession if we do not see a light at the end of this budget cut tunnel.”

I gave coordinators the opportunity to tell their legislators what they would like to say if they had the opportunity. The first comment came from a coordinator from the largest school district; “I wish the legislators could shadow us for just one week. Then they could see what all their legislation is doing to us on a daily basis.” Several other

coordinators joined in when I asked for clarification. They talked about the “complete waste of time state testing is for our students with intellectual disabilities.” The required courses for graduation make it difficult to “fit into their schedule courses that would be of much greater benefit to their future success.” For example, instead of requiring all of the English/Language Arts courses, some could be substituted for more functional education, vocational training, life-skills coaching, and social skills, as well as some career and technology courses that are offered at most high schools.

One of the coordinators expressed herself in such a way that the group collectively agreed that this would be of utmost importance; “We, the ISDs are also a state agency. Why can’t we join forces with the agencies that provide Medicaid and have collaboration of efforts? Instead of having such a complicated system to navigate, why can’t we come together to provide a seamless transition for our students into the community?”

Analysis From the Focus Group

Transition coordinators felt a great sense of responsibility for the students they serve in order for them to be productive and have purposeful and meaningful lives when they leave school. Transition practices have come a long way since the first introduction of the Individuals with Disabilities Education Act (IDEA, 1990). Importance is placed on transition now. Research supports the practice of transition and what it can provide for students (Wagner, Newman, Cameto, Garza, & Levine, 2005). Coordinators’ frustration centers around the way outside agencies are disjointed, do not collaborate, and are difficult to navigate. Parents become frustrated and come back to the school transition coordinators for help.

Transition coordinators would like to invite their legislators to visit them in their schools and let them experience the difficulty that budget cuts cause and to see how inane the state testing is for our students with intellectual disabilities. The suggestion was made to look at the ISDs as state agencies and to coordinate their efforts with the other agencies in order to provide a smooth continuum of services.

The Case for Inclusion

The annual report from United Cerebral Palsy Organization (Bragdon, 2012) ranks how well state Medicaid programs serve Americans with intellectual and/or developmental disabilities. Medicaid is a crucial safety net, providing financial and healthcare security and community supports to Americans with intellectual and/or developmental disabilities. The report ranks all 50 states and the District of Columbia, not on their spending, but on the outcomes they provide for Americans with disabilities (Bragdon, 2012). The report documents how well each state is performing overall, how each state compares against other states regarding key measures, the top performing states, and which of these states' policies and practices that should be replicated. The latest report, (Bragdon, 2012) explains the increased attention given to community living challenges and the resources needed to support citizens with disabilities, as this population increases.

Background

United Cerebral Palsy was founded in 1949, when parents of children with cerebral palsy united in their efforts to seek help and information (Bragdon, 2006). Since its inception, United Cerebral Palsy has been a voice for issues important to people with disabilities. In the 1950s and 1960s, United Cerebral Palsy raised awareness about the

“horrific” (Bragdon, 2012, p. 1) living conditions in state institutions, which eventually lead to the liberation of thousands of people with disabilities from these large institutions nation wide.

United Cerebral Palsy brought the injustices of these large institutions to the forefront and helped create an affiliate network that provided new housing and support solutions to ensure greater independence for people with disabilities (Bragdon, 2012). The combination of advocacy, strategic policy direction, and provision of services to maximize independence has been the hallmark of the United Cerebral Palsy efforts (Bragdon, 2006).

State and local governments increasingly depend on federal dollars, especially in light of today’s economic crisis (Bragdon, 2012). The federal government monitors state and local governments in regards to quality services and supports, and the civil rights of those with disabilities. State and local governments cannot replace the needed funding from the federal government (Bragdon, 2012). The United Cerebral Palsy Organization works to improve federal disability policies through advocacy efforts.

It is critical that the U.S. Congress, as well as state and local governments, adhere to the principles established by the landmark legislation for people with disabilities. The Individuals with Disabilities Education Act (IDEA) of 1975, and the Americans with Disabilities Act (ADA) of 1990. Both of these laws embodies the fundamental values expressed in the Developmental Disabilities and Bill of Rights Act of 2000 which states:

Disability is a natural part of the human experience that does not diminish the right of individuals with developmental disabilities to live independently, to exert control and choice over their own lives, and to fully participate in and contribute

to their communities through full integration and inclusion in the economic, political, social, cultural, and educational mainstream of United States society.

(Public Law 106-402, SEC. 101. [42 USC 15001])

Disabilities Today: America Is Aging

In 2010, we had 40 million Americans age 65 or older. By 2020, the calculations have these numbers up to 55 million (U.S. Agency on Aging, 2008). For Americans with intellectual and/or developmental disabilities, this aging population will cause a tremendous increase in the demand for community-based services. Community-based services means having high quality services accessible to families in the least restrictive setting possible (Boyes-Watson, 2005), and as Braddock explained (2012), community-based services became the example of best practice after a precedent was set after the Olmstead case (1999).

The Olmstead case involved two women from Georgia, with disabilities, who filed suit. Olmstead was the acting Commissioner of Georgia's Health Care Officials. Both plaintiffs lived in state-run institutions, despite the fact that their treatment professionals had determined that they could be appropriately served in a community setting. The plaintiffs asserted that continued institutionalization was a violation of their right under the American with Disabilities Act (ADA) to live in the most integrated setting appropriate. The U. S. Supreme Court ruled that institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that people with disabilities are unworthy of participating in community life, and confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic

independence, educational advancement, and cultural enrichment (Olmstead v. L.C. & E.W., 1999).

Lakin & Larson (1999) explained that moving from large state institutions to community settings improved adaptive skills. Individuals who left institutions for community settings engaged in significantly more social activities, experienced significantly more personal integration, had significantly more family contacts, and made significantly more independent choices. Significant improvements (e.g., reductions of incidents and/or severity of behavior) once the people transitioned to the community. Parents, who as a group were often initially opposed to deinstitutionalization, were almost always satisfied with the results of the move to the community after it occurred (Lakin & Larson, 1999).

Following the Court's decision (Olmstead, 1999), and in line with the leading studies, states are now required to consider and provide community-based services for persons with disabilities (Bragdon, 2006). Similarly, the University of Minnesota's Research and Training Center on Community Living (2005) developed four key characteristics of a high functioning Medicaid program. These include: (1) People with disabilities will live in and participate in their communities; (2) people with disabilities will have satisfying lives and valued social roles; (3) people with disabilities will have sufficient access to needed support and control over that support so that the assistance they receive contributes to lifestyles they desire; and (4) people will be safe and healthy in the environments in which they live (Lakin et al. 2006).

These characteristics align with the five major outcome areas included in the ranking of each state by the United Cerebral Palsy Organization (Bragdon, 2006). These

areas include: (1) promoting independence; (2) tracking quality and safety; (3) keeping families together; (4) promoting productivity; and (5) reaching those in need.

The Human Services Research Institute developed the National Core Indicators (Jengler, 2009), which is a voluntary effort by public developmental disabilities agencies to measure and track their own performance. The core indicators are standard measures used across states to assess the outcome of the services provided. The indicators include more than 100 data measures that fall under two main categories; those of individual outcomes, including health, welfare, and rights, and system performance, which includes staff stability and family indicators.

The United Cerebral Palsy Organization recognized states that participate in the National Core Indicators. The National Association of State Directors of Developmental Disabilities Services (NASDDDS) will provide \$1.5 million over the next five years to encourage more states to use the National Core Indicators to provide comprehensive quality assurances that can be benchmarked to track individual state's progress (Bragdon, 2012). To date, 29 states participate in the National Core Indicators model. Texas participates.

Significance of the 2012 Rankings

Nationally, Medicaid paid out a total of \$404.9 billion, of that, \$32.9 billion, or 8.1%, was direct support for individuals with intellectual and/or developmental disabilities. The total enrollment in Medicaid was 52.9 million people, of that, 666,000, or 1.3%, were individuals with disabilities (Medicaid Actuarial, 2010). States have room for improvement, but some states have consistently remained at the bottom since 2006, one such state is Texas.

The Standards

Despite the poor quality of life they offer, large institutions are extremely expensive, costing more than \$200,000 per person, per year, compared to \$84,000 per person per year in community settings (Anthony, 2012). Thirty-six states now meet the 80/80 community standard. This standard states that at least 80% of all individuals with intellectual and/or developmental disabilities should be served in the community, and 80% of all monies allocated are spent for community support on those with disabilities. Texas does not meet the 80/80 standard (Bragdon, 2012).

Bragdon (2012) explained that eleven states no longer have large state institutions to house those with intellectual and/or developmental disabilities. Since 1960, 205 of the 354 state institutions have closed (University of Minnesota, RTCCL, 2012). Twenty-two states now meet the 80% home living standard, meaning being supported in their own home, or small group home support.

Family Support

Fifteen of the fifty-one states support a large percentage of families through family support. These support services provide assistance to families that are caring for children with disabilities at home, which helps keep families together and people with disabilities living in the community. Texas is not one of the fifteen (Bragdon, 2012).

Nine states have a least 33% of their individuals with disabilities working in competitive employment (Bragdon, 2012). This indicates that a state supports work as a key component of a meaningful life. Texas does not. In Texas, waiting lists for residential and community services continue to rise. More than 70,000 people are on

wait lists for Home and Community Based Services (HCBS). Fourteen states do not have a waiting list. Texas has one of the longest (Bragdon, 2012).

State Comparisons

For the purpose of this study, I examined the similarities and differences between the 1st, 25th, and 50th states as ranked by the United Cerebral Palsy Organization. The Number One state, as ranked by the report, is Arizona. Number Twenty-Five is Louisiana. Texas is fiftieth (Bragdon, 2012) (See Appendix B). In the past six years, nine states have improved dramatically in the rankings. The major portion of these states' improvement is attributed to their providing more competitive employment support. Louisiana has moved up nineteen places since 2007 by shifting Medicaid resources dedicated to community services in place of large institutions, and had a large drop in the portion of individuals served in large institutions.

Best Performing States

For the best performing states, size does not matter. Those with large populations, California, for example, and those with small populations, such as Vermont, are among the top ten states (Bragdon, 2012). Top performers include both rich and poor states. Top performing states have both high and low tax brackets and high and low spending per person served through the Home and Community Based Services. For example Connecticut is a relatively big spender, versus the state of Washington, which is a relatively low spender and yet both states are in the top ten of the state rankings (see Appendix B). The political party in power in the state, whether a democrat or republican, did not seem to play a factor in the rankings (Bragdon, 2012).

Texas is one of the ten worst performing states on all the indicators in the ranking. To understand why, I present a comparison of the top, middle, and lowest states. The top state, Arizona had one large state facility, housing 115, at a cost of \$127,896 per person, per year. Arizona does participate in the National Core Indicators, the premier quality assurance program, and has a waiting list for services yet to be provided that would require their programs to grow by 1% on average, per annum to accommodate the need (Bragdon, 2012).

Louisiana, the 25th - ranked state, operates seven large institutions, with 1,124 citizens with disabilities at a cost of \$181,770 per person, per year. Louisiana participates in the National Core Indicator program. They have over 4,000 citizens on wait lists for services that would require their programs to grow by 58% on average per annum to accommodate their needs (Bragdon, 2012).

Texas, according to Bragdon (2012), is ranked 50th and operates 13 large state institutions that house over 4,200 citizens at a cost of \$166,502 per person, per year. Texas participates in the National Core Indicators Program. Texas has a waiting list of over 70,100 people with disabilities. This would require the programs to grow by 334% on average per annum to accommodate the needs.

Federal Level

As stated earlier, the United States Government Accountability Office report (GAO, 2012) on Students with Disabilities to the Ranking Member Committee on Education and the Workforce, and House of Representatives made three recommendations. One recommendation was that in order to improve the provision of transition services for students with disabilities, the Department of Education, Health and

Human Services, Labor, and the Social Security Administration would need to develop an interagency transition strategy to address common outcome goals for transitioning youth, increase awareness of available transition services, and assess the effectiveness of their coordination efforts. All four agencies agreed with these recommendations (GAO, 2012).

The Top State: Arizona

In the process of conducting this research, I found that the place to find the most pertinent information about how the state of Arizona moved to the top in services offered to their citizens with disabilities was from their local advocacy groups. That is how I met Bryan (pseudonym). Bryan works for the Arizona Bridge to Independent Living and he explained that, like Texas, Arizona has county agencies that manage Medicaid funding and expenditures. Arizona calls their Medicaid agencies Arizona Health Care Cost Containment System (AHCCCS). The agency, I was told, has changed quite a bit over the past 20 years.

Brian explained that The Arizona Bridge to Independent Living (ABIL) is the group that helped push for these changes. The Arizona Bridge to Independent Living is a non-profit corporation that provides comprehensive programs to address the concerns of Arizona citizens with disabilities and their families, co-workers, and employers. It began in 1977, as the Arizona Congress for Action, started by a group of people with diverse disabilities who launched a grassroots effort to educate the community and policymakers about disability-related issues. In 1978, Congress enacted Independent Living Center Legislation as part of the amended Rehabilitation Act of 1973 (ABIL, 2012). In 1981,

The Arizona Bridge to Independent Living received funding through private grants and began advocating for a more independent plan for their citizens with disabilities.

Today, the Arizona Bridge to Independent Living provides training and information for people with disabilities to live as independently as possible (ABIL, 2012). ABIL provides training in areas of independent living, how to access services such as Social Security, Americans with Disabilities Act counseling, home modifications, where to live with support, employment options, personal assistance programs, transition issues, social and recreation programs, peer support, and how to advocate before the state legislature.

One of my research participants moved from Texas to Arizona because he is an adult with disabilities and said that the services that were made available to him in Arizona greatly improved his quality of life, over that which he had had previously in Texas. He now has a job as an advocacy specialist for the Arizona Bridge to Independent Living. Bryan was able to tell me the history of people with disabilities advocating for deinstitutionalizing and how that began to take shape in Arizona.

According to Bryan, the Arizona Bridge to Independent Living is closely linked with the Arizona Statewide Independent Living Council (ASILC). The council has worked alongside the Arizona Bridge to Independent Living, advocating for more resources for independent living and support for those with disabilities. The mission of the Arizona Statewide Independent Living Council is to advocate for policies and laws intended to help people with disabilities to live and participate in an integrated community.

These goals, according to Bryan, aim toward people with disabilities having equal access to programs and services, making their own decisions and controlling the care they receive, getting the support of other persons with disabilities, becoming leaders, and having a chance to make changes, and being productive and contributing members of their communities. The stated focus of the Arizona Statewide Independent Living Center is to promote and support the enhancement and expansion of independent living programs and services (ABIL, 2012).

Bryan explained that it has been at least a 20-year battle for Arizona to become a model for other states for disability support. He confirmed that there is one large institution still open, but that it is no longer taking new residents and as people leave or die, it will decrease in size and then it will be closed. Bryan said that Arizona policymakers began to listen to the advocates for independent living when they showed the data on how much money they would save looking at a new model of small group homes and more community supports.

The struggle to be heard was very political, according to Bryan. Large institutions employ a lot of people and warehoused those with significant disabilities. Legislators were concerned about job loss, in addition to the care for citizens with intellectual disabilities. It was not until the advocacy groups were able to show the amount of money that could be saved and alternatives to the large institutions that legislation began to be written and passed.

Advocates had a long history of educating for their state policymakers on best practices for persons with disabilities (ABIL, 2012). They worked to develop long-term care legislation and regulations. Brian explained that today in Arizona, there is a great

deal of collaboration with the school districts to have students with disabilities complete what is known as an intake or registration with the Arizona Health Care Cost Containment System (AHCCCS) before graduation so that a plan would be in place for their transition into their community. This is completely funded through Medicaid. Although a student may receive special education services through the entitlement program under IDEA (2004), students have to qualify to show eligibility for the Medicaid programs after school. To qualify, a documented handicapping condition must exist.

Once eligibility is established, the recipient of services is provided a case manager who sets up his or her program (AHCCS, 2012). Depending on the individual needs of the recipient there is a long list of supports and services available. If a long-term care setting is needed - for example, a small group home with support - the recipient is shown a list of approved providers. The list catalogues providers of transportation, physical therapy, occupational therapy, vocational training, and employment support, to name a few.

Bryan was surprised by the complexity of the Texas system, especially the lengthy waiting list for services. In Arizona, he said they have moved to one state agency that manages Medicaid funds and provides collaboration with the different providers. This model provides a central place to house records, to coordinate services in order to prevent duplication, and it saves funding dollars by consolidating procedures and the staff needed to support the programs.

As an advocate, Bryan elaborated on what they are currently working to change. His group is trying to make access to medical equipment happen easier and quicker, and they are pushing for more funding to support vocational rehabilitation services. These

are the services that provide job training and coaching. They now have a program called the Freedom to Work Act. This act was developed by disability rights advocates, with the support of some Arizona lawmakers to enhance the federal program known as Ticket to Work (AHCCS, 2012).

In order to encourage employment, the Social Security Administration created the Ticket to Work program, which enabled people with disabilities to earn more while they work to build employment skills and eventually be able to be self-sustaining. The program, according to Bryan, has many limits and deadlines and is a complicated program to access. An adult with a disability who receives Medicaid benefits for health care and living support cannot earn more than about \$2,000.00 per year, or risk losing their Medicaid support (Ticket to Work, 2001).

The State of Arizona developed an additional component to the Ticket to Work program. Qualifying for the program means qualifying for the Arizona Freedom to Work Act. This has no time limit. As long as a recipient is working, he or she will keep all of the Medicaid benefits for life, for a nominal charge of about \$30.00 per month. The Freedom to Work Act brought the average income ceiling limit for the program up to \$52,000.00 per year, from \$2,000.00 per year. This, Bryan explained, is a large part of the reason why Arizona is a model for other states.

In the Middle: Louisiana

I conducted an interview with Jen (pseudonym), is an employee of the Louisiana State Supervisor of Secondary Transition Services. This is a statewide agency that supports transition practices in schools throughout Louisiana. I also conducted an interview with Martha (pseudonym), an advocate for the Families Helping Families of

Southeast Louisiana, Inc., a privately-funded advocacy group that provides training and information to parents and advocates for citizens with disabilities.

Jen shared that in her eight years in this position she has seen many changes in the process of transition. Jen said that the laws have evolved over the years and have “definitely improved how we are serving our children with disabilities. The biggest change has been to move from the warehouse mentality of large state institutions and move our children and young adults into the communities right along with their peers” (Interview, December 10, 2012).

Jen was not familiar with *The Case For Inclusion* (Bragdon, 2012). After I reviewed the main points with her, she seemed surprised that Louisiana was rated as highly as it was. She said, “Services are still difficult to access, mainly because we have a waiting list that is over 5,000 people and the average time on the list is eight years.” She added that, “the schools end up spending a lot of time convincing parents to sign up early in order to have access to services by the time their child leaves high school.”

There is no counterpart to Jen’s position for the schools in Texas. Jen is the supervisor of a state agency that oversees transition services for all schools in the State of Louisiana. The agency is a division of the Louisiana Department of Education. The Texas counterpart to this agency is the Texas Education Agency. Seven years ago a transition position was cut from the budget of the Texas Education Agency. Texas has regional service centers that support area transition practices, and funnel information regarding legislation and regulations to the districts in their area. However, as Jen and I compared notes, our school districts were functioning similarly when it came to the day-

to-day transition practices, especially in the area of writing individual education plans (IEPs) for our students. We saw parallels in our processes.

Louisiana Advocacy Group

Families Helping Families is very similar to the Texas advocacy group, Texas Parent to Parent. Both groups work to support families by providing them with information on how to get the support needed for an individual with disabilities. Another key mission of these groups is advocacy for change in state support. The group, the Louisiana Citizens for Action Now (LaCAN), was founded in 1988. This group collaborates with Families Helping Families of Southeast Louisiana, Inc., to provide added support with the policymakers.

Martha has worked with and for the Families Helping Families organization for the past six years. She became involved with the organization because she has a child with a significant disability. Martha stated that she was familiar with *The Case For Inclusion* report and “considers it an honor for Louisiana to be named number 25 in the list.” She said that Louisiana has come a long way in the last six years. “And I believe the changes were the direct result of advocating for what is right for our citizens with disabilities.” Martha was very proud to tell me that because of successful advocating, Louisiana now has a regional and state advisory committee, set up by legislative act, which ensures public input in the development and implementation of policies and Louisiana’s allocation of resources.

According to Martha, the creation of the Office for Citizens with Developmental Disabilities was a major improvement in the Louisiana system. This is the State Point of Entrance (SPOE). The state is divided into nine regions. Each region has an SPOE

office. When a person with disabilities applies for services through the SPOE office, he or she is assessed for eligibility. If he or she qualifies for services, he or she will be assigned a case manager who manages their care for every need.

Martha directed me to a state web site that explains how state agencies in Louisiana disburse Medicaid funds to its citizens with disabilities. This seemed to me to be a very user-friendly site. It explains the purpose of each center and how to gain access to the services needed.

These federal centers have a division called “My Place Louisiana,” the state’s program for Medicaid Services Money Follows the Person (MFP). The centers are designed to help people transition from an institution into home - and community-based living settings, such as a house or an apartment. My Place Louisiana is funded through 2016. Its focus is on Medicaid funding and participants’ in transition from large facilities to home and community-based living settings. Support for more community-based living services is one of the reasons Louisiana has improved its ranking in the United Cerebral Palsy’s list for effective use of Medicaid funds (Bragdon, 2012).

The Families Helping Families organization helped write and advocate for key legislation in Louisiana. Passage of this legislation is another reason Louisiana has improved its ranking. The legislation covers inclusion in the community, respect, family-to-family support, independence, and transparency in the process.

Frequently Asked Questions

An important document included in the Families Helping Families data base that is pertinent to this research is a FAQ sheet made available that refers to the fears and concerns of families when the state began closing its large institutions (LaCan, 2012).

Louisiana has been successful in moving people from institutions to community settings, with better outcomes for people than they saw when segregated in institutions.

(Wehman, 2006): “Deinstitutionalization of people with developmental disabilities in America has been one of the most successful and cost effective social experiments in the past two decades.” (University of Minnesota Research Center Report on Medicaid, 2005, p. 3) Results from a satisfaction survey of former residents of a Louisiana Metropolitan Developmental Center, after its closure, indicated that 91% of individuals liked where they were living and 93% liked who they were living with (Sevin, Sarna, Knight, Smirolids, Andrus, & Wilson, as cited in The Louisiana Developmental Disabilities Council Report February 20, 2009).

In Louisiana, those who leave a developmental center does so only after thorough individualized team planning and when all needed community-based supports and services have been identified. In addition, anyone leaving a center is assigned a support coordinator to monitor and assist in carrying out his or her plan.

In Louisiana, elderly parents are not expected to care for their older sons or daughters with disabilities when a developmental center closes. Most individuals and their families will choose for them to live in their own apartment with one or two roommates where staff is provided to support the needs and care for the individual with disabilities in a community home.

Martha said “offering these services to families as we begin the discussion of moving their sons or daughters with disabilities from the large state institutions has been extremely helpful.” The fact that Louisiana is having these discussions with their citizens shows the intent to continue to improve their services.

Texas

According to *The Case for Inclusion* (Bragdon, 2012), Texas ranks 50th out of 51 states (50 states and the District of Columbia) on how well it uses Medicaid funds to serve those with intellectual and/or developmental disabilities. Texas has 13 large state facilities, housing 4,207 people with disabilities at a cost of over \$167,000 per person, per year, and has over 70,000 people with disabilities on lists waiting for services. The agency responsible for overseeing Medicaid spending is the Texas Department of Health and Human Services.

The stated mission of the Texas Department of Health and Human Services (HHSC) is to maintain and improve the health and human services system in Texas and to administer its programs in accordance with the highest standards of customer service and accountability for the effective use of funds (Health and Human Services online, n.d.). The Health and Human Services Commission oversees an annual budget of \$16 billion and employs 9,300 people.

The Texas Health and Human Services system is comprised of five agencies: (1) The Health and Human Services Commission, (2) The Department of Aging and Disability Services, (3) The Department of State Health Services, (4) The Department of Assistive and Rehabilitative Services, and (5) The Department of Family and Protective Services. The Texas Medicaid plan is supported by many of the programs within each of these five agencies.

I interviewed one of the Policy Analysts employed through the Texas Health and Human Services Commission. Andy (pseudonym) was aware of the United Cerebral Palsy (2012) publication. She has worked as a political analyst for the Commission for

five years and knows of “one legislator who might be aware of the publication.” Andy said that she thought that within the last few years “there has been legislation passed that will make a difference in the long run for where we stand on the list, but it is going to take some time” (Interview, 1/16/2013).

To explain the changes in the works, Andy mentioned a bill passed during the 2007 legislative session that directed that a workgroup be formed to make recommendations about improving employment outcomes for transitioning youth and young adults with disabilities. HB 1230, was enacted during the 80th Legislative Regular Session in 2007. According to Andy, HB 1230s purpose was to improve the services provided to Texas youth with disabilities as they transition from school to adult living, with an emphasis on transition into successful employment. A stakeholder workgroup developed and submitted a plan to the Executive Commissioner of the Health and Human Services Commission on August 13, 2008. The plan consisted of five major goals for the delivery of employment/supported employment services to youth with disabilities and recommendations to accomplish these goals.

This report highlighted health and human service agencies’ current or planned implementation of the tasks and activities required to carry out recommendations from the workgroup, and noted which recommendations would require legislative funding and legislative direction to accomplish. The agencies’ report of implementation activities addressed recommendations for each of the five goals: (1) program changes, (2) infrastructure model reform, (3) capacity building, (4) outreach and public awareness, and (5) Texas Education Agency (TEA) transition services and employment programs.

Andy told me about a new committee developed by the commission, the Promoting Independence Advisory Committee. The committee works through the Department of Aging and Disability Services (DADS). “Their most recent quarterly report shows that they’re working on issues related to promoting independence for individuals served,” according to Andy.

Andy directed me to the Department of Aging and Disability Services website, a resource for the stakeholders of this department (providers, advocates, recipients, etc.) interested in improving employment outcomes for people receiving services. According to Andy: “there’s a lot of information here, but I’d recommend, in particular, the tab ‘Subcommittee on Employment for People with Disabilities. This is the group I mentioned that meets monthly on the third Thursday. The tab, ‘Collaboration with DARS’; here you’ll find the agencies’ Memorandum of Agreement, and the tab ‘Resources and Reports,’ here are several resources from other entities and states, but in particular see the information from the Institute for Community Inclusion (including their report on how states are doing with employment for people with disabilities)” (Interview, 1/16/2013).

The website includes a link to help build charts and graphs that compile data on workforce outcomes for citizens with disabilities. Andy said that “awareness is the start of being able to advocate for change and these different bills and programs show that our state policy makers are becoming aware” of the needs of individuals with developmental and/or intellectual disabilities. One of the key changes that Andy mentioned as most hopeful is the effort to try to improve inter-agency coordination among the five agencies that the Department of Health and Human Services Commission regulates.

Andy explained that at issue is the way some of the agencies receive their funding. For example, “DARS (the Department of Assistive Rehabilitative Services) receives its funding when it ‘closes a case,’ meaning they found a job for the individual they are serving and he or she has worked successfully for 18 months. Then DARS is paid for their time as job coaches. If the individual loses his or her job before that time, DARS continues to work to find employment but they do not receive any funding for that individual” (Interview, 1/16/2013).

There is now a Legislative sub-committee to investigate how the agencies under the Commission’s oversight receive their funding and the sub-committee makes recommendations for improvements. Andy said, “they are conducting a qualitative study to look at the successes of the different employment support programs.” “There is a problem with agencies playing the blame game.” For example, HB 1230 (2007), mandates that all five Health and Human Services agencies, the Texas Education Agency, and the Texas Workforce Commission work together to improve services. The Texas Education Agency was supposed to publish a Transition Guide using the documents collected as mentioned in HB 1230. The report has not been completed. So, now the Legislature is going back to make it a mandate that the Texas Education Agency produce this guide.

When asked if she thought that legislators would be interested in seeing the results of my research. Andy said, “Yes, if it saves money!”

As a result of our conversation, Andy extended me an invitation to be a part of their Advisory Sub-Committee for coordination of efforts for individuals with disabilities. She said they “will end the meetings reporting to the Governor our findings,”

and she thought I “would be able to add valuable information based on what I shared with her from my research.” I agreed to be at the next meeting.

Table 1 Summary of the Ranking States

State Ranking	Number of large facilities	Participates in NCI	People on lists
Arizona #1	1	Yes	29
Louisiana # 25	7	Yes	4,572
Texas #50	13	Yes	70,113

(Bragdon, 2012)

Lived Experience

In this section, I present a narrative to capture the experiences of one family I selected to represent those transitioning a son or daughter from school to their community. A pseudonym was assigned to each individual to protect confidentiality. The mother is an educator and the father is a city employee. They chose to meet me in my office one evening. The conversation was relaxed and comfortable. The mother did most of the talking. I asked them to begin by telling me about their son with disabilities.

Ricky (pseudonym) was born in 1986 in Houston, Texas. There was nothing unusual about his birth or the first few months of his development. Ricky’s mother was not working in education at the time. She was employed in a large corporation and both mother and father admit to not having much knowledge about the typical development of an infant and toddler. They began to have concerns by the time Ricky reached about eighteen months old. At that time, the father was relocated to Colorado Springs, Colorado.

As a family, they made a good income and lived well. Mother gave birth to a second son, who showed such remarkable development that they began to seek out doctors for advice or information about “what could be going on with Ricky.” Doctors

referred the family to psychologists, and to other specialists for tests for Ricky, it was not until another year had passed that the mother and father were finally told their son had Autism. He was considered “mentally retarded” and they were referred to a speech pathologist, and other specialists.

According to them, no one mentioned programs that supported families with children with disabilities. They felt they were being passed off from one specialist to another. Mother said “we didn’t have the internet like parents do today, to research Autism or what supports might be out there for us.” “Most of what we found was through word of mouth and trial and error.” “Fortunately, at the time, we were able to pay for his different therapies, like speech and behavior support, out of pocket. Our insurance did not cover these needed services, but we were able to pay ourselves.”

When Ricky turned five years old, Ricky’s father was transferred to Central Texas. One factor in deciding where to live was based on the services they could find for Ricky. Ricky’s mother found that he qualified for a preschool program for children with disabilities through the area public school district.

In answer to my first question about how special education served their son, mother said, “it was a lifesaver for our family.” “We knew he was safe.” “We felt for the first time that we were getting support from people who understood him and what he was going through and would make sure he was reaching his full potential.”

Ricky was on a very different path from his brother, who was reading and talking and had surpassed his older brother in development and learning by “miles.” “We had complete trust in the school district. The majority of our knowledge about Autism came from Ricky’s teachers. We considered the special educators the experts.”

The mother continued; “When transition services were mentioned to us, it was very confusing. We were on an academic path, and then all of the sudden we were told to think about a vocational tract. In 10th grade, we seemed to hit a wall, academically. We didn’t have a lot of awareness about vocational training, especially for our son with a disability. There really wasn’t a lot of information about vocations and disabilities.” She debated, “That was the first time, we became very anxious about the future. What was ahead for Ricky? What if something happened to us? Who would care for him the way we do? We couldn’t expect his younger brother to take on our responsibility. Then we were told about an 18+ program for our son. He could stay in school until he was twenty-two years-old in a vocational training program. I was still pushing academics, we were so afraid to stop trying to shove math and reading down his throat. But he showed us he was so much happier in a work setting, that we finally gave in and he began to flourish.”

I asked the mother and father about their connection with outside agencies. The mother said, “we kept hearing about the MHMR (Mental Health, Mental Retardation) center. The school told us to do an intake at our county program and they would get us on waiting lists. I never understood what that would do, so I procrastinated. It wasn’t until we attended a transition fair and saw who the different agencies were in Texas. It was so confusing and very overwhelming. I finally made the appointment and did the three-hour long intake at MHMR. We felt like we were hearing a foreign language. I was put on several different waiting lists for services and was told that it could be ten years before Ricky’s name moves to the top of the list.”

The mother said that now Ricky is attending a private day program, a new program in the area. The program does not receive any government funding, but is an excellent vocational and social program. Ricky receives funding from Social Security and Medicaid. The cash goes to help pay for the day program. The Medicaid program provides some of his transportation to the program site and, twice a month he has a social outing with one of his case managers.

I asked whether the agencies have helped their son integrate into the community. The mother said that DARS (Department of Assistive Rehabilitation Services) helped Ricky find a job, “but it wasn’t a good fit and he got fired. This happened three times. That is when we made the decision to bring him to the day program he attends now.”

She continued; “The big question for us now is residential. One day we would like him to live in a home that is his, with friends and support. He would be happy doing that.” Further, she said: “but, we cannot afford to do that until we get called up on the list for services that will help provide a small group home. It haunts us what will happen to him.” She said “it would be such a disservice to Ricky if he had to live in a large institution. He is capable of so much more.”

I asked if the mother and father had the opportunity to sit with some policymakers, what would they like to tell them? The mother replied; “We have had to walk a very complicated game of life. The ‘system’ is so convoluted and complicated in this state. All of our agencies are siloed. Agencies are very isolated. Today the special education staff is breaking down walls, but the agency does not work well with others. The agencies cannot even show you what they do. They talk at you, and it frustrates so many parents.”

She continued: “What is needed is a central place that can give us information about what we need for our particular child. Then we need a case manager that can talk us through where to go to get what service. There is no need for all of this confusion. We were even approached by a company that is charging to be a case manager for your child with disabilities and navigate the system for you so that you can take care of your other needs. It almost seems worth it.”

She further commented; “there is such a lack of collaboration, a lack of sensible talk, a lack of information. It is awful,” and added, “we would like to have the opportunity to sit with about five other families and several of our legislative representatives and tell them our story. It may be one way for them to see what the reality is for us.”

She elaborated that “as for Ricky, he will continue at this program that we are struggling to pay for because he is happy and flourishing, and has a real sense of fulfillment. We are some of the fortunate ones who can provide this for our son for now.”

Conclusions. Twenty-six year-old Ricky has Autism. Today, he lives with his family and attends a private vocational day program. His parents described the road they had to travel to get Ricky to where he is today. They had difficulty getting a diagnosis of Autism when Ricky was a toddler and then had great difficulty finding out how to get Ricky the help and support that he needed.

The public school became a safety net for the family. They were able to get answers to their questions and have a better understanding of how to meet Ricky’s needs. It was when Ricky was in high school that his parents began to panic about what was

next for him. His mother described her confusion in trying to understand the different state agencies and how to access their services. Ricky is happy where he is right now, but eventually his family will need to solve the issue of where Ricky will live for the rest of his life.

Ricky's parents would suggest to our policymakers that we create a central place that can provide all the information needed to access whatever Medicaid support would be appropriate for each individual person with a disability. They would like to end the confusion and streamline the services that are provided to their son and others with developmental and or intellectual disabilities.

The Fear of Every Parent

CNN.com shared an article written by Rob Gorski (2012) that expressed the same fear that so many of the families I work with have shared with me. Gorski is the father of three boys on the autism spectrum. On a snowy day in Ohio, Gorski was stopping at a grocery store to pick up a few things on his way home from work. When he pulled into the parking lot, a man reached over the hood of his car and started wiping the snow off his windshield with his bare hands. The man was not dressed for the twenty-degree weather. He spoke with great difficulty, asking Gorski to help him get some food. Other people in the parking lot were looking on with horror. Then Gorski said, "something shook me to the core and completely broke my heart. As I was about to tell this man 'no,' I suddenly realized that this could be one of my children twenty or thirty years from now." "I felt like I was hit by a train" "Someday, I won't be here to take care of my children. What happens to them? What if they end up on the street begging for food? I

can't let that happen I won't." Gorsky used the rest of his article to beg our policymakers to help provide better support and services for people with disabilities.

Transition

Transition services obligated in Texas Public Schools when a student who receives special education services turns fourteen years of age. For those students with more significant disabilities, the earlier transition begins, the better the outcome for the student (Wehman, 2006). To have a purposeful and meaningful life, transition coordinators must consider the social goals, recreation goals, and leisure activity goals, lifelong living goals, lifelong learning goals, and employment goals for each student. The student should be seen as having potential, not simply as a type of disability - what he can do, rather than what his limitations are.

The transition practices may vary among districts and states, however, the intent of the law (IDEA, 2004) must be considered in establishing policies. Especially significant is the need for educators to be concerned with what happens to students when they leave their care. Transition services should provide the framework of the bridge that connects a student moving from their learning experiences in school, to lives as members of their communities. The National Longitudinal Transition Study (Wagner, Newman, Cameto, Garza, & Levine, 2005), substantiated these needs by finding that students with intellectual and/or developmental disabilities had lower rates of accessing their communities, whether it be through employment, volunteerism, social settings, or the four life domains that provide for purposeful and meaningful lives.

State Performance Plan 14

In Texas, transition coordinators are required to annually report each transition practice to the Texas Education Agency. State Performance Plan Fourteen asks for existing demographic information on our graduates who receive special education services. The data include the student's transition plan for post-high school. The Texas Education Agency then contacts students across the state to chart their post-school outcomes. Across the State of Texas, the 2012 data confirms that one year after leaving high school, 31% of people with disabilities have graduated to "their couch" or no activities. They are not working or in school, they are in their parent's homes sitting all day. Granted, 58% are working or in higher education, but a huge concern is the 31% that have no post school activity. Is Transition successful at bridging students from school to community?

Summary

The U.S. Government Accountability Report (2012) recommended that, to improve transition services, Education agencies, Health and Human Services Commission, the Department of Labor, and the Social Security Administration develop an interagency transition strategy that addresses outcomes, increases awareness, and assess the effectiveness of their collaboration to provide support for transition. The report explained that collaboration between the schools and these agencies is the key to providing purposeful and meaningful lives for people with disabilities.

United Cerebral Palsy Report (2012). Agrees with the U.S. Government Accountability Report (Bragdon, 2012). Halpren (1993) proposed that education

and employment are the primary indicators of quality of life. He developed three domains that measure a person's quality of life: (1) Physical and mental well being, (2) performance in adult roles through completion of adult tasks, and (3) personal fulfillment. In the early 1990's placement in institutions that warehoused people with disabilities, or their placement in sheltered workshops was considered an antiquated practice. Advocates were working on a national level to change the practice according to Bragdon (2012).

Number One Arizona

Arizona policymakers, in part, out of response to advocacy groups, realized that they needed to make some changes to the services being provided for persons with disabilities. The cost analysis proved to be a driving force for state governments to move to make the changes. They began closing their large institutions and moving their citizens with disabilities into community settings. Arizona does not have a waiting list to access the services and they were able to have collaboration among the agencies. They were able to streamline the process of transition, from high school into the community.

Number Twenty-five: Louisiana

Louisiana has made great strides in the last six years in regards to the transition of people with disabilities. The state moved up nineteen places on the list improving community support and services instead of only looking at what placement in a large institution could provide. The state is working now on the collaboration among state agencies. Louisiana has a waiting list for access to services but people do not have a long wait to be served. Advocacy has been the impetus to create the change in Louisiana and many of the advocates were parents and grassroots groups who saw a need and worked together.

Number Fifty: Texas

The state of Texas has a lot of work to do. The policy makers are being made aware of the issues, slowly. Texas still has thirteen large institutions open and running with no plans to close them. Texas has a list of over 70,000 people waiting for services. Texas as a state is very slow to change and respond to the information regarding our citizens with disabilities. Directives that were introduced six years ago have yet to be implemented and now policymakers voted to mandate the directives be followed.

Texas legislators have begun to work on the issue of the disjointed agencies, as referenced in the U.S. Government Accountability Report (2012). Committees from the five departments within the Commission of Health and Human Services have been formed to work on a memorandum of understanding. They have been meeting once a month for over a year (Interview, 1/16/2013) and when I expressed my concern that school districts were not included in the discussion, I was handed an invitation to join the committee.

Advocacy In Texas

Texas Parent to Parent Advocacy group mentioned earlier in this study has a vision for the future for adults with disabilities. Their vision: adults with a disability in Texas will:

- Have access to appropriate services and supports
- Have transportation to work, social, and recreational opportunities
- Have appropriate medical care
- Work in a supportive, fulfilling community setting

- Live in a home that maximizes personal preferences and provides supports as needed
- Be surrounded by people who can understand and honor the person's communication
- Be surrounded by people who appreciate the person's talents and strengths and share laughter and delight

CHAPTER V

Interpretation, Implications, And Conclusions

In this chapter, I interpret the findings obtained through this advocacy research and discuss its implications. I show how the current policies in Texas impinge on people with intellectual and /or developmental disabilities as they transition from school to community. I also provide Texas policy-makers models of the top-performing states, according to the United Cerebral Palsy report (Bragdon, 2012), to create a roadmap of improvements for some key outcomes. Replicating proven practices for other states is one way. Listening to the advocates for change may be another, as well as further research.

I chose advocacy research consciously. I believe the work I do on a daily basis as well as others in similar positions is instrumental in helping students with intellectual and/or developmental disabilities live purposeful and meaningful lives as they transition from school to their community. The impetus for this research started when the transition to the needed agency supports within the community proved to be difficult to access for my students. I found problems that were difficult to resolve due to the erratic, ever-changing, and hard-to-manage social service systems encompassing the transition field. The passion I have for my students pushed me to search for answers, to advocate for my students, and to work for improving the policies and procedures governing the services my students and so many others desperately need.

In Chapters Three and Four, I detailed the history and progression made of services required under special education policies and procedures. The reauthorization of

the Individuals with Disabilities Education Act (IDEA, 2004), meant that, public schools were to work to improve education for students with intellectual and/or developmental disabilities. Educators were asked to better prepare our students who receive special education services for work, continued learning, and to become as independent as possible. The school leaders and teachers were called on to increase planning and coordination between those at school and the families in order to help students meet the challenges they face from early childhood on through post-secondary education. Further, IDEA mandates that educators facilitate students' access to supports and services before they leave the school. This was meant to promote successful transition from school to post-secondary education, training, employment, independent living, and community participation. The focus shifted from what the student with a disability could not do to what he or she could do, reframing disabilities as capabilities.

The transition component of IDEA asked that the responsible parties in school districts coach every student with a disability, along with his or her family, to think about goals for life after high school and to develop a long range plan to get there. Special educators were to design a curriculum for those they served to ensure that the students with a disability gained the skills and competencies they needed to achieve their desired post-school goals. Additionally, transition coordinators were to link students and families to any agencies that provide their needed post-secondary services, supports, or programs before the student leaves the school system.

All of these transition requirements, as spelled out in IDEA, have a track record of improving the school experience for students with disabilities, as well as providing their families with much needed information and support (Wehman, 2011). However, the

post-school outcomes for students with disabilities in Texas are bleak, at best (Bragdon, 2012). An old adage is that “someone’s greatest strength can also be his or her greatest weakness, a saying that is true of transition” (Bullis, 2013, p. 36). The goal for transition, preparing young adults with disabilities to succeed in post-secondary education and careers, I believe, is perhaps the most important objective of special education and education in general. This is hard to affect, because it is predicated not only on what happens in schools and in transition programs but also, and most importantly, on such factors as access to agency support for those with intellectual and/or developmental disabilities as they transition into their communities.

In Texas, young adults with disabilities are on long waiting lists, and the bureaucracy they have to navigate to access their needed support becomes a winding, and complicated road. While transition coordinators work to bridge the gap from school to the community for students receiving special education services, the agencies that should be providing the structure for the bridge are ineffective, unproductive, are difficult to work with, and have created a complicated system of access to the services they are supposed to provide.

Advocacy

Advocacy research is used to create change and improvement in people’s lives. It is best viewed as a means to an end and can actively promote a cause or principle. The core values of advocacy research are social responsibility and community empowerment (Padgett, 2008). My research has involved a very purposeful method. The purpose is for the research to provide a clear understanding of the issues in the eyes of the people involved and to find out what they believe the solution to be. Good advocacy research

should build an understanding of the causes and effects of the issues affecting a group of people and lead to the identification of solutions and recommendations for policy-makers. Advocacy research should help bridge the gap between research, policy analysis and reality (Tweedie, 2004). This research challenges the root causes of issues, and seeks specific changes in policies, processes, and practices that are vital to the lives of people with disabilities.

Qualitative research is extremely useful for advocacy, as it allows for the collection of rich, insightful data that highlights the experiences of people, not just facts and figures. When combined with disability studies, this research allows advocacy and conscientization to take place from the beginning. Conscientization means:

becoming aware of the extent to which problems arise from the systematic discrimination against a social group which puts all members of the system as a whole at a disadvantage. This is the basis for action to overcome and dismantle the obstacles that have been holding them back (Tweedie, 2006, p. 10).

Advocacy research is not typically based on a strength model. It is usually based on a deficit model or looking at what is wrong. When problem based, advocacy research gives an issue momentum or a way to keep a story going. As I explained in earlier, advocacy is the active promotion of a cause or principle (Tweedie, 2006). Disability Studies is an interdisciplinary field of scholarship that unites critical inquiry with political advocacy by using approaches from the humanities and social sciences to improve the lives of disabled people on the basis of their expressed needs and desires (Gabel, 2005). It is critical that we examine the policies and practices, which influence how a person

with disabilities transitions from school to community. This will unearth evidence of the inequities in the state of Texas that force stakeholders and advocates to push for change.

Combining advocacy research within disability studies supports looking beyond the deficits to include strength models. In order to advocate for changes that would improve the lives of those with disabilities in Texas, I chose to not only bring to light what the deficits are, but also to offer solutions.

In this study, I described the policies in place for transition services, and what is happening in regards to bridging the school and community for our students with intellectual and/or developmental disabilities. I examined the similarities and differences in public policies, laws, and procedures among the 1st, 25th, and 50th states as ranked by the United Cerebral Palsy Organization (Bragdon, 2012). I documented my work informing policy makers as to the effects of their policies by recounting the experiences of a family with a son who has intellectual and developmental disabilities as he transitions into his community.

Interpretation

Texas has a lot to learn from the examples that Arizona, ranked number one by the United Cerebral Palsy report (Bragdon, 2013), and Louisiana, ranked number twenty-five, have set. In my work, I hear parents tell their stories about transitioning their sons or daughters with disabilities into the community and the frustrations they have in dealing with the bureaucracies that are supposed to be helping them. I also hear the frustrations of area transition coordinators as they try to help students navigate this complicated system of agencies.

What I hear is that transition coordinators are working to connect students to the appropriate agencies and the agencies will tell the students that they will provide the supports they need. However, parents are calling the schools after their children graduate, asking for help. Their sons or daughters are sitting at home with nothing to do because the support they had in school has not transferred to the agencies and they are not able to participate in their communities. Former students lose jobs and not able to find new ones. Parents are not able to work out transportation or job training and support, and if there were plans for living in small group homes with their peers, the Medicaid programs that promise provision for this have waiting lists of people in the thousands.

Recently, the advocacy group, Texas Parent to Parent, sent out a mass email celebrating the announcement that the State of Texas has agreed to provide enough financial support to certain Medicaid programs that would allow over 18,000 people with disabilities to move up on the waiting lists and begin receiving the support they so desperately need. This announcement encouraged so many families you could almost hear a collective sigh of relief.

The family I interviewed told me that their son was high enough on one of the waiting lists that they were now going to be able to move him to a wonderful small group home that would allow him to live with his peers and have the social interaction he enjoys while the parents have the assurance that he is well cared for. Now they have learned that the money released for this Medicaid program would not be enough to provide for all 18,000, so the agencies chose to limit services for those on the lists. This family was disappointed to hear they were going to have to wait longer still.

The family wanted me to know that they are not expecting a government handout. Mother and father are both hard working, responsible, and what they described as middle-class people who just need some help for their son. This is one thing I am glad my tax dollars support.

Some of the families I have worked with are so dissatisfied with the quality of the agency programs available for their adult children with disabilities that they have worked to open their own programs. One program in the Central Texas area refuses to take any government funding, because when the government provides funding, the programs must follow government regulations that would severely limit what those who started the program felt they would like to provide. They rely on tuition, grants, gifts, and fundraisers. The program is one I have visited and found to be a model program. It is one of the most powerful examples I have seen of working to create purposeful and meaningful lives for people no matter how severe their disability.

An issue for these privately funded programs is that they are expensive to run. Which means the tuition is relatively high. There are scholarships available for those who cannot afford the tuition. All of the scholarships come from donations and grants. Despite the large sum allocated to scholarships, many cannot afford to participate.

The government expenditure for Texas to place a person with a disability in a large group home is more than twice the cost of the private program mentioned above (Bragdon, 2012). And yet, state funded programs cannot compare to the quality of services offered through this private program. So much so that the family I interviewed cringed at the thought of having to place their son in one of the large government-run programs.

Texas' reliance on the institutional model of care for people with intellectual and/or developmental disabilities persists despite a forty-year nationwide trend of deinstitutionalization and expansion of community services. Texas has the largest number of institutionalized people with intellectual and/or developmental disabilities and that population comprises a disproportionate amount of the U.S. total (Bragdon, 2012). Texas continues to operate thirteen state-supported living centers for persons with disabilities, even as demand for those services has declined.

Decreasing the number of residents instead of closing facilities has resulted in a costly arrangement of dual-funded systems of care in which funding for community and institutional services continue to increase (Bragdon, 2012). Closing at least one institution and establishing a process to continually review Texas' system of state-supported living centers would enable the state to concentrate resources on the people remaining in the system and redirect savings to expansion of community programs (O'Brien, 2011). Texas has confirmed allegations of abuse, neglect and exploitation in the state supported living centers and the number of these very allegations increased 65.1% since 2006, despite increased appropriations to the Department of Aging and Disability Services (DADS) to hire more staff and improve training and services (O'Brien, 2011).

State Agencies

The transition coordinators who participated in the focus group I facilitated shared their frustration over the fact that, in Texas, our agencies are not talking to each other. The schools are talking to each other and to the parents, but once our students graduate, transition coordinators are finding that they are not receiving the support we had been led

to believe they would. The transition coordinators discussed how they do not necessarily blame the agencies as much as they blame the legislators who are charged with overseeing how the agencies work and who controls their budgets. The majority of workers with the agencies are caring, hard working people. They, according to the focus group, want to see people with disabilities have purposeful and meaningful lives; the agencies are just stretched too thin and have too little resources.

Many of the agencies in Texas send representatives to the annual transition fair to set up booths and provide information for parents about what they do and how they can serve their sons or daughters with intellectual and/or developmental disabilities. I am always surprised at the number of different agency personnel who provide similar services and yet, do not even seem to know of each other. The agency personnel who themselves are not talking to each other, and yet their funding all comes from Medicaid allotments. It is the proverbial, the right hand doesn't know what the left hand is doing. They are "siloed," as the Mother I interviewed complained. Rather than come together and share resources, they work independently of each other and it is up to the schools and families to find the appropriate agency services.

In a perfect world, our state agencies would work with each other, combine their services and work with the school districts. They would come to the school and meet with the students and their families and they would begin serving our students before they ever left school. Recently, in a meeting with a Department of Assistive and Rehabilitative Services (DARS) representative, I was told that she could not come to the school and would not be able to provide support until the student we were discussing graduated from high school. That is a problem.

Transition Services and the Gap

Prior to the IDEA transition mandate in 1997, the most typical outcome of special education services was entry into a sheltered workshop or institutional setting in a centralized location, which was often away from the student's home community (Kohler & Field, 2003). In 1997, IDEA changed the focus on how transition-based special education services would be provided. No longer would it be a "one size fits all" approach. Instead, transition services were to take into account individual choices and post secondary needs in a variety of domains (Kohler & Field). From this point on, special education became a mechanism to help students with disabilities identify their personal goals, desires, and preferences in areas such as employment, independent living, education, and community participation along with social interaction.

The importance of appropriate employment for individuals with intellectual and/or developmental disabilities to integrate into the community cannot be overstated. Typically, employment is the common form of involvement in the community for those with disabilities. Through employment students have the opportunity to engage socially, to develop friendships, and to create social networks (Wehman, 2003). The National Longitudinal Transition Study data indicated that students with intellectual and/or developmental disabilities who receive the proper support from agencies when they leave school (such as paid employment and job training), are more likely to demonstrate purposeful and meaningful lives. They are more likely to give back to their communities, rather than need more support (Wagner, et al. 2005).

Integration into the community remains an unrealized aspect of community functionality for many adults with disabilities. Specifically, the extent to which an

individual with an intellectual and/or developmental disability integrates into his or her community will hinge on the existence of agency supports from the moment he or she leaves high school. As Wehman (2011) discussed, the type of support provided by agencies that take over where the schools leave off, will immensely influence the person's life opportunities and future success. Typically this support is primarily on the shoulders of the schools and the parents of the students receiving special education services, which greatly limits the amount of community integration that is possible after graduation (Wehman, 2011). Without the proper connections and support for students with disabilities when they graduate from high school, these young adults end up losing the vital momentum that was gained through the training and support provided by their school.

There are legislative committees working to figure out what needs to happen in Texas, but they are not bringing all of the stakeholders to the table. They are leaving out those from the schools, and the students, and their families. Some of the agencies are participating, but not all of them. These committees need to study the examples of the top-performing states and see what they did to improve the services they offer.

Critical Lenses On Current News

The United Cerebral Palsy organization published the latest edition of *The Case for Inclusion* in 2013 (Bragdon, 2013), and although Texas was no longer second to last on the list of state rankings, it had moved up only one ranking. This is because Arkansas and Mississippi ranked even lower this year. Those in Texas know they will have a problem. The last legislative session saw several bills passed meant to change the

Medicaid system that supports citizens with disabilities, however, the bureaucracy that comes with what is written into the legislation will frustrate the stakeholders even more.

SB 7 consists of ninety-seven pages of bureaucratic entanglements that will take years to develop after committees meet and write reports about how to improve the delivery and quality of Medicaid services for individuals with intellectual and/or developmental disabilities. The bill (SB 7, 2013) establishes committees to provide annual reports to legislators regarding the implementation of the provisions of care for citizens with disabilities. The problem is that these reports are already available. The bill calls for creation of an advisory committee that will be called the “Intellectual and Developmental Disability System Redesign Advisory Committee.” We already have several of these committees that have been working for years, and no one is listening to them.

Advocacy groups such as the ARC of Texas have been making recommendations for years (ARC, 2013). The United Cerebral Palsy report (Bragdon, 2013) is in its eighth year of publication, offering example after example of best practice in making Medicaid services better for individuals with disabilities. We do not need another five years of committee meetings and reports (SB. 7, 2013) to see what is working and what Texas could do to improve the services provided.

Senate Bill 45 (SB 45), is an act relating to the provision of employment assistance and support to certain Medicaid waiver program participants. This refers to how the Department of Assistive Rehabilitation Services (DARS) provides employment support for those with significant disabilities. The problem with this bill is that if one examines the purpose of DARS as written in their brochures, these provisions are already

a description of their services. So after years of stating that this is what they do, the Texas legislators chose to enact a bill that requires them to follow through. That is, of course, unless as they invoke Line Twenty-One which states that the, “commission may delay implementing this Act until the waiver or authorization is granted” (SB. 45, 2013, p. 2). In other words, until the commissioner applies for funding to implement the Act and the funding is approved, these services will not take effect.

House Bill 617 (HB 617) relates to transition and employment services for public school students enrolled in special education programs in Texas. The bill states that the commissioner will be in compliance with federal requirements relating to transition services. In other words, Texas is required to follow federal laws. HB 617 also calls for each school district to designate at least one employee to serve as an overseer of transition and employment services. This designee must provide information and resources about

“effective transition planning and services and interagency coordination to ensure that local school staff communicate and collaborate with students and their families who are enrolled in special education programs as well as appropriate local and regional staff with the Health and Human Services Commission, the Department of Aging and Disability Services, the Department of Assistive and Rehabilitative Services, the Department of State Health Services, and the Department of Family and Protective Services.” (HB 617)

Public schools are already doing this. The section of the bill that grabbed my attention was the requirement that the Texas Education Agency, with the help of the Health and Human Services Commission, develop a transition guide for students that

provides information “on statewide services and programs that assist in the transition to life outside the public school system” (HB. 617, 2013, p. 3). Production of such a guide has already been included in past bills and has yet to be produced (HB. 1230, 2007).

At a time when health care will change nation-wide with the passing of the Affordable Care Act, the federal government has made provisions to increase Medicaid funding for states to address the additional costs the Act will create. The additional Medicaid funding would also provide sustained support for Texans with disabilities. The funds would add services to provide for those on our long waiting lists. However, Texas Governor Rick Perry has made the decision to not accept this federal aide.

A recent editorial stated:

If there's a Republican governor who's a more outspoken opponent of “Obamacare” than our Rick Perry, it's Arizona Gov. Jan Brewer. Yet Brewer has become the latest GOP governor – like Chris Christie of New Jersey, Rick Scott of Florida, etc. to finally accept Medicaid expansion in her state under Obamacare. “We were all so adamant that we didn't like Obamacare,” she said. “We fought tooth and nail. But there comes a time, and you have to look at the reality. It's not only a mathematical issue, but it's a moral issue.” Every syllable of that sentence applies to Perry and Texas. If Texas commits \$15 billion to expand Medicaid over the next decade, the feds will kick in \$100 billion. That's real money for unmet needs. Perry is still rejecting that deal to make a political point. It's high time for him to drop the stubborn opposition and do what's right for the Medicaid recipients, doctors and hospitals in his state.

(Beaumont Enterprise, June 10, 2013, p. A-11)

Implications and Conclusions

The 2013 Case for Inclusion (Bragdon, 2013) states that about half of all Americans with intellectual and/or developmental disabilities want to work, whether they are in an institution or living independently. But the actual rate of these Americans achieving their dream of an honest day's work is just 2% for those isolated at institutions. By comparison, 33% of independent Americans with disabilities are realizing this dream. Americans with intellectual and/or developmental disabilities want the same things as everyone else – to live a purposeful and meaningful lives. They realize that meaningful work is a part of that. “Sadly, only those living independently or in the community ever come close to achieving that goal” (Bragdon, p. 13). Those who are living within the community and are working report a 48% higher rate of going shopping, a 39% higher rate of enjoying social outings, and a 42% higher rate of exercising. The independence that employment provides for individuals with disabilities enhances every other area of their lives.

The difference in the quality of life of those within the community vs. those in institutions is vast. The difference in the cost of supporting individuals with disabilities within the large state institutions is also vast. Today, Texas spends an average of \$141,246.00 per person in large institutions vs. an average of \$42,663.00 per person living with support within their communities.

When statistics show that 88% of working-age adults with developmental disabilities are unemployed given the following information, this is particularly tragic: As Bragdon explained:

From an individual's perspective, working in competitive employment means:

More pay, more friends, more happiness – work increases an individual’s self-worth and provides them resources that allow them to contribute to their community.

From a taxpayer’s perspective, achieving competitive employment means:

More return on investment – for every \$1 spent on supported employment services yields a return of \$1.46, based on taxes alone generated by the individual working. Simply put, supported employment and living within the community is good fiscal policy, resulting in a 46% return on investment. (p.14)

It is time to listen to the advocacy groups. Bring all of the stakeholders together in one room and leave the egos outside the door. It is time for all of the agencies to come together and agree on one point of entry for families to access Medicaid services. It is time for the Governor of Texas to leave his political agenda outside the door and care for his constituents with disabilities by accepting the additional support at the federal level that will open the door to expand what Texas is able to provide in services and support.

It is time to consolidate the agencies and un-complicate the bureaucracy within the maze of various agencies. By providing a central point of entry for services to be created and developed to meet the individual needs, the agency maze will become more user-friendly, more readily available and less costly for the state. Arizona and Louisiana have already proven this to be true. Use the already available resources to examine best practice and work to make the necessary changes. Bring the agencies, the schools, and the families together and have our legislators listen.

I have a tremendous amount of respect for the advocates that came before me and fought for change to special education, and to bring services and support post high school

for the children with disabilities. The significance of this study is in the description of what happens when individuals with intellectual and/or developmental disabilities leave special education programs in public schools, and become lost in a maze of departments, agencies, and bureaucracies.

Special education as a discipline is based on advocacy and, as much as possible, an attempt to level the playing field for individuals with disabilities. Only through understanding the experiences of such individuals can policy makers create the change that is meaningful, appropriate, and enduring, and change that will lead to more purposeful and meaningful lives for people with disabilities as they transition from school into their communities.

APPENDIX A

IDEA REGULATIONS

SECONDARY TRANSITION

The reauthorized *Individuals with Disabilities Education Act (IDEA)* was signed into law on Dec. 3, 2004, by President George W. Bush. The provisions of the act became effective on July 1, 2005, with the exception of some of the elements pertaining to the definition of a “highly qualified teacher” that took effect upon the signing of the act. The final regulations were published on Aug. 14, 2006. This is one in a series of documents, prepared by the Office of Special Education and Rehabilitative Services (OSERS) in the U.S. Department of Education that covers a variety of high-interest topics and brings together the regulatory requirements related to those topics to support constituents in preparing to implement the new regulations.¹ This document addresses significant changes from preexisting regulations to the final regulatory requirements regarding secondary transition.

IDEA Regulations

1. Add “further education” of children with disabilities to the IDEA’s purposes.

The purposes of IDEA include ensuring that all children with disabilities have available to them a free appropriate public education (FAPE) that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment and independent living.

[34 CFR 300.1(a)] [20 U.S.C. 1400(d)(1)(A)]

2. Refer to a “child” instead of a “student.”

The definition of “transition services” is changed to refer to a “child,” rather than a “student,” with a disability.

[34 CFR 300.43] [20 U.S.C. 1401(34)]

3. Change the definition of “transition services.”

The term “transition services” means a coordinated set of activities for a child with a disability that:

- 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 postsecondary education, vocational education, integrated employment (including supported employment);
- Is based on the individual child’s needs, taking into account the child’s strengths, preferences, and interests; and

- Includes instruction, related services, community experiences, the development of employment and other post-school adult living objectives, and, if appropriate, acquisition of daily living skills and functional vocational evaluation. [34 CFR 300.43 (a)] [20 U.S.C. 1401(34)]

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4. Require changes to performance goals and indicators.

The State has established goals for the performance of children with disabilities in the State that ... address graduation rates and dropout rates, as well as such other factors as the State may determine. [34 CFR 300.157(a)(3)] [20 U.S.C. 1412(a)(15)(A)(iii)]

5. Establish an exception to requirements for evaluation before a change in eligibility.

The evaluation described in §300.305(e)(1) [see 20 U.S.C. 1414(c)(5)(B)(i)] is not required before the termination of a child's eligibility under Part B due to graduation from secondary school with a regular diploma, or due to exceeding the age eligibility for FAPE under State law. [34 CFR 300.305(e)(2)] [20 U.S.C. 1414(c)(5)(B)(i)]

For a child whose eligibility under Part B terminates under circumstances described above, the LEA shall provide the child with a summary of the child's academic achievement and functional performance, which shall include recommendations on how to assist the child in meeting the child's postsecondary goals. [34 CFR 300.305(e)(3)] [20 U.S.C. 1414(c)(5)(B)(ii)]

6. Change the secondary transition requirements in the IEP.

Beginning not later than the first IEP to be in effect when the child turns 16, or younger if determined appropriate by the IEP Team, and updated annually thereafter, the IEP must include:

- Appropriate measurable postsecondary goals based upon age-appropriate transition assessments related to training, education, employment and, where appropriate, independent living skills;
- The transition services (including courses of study) needed to assist the child in reaching those goals; and
- Beginning not later than one year before the child reaches the age of majority under State law, a statement that the child has been informed of the child's rights under Part B, if any, that will transfer to the child on reaching the age of majority under §300.520 [see 20 U.S.C. 1415(m)]. [34 CFR 300.320(b) and (c)] [20 U.S.C. 1414 (d)(1)(A)(i)(VIII)]

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7. Add requirement to invite child to IEP Team meeting when purpose includes “consideration of postsecondary goals.”

The LEA must invite a child with a disability to attend the child’s IEP Team meeting if a purpose of the meeting will be the consideration of the postsecondary goals for the child and the transition services needed to assist the child in reaching those goals under §300.320(b). [34 CFR 300.321(b)] [20 U.S.C. 1414(d)(1)(B)]

8. Add development and implementation of transition programs to list of permissible uses of State–level funds under Part B.

States may use funds reserved under §300.704(b)(1) for the development and implementation of transition programs, including coordination of services with agencies involved in supporting the transition of students with disabilities to postsecondary activities. [34 CFR 300.704(b)(4)(vi)] [20 U.S.C. 1411(e)(2)(C)(vi)]

9. Delete requirement that an LEA take other steps if an invited agency does not attend an IEP meeting during which transition services will be discussed.

If a purpose of a child’s IEP Team meeting will be the consideration of postsecondary goals for the child and the transition services needed to assist the child in reaching those goals, the LEA, to the extent appropriate, and with consent, must invite a representative of any participating agency that is likely to be responsible for providing or paying for transition services to attend the child’s IEP Team meeting. However, if the participating agency does not attend the meeting, the LEA is no longer required to take other steps to obtain participation of an agency in the planning of any transition services. [34 CFR 300.321(b)(1) and (3)] [20 U.S.C. 1414(d)(1)]

10. Add requirement for consent prior to inviting a representative of any participating agency likely to be responsible for providing or paying for transition services to attend a child’s IEP Team meeting.

To the extent appropriate, with the consent of the parents or a child who has reached the age of majority, in implementing the requirements of §300.321(b)(1), the public agency must invite a representative of any participating agency that is likely to be responsible for providing or paying for transition services. [34 CFR 300.321(b)(3)]

APPENDIX B

STATE RANKINGS

2012 The Case for Inclusion Rankings

- #1 Arizona
- 2 Michigan
- 3 California
- 4 New Hampshire
- 5 Vermont
- 6 Massachusetts
- 7 Connecticut
- 8 Washington
- 9 New York
- 10 Pennsylvania
- 11 Maryland
- 12 Idaho
- 13 South Carolina
- 14 New Mexico
- 15 South Dakota
- 16 Delaware
- 17 Nevada
- 18 Montana
- 19 Hawaii
- 20 Florida
- 21 Georgia
- 22 Oregon
- 23 Missouri
- 24 Maine
- 25 Louisiana
- 26 Minnesota
- 27 Wisconsin
- 28 Colorado
- 29 West Virginia
- 30 Alaska
- 31 Kentucky
- 32 Rhode Island
- 33 Alabama
- 34 Ohio
- 35 Wyoming
- 36 Kansas
- 37 New Jersey
- 38 Oklahoma

39 North Dakota
40 Dist. of Columbia
41 Nebraska
42 Tennessee
43 Iowa
44 North Carolina
45 Utah
46 Indiana
47 Virginia
48 Illinois
49 Arkansas
50 Texas
51 Mississippi

APPENDIX C

FAMILY INTERVIEW PROTOCOL

A Texas family navigating the system from Special Education to life after school.

The focus of this interview is to understand the real lived experiences of a Texas family as they transition their child with disabilities from public school into the community.

Introduction: During the next hour I will be asking about your experience transitioning your child with disabilities into the community in which you live.

Review the aspects of a high functioning medicaid program for the policymaker as developed by the University of Minnesota's Research and Training Center on Independent Living:

- * People with disabilities will live in and participate in their communities (promoting independence)
- * People with disabilities will have satisfying lives and valued social roles (promoting productivity)
- * People with disabilities will have sufficient access to needed support, and control over the support so that the assistance they receives contributes to lifestyles they desire; and keeping families together and reaching those in need
- * People will be safe and healthy in the environments in which they live. Tracking quality and safety

Prompt Questions:

- 1) Tell me about how Special Education served your child
 - 2) Tell me about the transition services offered at your school
 - 3) When did you first hear about outside service agencies?
 - 4) Please describe the process you went through to access these services before you left the public school
 - 5) Describe any agencies or individuals who have helped your child connect to certain community resources
 - 6) What services do you receive from Medicaid funding?
 - 7) In your opinion, how has your child's participation with adult agencies prepared him/her for life in the community?
- What changes, if any would you like to suggest?

APPENDIX D

FOCUS GROUP INTERVIEW PROTOCOL

Focus Group of Special Education Transition Coordinators from Texas Public Schools

The focus of this interview is to explore the challenges that school transition coordinators face as they work to move their students who receive special education services from high school into their communities and live purposeful and meaningful lives.

Introduction: During the next hour we will be talking about your practices for the transition of your students into their communities and the access to services for your students with intellectual and/or developmental disabilities.

Review the aspects of a high functioning medicaid program for the policymaker as developed by the University of Minnesota's Research and Training Center on Independent Living:

- * People with disabilities will live in and participate in their communities (promoting independence)
- * People with disabilities will have satisfying lives and valued social roles (promoting productivity)
- * People with disabilities will have sufficient access to needed support, and control over the support so that the assistance they receives contributes to lifestyles they desire; and keeping families together and reaching those in need
- * People will be safe and healthy in the environments in which they live. Tracking quality and safety

Prompt Questions:

- 8) As Texas transition coordinators what is your responsibility in the post-school outcomes for the students you serve?
- 9) What is working well?
- 10) Where are the frustrations?
- 11) What do you see as the greatest need on the school's side of transition?
- 12) What would you like to tell our policy makers about transition?

APPENDIX E

ADVOCATES INTERVIEW PROTOCOL

Advocates for Individuals with Disabilities in Arizona and Louisiana

The focus of this interview is the successes that policymakers through the work of advocates have been able to deliver over the years in the area of Medicaid funding and how that funding has changed the delivery of services agencies are able to provide and to gain an understanding of the differences in practices from state to state.

Introduction: During the next hour we will be talking about your practices on Medicaid funding and the access to services for your citizens with intellectual and/or developmental disabilities. Your state policies have brought you to the forefront of successful transition practices for adults with disabilities to be integrated into their communities and sustain purposeful and meaningful lives. I'd like to know how you were able to build and sustain these practices.

Review the aspects of a high functioning medicaid program for the policymaker as developed by the University of Minnesota's Research and Training Center on Independent Living:

- * People with disabilities will live in and participate in their communities (promoting independence)
- * People with disabilities will have satisfying lives and valued social roles (promoting productivity)
- * People with disabilities will have sufficient access to needed support, and control over the support so that the assistance they receives contributes to lifestyles they desire; and keeping families together and reaching those in need
- * People will be safe and healthy in the environments in which they live. Tracking quality and safety

Prompt Questions:

- 13) Your state has made many changes in the way you provide services for your citizens with disabilities. How do you think this change came about? Where did the push come from?
- 14) What did you do to ease the fear of closing the long established system of state institutions?
- 15) How did you track the citizens moving out of the now closed institutions?
- 16) How do your Medicaid waver programs work?
- 17) What is your intake process for needed services?
- 18) Who if any are the other agencies or service providers that you work with? How do you collaborate?

- 19) What has been your greatest challenge in making these changes?
- 20) What advice would you give to other state service providers in the process of making these changes?

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