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Non-Restrictive Environment After Age 21: Program Placement for Young Adults With Severe Developmental Disabilities

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by

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Declaration of Originality

I do hereby declare and attest to the fact that this is an original study based solely upon my own scholarly work here at Lindenwood University and that I have not submitted it for any other college or university course or degree here or elsewhere.

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Abstract

For students with significant disabilities, the process of transitioning from their secondary school setting to their post-secondary setting includes the exploration of potential adult settings. This paper explored the perspectives of secondary school personnel, as well as the viewpoints of personnel from St. Louis area post-secondary programs, as to the characteristics which determine adult program placement. State agencies that facilitate Person Centered Plans were also interviewed regarding viewpoints as to how secondary students with significant disabilities could seek and secure their most non-restrictive adult program placements. Research questions included: (1) How do the Missouri Alternative Frameworks utilized in secondary programming differ from the eligibility criteria utilized in post -secondary programs?; (2) How does the post-secondary eligibility process relate to the Missouri Alternative Frameworks Curriculum guidelines?; (3) What specific self-care skills and academic skills determine criteria for students with severe cognitive disabilities in post-secondary adult programs in the St. Louis area?; and (4) In addition to self-care and academic skills, what other factors determine student placement in post-secondary programs for the severely developmentally disabled within the St. Louis area? Revealed in this study was the importance of the development of lifelong relationships with post-secondary program organizations. Age, type of residence as well as the geographical location of residence, can be paramount to the applicants' skills or ability levels as adult program placement is determined for individuals with significant disabilities. Funding sources, as well as specific skill sets, were explored as they related to post-secondary clients achieving their most non- restrictive post-secondary placement.

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Chapter One: Introduction

Background of the Study

Several years ago, as a seasoned special educator and new stepparent of a child with multiple disabilities, I eagerly entered our local school district special education transition fair seeking knowledge about various post-secondary opportunities for my multiply handicapped stepson. My eyes darted around a large gymnasium filled with vendors, numerous program managers, and coordinators. I began speaking with the different representatives, and each one asked me just a few questions related to his abilities or disabilities. After hearing my responses, each informed me that my stepson would not qualify for their programs. At every table I went to I heard the same response, and as my frustration built I finally ran out to my car crying. This frustration was twofold; I could not believe my stepson did not qualify for any of the programs, and I was shocked at my feeling of ignorance regarding the existing eligibility requirements. What began as a simple hope-filled, fact-finding parental mission turned out to be not only the beginning of my stepson's transition to adulthood but also a personal career-altering experience.

Two years after this encounter, I accepted a position as the teacher of a new multiple disabilities inclusion program. One of my students was getting ready to transition from middle school to high school. As we began planning for his transition meeting, my mind returned to the questions that were asked of me by the participants at the special education transition fair two years earlier. My stepson was not eligible for the transition fair programs due to his high level of personal care needs; specifically his need to be diapered. At the time, there were only two or three area programs that would accept

someone with the high-level of personal assistance that he required. All of the other programs I had encountered at the transition fair could accommodate many personal care needs but they were not set up to accommodate an individual that required diapering. I then shared my experience with my student's family, school administrators, and his Individualized Education Plan (IEP) team. The resulting team decision determined that, since he was so very close to mastering the skill of toileting, he would benefit from remaining at the middle school for one additional year to be allowed to complete his skill mastery with familiar staff and surroundings. He is now a senior in high school and has been toilet trained for several years now. Because he attained a higher level of personal care skills, his options to participate in varied area adult programs increased. Based upon my experiences both personal and job-related, I sought to learn more about post-secondary program entrance skill requirements that might possibly result in my own students attaining a more non-restrictive adult placement.

Statement of Problem

My experience as a special educator and a step-parent of an adult with multiple disabilities revealed a disparity between what was available for a student's secondary experience (middle and high school) and curriculum objectives noted in the Alternative Frameworks (Missouri Department of Elementary and Secondary Education [MODESE], 2005b). When graduating students leave school, they may seek eligibility for services from adult agencies (Special School District of St. Louis County, 2008). "Early transition planning is especially important if your young person has severe disabilities or if adult services in your area are very limited" (Special School District, 2012, pp. i-3). This eligibility determination is ideally determined prior to leaving school, so adult services

will not be delayed upon graduation. Just as the typical developing young adult transitions into either the world of work or post- secondary educational opportunity, so do young adults with severe developmental disabilities. Post –secondary colleges, universities, and technical schools have entrance requirements to help frame the student's placement in his/her post-secondary programming. Participants with disabilities can participate in a spectrum of post-secondary options located throughout the St. Louis area.

Families of individuals with disabilities may often find the preparation for those that select an adult day service program is inconsistent and uncoordinated. Secondary transition programs consisted of varied models, some students were enrolled only in 'encore' classes and did not participate in any core academic, regular education classes. Teachers were charged with providing programming to a highly differentiated student population. Some students in the classes may be non-verbal and have significant cognitive deficits. Other students enrolled in the same programs may very well be enrolled in several general education academic classes and receive only a slightly modified curriculum.

Purpose of the Study

Li, Bassett, and Hutchinson (2009) noted that to provide each student with opportunities for successful transition outcomes, transition planning must focus on improving both the academic and functional achievement of the student with a disability to facilitate his/her transition from school to post-school activities. Transition planners are typically either school personnel or service delivery personnel.

Young adults making the transition from public school secondary programs to private or public post-secondary programs must meet eligibility criteria for these

programs. The transition team identified post-school outcomes for students and should include “activities in the transitional IEP that prepare for the child’s participation in the adult community” (Pierangelo & Crane, 1997, p. 14). The programs varied in degree from residential, work, and volunteer related opportunities. The programs differed in structure and components. Some programs required that the participants stay on the program site in a very controlled environment, others offered participants opportunity to work in their community or offered community-based life experiences. Students who have taken part in supported community experiences during their high school attendance frame the future for their supported postsecondary programming (Sax & Thoma, 2002). The support required originated from a variety of entities.

> Each community agency has a different set of eligibility requirements and rules that must be met in order for a student to access funding. This can be particularly confusing to both school personnel as well as family members when attempting to blend resources to obtain the supports and services needed for each student. Although schools must take the lead in coordinating the planning process and providing initial case management and skills training, the process cannot be completed until other community agencies or individuals assume the responsibility for follow-up services and continual case management. (Snell & Brown, 2006, p. 575)

Both social workers and adult program administrators worked with the families and schools to determine what programs the transitioning young adult was eligible for and to navigate the varied entry-level eligibility requirements.

This Grounded Theory Qualitative study evaluated how the secondary school curriculum, Missouri Alternative Frameworks, compared to the eligibility requirements of the post-secondary adult programs. This comparison could help those charged with determining secondary curriculum align student secondary transition goals with post-secondary eligibility requirements, thus providing students opportunity to receive the 'least restrictive placement' as required by The Individuals with Disabilities Education Act (IDEA) not only in their secondary setting, but also in their post-secondary setting. It also could provide secondary educators with an insight into the different types of programs that their students may be transitioning to and the various types of adult services offered. This study identified requirements and related them to transition practices current at the time of writing.

Many stakeholders were involved in the transition process, in both the decision-making process and the provision of services, when an individual with significant developmental disabilities transitioned to their post-secondary adult program. Effective teaching was viewed as content specific. The result of this process could pave the way for a heightened collaborative effort between secondary and post-secondary providers.

Research Questions and Hypotheses

The research questions pursued by this investigation include: (1) How do the Missouri Alternative Frameworks utilized in secondary programming differ from the eligibility criteria utilized in post -secondary programs?; (2) How does the post-secondary eligibility process relate to the Missouri Alternative Frameworks Curriculum guidelines?; (3) What specific self-care skills and academic skills determine criteria for students with severe cognitive disabilities in post-secondary adult programs in the St.

Louis area?; and (4) In addition to self-care and academic skills, what other factors determine student placement in post-secondary programs for the severely developmentally disabled within the St. Louis area?

In order to answer the research questions I interviewed adult agency providers and secondary school personnel. Adult day program managers and support personnel participated in a semi-structured interview with questions prepared in advance. Semi-structured interviews were also conducted with secondary school administrators and teachers. These interviews with the adult agencies provided insight into their employees' perceptions of what types of skills framed client placement and success in their programs. The interviews with secondary school teachers and administrators provided me with an understanding of how their transition curriculum aligned with the Missouri State Alternative Frameworks (MODESE, 2005b). Results for all interviews in this study were reported with use of pseudonyms to protect identities.

At the time of this writing, schools were required to show progress toward a state-designated standard of educational proficiency. In the state of Missouri, the Missouri Assessment Program (MAP) test was administered. Some students qualified for an alternative assessment due to cognitive deficits. This test was called the MAP-Alternate (MAP-A). As the MAP test was based upon grade level standards, the MAP-A test was based upon Alternative Grade Level Standards. The alternate grade level expectations met the wide range of needs of the severely disabled student while making sure the students with significant cognitive disabilities had access to and made progress in the general curriculum (Dickneite, 2007).

Although transition planning services had been offered to students for quite some time, there were still a substantial number of young people with disability experiencing difficult transitions from school to adulthood (Browning, 1997). A gap was indicated between special educators' knowledge and their involvement in the extending transition services (Asselin, Todd-Allen, & DeFur, 1998). The transition process for students with multiple disabilities could result in a smoother change from secondary to post-secondary programming if the key components of placement were identified and educator's instructional practices were designed to ultimately contribute to student success in subsequent adult programming.

Definition of Terms

Adult Day Services - Adult day service centers provide a place outside the home for older adults and younger adults with all types of disabilities to be active in the community, socialize with their peers, and receive needed health and personal care services programs (Easter Seals. 2011).

Community Supports - Community supports are generally defined as local groups, businesses, and organizations, which include churches, parks and recreational activities, YMCA's, SB40's, and other local and state agencies (Missouri Department of Mental Health, 2006).

Contracted Service Providers – Contracted service providers are agencies and individuals that have a contract with the state to provide services to individuals who are developmentally disabled (Missouri Department of Mental Health, 2006).

Direct Support Professional - individuals who directly assist adults with daily living activities, including personal care and community outings (St. Louis Arc, 2011).

Developmental Disability - a term that includes disabilities that occur in the developmental years, before age 22. They may be caused by a mental or physical impairment or a combination of both. Developmental disabilities cannot be cured; they are life-long and chronic. Developmental disabilities include, but are not limited to: mental retardation, cerebral palsy, epilepsy, autism, Down syndrome, or Prader-Willi Syndrome. They may also include head injury if the injury occurred before age 22 or other learning disabilities related to brain dysfunction. A person with a developmental disability will have substantial functional limitation in two or more of the following six areas of major life activities: self-care, receptive and expressive language development and use, learning, self-direction, capacity for independent living or economic self-sufficiency, and mobility (Special School District, 2010).

Functional Skills - Uses real-life experiences to plan a curriculum that meets the student's present and future needs (Special School District, 2010).

Independent Living Skills - Appropriate behavior necessary for living in a non-institutional setting. Skills include arranging transportation, maintenance of clothes and living quarters, personal hygiene, money handling, group living, and recreation (Special School District, 2010).

Least Restrictive Environment (LRE) - Provision of Public Law 94-142 (IDEA) that states that children with disabilities must be educated with their non-disabled peers to the maximum extent possible (Special School District, 2010).

Mental Retardation – term that continues to be used in federal law referring to educating students with disabilities (IDEA) and may be the classification that educators utilize on psychological assessments (Browder & Spooner, 2011, p. 6).

Missouri Assessment Program (MAP; MAP-A) - Statewide testing program with subject-area assessments or alternate assessments (MODESE, 2005b).

Missouri Alternative Frameworks - This document is designed to encompass a wide spectrum of student ability levels and to reflect the alternate application of the *Show-Me Standards* for students participating in the MAP-A (MODESE, 2005b).

Natural Supports - Natural supports are unpaid services and supports, which are typically found in a person's home or daily routine. The most important source of support for people is their family. Family includes immediate as well as extended family members (Missouri Department of Mental Health, 2006).

Self-Determination - Rights of students with disabilities to make plans for their lives that reflect their wishes and those of their families, not just those of professionals (Friend, 2008, p. 524).

Severe Disabilities - Those disabilities that impact on a child's performance to such an extent that there are significant limitations on his/her ability to perform (Special School District, 2010). This term is also used as shorthand for students who have moderate and severe disabilities (Browder & Spooner, 2011, p. 6).

Students with Significant Cognitive Disabilities – a term found in law that describes a student who requires substantial modifications, adaptations, or supports to meaningfully access the grade-level content (Browder & Spooner, 2011, p. 6).

Transition Services - The coordinated set of activities based upon the individual student's needs, taking into account the student's strengths, preferences, and interests, which includes instruction, related services, community experiences, the development of employment and other post-school adult living objectives, and, when appropriate,

acquisition of daily living skills and functional vocational evaluation (Luetkemeyer, 2007).

Limitations

Both the study participant geographical size and participant numbers were limited in this research. Interview participants served one greater metropolitan area. Because of participants' proximity to a large city, several types of program stakeholders could be interviewed. While the purpose and diversity of program participants enhanced the depth of the study, not all geographical areas offer such programming due to limited populations. The study participation was limited to two school administrators, two teachers, ten programs managers, and three on-site program personnel. Because of the limited participant size, the findings may not be representative of all types of entities serving transitioning individuals with severe developmental disabilities (Frankel & Wallen, 2009). Narrowing the focus of the study to include only general education inclusionary programs limited the opportunity to study teams originating from self-contained schools.

As the primary investigator, my role as both a teacher and a parent of a consumer of adult services was another limitation. Frankel and Wallen (2009) discussed how "the researcher does not go in with a theory ahead of time; rather he or she develops a theory out of the data that are collected—that is, one that is *grounded in the data"* (p. 430). Thus, the resulting data is dependent upon the insight of the researcher. In order to insure that personal bias would not interfere with the project, I asked interview questions that were shaped to permit participants to provide their own viewpoint on the transition process. Interviews were analyzed, coded, and resulting common themes were developed.

Letters requesting participation were sent to all contributors. Along with the letters, participants received a list of interview questions. One-on-one interviews were conducted with 11 out of 14 participating agencies. Three focus group interview sessions were held. The interviews were transcribed and coded.

Conclusion

The researcher explored and identified the post-secondary eligibility requirements for individuals with developmental disabilities, which provided the framework of academic, and self-care skills used to determine adult programming. This research provided a synthesized analysis of the entry-level expectations and requirements, which were utilized to place individuals with severe developmental disabilities, which was not found in the current body of research.

In this chapter, I explained the background of the study, which began with a personal experience of confusion and frustration when searching for adult day programming choices for my stepson with developmental disabilities. The problem that both parents and transition planners faced when seeking the most non-restrictive placement for post-secondary adults with developmental disabilities was outlined. A general explanation of the research questions and definition of terms was given. I outlined how day-program eligibility requirements were pinpointed along with the academic, self-care skills, and miscellaneous entry requirements.

As school transition teams develop transition goals, the utilization of the identified entry-level criteria may be helpful in the development of educational plans, which may allow the students to maximize their post-secondary program placement opportunities. Schools became responsible for not only the results of general education students but also

for the results of students with severe disabilities (Sax & Thoma, 2002). This research also explored secondary school curriculums, compared the curriculums and skills identified by post- secondary agencies to each other and to the Missouri Alternate Frameworks.

In Chapter Two, a review of literature is presented. The literature considered for the comparison with my research included a review of both the history and laws related to special education within the United States. I also reviewed literature related to transition planning and special education curriculum standards.

Chapter Two: Review of Literature

Overview

Secondary school teachers and administrators were challenged with the task of reviewing and selecting from a myriad of sources regarding relevant curriculum for their transitioning students. “A compelling need exists to improve the outcomes for students with disabilities” (Ysseldyke & Algozzine, 2006, p. 23). Secondary teachers were charged with the responsibility of writing transition IEPs. “It is the responsibility of school IEP transition teams to develop appropriate measurable post-secondary goals that relate to training, education, employment and independent living skills” (MODESE, 2008, p. 13). As schoolteachers and administrators sought to smooth the transition process for students with severe disabilities, they sought adult stakeholder input into the development of transition IEPs.

Secondary school personnel sought to align their students’ individual transition goals and curriculums; they may utilize various components involved in determining the composition of the transition programs. This literature review provides an overview of the history and law regarding special education services, best practices in providing transition curriculums, and a review of alternative standardized assessments.

History of Special Education

The history of special education can perhaps best by characterized as one of developing or shifting views and attitudes about individuals with disabilities (Gargiulo, 2006). As early as 1799, Itard (1775-1850) worked with a captured boy named Victor, who that was known for running with wolves and exhibiting violently resistant behaviors (Winzer, 1993). Itard hoped that by engaging his student (Victor) in a series of

educational activities he could restore him to normalcy. Itard utilized what, would at the time of this writing, be termed a type of sensory integration program combined with behavior modification techniques. Because of his groundbreaking work over 200 years ago, Itard is known as the "Father of Special Education" disabilities (Gargiulo, 2006, p. 17). As the century ended, other special education pioneers applied principals of sensorimotor activities with the hope of remediating specific targeted incapacities.

During the 1800s, Europe's academia was promoting ideas regarding equality and freedom. Seguin (1812-1880) a student of Itard, developed a systematic training sequence, which focused on three main components, "These components included motor and sensory physical training; intellectual training, including academic and speech techniques; and moral training or socialization" (Winzer, 1993, p. 69). New approaches continued to evolve regarding the education of people with disabilities.

Within the United States, the education of the deaf and blind students began when the Connecticut Asylum for the Education and Instruction of the Deaf and Dumb Persons opened in Hartford, CT. Gallaudet, an early pioneer in deaf education, was instrumental in implementing designs for teacher training and professionalism. He spent time in both England and France studying institutional practices and then taught at the Connecticut Asylum, promoting the ideals and methods of the education of deaf students (Winzer, 1993). The servicing of families and individuals with severe disabilities took on a different light for the next several decades, following Gallaudet's work, as specialized institutions were established. In 1853, Howe, a social reformer from Massachusetts, who was considered a pioneer in special education identified "institutions for the blind, deaf and dumb and feebleminded as necessary in order to embrace all of the children in the

State" (Osgood, 2008, p. 8). Howe defined three grades of retardation, low grade or idiots, middle grade or fools, and high grade or simpletons (Winzer, 1993). Problems could evolve when discussing the history of the special education of persons with severe disabilities, since the descriptors can overlook the unique qualities of the individual and the many other subgroups to which that individual may belong (Spooner, Browder, & Uphold, 2011, p. 4). The naming of disabilities had implication for both the categorizing of and labeling of individuals. "What were once professional categorizations, such as imbecile, retarded, moron and feebleminded are now considered not appropriate" (Spooner et al., 2011, p. 5).

"By 1916, all children in every state were required to attend school" (Algozzine & Ysseldyke, 2006, p. 11). During the second half of the 19th century, and the early years of the 20th century, special education classes began to appear in public schools. Compulsory school attendance began in the United States around 1850. During the second half of the 19th century, education was considered a luxury; many children, even as young as five or six-years-old, were expected to subsidize their families' financial security and expected to work in factories or on farms (Winzer, 1993). Special education continued to evolve as the focus changed from an institutional service model to a public school model.

By the 1930s, establishments for the mentally disabled were becoming overcrowded and family members and worried activists were beginning to express concern (Browning, 1997). During the next 50 years, and up to World War II, special education students were grouped and segregated from other pupils in their schools. Their school day was spent isolated from their general education peers, and their activities

centered on the activities within their classroom walls (Gargiulo, 2006). After World War II, political activism, litigation, legislation and leadership at the federal government level provided the special education delivery framework in the United States, current at the time of this writing. “During the late nineteenth and early twentieth centuries, urbanization, immigration and industrialization flourished in the United States” (Friend, 2008, p. 6). In response to the changes in society, compulsory education began to develop.

The Law and Modern Day Special Education

The 1954 Supreme Court Decision regarding *Brown v. Board of Education of Topeka, Kansas* ended the ‘separate but equal’ philosophy. This case provided the basis for future rulings for children with disabilities which insured that they would be allowed to attend public school without threat of exclusion (Crabtree, Gartin, & Murdick, 2007).

The election of John F. Kennedy in 1960 signified a new focus in the federal government’s involvement in the provision of services to persons with disabilities. (Crabtree et al., 2007, p. 9). In response to his own personal family experience, Kennedy formed the President’s Panel on Mental Retardation to formulate ways to improve the quality of life for individuals with disabilities. The panel’s finding resulted in two major pieces of legislation, the Maternal and Child Health and Mental Retardation Amendments of 1963 and the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963 (“JFK and people with disabilities”, 2014). President Kennedy challenged Congress, requiring it to focus on finding solutions to the problems of individuals with mental retardation, which became a precursor and inspiration to both academic and private initiatives to improve life for those with mental retardation.

Simultaneously, the field of special education began changing in response to special reform reports and agendas and new concepts in special education evolved.

The concept of normalization, which originated in Scandinavian countries, was introduced by Bank-Mikkelson and Nirge, The intent of normalization was to provide services and settings for individuals with mental retardation so their lives could be more like the lives of individuals who did not live in institutions (Crabtree et al., 2007). During the 1960s, as the concepts of normalization and deinstitutionalization were becoming popular, a small group of parents and advocates formed what is known at the time of this writing as The Arc of the United States. Parents, at that time, were commonly told that the only solution to finding the care and education of their child with mental retardation was to place the child in an institution, as very few programs or community activities were available to these children (The Arc, 2014).

> In response to advocates, parents and concerned governmental leaders the United Nations General Assembly of 1971 adapted basic right statements of 'Bill of Rights' for citizens with mental retardation. This bill of rights provided the philosophical base for later legislation. (Crabtree et al., 2007, p. 8)

Thus began a shift in the nature of the catalyst for special education from isolated individual efforts to that of group initiatives and legislation.

The first special education classes were self-contained, and this concept remained the mainstay of special education services until the mid-1970s (Gargiulo, 2006). In 1973 the Vocational Rehabilitation Act was enacted. Section 504 of this law prohibited discrimination against individuals with disabilities. This was followed by The Education for All Handicapped Children Act (EAHCA) of 1975, P.L. 94-142. This special

education legislation provided a free and appropriate education for all children with disabilities (Crabtree, et al., 2007). Additional amendments were passed in 1986 (P.L. 99-457) mandating special education for preschoolers with disabilities and providing incentives for early intervention services (Gargiulo, 2006). While these laws provided access and entitlement to individuals with disability, future legislation would target specific educational guidelines, such as the transition of students from the public school setting to their adult world.

Three federal mandates supported the provision of transition services for individuals with disabilities. These laws provided the framework students with disabilities may utilize to build their future living and possibilities for working in their communities as adult citizens. The Individuals with Disabilities Education Act (IDEA), Section 504 of the Rehabilitation Act of 1973, and the Americans With Disabilities Act (ADA) all 'expanded the world' (Special School District, 2012) for students with disabilities. They provided an accountability process by which students were to receive an outcome-oriented secondary learning process and discrimination free employment opportunities, as well as accessible housing and transportation.

IDEA and the IEP

In 1990, IDEA was the revision of the original Education of the Handicapped Act; "This revision targeted the use of people first language in order to ensure that individuals with disabilities are considered as people first, not a diagnosis or characteristic" (Special School District, 2012, pp. i-1). IDEA required that schools provide transition services as part of the IEP process. These transition services were defined as a "coordinated set of activities for a student with a disability that is designed with an outcome-oriented process

that promotes movement from school to post-school activities" (Gargiulo., 2010 p. 38). Part B of the IDEA of 1990 called for schools to provide services to children with disabilities between the ages of 18 and 21. During the student's transition IEP, it was required that the IEP team determine the least restrictive environment possible (LRE) in order that the necessary special education services could be delivered (Algozzine & Ysseldyke, 2006). Least restrictive environment meant that students with disabilities, such as Intellectually Disabled, Autism, and Cerebral Palsy, were placed in special classes, separate schools, or removed from the regular educational environment only when the nature or severity of the disability was such that, even with the use of supplementary aids and services, education could not be satisfactorily achieved (Special School District, 2012). The IEP teams were, "The more severe the child's needs, the more the educational environment may become restrictive or segregated" (Crabtree et al., 2007, p. 123).This process was designed to ease the process of transitioning from school life to adult life.

IEP teams determined special education services. These teams were composed of parents, the student (when appropriate), and school personnel. The team determined the level of intervention required to provide a free and appropriate education, and also set individualized educational goals. The special education placement continuum ranged from services, which were delivered on a consultative basis (student remained with non-disabled peers at all times) to services which were delivered in a self-contained special education building that only serviced students with disabilities (zero non-disabled peers) (Browder & Spooner, 2006). After careful consideration of the student's educational goals, the IEP team, in accordance with federal laws, determined student placement. The

IEP team also developed a transition plan which addressed areas of employment, and/or training, independent living and education. Students for whom the IEP team determined a regular academic curriculum was not appropriate could receive what was called a functional skill curriculum (skills that were important for everyday living), and their academic curriculum was adapted and modified (West, 1999). Just as the state provided curriculum guidelines for the regular academic curriculum, it also provided adapted guidelines for adapted curriculums.

IDEA 2004 and Transition

In 2004, the Individuals with Disabilities Education Act Improvement Act was revised and reauthorized. While the new law maintained the basic tenants of the original law, it made significant changes, which included the addressing of student transition services based upon the individual child's needs, preferences, and interests (Special School District, 2012). This revision provided schools with specific regulations as to how to deliver, maintain, and alter educational services, including not just instruction, but also related services, the formulation of employment, education, and living outcomes, as well as the acquisition of daily living skills.

Americans with Disabilities Act

Originally passed in 1973, the Rehabilitation Act was revised in 1990, and became known as the Americans with Disabilities Act (ADA). This act was passed to address statutes considered to be too fragmented and narrow to provide adequate protection (Crabtree et al., 2007). The ADA not only defined those who were covered by federal law, but also prohibited discriminatory employment practices for both public and private services. It mandated that reasonable accommodations be provided for individuals

with disabilities in both public and work settings. “These three laws (IDEA, IDEA 2004, and ADA) really expand the world for persons with disabilities” (Special School District, 2012, p. 3). Students with disabilities must receive a results-oriented education and transition planning to help them be successful in the real world.

No Child Left Behind

In 2001, the No Child Left Behind Act (NCLB) was passed. The intent of this act was to improve the academic achievement of all students, including those with disabilities and other special needs (Friend, 2008). The act stipulated that children in grades three through eight, and then in grades ten through twelve, were assessed in the areas of math, reading and science. See Table 1 for a summary of laws that impacted transitioning special education students.

Table 1.

Summary of Laws Affecting Special Education Transition

Law	Description
1975- Education for All Handicapped Children Act (EAHCA) Public Law 94-142	-Guaranteed a free and appropriate public (FAPE)education with special education and related services designed to meet children's unique needs -Least Restrictive Environment (LRE) – Children with disabilities are to be educated to the maximum extend appropriate with students without disabilities -Individualized Education Program (IEP) – An individually tailored document to be developed in conjunction with parent(s)/guardian(s) that describes and education plan for each learner with disabilities -Procedural due process – Provides safeguards for parent(s)/guardian(s) regarding confidentiality and the right to examine school records, to obtain an independent evaluation and to receive written notification of proposed IEP changes -Nondiscriminatory assessment – Prior to special education placement, a child must be evaluated by a multidisciplinary team in all areas of suspected disability -Parental participation – requires that parents participate fully in the decision making process that affects their child's education
1986 – Public Law 99-457 (1986 Amendments to PL 94-142)	-Preschoolers with special needs ages 3-5 are guaranteed a free and appropriate public education
Individuals with Disability Act - 1990 (IDEA) (1990 Amendments to PL 94-142)	Emphasized the use of first person when referring to individuals with disabilities -Requires that no later than the age of 16, each student with an IEP must have a transition plan addressing a coordinated set of activities are outcome oriented -Expanded the scope of related services to include social workers and rehabilitation counseling -Repealed states' immunity from lawsuits for violating IDEA
Americans with Disabilities Act (ADA) -1990	-Forbids discrimination against persons with disabilities in both the public and private sectors -Covers any person with an impairment that substantially limits a major life activity -Employers must make "reasonable accommodations' -Mass transit systems must be accessible
IDEA – Revised - 1997	IEPs must state how the student with disabilities will be involved with and progress in the general education curriculum Addressed discipline issues regarding students with disabilities as well as reevaluation procedures
No Child Left Behind (NCLB) – PL 107-110	-All pupils including those in special education are expected to demonstrate proficiency in mathematics, reading and science to be demonstrated by annual testing

Note: Source: Gargiulo, R. (2006). .

Secondary Transition Curriculum

As students entered their transition years, the IEP team broadened to include necessary stakeholders. These stakeholders could include individuals from the school, parents, local businesses, area agencies, and post-secondary placement organizations. The IEP team was charged with determining transition goals for the student, and the school district was charged with the implementation of instruction to ensure the students were able to work towards the progress of their IEP goals. In transition-centered learning, the emphasis was on the student's future (Browder & Spooner, 2011). Transition IEPs addressed the areas of education, employment, and independent living for the student's life after graduation. The *SSD Transition Guidebook* described transition as a "movement from one situation to another" (Special School District, 2012, pp. i-1). This journey was a process, which entailed the acquisition of the knowledge, supports, and skills necessary to ensure that an individual's transition into his or her adult years would be as trouble-free and satisfying as possible.

The first of two National Longitudinal Studies on Transition (NLTS) sponsored by the U.S. Department of Education indicated "students with disabilities who stayed in school and completed their education and vocational training experiences had consistently better employment outcomes than did their peers who did not stay in school" (Wehman, 2006, p. 401). As IDEA set forth that students for whom the IEP team determined needed more time to work on their transition goals, the additional time in school may be beneficial. The transition years could offer the student additional time to work on IEP goals and objectives, including those related to their chosen post-secondary outcomes. One of the main outcomes of school was to assist students in the planning and

preparation for the rest of their lives (Kellems & Morningstar, 2010). The follow-up study, NLTS2 was a 10-year study focusing on the characteristics, experiences and outcomes of students with disabilities. Results of the study stressed that students with disabilities were less likely to enroll in post-secondary programs than were their peers in the general population (45% vs. 53%) (Kellems & Morningstar, 2010, p. 60). These students were less likely than their peers to be employed after leaving school (57% vs. 66%) and they were also less likely to have either a checking account (46% vs. 68%) or a credit card (28% vs. 50%) (Kellems & Morningstar, 2010, p. 60). NLTS2 additionally revealed that students with multiple disabilities were the least likely to have completed high school and to graduate with a regular diploma (Wagner, Neuman, Garza, & Levine, 2005). The passing of legislation in 2004 stressed the importance of providing transition curriculums beyond the age of 18 to individuals with severe disabilities and provided the legislation to provide the legal and financial framework for the programs.

With the passing of IDEA, school districts and administrators were challenged with the task of providing appropriate curriculum's to transitioning students. IDEA was reauthorized and transition requirements were further strengthened as transition services were defined as the following:

> A coordinated set of activities for a student 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-secondary activities including post-secondary education, vocational education, integrated employment (including supported

> employment), continuing, and adult education, adult services, independent living or community participation [20USC 1401 Sec602 (30)]. (Gargiulo, 2010, p. 38)

With this reauthorization, the child was eligible for appropriate services through the education system. (Special School District, 2012) For students age 16 and over, IDEA guaranteed by law an outcome/results-oriented education. It was important to consider the tangible everyday life skills that allowed students to achieve the adult life that they and their families aspired to them (Special School District, 2010). Both academic and functional life skills comprised the secondary transition curriculum.

When a student's education was focused on the future, he or she was said to be transition focused (Spooner et al., 2011, p. 367). Each year students' IEP team meetings were held, and when they reached the age of 16 a Transition Plan, in accordance with IDEA 2004, was added to the IEP by the IEP educational team (Special School District, 2012). This plan outlined how the members of the IEP team would contribute to the student's achievement of the transition goals.

IDEA 2004 called for transition curriculums to be designed as outcome-based, as well as based upon the individual student's needs. These needs could be related to student need for instruction, related services, community experiences, development of employment, and other post-school living objectives, as well as the acquisition of daily living and functional skills (Baker, 2005). As transition curriculums and IEPs addressed the individual needs of the person with disabilities, they could include a variety of stakeholders.

The implementation of best practices when providing curricular instruction at the secondary level could encompass many planning aspects. "Several elements are

important to the planning for students' access to the curriculum, including acquiring academic curriculum skills, developing functional or life skills, developing social and friendship skills and building on students'" developmental skills (Wehman, 2006, p. 171). It could be challenging to provide 'appropriate' curriculums. Students with moderate to severe disabilities benefitted from a curriculum that included functional skills that would facilitate a successful transition into adulthood (Collins, Karl, Riggs, Galloway, & Hager, 2010). However, teachers needed to find a way to balance a functional skills curriculum with their needs to teach core content skills that were the foundations of required state assessments (Council for Exceptional Children, 2004).

Osgood, Foster and Courtney (2012) examined the transition to adulthood for youth who were receiving social services and were part of the justice systems during their youth. Services these students received were abruptly eliminated when they graduated from school, with the exception of those students who received special education services and were deemed eligible to receive them into their early adult years. These students received services designed for their individual needs (Osgood et al., 2012). The provision of the many services provided within the school setting could call for varied curricular subject matter. Many approaches to curriculum design existed. The designs ranged from commercially available 'canned' programs to those that were homemade. The differing approaches to curriculum design were some of the reasons that many students left school without the necessary building blocks of independent living skills essential for competence in society (Wehman & Kregel, 2004, p. 3). The provision of individually designed transition curriculums could entail input from many stakeholders. "Successful transition depends on local collaboration among educational and community agencies,

businesses and families" (Snell & Brown, 2006, p. 575).The transition IEP team worked together to determine the appropriate curriculum. While federal legislation called for each student's transition goals to be highly meaningful, this could be challenging, as teachers and administrators worked to develop outcome-based transition programming.

IDEA 2004 called for transition curriculums to be designed as outcome-based, as well as based upon the individuals student's needs. These needs could be related to student need for instruction, related services, community experiences, development of employment, and other post-school living objectives, as well as the acquisition of daily living and functional skills (Baker, 2005). Transition services could be provided in a variety of settings in either the school or community. The IEP dictated in which particular setting the students would receive their special education instruction, either in a general education setting or in a special education setting. The Special Educational Longitudinal Study (SEELS) was a study of more than 11,000 school age special education students. The study indicated that students with disabilities who spent more time in general education classroom tended to be absent less, performed closer to grade level than their peers in pullout settings, and had higher achievement test scores (Wagoner & Blackerboy, 2004). When a student reached the age of 16, IDEA stipulated that a Transition Plan be added to the IEP (Special School District, 2012, pp. i-3). This plan detailed the education and supports the team felt necessary for the student to both reside and work in his or her community.

Transition and the IEP. The importance of preparing for adult life via secondary school curriculum developed from transition planning focused on simply employment, residential, and medical needs, to the inclusion a number of components (Mazzotti et al.,

2009). Components could include student –focused planning, family involvement and interagency collaboration. “Major components of transition (e.g. independent living, assessment and instruction, employment), and self-determination (e.g. Identifying and teaching goals, providing opportunities for self-determination) should be the focus of transition to facilitate the student’s future success” (Spooner et al., 2011, p. 381). IEP teams provided the delivery service framework and plan. “By aligning IEP goals with transition services and postsecondary goals provides students the opportunity to acquire specific skills that will allow them to attain their postsecondary goals” (Mazzotti et al., p. 50). A collaborative effort was required between the varied agencies involved in the transition process, in order for the student and family to maximize the effectiveness of the transition team.

IDEA 1997 required that IEPs be developed and offered for each special education student. “IDEA 2004 increased the age requirements to 16 years and older” (Wehman, 2006, p. 180). While federal law stipulated that transition IEPs be developed at the age of 16 and older, this does not mean that transition could not be addressed at an earlier age:

> The transition planning team will bring the parent, the child, teacher and members of the community together to develop a plan that will determine how each will contribute toward helping your young person fulfill his/her dreams for life after high school. (Special School District, 2012, pp. i-3)

Special education teachers and administrators were legally required to develop pertinent IEPs for students with disabilities and at the same time to align their teaching to state standards (Peterson et al., 2013). “The student curriculum needs to prepare the student for their postsecondary education, employment and independent living and still meet

standard or modified curricular expectations" (Peterson et al., 2013, p. 46). The IEP was a management tool that followed the guidelines of IDEA to provide a detailed stipulation of what services were offered, where they would be provided, and for what duration of time (Gargiulo, 2006). "The IEP is also a process that provides a method for holding schools accountable to the parents for the provision of an appropriate education for children with disabilities" (Crabtree et al., 2007, p. 28). The transition IEP additionally focused, not only on the type of curriculum necessary to implement a student's goals, but also dictated the student's educational setting. Educational settings that provided transition instruction could range from the typical special education classroom to actual on-site work experiences.

The IEP also addressed where the student's education would take place. "Effective delivery of a special education requires an array or continuum of placement possibilities customized to the individual requirements of each pupil" (Gargiulo, 2006, p. 71). IEPs required that a student's placement be determined; this placement was dependent upon how much time that child received their special education services with their general education peers and where they received these services. The concept of the least restrictive environment (LRE) was central to both services delivered and student placement. IDEA 2004 detailed the concept of least restrictive environment. Federal law stated:

> To the maximum extent appropriate, children with disabilities, including those children in public and private institutions or other care facilities, are educated with children who are not disabled, and special classes, separate schooling, or other removal of children with disabilities from the regular educational

> environment occurs only when the nature or severity of the disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily [IDEA 2004 [Part B, Sec 612 (a) (5)]. (Wehman, 2006).

Wehman (2006) spoke to the use of three commonly used terms when identifying the type of placement a student received: mainstreaming, inclusion, and full inclusion. Mainstreaming or integration referred to the social and instructional integration of students with disabilities into programs or services that serviced typically developing students (Gargiulo, 2006). Inclusion was similar to mainstreaming in that students received their services within the general education classroom; however there was no expectation that they would 'keep up.'

> Students are placed in general education classrooms so as to benefit from the inclusive setting. The combining of the IEP and transition IEP processes and the inclusion of students and their parents as well general education staff, special education staff and related service providers as active participants in planning is not only good for a student's school life but also for life beyond school. (Wehman, 2006, p. 181).

A collaborative effort between both the general education staff, as well as the special IEP documents, simultaneously included information from IEP team members when addressing transition specific goals.

Typically, the delivery of transition services fell on two types of educators, transition coordinators/specialists and secondary special education teachers. They were expected to assure "a coordinated set of activities" as required under IDEA (Li et al.,

2009 p.34). These activities could include varied components. “Life skills, vocational experiences and social skills should all be included in the IEP transition plan” (Special School District, 2012, pp. i-4). IDEA 2004 stipulated that not only did the student’s IEP team need to provide a transition plan beginning at the age of 16, this plan must include the following:

> (1) Measurable and appropriate postsecondary goals based upon age appropriate transition assessments related to training, education, employment, and, where appropriate, independent living skills; and
>
> (2) The transition services (including courses of study) needed to assist the child in reaching those goals
>
> A clearly written IEP, based on documented student needs, can and should be a guidepost for selecting and designing effective instructional strategies to best meet a student's needs. (Mazzotti et al., 2009, p. 44)

After IDEA 2004 was passed, the Office of Special Education Programs (OSEP) started necessitating that school districts submit data on 20 indicators for Part B. The National Secondary Transition Assistance Center (2013) connected how the 13th indicator concerned transition services for students:

> IEP transition goals are annually updated and based upon an age appropriate transition assessment, transition services, including courses of study, that will reasonably enable the student to meet those postsecondary goals, and annual IEP goals related to the student’s transition service’s needs. There also must be evidence that the student was invited to the IEP Team meeting where transition services are to be discussed and evidence that, if appropriate, a representative of

> any participating agency was invited to the IEP Team meeting with the prior consent of the parent or student who has reached the age of majority. (para. 2)

In response to OSEP's accountability indictors, the state of Missouri required annual data regarding the assessment of students with a disability. For some special education students, standardized assessment was given in the form of an alternative assessment (MODESE, 2005b). Alternative Assessments were administered through the 11th grade and were aligned with state learning standards; however, they were administered in an applicatory fashion which involved an interpretation of the general education standard. However, there existed alternative transition assessments which specifically assessed areas other than academic. These tools could assess many components of the individual's daily experience.

Alternative Frameworks

Legislation from the Outstanding Schools of 1993 to the No Child Left Behind Act of 2001 (NCLB) called for schools to increase both their expectations and opportunities for all students (MODESE, 2005b). The Missouri Alternative Frameworks were developed in answer to legislative requirements to provide standardized assessment to students with significant disabilities whose learning styles were not appropriate for traditional testing.

Alternate Assessments

The interaction of transition assessments and a student's IEP goals was considered key in secondary transition planning. "Transition assessment was the starting point in the transition planning process" (Mazzotti et al., 2009, p. 46). There were two types of transition assessments: formal and informal. The National Secondary Transition

Technical Assistance Center (2010) described formal transition assessments as instruments that included explanations of their norming process, reliability and validity, and suggested uses. These assess such areas as adaptive behavior, aptitude, achievement, and intelligence. In comparison, informal assessments "require more subjectivity to complete and center on functional skill inventories, personal-future planning activities and situational assessments" (National Secondary Transition Technical Assistance Center, 2010, pp. 1-2). Schools were charged with the administration of high-stakes standardized alternative testing and could utilize some alternative assessments as a way to learn more about their students' strengths, weaknesses and preferences.

For a long time, schools operated on the premise that most students could learn the normally offered content and skills, but some students were not going to learn much. Thus, some students were not assessed with their peers or not assessed at all (Thompson, Quenemoen, Thurlow, & Ysseldyke, 2001). In December 2003, the U.S. Department of Education, under NCLB, issued regulations to states allowing them to develop alternate assessments:

> via a documented and validated standards-setting process" alternate achievement standards for students with the most significant cognitive disabilities, "provided that those standards (1) Are aligned with the State's academic content standards; (2) Promote access to the general curriculum; and (3) Reflect professional judgment of the highest achievement standards possible (34 C.F.R. § 200.1, 2003; Cameto et al., 2009). Building on the 1994 requirements, NCLB mandated that states hold schools accountable for ensuring that all students reach proficiency on state standards in reading, math and science. (Wehman & Kregel, 2004, p. 3)

However, “the most recent wave of school reform has focused on the articulation of standards that all students should achieve” (Browder & Spooner, 2011, p. 23). A significant part of NCLB was that schools be responsible for the performance of particular subgroups including those who receive special education (Wehman, 2006). NCLB, like IDEA required that states must provide alternate assessments for students with the most significant cognitive disabilities who could not participate in the state assessment. No Child Left Behind (NCLB) had been in existence for over a decade and one of the most challenging aspects of the law for school districts was the administration of alternative assessments. IDEA 2004 called for states to establish requirements for alternate assessments.

> A. Alternate assessments much be aligned the State’s challenging academic content standards and challenging student academic achievement standards
>
> B. If the State has adopted alternate academic achievement standards to measure the achievement of children with disabilities against those standards [IDEA of 2004, PL 108-446, §612[16], 118 Stat 2647]. (Crabtree et al., 2007, p. 85)

IDEA of 2004 required that states include all students in their assessment process or alternative assessment process and that report all scores (Crabtree et al., 2007). The National Association of State Directors of Special Education, (NASDSE) stated: “It has been well established that there is a small percentage of students who will not be able to achieve proficiency on grade level standards and they do support the need for assessment of all students” (NASDE, 2007, p. 1).

IDEA was specific regarding the requirements for alternate assessments. IDEA 2004 called for states to establish requirements for alternate assessments:

> C. Alternate assessments must be aligned to the State's challenging academic content standards and challenging student academic achievement standards
>
> D. If the State has adopted alternate academic achievement standards to measure the achievement of children with disabilities against those standards [IDEA of 2004, PL 108-446, §612[16], 118 Stat 2647]. (Crabtree et al., 2007, p. 85)

Aligning IEP outcomes to state curricular standards could be challenging to teachers and administrators when the outcomes of students' IEPs during the transition years were based upon potential post-secondary placement. "Standards-based reform promotes the setting of high standards, identifying indicators of successfully meeting those standards, and ways to measure student progress toward the indicators" (Thurlow, Elliott, & Ysseldyke, 2003, p. 4). Missouri's Alternative Assessment Program (MAP-A) was the statewide assessment program which met the federal requirements of IDEA, ESEA, and NCLB (MODESE, 2013a). During the 10th and 11th grades students participated in secondary alternative assessments. When discussing who was assessed by alternate assessments, Browder and Spooner (2011) referred to a survey of special education teachers across three states, completed by Towles-Reeves, Kearn, Kleinert and Kleinert. Teachers who participated in the survey "indicated that many students used symbolic communication (63%) or more, could read sight words or simple sentences (33%) or more, and could solve computational problems with or without a calculator

(37%) or more" (Browder & Spooner, 2011, p. 26). The state of Missouri developed criteria which provided the stipulations under which IEP teams may determine that a student was eligible for alternative standardized testing. The state of Missouri's MAP-A eligibility criteria contained five eligibility requirements that must all be met (Figure 1).

"Under federal law, all students are expected to work toward the same high expectations or standards. States and districts must measure how well students are doing by using assessments that are aligned to standards" (Thompson et al., 2001, p. 7). At the time of this writing, the state of Missouri administered the MAP Assessment test to all students in grades 3-8 and in grades 10 and 11. The Alternative MAP-A test was available to qualifying students. The tests were first aligned to the state's Show-Me-Standards which were guides for what students should know and how they should demonstrate their knowledge. The text was then further aligned to the more detailed Grade-Level Expectations. These expectations outlined for both teachers and parents exactly what was to be taught and what the learning expectations were ("Practical parenting partnerships", 2008-2009).

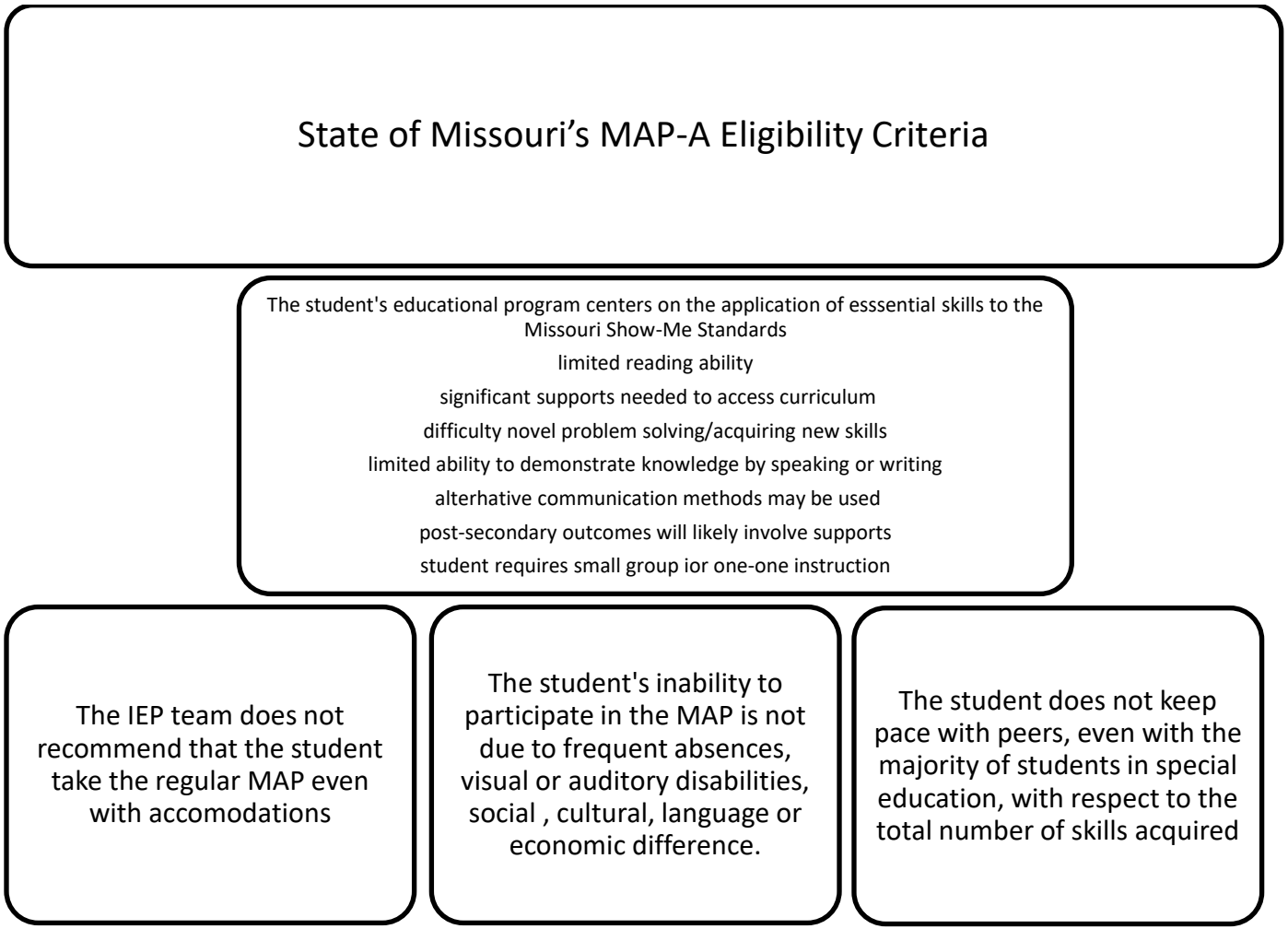

Figure 1. State of Missouri's MAP-A eligibility criteria. Source: *MAP-A* (2013).

Since IDEA called for all students to be tested, there was a movement towards a common set of assessment standards. Legislation at the time of this writing provided the framework from which these standards have evolved. The reauthorization of NCLB required that "all students who receive special education services have access to grade level core content in language arts, mathematics and science" (Collins et al., 2010, p. 52). At the conclusion of the 1990s, most states had developed educational standards, along with the assessments to measure those standards and a system for accountability. "With the reauthorization of ESEA, NCLB and IDEA 2004, states received the flexibility to utilize alternate assessments based upon alternate achievement standards" (Browder & Spooner, 2011, p. 24). According to Thompson et al. (2001) in their book *Alternate Assessments for Students with Disabilities*, "Alternate assessments provide a mechanism for students with even the most significant disabilities to be included in the assessment system" (p. 9). The bridging of IEP goals and objectives to state content and performance standards was the foundation for standards-based IEPs designed for students with severe disabilities (Thompson et al., 2001). In the past teachers would administer criterion referenced measures and developed IEP objectives based upon items not mastered. A problem with this approach is that criterion-referenced measures were not necessarily based upon state standards (Lynch, 2008). The designing of programs that encompassed access to both the general education environment and special education environment while addressing specific IEP goals and objectives could provide many challenges to the classroom teacher. Federal legislation called for special education students to be included as much as possible with their general education peers. The process of inclusion was the focus of debate and dialogue (Friend, 2008). Schools were challenged with balancing the

student's general education, as well as special education curricular requirements (Algozzine & Ysseldyke, 2006). Another challenge for school personnel was the balance between high stakes testing and informal transition assessment testing. IDEA and NCLM both required that teachers use evidence-based practices. Direct Instruction, developed in the 1960's, taught both adults and children to learn to read via a high-paced, highly structured approach (Friend, 2008). The utilization of assistive technology provided students with the devices and services that improved their functional capabilities. This was also a requirement of IDEA (Gargiulo, 2006). Another evidenced-based educational practice was the utilization of positive behavior supports. Positive behavior supports helped to establish both school and classroom behavior standards. Teachers rewarded students for acceptable behaviors instead of providing a negative consequence. School personnel worked closely with the families to collaborate in the provision of consistency and the development of a behavior program (Friend, 2008). While teachers and administrators worked to provide curriculums and practices that would contribute to their students' achievement, they still were compelled by law to administer standardized tests.

Transition IEP Stakeholders. There were three significant early transitions for children with special needs and their families. The first happened as a referral was made for early intervention services because of the child's disability, developmental delay, or risky condition (Rosenkotter, Hains, & Dogaru, 2007).The second occurred when the child was referred for Part C Early Child Intervention Services, and the third happened when the child began the career in public school kindergarten. Throughout these early years, social workers could be co-planners and co-providers of the services provided, and they delivered coordination of area services (Rosenkotter et al., 2007). Social workers

were especially well prepared to bridge people and programs and fostered shared efforts. Once students turned 16, transition assessment (Figure 2) was the beginning element of the transition journey (Mazzotti et al., 2009).

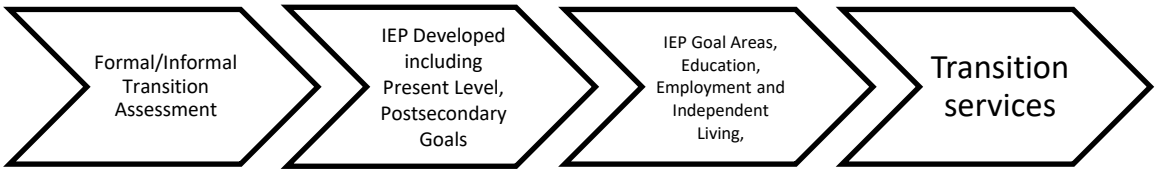

Figure 2. Development of transition services (Mazzotti et al., 2009).

During a student's IEP transition years, teachers were required to develop IEP Goals and Objectives based upon both formal and informal transition assessments (Special School District, 2012). The completion of transition planning checklists helped everyone on the IEP begin to become aware of possible transition need areas. The information gathered could help develop the IEP present level of academic and functional performance, transition goals, and plans of action (Special School District, 2012). There existed a variety of informal transition assessments available designed to appropriately reflect the student's needs, dreams and aspirations. Typically IEP teams would have available to them sources of educational, psychological, health and medical, behavioral, and vocational data focused on the student's shortfalls. "During the transition planning process, it is essential to move beyond traditional ways of describing and assessing students' with disability" (Wehman, 2006, p. 84). As the student neared the age where the IEP team addressed transition there have been many previous transition teams. Once strengths, preferences, and areas of weakness were identified, the IEP team could then utilize that data to develop current academic, as well as transitional post-secondary goals

in compliance with IDEA's federal guidelines, and transitional services could then be determined.

Targeted Adult Outcomes/Person Centered Plan

Expected adult post-secondary opportunities could be targeted based upon assessment data, IEP team contributions, family beliefs, student preferences, and funding sources (West, 1999). The Person Centered Plan (PPP) was different from the IEP, since IEPs were virtually identical in content and scope (Wehman & Kregel, 2004, p. 3). While the IEP dictated special education services when a student is enrolled in school, the PPP served as the document developed as a framework from which eligible individuals received funding for services and supports from the St. Louis Area Regional Center (Kansas Center for Autism Research and Training, 2014). A valid PPP addressed each area of an individual's life (Mandik, 2006).The focus of the plan was driven by the concept of 'self –determination.' Self-determined individuals had the knowledge to decide for themselves or to employ the assistance to do what they wanted and determined how they wanted to get it (Wehman, 2006). The Arc of the United States (2011) emphasized, "People with intellectual and/or developmental disabilities have the same right to self-determination as all people and must have the freedom, authority, and support to exercise control over their lives" (p. 1). Funded services received via St. Louis Regional Center had to address a need outlined in the individual's PPP. Person-centered planning could provide a positive plan, or road map, of the future (Wehman & Kregel, 2004, p. 3). A key component of the Person Centered Plan was funding. Funding for programs could be provided by both private and public sources; however, due to the cost

of services, most individuals with severe developmental disabilities received funding from their state Medicaid programs.

Many states were using Medicaid waivers to design innovative and fiscally responsible long-term service program. These programs were designed to provide for individuals to live and work (volunteer) their community.

> Some states have flexibility in designing their waiver programs, allowing them to use funds to reimburse service providers for extended habilitation services such as personal care assistance, assistive technology, In-home residential support, day support, respite care and supported employment. Transition teams should work within their states to determine the range and types of waivers that are available that can support integrated community employment outcomes (Snell & Brown, 2006, p. 279).

As individuals with a disability usually do not have access to health insurance from employers or other sources, "Medicaid is the primary source for the funding of services for individuals with disabilities in the United States, with approximately 15 million adults and 8 million non-elderly people with disabilities currently being served in the United States" (The Arc of the United States, 2014, p. 1). IEP team members often included state employed case-managers who acted as the individual's gateway to receive various program funding.

Summary

Just as high school counselors and teachers were charged with providing a curriculum appropriate for their general education students to maximize their post-

secondary choices, so were the administrators and teachers who serviced transitions students with severe disabilities.

During school years, the special education students' programming and curriculum was framed by their IEPs. The IEP served as the document from which all general education, special education, and related services were planned and provided. However, once a student graduated from high school, services are no longer dictated or framed by the federal laws which outlined how IEPs were to be written and services delivered.

This chapter provided a review of the history of special education, as well as how legislation impacted IEP services. Best practices in secondary transition curriculums were shared, along with how the transition IEP could provide the student with opportunities to focus on key components of their journey to adulthood. Finally, as students matriculated and their services were no longer delivered via the school system, this chapter provided insight as to how adult services were determined and funded.

Chapter Three: Research Design & Methodology

Overview

This study sought to identify the self-care, academic, and other skills and requirements that determine adult post-secondary program placement. This study included interviews with adult day programming administrators and caregivers, as well as secondary school teachers and administrators, and then compared their responses to the Missouri State Alternative Frameworks and to each other. In this comparison, I placed special focus on the specific self-care and academic skills that framed the criteria which determine adult program eligibility. In order to identify the key components of program placement, I conducted interviews with individuals who serviced transitioning severely disabled adults, which included personnel from state and county agencies, as well as secondary schools. As the researcher examined and develops a theory over time, the data were collected and the theory which emerged is indeed grounded in the data. “This approach is obviously highly dependent on the insight of the individual researcher” (Frankel & Wallen, 2009, p. 430). As a special educator and a step-parent of an adult with multiple disabilities, I am both a colleague and a client of the agencies involved.

Figure 3 depicts the methodology and sequence of my data collection. Data obtained regarding adult day program skills, combined with secondary school transition curriculum data, was compared to the Missouri Alternative Frameworks Curriculum to determine the skills my interviewees indicated would determine adult program placement. The sources of my data included the interviews of adult day program managers and service providers, the interviews of secondary teachers and administrators, and the Missouri Alternative Frameworks Curriculum.

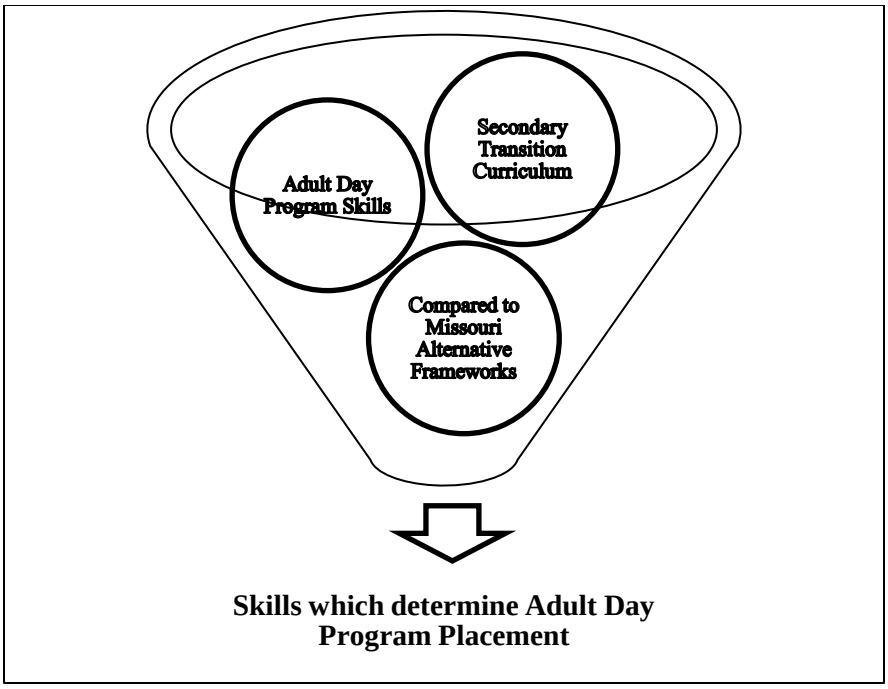

Figure 3. Interview design components.

Research Questions and Framework

As a researcher, I elected to utilize an exploratory Grounded Theory Qualitative Study approach. “In a grounded theory study, the researchers intend to generate a theory that is ’grounded’ in data from participants who have experienced the process” (as cited in Frankel & Wallen, 2009, p. 429). Questions were designed to explore the thoughts and perspectives of school administrators, teachers, and adult program managers and caregivers to seek a better understanding of the skill factors that could result in students being placed in their most non-restrictive post-secondary programs.

When describing the use of qualitative and quantitative methods, Maxwell (2005) contended they have varying strengths and rationalities, and are often ideally used to focus on different kinds of inquiries and desired outcomes. One of three intellectual goals for which qualitative studies are particularly suited included the identifying of unanticipated phenomena and influences and generating new grounded theories.

"Qualitative research has an inherent openness and flexibility that allows you to modify your design and focus during the research to understand new discoveries and relationships" (Maxwell, 2013, p. 30). I wished to inductively identify both the academic and self-care skills that were considered by professionals who delivered a myriad of levels of services to the severely disabled during both their high school transition years and, subsequently when they were enrolled in their post-secondary programs. I chose the grounded theory approach, as it provided me the venue to begin with an area "of study, and develop what was relevant to that area and allow it to emerge" (Frankel & Wallen, 2009, p. 429). This research made use of secondary school teacher and administrator interviews, as well as interviews of adult day program managers and caregivers. Fraenkel and Wallen (2009) discussed how the data of a grounded theory study utilizes one-on-one interviews, focus groups, and that it is an 'ongoing process.' Data were collected and analyzed; a theory was suggested; more data were collected; the theory was revised then more data were collected; the theory was further developed, clarified, revised; and the process continued. Both secondary school interview responses and post-secondary adult program entry level criteria were compared to the Missouri Alternative Frameworks and to each other, with special focus on the identification of the specific self-care and academic skills that determined program eligibility criteria. The interviews served as the primary source of data collection. In order to base my research, I developed four research questions:

RQ1: How do the Missouri Alternative Frameworks utilized in secondary programming differ from the eligibility criteria utilized in post-secondary programs?

RQ2: How does the post-secondary eligibility process relate to the Missouri Alternative Frameworks Curriculum guidelines?

RQ3: What specific self-care skills and academic skills determine criteria for students with severe cognitive disabilities in post-secondary adult programs in the St. Louis area?

RQ4: In addition to self-care and academic skills, what other factors determine student placement in post-secondary programs for the severely developmentally disabled within the St. Louis area?

Using my research questions to provide the background, I then developed two sets of interview questions, one designed for agencies who currently offered adult day programs and/or supports to individuals with developmental disabilities and one designed for secondary school administrators and personnel who provided service for individuals who participate in the MAP-A. These questions are located in Appendices D and E.

Sample

I interviewed individuals and groups associated with the preparation of individuals with severe disabilities for their post-secondary placement and who were involved in post-secondary programs. Individual and focus group interviews consisted of participants from school districts, as well as from county and state-funded agencies. I interviewed one social worker from the state of Missouri who was responsible for assisting families of and individuals with severe developmental disabilities in securing a post-secondary placement. I interviewed two Midwestern School District teachers currently working with students who were both participating in MAP-A and working on their post-secondary IEP goals. I interviewed three high school administrators, all of

whom currently held job titles directly related to facilitating the successful transition of their secondary students with developmental disabilities to their post-secondary programs. I conducted post-secondary agency interviews with staff members at the Association for Handicapped Citizens (AHC) and with a focus group at Lebanon Industries, a sheltered workshop. Local area agency interviews included staff from Next Step Council, Leisure/Sport Council, Funding Agency One, Funding Agency Two, St. Louis County Productive Living Board, and Lafayette Industries. Table 2 presents the various teachers and administrators, state, and county agencies who were interviewed for this study.

Table 2.

Teacher/Administrators, State and Local Agencies Interviewed

Teachers & Administrators	Post-Secondary Agencies	Local Area Agencies	State Agencies
Midwestern School District – Director, Vocational Skills Program	Association for Handicapped Citizens (AHC) – Community Integration Site – Manager Focus Group	Next Step Council of Greater St. Louis	Midwestern State Social Worker
Midwestern School District – Transition Effective Practice Specialist	AHC – Community Integration Program Director	Leisure/Sport Council - Director	
Midwestern School District – Autism Teacher	AHC – Coordinator of Leisure Services	County Funding Agency Two – Focus Group	
Midwestern School District-Self Contained Community Based Vocational Instruction Program	AHC – Asst. Dir. of Leisure Services	County Funding Agency One – Director	
	Lebanon Industries		

As secondary educators prepared students with severe disabilities for their post-secondary outcomes, IDEA 2004 required them to address three areas of transition and to

develop goals for each area: (a) education, (b) employment, and (c) independent living. Each student, along with his/her teachers, families, and various state and county agencies all contributed to the achievement of the individual's transition IEP goals.

I developed the interview questions by working with special education and qualitative research experts within the Lindenwood University faculty. I also employed the guidance of school social workers to review the relevance and focus of question topics. I chose to interview the participants face-to-face, so I would be able to take advantage of observing body language and possibly avoid misinterpreting statements. By completing the face-to-face interviews, I was able to follow up with additional questions based on the answers provided. Often, I found it necessary to clarify or to expound upon the data and information provided. "Researchers doing a grounded theory study use what is called the *constant comparative method*. There is a continual interplay between the researcher, his or her data, and the theory that is being developed" (Frankel & Wallen, 2009, p. 429). As I learned more details regarding each interviewee's specific program, I was able to ask questions more pertinent to the services they delivered to individuals with developmental disabilities.

The participants in this study were contacted and recruited verbally over a period of 13 months. I recruited many of the school teachers, administrators, and state agency representatives through face-to-face conversations over a period of seven months. An information letter, as well as an informed consent letter for adults, was provided to each participant. Interview questions were sent electronically in advance. The interviews generally took place at the interviewee's place of work or, in a few instances, at local

coffee shops chosen by the participants. The interviews took anywhere from 30 minutes to nearly two hours. I recorded all of the interviews to facilitate transcription and coding.

Data Collection

Prior to interviewing, I received permission from the Lindenwood University Institutional Review Board (IRB) to conduct my research. Additionally, I secured consent from the Midwestern School District to obtain information and data via the interviewing of teachers and administrators of students who were eligible to take the MAP-A. The interviews with the secondary teachers, administrators, and post-secondary providers at their places of work were semi-structured with ten questions prepared ahead of time for school-related personnel; 12 questions were prepared for post-secondary personnel. (Appendices A through E).

Analysis

Once all interviews were transcribed, I highlighted all of the words that were reoccurring, or that I felt were significant. I utilized a coding process as described by Glaser (1992), as cited by Walker and Myrick (2011), in which he defined coding as "conceptualizing data by constant comparison of incident with incident, and incident with concept" (p. 38). As I collected and analyzed data, I continued to develop and formulate constant themes and specific commonalities. After the interviews were transcribed and coded, I added additional categories to allow for themes that emerged as I continued to develop common topics. When interviewing post-secondary providers, their perspectives, experiences, and guidelines for client program placement were my focus. As I interviewed secondary school personnel, the interview questions emphasized not only

their current curricular practices, but also their engagement in obtaining post-secondary placements for their students. Each of these categories is addressed in Chapter Four.

Summary

This chapter has summarized the procedure used in exploring the self-care and academic skills as well as other factors that the school, state, county, and local agencies emphasized as being important to individuals with severe developmental disabilities in obtaining their most non-restrictive post-secondary placement. This qualitative study utilized both one-on-one and group focus interviews to obtain information. Chapter Four presents the findings of this study.

Chapter Four: From Zero to Zero

Introduction

As the teacher of a multiple disabilities room, I worked with families of students who were just beginning to contemplate their son or daughter's transition journey. The students I served all required close adult supervision, as well as a highly adapted general education curriculum. Students were most always accompanied by an adult to assist and facilitate every aspect of their school day, including academic classes, lunchtime, and any self-care/personal needs. By the time most of the multiple handicapped students and families reached their transition years, they were very accustomed to receiving, at no cost, the adult support necessary to take part in various school programs.

At each student's annual IEP meeting parents or guardians, along with school members, determined the level of adult assistance required for the student to be educated in the least restrictive environment possible to the maximum extent appropriate. A free appropriate public education (FAPE) was guaranteed by law to all children irrespective of their disability, termed a 'zero reject' philosophy (Gargiulo, 2006); the level of adult assistance provided to students at no cost to their parents or guardians was mandated by FAPE. Parents and guardians could choose to advocate for a high level of adult support so their child could receive the maximum amount of care/attention and ability to access as many programs as possible throughout their school day.

With FAPE, students with disabilities were entitled to services throughout their tenure in the public education system (Special School District, 2012). However, if a student with disabilities had not been declared eligible for adult services when they graduated from school, they had no legal right to receive them. Going from the mindset

of services received via entitlement and zero reject (Gargiulo, 2006) to zero services offered to graduating students with disabilities can be quite a mind switch and shock to students and families. The purpose of this study was to help determine the academic, self-care, and other skills that can define adult program placement for individuals with severe developmental disabilities. Equipped with these findings, teachers and families might be able to develop targeted transition goals, possibly resulting in the student acquiring the most non-restrictive program placement once at the zero services end of the transition continuum.

In Chapter Three, I outlined my research procedures and questions. In Chapter Four, I present a timeline which highlights, in chronological order, the experiences individuals with disabilities and their families might face during the journey to post-secondary placement. These experiences included school-related transitions and service agency opportunities, and may indicate supportive legislation. Various findings are presented that resulted from the interviewing of secondary school personnel, adult leisure and day program providers, and state and locally funded support agency representatives.

Transition Timeline

With the passage of Public Law 99-457 (1986 Amendments to PL 94-142), a national policy was devised to address the needs of infants and toddlers who were found to be at risk for, or identified with, disabilities (Gargiulo, 2006). The timeline to receive special services at ‘zero-cost’ then began at a very early age. When an individual with developmental disabilities is very young, most often that person has experienced some type of medical issue or problem. After the child is born, parents concentrate on the health and safety of their infant, often spending long hours dealing with medical issues

(personal communication, B. Moore, parent, July 16, 2013). The Missouri First Steps guide included personal experiences as told by parents of young children with disabilities.

> At the age of one, we knew it was necessary to get him help. We decided to refer him for a First Steps evaluation and had a speech therapist from the hospital make the referral. Upon the evaluation, we were not surprised to find he had a distinct delay in physical development and in speech. (MODESE, 2013b, p. 6)

As each medical 'crisis' or problem is dealt with or taken care of, parents begin to realize that not only may their child's health be different from that of a normal developing child but their ability to learn and participate in daily life's activities may possibly take a different path than that of the typical developing child. The family's physician may suggest the child begin partaking in various therapies viewed to address the medically identified 'developmental delay'. The First Steps guide indicated that in order to be eligible for early intervention services in the state of Missouri, state eligibility criteria must be met. These criteria provided for children with specific newborn and diagnosed conditions to receive services, as well as those who met the state definition of a developmental delay (MODESE, 2013b). The delays could result from the following areas: cognitive, communication, adaptive, physical, or social emotional.

Once families receive a 'qualifying diagnosis' their child may partake in early intervention services under Missouri's First Steps program, and thus begin their journey through a timeline that encompasses many stakeholders and hopefully will end with the child experiencing a very successful transition into adult life. For those whose journey

included seeking appropriate programming to accommodate severe developmental disabilities, their transition programs may address and/or include the areas of day programming, leisure activities, and self-care needs.

The transition timeline in Figure 4 illustrates how federal laws provided the driving funding force for special education services throughout an individual's school years. Pre-school interventions began with early intervention services, the development of an early childhood diagnosis, and subsequent early childhood educational plan.

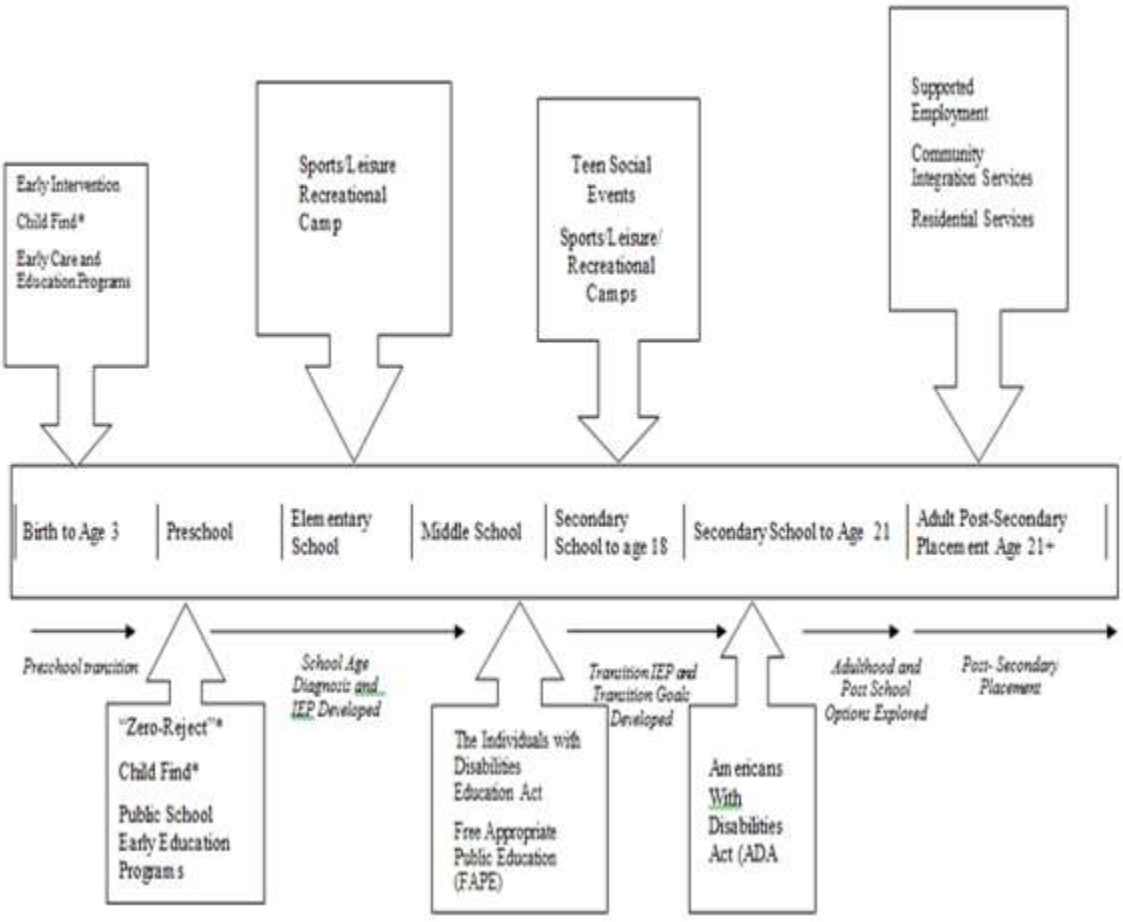

Figure 4. Transition timeline. *Individuals with Disabilities Education Improvement Act of 2004 (P.I. 108-445) is the extension of Part C of IDEA to include services beyond the age of 2, thus beginning the principal of 'zero reject', whereby all children with disabilities are entitled to receive a free and appropriate education (FAPE) (Crabtree, et al., 2007). *IDEA 2004 provided for Local Education Agencies (LEAs) to utilize federal grant monies for early intervention services (U.S. Department of Education, 2014).

Once the child reached school age, a school-age diagnosis and IEP were developed. Every three years, each student's IEP was reevaluated. Once the child reached age 16, a transition plan was formulated and thus began their introduction to the adult post-secondary experience.

Post-Secondary Agencies

The Association for Handicapped Citizens (AHC) was a non-profit organization that served citizens of St. Louis County, Missouri. The AHC's services were mainly funded by the Productive Living Board, which oversaw taxpayer monies that were designated to support programs for the developmentally disabled. The AHC's services were all-encompassing as they provided programs for citizens of all ages from birth through adulthood (personal communication, agency director, July, 2012). For adults with developmental disabilities, the agency provided services in the areas of family, leisure, employment, day, and residential support. Children's services included childcare, early intervention, and leisure activities. The AHC also provided respite services, family education, and advocacy, and reaches out to the community by providing leadership, training, and public awareness (personal communication, agency director, July, 2012). The agency teamed up with local school districts in order to collaboratively work together to enhance programmatic opportunities.

For the purposes of this study, interviews were conducted with both program directors and program managers who were responsible for the on-site, day-to-day operations of their respective programs. Scrazzo was the AHC director of Community Integration Services and supervised the on-site managerial staff consisting of Daniel and Celia. The AHC Day program provided services to people with developmental

disabilities so they could partake in their community. Barbara served as the Assistant Director of Leisure Services and supervised Derek, who was a coordinator of leisure services and whose responsibilities included the management of the weekend leisure camping program. The Camp program provided services to both school-aged children and adults with developmental disabilities. Personnel from these programs often attended area IEPs. They contributed to the IEP decision-making process as IEP team members selected as Part C Agency personnel, as called for in the transition section of the IEP.

Grace. Grace was the director of the Community Integration Program at the AHC. Grace came to the organization after working as a teacher in the New York City Public School system. She began working for the AHC in a direct support position and shared that the AHC's organizational philosophy towards people with disabilities was much in line with her own. At the time, she was,

> really impressed by the way the AHC treats those they serve with respect and how it focuses on getting people out into the community and not isolating them the way NYC public schools did . . . I fell in love with the values of AHC. Unfortunately, the values of the New York City Public schools, where I previously taught, were not as progressive. (Grace)

After serving as a direct support provider, Grace was promoted and then served as the program director.

When describing her program, Grace shared that the idea behind the community integration program was to help people with disabilities get out and be a natural part of the community. "As you know, the history of people with disabilities is really about keeping them behind closed doors and not having them be a part of the community. The

design of the AHC's program is to combat that" (Grace). Grace expressed that the program tended to serve people with a wide variety of abilities and needs. Most of the clients have not chosen employment. Clients may decide to enter the program to gain, and polish, the skills necessary to be employed. For some, the program served as the post-employment retirement placement. As Grace explained how eligibility for program placement was determined, she shared the two-fold process, "For a lot of people, funding is an important piece; it is not a requirement, but it can determine their ability to participate." She also stressed, "All individuals participating in their programs must meet the state's definition of a developmental disability." Grace also shared additional requirements for placement, which included meeting the 19-year-old age requirement and receiving proper funding through the Medicaid waiver. Of most importance, determinations were made to ensure the individual was safe within the community.

The AHC program was community based and some individuals were able to display appropriate behaviors within a controlled on-site setting, but not out in the community in a much less controlled and structured environment.

> A lot of people are fine if they are just in one place all day, but if they are out in the community they cannot successfully interact with members of the community or they do not want to, some people just do not want to get out. If they need a controlled environment, then that would make them not a good fit for our program. (Grace)

When asked about the type of functional skills that would be considered an important eligibility factor, Grace relayed that being able to communicate to others was vital--whether by voice, signs, or the use of an augmentative device. The clients often utilized

augmentative communication devices, special sign language, or gestures to communicate their wants, needs, and desires on a regular basis. Often, these communication devices and methods did not get successfully carried over to the client's adult setting.

> To be able to communicate with the community at large, because the point of our program is to integrate and if the staff is there as a barrier between them and the community, we do not want that. We want our staff to just be a support and not be in the foreground of those interactions. (Grace)

Grace stressed while she feels that there was currently a high level of cooperation between area school districts' secondary providers and her staff, there were instances in which secondary teachers "sugar-coat" students' actual abilities. More efforts made on the part of current secondary teachers not to sugar-coat the current abilities of their students so they would be perceived as being better candidates for her programs. She felt there had been "a few instances where we are missing some key information where people wanted to present such a positive image, but we need the whole true picture" (Grace). She stressed they would not allow anyone to go through the program without a tryout process.

Daniel and Celia. Daniel and Celia managed a Community Integration Day Program within the AHC system. They participated in a focus group interview session and provided their insights into both the process of client eligibility and how their program serviced those with more severe developmental disabilities. When describing the Community Integration Day Program she coordinated, Celia, explained the program supported people performing activities or volunteer work in their local community. It also focused on educating the community about opportunities to include individuals with

developmental disabilities. Daniel, the assistant coordinator, added that their daily programming was centered upon the individual client achieving the goals as set forth in their person-centered plan. The community and volunteer opportunities provided throughout the day were designed to help meet the goals of the participants' person-centered plans. Celia further explained that while the range of developmental disabilities they served was very wide, their job with each client was the same, "We give them the opportunity to do something new, make friendships and learn about what it means to be an adult" (Celia). Although many of their clients came out of high school, they did serve an older population. Most clients, received approval for funding as they graduated from school.

When asked how eligibility for program placement was determined, Celia stressed the importance of the program staff having the opportunity to evaluate the potential client to see if the program would be an appropriate fit. Once paperwork was completed, the potential clients were required to spend one to two days to "try out" the program. The program was based on two types of client/staff support ratios. Clients received either a 1:1 ratio or a group ratio, which typically would be 4:1. Many factors fell into the consideration of the support ratio determined to be necessary to support a client. Some of these factors included behavior needs, safety needs, and feeding or personal care requirements. If funding was not in place by the Division of Mental Health, the individual would have to privately pay for services.

Celia and Daniel explained the day program was a Medicaid-funded one. In order to receive Medicaid funding for a day program, a Medicaid waiver was required. The Medicaid waiver program received funds from both the state of Missouri and the federal

government. According to Celia, there existed a limited number of allowable Medicaid waiver slots in the state of Missouri, and regional case managers, or social workers, handled the applications of those requesting waiver funding.

When asked about the types of functional skills evaluated for program placement, Celia and Daniel explained once they have an initial meeting, they set up the first trial day and completed an informal evaluation form:

> Once the form is completed, the staff reviews the form to determine what worked and what did not work. On the second day, they seek to align the evaluation with the individual's person-centered plan to determine exactly what barriers we are facing to make placement work. For example, someone who, at home, may be able to use the restroom independently, but in the community, it may be a whole. (Daniel & Celia)

Celia continued to elaborate on the importance of spending time in the community:

> I think the community is the best teacher of anything. It teaches you how to interact with each other and the community. What is appropriate and what is not . . . the kind of exposure you get out in the community is very different from that of on-site. (Celia)

When discussing how their program dealt with regression in a person's skillset, they stressed the importance of the team coming together. "The family or guardian, the service coordinator, the managers come together and discuss the regression" (Daniel & Celia). Celia shared people enrolled in the program had access to physical therapy or behavior therapy, or they chose to get their own personal doctors involved. Daniel and Celia also tried to determine what is triggering the behavior to then determine what

treatment to pursue, and if they are not able to meet the determined needs of the individual then services would either be interrupted or stopped.

When responding to the interview question, “What factors other than those related to the client’s individual skill set determines eligibility?” Daniel replied, “Given their biggest skillset, can we help the person achieve their goals through the services we provide. If we can, we sit down and plan how that is going to look and what we can do.”

Celia conveyed the original purpose of her job was to train individuals for employment, but then discovered not everyone wants a job, nor is a job right for everyone. Daniel further shared one of the important things they taught people was about their rights, “They have are rights just like anybody else; you want to have a girlfriend, then how can we educate you enough to know what that means.” He explained they then would teach them how to respect someone and break down that process for them.

As we concluded our focus group session, I asked each to share what methodologies or strategies they would recommend to the providers of secondary instruction. Celia responded she would stress honesty:

> I think most I wish they would help educate families as to what their rights are when they reach adulthood. Some families come to program and they do fine transitioning and it works for their families. Then there are those that have the mindset that they cannot do it. However, there is so much they can do, but have not been exposed to. (Grace)

Both Celia and Daniel stressed the need for more community-based high school programs:

> You know, sitting behind a desk until you are twenty years old and doing a weather chart, is that really preparing someone for the future? No. I think it just keeps routines in place. Once those are gone and school is finished, you see a lot of the behavior. So how can you stop those routines gradually and prepare them the right way? (Daniel & Celia)

When asked about the type of collaboration efforts secondary school personnel could make to contribute to a smoother transition for both clients and the program, they both conveyed while schools were connected, they would like to see the schools help foster the connection sooner in the individual's transition journey. They would like to be invited to IEPs when the student is aged 18. "We want to carry over the use of augmentative devices and practices that contribute to the student's ability to interact effectively" (Daniel & Celia). Daniel further shared, "Even after they are placed in our program, some follow-up with the teachers would be helpful. We need follow up afterwards to partner together at least for the first year."

Barbara. Barbara served as the Assistant Director of the Leisure Services Department of the AHC. She oversaw five full-time coordinators who serviced about 700 clients who participated in leisure programs. At the time of interview, 90 part-time staff members, along with 300 volunteers, comprised the workforce of the leisure program.

The leisure program provided opportunities for all ages (five through adult) to participate in programs primarily funded by the County Funding Agency. The program had 19 different programs, from sports to social clubs, in which anyone could be involved. Some of the programs were age-specific and some were disability or ability-specific, such as the Asperger's teen group. The program also started a 20-something

meet-up for adults with Asperger's: "Our agency has been having a big push on autism training and wanting more people with autism to look at the AHC as a premier place to come and get a really quality activity or event" (Barbara).

When describing the eligibility process for the leisure programs, Barbara first explained how the financing of programs worked. She used the term 'funding stream' to pictorialize how important the funding was to the existence of the programs. The first qualifier was participants must reside within the county of the program's main funding agency, which was the County Funding Agency (CFA). Secondly, program participants may pay for services through waiver programs that were procured through the State Department of Mental Health via state-assigned family social workers or case managers. Comprehensive and community waivers were funds individuals could receive if they live in their natural home.

> In the past, it was an entitlement. Anyone who graduated from Midwest School District was entitled to go on to a day program or they could go to supported employment. Since the 90s, that money has run dry; sometimes (waiver) slots open up. (Barbara)

Barbara further explained a comprehensive waiver allowed a portion of the funding to cover residential costs. If someone had a community waiver, they lived in their natural homes. Families received a certain amount, which she believed to be $22,000 per year, to compensate contract service providers. "Some families will participate in day programs for a partial week and they may pay what is left over at the end" (Barbara). She further related some of the programs were funded by the United Way, and those

programs were open to all people with any abilities. These programs included sports, basketball, bowling, soccer, cooking, and dancing.

In response to the question regarding the types of functional skills evaluated for program placement, Barbara explained each of the programs was different. “When applying for a program, they sit down and talk with the family and complete an intake packet; together the individual’s support needs are determined” (Barbara). When a client experienced a regression in the ability to effectively participate in program activities, the organization stressed the importance of looking at other program options within the agency, hoping to possibly find the selection of another program that focused on the determined needed skillset, such as independent living skills.

When discussing the types of methodologies or strategies Barbara would recommend to providers of instruction to assist the clients to obtain the least restrictive post- secondary placement, she focused her answer on the servicing of people on the autism spectrum:

> I think the population of Asperger’s and autism is growing and families want their children in their own school districts. The younger they are and the faster they get into a socialization skills class to learn proper etiquette , manners, politeness, eye to eye contact, how to shake a hand, those types of things, will really help them as they progress and get older. (Barbara)

She further shared that teacher assistants needed to learn how to effectively and positively deal with autism. The use of “social stories and, um, scrapbooking, making poems for the day and living out the poem and living out a play, being very structured with picture books I think that would really help” (Barbara). She referred to “hard skills

vs. soft skills" and recommended teachers spend more time developing the social skills necessary instead of the actual skillset needed to complete a task. She emphasized the soft skill development was far more important as her staff could teach the actual hard skills necessary to partake in a leisure program.

When answering the question regarding what efforts a teacher could make to create a smoother transition from high school to post-secondary programs, Barbara stressed the importance of school or agency collaboration.

> I love to go to an IEP and see what is going on in school so we are collaborating and cooperative on what plans are and we can carry them on in the summer. I also like to be invited to futures plans so I can support them; it is mainly the ones that I know. I have more to contribute if I have met them. I also get to meet the regional center case manager. I deal with getting them family funding for camp, teens in motion, etc., so I am seeing them personally up front it helps to build the village that support the child. (Barbara)

Derek. One of the leisure programs managed by Barbara was the camping program. Derek, who was one of the coordinators for leisure services, managed this camping program. He shared that it was an overnight camping program that consisted of 13 camping weekends from September through May. The camp currently served 55 people and each person could choose to attend up to four weekends per calendar year. "We primarily support people who have multiple-support needs whether it is cognitive, social, or physical" (Derek) and he added they serviced a highly diverse group of people with all types of interests. They scheduled camping weekends by age; there were weekend camps for those under the age of 21 and those over the age of 21.

> Essentially we are here to serve folks with intellectual disabilities and to participate in life, um, but to receive support to habilitate that or any what we can help support people to participate in their communities make fuller lives at home, make friends, keep friend, establish other types of relationships, kind of the whole gamut really. (Derek)

When asked how eligibility for program placement was determined, Derek explained it depended upon the source of funding for the particular program; that all clients must meet the CFA requirements, foremost of which were that the individuals participating must have a diagnosed developmental disability and must reside within the county. He shared that individuals that did not receive waiver funding got the first priority, as that was also a policy set forth by the CFA. He added, in some programs, there was some flexibility but most CFA eligibility requirements were followed.

When asked about the types of functional skills evaluated for program placement, Derek shared that during initial conversations with potential participants he related to the families that the program was there to find a way to support them.

> I do believe that I would say it feels really good to stop right there and tell them everyone is welcome. I don't want to make people feel bad for who they are and what they struggle with, that we are there to try to help them and help them find other ways to express, and we are there to validate them and listen. (Derek)

It is critical for the agency to determine the level of service or support a person would need when attending camp. Derek conveyed if they were dealing with an individual who had not been supported in another AHC program, they must rely on communication from

the families and schools. They also reviewed documentation from the individual's person-centered plan.

> Sometimes we find that their skill level presented by teachers or family members has been off by a little bit. Alternatively, maybe they do not need one-one support everywhere or in just one environment. So then you find that they can be supported in a group but they do need that one-one support. It is collection of communication and it is always in flux. Additional eligibility requirements include that participants must be at least seven years old and must live in their natural home, not a residential facility or group home situation. (Derek)

When asked to share methodologies or practices that secondary providers could offer to help his clients be more successful in the camping program, Derek shared a recent experience at an IEP meeting:

> I was at school where some of the teachers were frustrated. We have to respect their talents and unique abilities and I feel like if what I want to do is provide a platform for them to teach anything and lead by example and step up to the plate to initiate. At this IEP meeting, I found their potential was being squashed and put in a box. I had seen so much more out of the person when she was given responsibility; it is on you; I am counting on you. Give them at the young age the power to be a leader. Seeing that this message gets spread and people are given opportunities to take responsibility. Leadership and responsibility I would like to see more of. (Derek)

When asked the question regarding high school transition preparation, Derek shared he would like to be present at IEPs for any age participant. The less communication he had,

the worse it was; the more the better. “We will be serving some of these kiddos for years; the better picture we have of when they are young, the better we can set them up for success” (Derek).

Lebanon Industries

Lebanon Industries was a sheltered workshop non-profit business which specialized in packaging. I conducted a focus interview with Don, the executive director, along with several members of the management staff. They shared that Lebanon Industries was the single largest employer of individuals with developmental disabilities in the state of Missouri. They prided themselves because they competed with the private sector industry for packaging contracts. There were currently 373 adults employed. Larry, who worked in the employment development program, shared that all employees hired had a diagnosed developmental disability. The first priority of the production manager, Mary, was to provide a safe working environment and at the same time ensure that employees completed their assigned jobs. Additionally, she was responsible for contract packaging orders, while at the same time keeping everyone working towards their individual skill levels. She shared that the company did provide cross-training opportunities for employees.

The 43 staff members comprised both administrative and sales staff. While the company did not offer one-on-one support, they provided trainers who could give extra support periodically throughout the day to their employees. In order to maximize the best use of skills and ensure safety, workers were organized into production teams consisting of one production supervisor to approximately 20-25 adults. The role the workshop played in the lives of adults with developmental disabilities was described as providing

their primary place of work; Lebanon Industries had nothing to do with their residence or transportation. “We do not provide one-on-one support. We are a work environment” (Lebanon Industries). The workers ranged in age from 20 to 70, as most people were still in secondary school until the age of 21. They had workers retire, but there was no mandatory retirement age.

The focus group shared the people they employed must have the ability to work and be a part of a production team. They added one of the greatest challenges workers faced was in the area of behavior management. Additionally, since there was no one-on-one supervision, they must possess the self-care and behavioral skills necessary to perform the job.

Local Area Agencies.

Next Step Council. Beverly was a representative from the Next Step Council. The Next Step Council was comprised of agencies and organizations that serve adults with disabilities, parents and advocates, educators, and persons with disabilities, as well as employers and business partners. The Next Step Council was formed to provide a mechanism for two geographical area agencies to come together and share program ideas and practices with meeting focus on ‘hot topics’ in transition. The council members met once per school semester to discuss and share issues. When asked about the mission of the council, Beverly shared the organization was committed to successful transition from school-to-adult life for individuals with disabilities. “We strive to facilitate interagency coordination of transition services, and help educate parents, students, advocates, and professionals about transition planning” (Beverly). Meeting topics revolved around group discussions regarding the issues that faced students with disabilities and formulated

actions to make transition services smoother and more effective for young adults with disabilities. Beverly spoke to the importance of the history of the council.

> Therefore, when the transition council was developed, we had folks going through transition services in the city and folks going through in the county and these two entities did not talk to each other. There was a lot of cool stuff happening in both areas but they would not communicate so they would start over and reinvent the whole wheel. In the beginning, parents were very active; in fact, a parent developed a transition guide, which continues is utilized by area school districts. (Beverly)

Beverly shared one previous role the council played was in the development of legislation to facilitate the efforts of agencies to collaboratively share practices; however, the statewide agency never came to fruition. She conveyed most of the members saw their membership as a part of their job. “We are essentially a group of service providers that come to the table and we work on a variety of issues” (Beverly).

When describing some of the challenges all stakeholders in the process of transition face, Beverly shared the council seeks to focus on many of the differing client needs.

> Every person or child that comes to us is different. You want to develop a program that has enough flexibility in it to meet a variety of needs but that it is not so flexible that it has no parameters or boundaries. You have to create a one-size-fits-most and deal with the anomalies that occur. I think the fragmented feel that you get is the anomalies that occur with everyone. You have a program that is one-size-fits-most, but my child has an anomaly on this end. (Beverly)

When asked to elaborate on which skills or abilities make a difference where a client is placed and what doors might be opened after the age of 21, Beverly stressed that the main program placement factors were toileting ability (self-care skills) and behavior management skills.

> Being able to take care of your personal needs is first, and the second one, is behavioral issues, typically when we see an individual asked to leave a program it is because of one of these . . . even individuals from residential programs can be asked to leave. I would say: physical needs, personal care needs, and behavior needs are the top three that make a successful transition. (Beverly)

Leisure/Sport Council. Bonnie was the director of the Leisure/Sport Council. The council, formed as the result of Senate Bill 40, served as a programmatic informational/funding management source for individuals with developmental disabilities. The council supported citizens in three neighboring geographical areas, each with its own funding source. These three sources provided the funding for the council to both manage and promote multiple programs with the local areas. While it served as a 'clearinghouse' for recreation and leisure opportunities for individuals with developmental disabilities, the council also strove to achieve public awareness of programs and opportunities available to facilitate and/or fund participation.

When asked about the mission of the council, Bonnie shared, "The Leisure/Sport Council works to ensure that individuals with developmental disabilities are aware of, and have opportunities to participate in leisure/recreation programs and activities of their choice." This was achieved by the provision of the following:

- Publications that promote leisure and recreation opportunities

- Information/Referral services
- Voucher programs that allow individuals with disabilities and their families' opportunities to choose programs and activities that best meet their interests and support needs
- Presentations/Trainings and workshops
- Networking Opportunities between recreation agencies, both specialized and community-based. (Leisure/Sport Council)

When asked how eligibility for program placement was determined, Bonnie first explained that the funding source was the driving eligibility factor.

> There are three different levels of requirements and we have an eligibility form that has to be completed by the individual's state-appointed regional case manager. First, they must live in the regional area supported by the funding source; second, age is a program participation factor, and thirdly they must meet residential, developmental disability and then individual program requirements. (Bonnie)

When asked what happens when there was regression in a person's skill sets, Bonnie explained that since their organization was a "clearinghouse" for all programs serving the developmentally disabled, they would help them search for a program that might help them further develop their skills, so they may be able to participate in more types of programs. "Families or the individuals themselves determine the level at which they feel they participate. They enroll in the program and the program provider assesses the level of services to be provided along with the participant" (Bonnie).

Bonnie conveyed the importance of workshops for families that help families increase their awareness about and the importance of recreation

> In a school setting, sometimes they feel like the school should provide all those services. I would love for students to learn about what leisure is, how do you use your leisure time and to develop a mindset that there is leisure and to learn about it……saving money, socialization, appropriate social skills and how do you use transportation. Those are the types of things I would love to see the schools adopt. I would recommend some type of leisure program participation during school years. (Bonnie)

Funding Agency One. Funding Agency One managed funds that were collected via taxes from a designated geographical area. A focus interview was conducted with three members of the agency: Beth, Betty, and Barb. Beth was the program manager and described her job as working directly with 30 service agencies to make sure they were implementing the programs as prescribed. Betty was the Community Research Specialist and worked with families that called in. Parents contacted her when their child was initially diagnosed and they were feeling frustrated and had nowhere else to turn to learn about resources and the various funding silos. Betty shared that she helped parents learn how to navigate the system and its various surfaces. “I help answer questions such as, ‘What does residential or employment [placement] look like?’ I am just trying to educate families on the different types of services that are out there as well as available community resources” (Betty).

Barb was the quality review specialist, responsible for making sure the funds that the agency managed and distributed were being properly appropriated and that they were

funding quality programs. Barb shared they funded programs for all ages, from birth to senior citizens. Funding Agency One, itself, did not provide any direct services with the exception of case management to citizens over the age of 17.

> The state also provides case management however our assigned caseload is limited to 15. We have the same qualifications as the state; Medicaid funds it. Most individuals 18 and over qualify for Medicaid based upon their own income. For those under 18, eligibility amount of income is the major factor in eligibility. We do not use county funds to pay for case management. We realize that transition is a big issue and that is why we start at 17. We would love to get down lower, um, maybe to 15 so we can really affect transition. (Barb)

Funding Agency One provided the funding for approximately 30 agencies which included varying types of services ranging from child care, camp and recreation opportunities, employment services, residential services, selected therapies, adaptive equipment, and behavior training for families. When explaining the agencies' eligibility requirements, Betty shared the individuals they served must have their eligibility determined by the Department of Mental Health.

> While we changed our rule about four years ago, that they do not have to keep a case manager, although we highly recommend it, they just have to be eligible because if we determined eligibility then we would have to use our resources and we want the state to have to pay the cost of eligibility determination. (Betty)

The group paraphrased their mission statement by saying:

> We are a leader in that we really want to be in the forefront of what is going on around the state and around the country. We have a county coalition in our

> community and we are an active member of that. We are very present in state issues and we are a leader in the programs that we fund and opportunities that happen in the community. (Funding Agency One)

The interviewees further explained the agency's mission statement was implemented as they offered information on gaps in services, needs assessments, and quality assessments. They also distributed customer surveys and performed a customer survey every couple of years to determine client needs and where gaps in services existed. They had a strategic plan, which outlined the areas of transition they have addressed, and they conducted some focus groups concentrating on early childhood transition and young adult to the end of life. They explained due to cost, many of their services only had one provider available, and so when there was an opportunity to do so they tried to offer a choice. "When people bring issues to us, we do look and see if there is a way we can try to provide that so people have choice" (Funding Agency One).

Other members of the organization included case managers, a finance director, and a community resource specialist. They had around 30 employees, 23 of whom were case managers. Their program was growing and they were currently looking for additional office space.

When asked how insurance, specifically Medicaid or no insurance, impacted client eligibility, they shared that having or not having medical insurance was not a factor; what was a factor was the individual's ability to obtain a Medicaid waiver.

> People who are on Medicaid can get Medicaid waiver services funded through the Department of Mental Health, but it really does not affect them obtaining our services. Some of our services are only for people who do not qualify for the

> Medicaid waiver. If they do qualify for the waiver, we feel that is a source that would meet their needs and so they do not receive our funds. (Federal Agency One)

When asked when in a child's life should parents apply for the waiver, they replied they should start the application process as soon as they need the service. For Medicaid, they should apply if they have a low income. Barb further explained the Sarah Lopez waiver which was usually for individuals that had a significant medical need and bypassed the low income requirement of Medicaid .The focus group informed me that there were several types of waivers.

> There is the partnership waiver whereby families can get $12,000 or less. It is a state and county thing. You have to have a county funder and a state funder. Our funding agency chooses to participate in this, but not all do. As an agency, we contribute about $100,000, the state puts in about $100,000 and the federal government contributes approximately $800,000. This fund allows people to not always need a high-needs waiver. With this waiver, citizens can obtain home modifications, therapy services, personal services, transportation. Most people who participate are over 18, but the purpose of it is to prevent the need for future services. The Community Support waiver is $22,00 a year, because there is so much room in the partnership for the hope waiver, there are people in that waiver that are getting services that would not get services in the community support waiver. (Federal Agency One)

Barb explained a rating system was utilized for the granting of the waivers and, at the time of interview, the rating was much higher for the Community Support waiver.

When discussing the age requirements for program participation, Barb conveyed that in order to receive case management services, clients must be 17. In order to qualify for the independent living program, clients must be 18 years old, due to the legalities of lease signing. “Generally, whatever the age appropriate age for any participant to partake in a program or execute a legal document will usually coincide with our program requirements” (Barb).

I asked the group to discuss the methodologies they would recommend to secondary providers. Barb shared that planning was critical:

> Therefore, our education system knows what the requirements are to get in a community college. In addition, if you are going to a college you have a curriculum to follow and if you do not have these classes you are not going to get in. You are going to go to college you are planning when you are 15. We do all this planning with our traditional students. However, my observation is that we do not do that level of planning with our students with disability at any level. (Barb)

Funding Agency Two. Katy was the director of program services and quality for Funding Agency Two which was the agency set up to oversee Senate Bill 40-funded projects in its specific countywide geographic funding zone. Katy shared that the agency serviced 39 agencies. The agency was responsible for the review of individual program health and safety standards, setting forth agency board policies, and the establishment of staff training and competencies. Each individually funded agency had project standards set forth by Funding Agency Two. These standards consisted primarily of required documentation reflecting that each agency was spending its allotted money appropriately. Each consumer of the 39 agencies was required to have a support plan, as well as a

documented need for the service. When describing the Funding Agency Two's role in the provision of services, she summarized:

> We review to check on accountability that the service billed is for the service provided and compare that to staff time sheets. Our individual agency reviews ensure that the staff is trained and that safety measures are in place as well as monitoring that the services requested are the services delivered. (Katy)

Katy further explained the agency was not only involved in the support of services but also funded the necessary development process and building projects for area agencies. "Vocational services include pre-employment options that might be volunteering, education opportunities, and employment opportunities" (Katy). She shared there were several projects in the area working on developing employment opportunities and the agency was active in funding these.

> Our finding comes in at the tail end. The beginning is funded by Vocational Rehab. Once the consumer decides what agency they want to work with, that agency helps determine what it is they want to do and hopefully that has been figured out and identified before you ever get out of school. (Katy)

Katy further conveyed another employment placement funded by the agency was sheltered workshops. Funding Agency Two provided support for five area workshops, which provided packaging or production work.

> Most people work five days a week, six hours per day. It depends upon the shop. We have assisted with the purchasing of buildings and renovations. So employment services are primarily supported employment, sheltered employment, and we also fund post-employment. (Katy)

Katy revealed the latest trend was in the provision of services for individuals who were entering their post-employment years. “Depending upon where you are going, you could spend some time in a day program, senior or community center, something like that” (Katy). At the time of interview, two projects were supported: one was a geriatric community program that coincided with a currently existing community program and the other was an agency that supported people who were aging with developmental disabilities.

> We know there is a huge need coming up the pike to get connected and with the rest of the baby boomer population; it is just going to explode. We have just completed a study on aging that will be presented to our board. It will be looking at bridging the gap between the existing services and what will be needed; there is not enough. We have to work with what exists, because there is not money and this is what the study looked at. (Katy)

The Funding Agency Two board also provided what was called ‘partial need.’ There existed a significant population of qualifying adults who did not require the high level of support offered by day or sheltered workshop programs. In the area of independent living, they may only require a limited amount of support to be able to successfully live independently within their community. Qualifying individuals required no more than 10 hours of assistance per month. These hours were utilized to assist with banking, budgeting, and shopping. The clients who received this type of service needed to be fairly independent and able to access the community independently. At the time of interview, they funded five agencies who serviced 350 people with this type of service need.

Katy provided further insight as she detailed both independent living and employment opportunities for those over 21:

> School districts are governed by IDEA, the rehab act, 94-143. There is a blueprint which targets schools. I think the biggest (problem) is that kids are surrounded by family and when you are an adult in the eyes of the law you are an adult with or without the disability. The whole thing shifts; parents have no say unless they have guardianship. There is entitlement up until 21. You need to have it figured out; the biggest problem is that families do not have it figured out and I do not know how you do that. Moms and dads are running around doing everything with the kids and it gets lost in the shuffle. (Katy)

As families considered which programs their child was eligible for once they graduated from the school system, Katy shared, first and foremost, participating individuals had to meet the criteria for being diagnosed with a developmental disability, and the funded agency had the responsibility to ensure that individuals met that qualification.

> Requirements, eligibility program standards….the remainder is up to the agency. For supported employment, you have to go through Vocational Rehab; you have to want to work. For in-home support, the primary issue for the agencies is the disability requirement. (Katy)

> We do not duplicate anything that is under other state statute requirements. Day programs are not funded at all because they are Medicaid waiver programs by design. We fund projects that duplicate or mirror state-funded services. Therefore, the idea is that we provide services that people that help maintain individuals in

> their homes and community. Our primary funding goes to adults for employment and residential services. (Katy)

As Katy shared her thoughts regarding individuals with severe developmental disabilities obtaining the most non-restrictive post-secondary placement, she emphasized the importance of family:

> We encourage families to recognize their child as an adult. That is huge. If mom and dad can go to the place and say my child is an adult and respect that, I think that speaks volumes. Families accessing agencies is a huge problem. There are a ton of providers and the hardest part is just putting the pieces together. We are in constant communication with the schools and we stay in communication with the funded agencies. The more the teacher know and can get that to families, the better it will be. It is the teacher's job to plant the seeds and repeat it and repeat it. (Katy)

Teachers and Administrators

Two administrators and two teachers from the Midwestern School District were interviewed. The Midwestern School District serviced special education students from 22 local area school districts. Transition services were delivered at each local high school by teachers, transition specialists, and administrators.

Mary Beth. Mary Beth was a secondary high school administrator who was in charge of the transition programs for a specific geographic zone of the Midwestern School District. She described her district's transition program as the composition of daily living skills, work skills, and self-help skills. She shared that her job was to ensure an offering of well-balanced transition opportunities in each skill area:

> We need to balance what are the skills you need to volunteer, the skills you need for daily living and the skills you need for leisure, or competitive or supportive employment. The school system has and owns the responsibility of all of the above, but how do we help people know that after the age of 21 that the responsibility is yours and that agencies, unless you seek them out or stay with them aren't there. (Mary Beth)

Mary Beth stressed the relationships between individuals with disabilities, their families, and post-secondary providers must be cultivated and developed many years prior to the student turning age 21. Mary Beth supervised teachers and administrators who served the district's transitioning students between the ages of 18 and 21. The focus of their work was driven by the department's mission statement:

> The mission of the Vocational Skills Program is to provide a continuum of supports and services to students and families to assist the students in gaining the skills needed to achieve realistic and meaningful post- secondary goals. We have come to realize that the reason kids are not getting employed is because they were learning only a part of the position, and gainful employment requires you to be able to do many things. (Mary Beth)

Mary Beth's program stressed very targeted and strategic instruction in order for students to acquire all the skills associated with the job they would obtain in the future.

> Now you can go back to really good people in high schools and say it is ok, as we as an organization teach people how to get a job description, task analyze the position, strategically monitor and develop those skills so that we know what we are working toward. (Mary Beth)

When asked if she was aware of the admission criteria for the post-secondary programs for those with severe cognitive disabilities, she described how the school district began the placement process:

> For me, my depth of knowledge, I know that you start with VR [Vocational Rehab] doing the assessment piece and that everything funnels out from there. VR does a level one, two, and three. It is a rubric and they rank you and the funding day placement, supported employment, or competitive employment. My knowledge is limited. The one might be the one who goes to college, there may not be any money, and they will still be VR certified. VR needs to look at all kids who may need some support. There are some VR services available for college. (Mary Beth)

As Mary Beth detailed the types of skills on which her program concentrated, she emphasized the importance of planning and providing an in-depth approach to the scope and sequence of transition programs.

> We were strategic as we created our new job sites, ensuring that the new sites had various ability level capabilities, so that we could look at how they use public transportation, which would be able to take kids to off-site for job coaching. How we could get to our job and get back and replicate something that would be realistic and would also include leisure activities. Everyone's lens is going to be different because we have the dichotomy of IDEA and academics. (Mary Beth)

Mary Beth emphasized, in her experience, the age at which the team begins speaking with adult day program personnel about possible student admission cannot

come too soon. She spoke to the challenges and difficulties in trying to get all of the transition IEP stakeholders to come together at one meeting:

> We do not get together soon enough because the adult day care providers cannot come to all the meetings. They do not have the resources to attend all meetings. They want to come in their final year of whatever that is because they don't want to spend their time in meetings for kids that are going to continue [in the school system]. (Mary Beth)

When answering the question regarding the methodologies and strategies utilized to assist the students in maximizing their post-secondary adult program choices, Mary Beth responded describing how they sought to deliver meaningful services:

> I think that we are better than most as we have we have had lots of opportunity and address a variety of skills; however, there are a plethora of jobs and we certainly do not mirror all of them, so I would say that we have done everything we can to look at the job market and say what are employment opportunities as post-secondary goals that are entry-level skills and we try to come up with divergent areas that have parents sometimes cringing at but that is reality. Maintenance, landscaping, warehouse; so looking at what important skills are. Retail jobs usually keep our kids in the back; they take things off the truck. I cannot think of any jobs that we have that are out in the public. (Mary Beth)

Mike. Mike was an Effective Practice specialist in the area of transition for Midwestern School District. His supervisor was Mary Beth who coordinated several area high school transition programs. Mike's responsibilities included guiding, assisting, and facilitating the district's focus on 18 to 21-year-olds who were transitioning from a high

school-based curriculum to a practical skills-based curriculum; one that provided a more functional workplace setting. When describing his program, he talked about how the focus was on 18 to 21-year-oldstudents.

> Our program is comprised of 18 to 21-year-old students for whom the team has determined that in order for them to meet their post-secondary goals, they need to work on specific skills as outlined by the IEP. We have 11 sites that have various skills sets that we work on. Students that would attend that site depending upon the site requirements, the student's requirements, and the staffing of that site. (Mike)

Mike explained the mission of the Vocational Skill Program was to provide the best education for the students (ages 18-21) in order to meet their practical post-secondary goals (skills).

> So within those skills, IEP goals would be written and the student's instruction would be individualized based upon goals within those three areas. Work sites focus on those three areas while looking at behavior and independence and trying to establish the highest level of independence around behavior. (Mike)

Mike explained as a student in his or her senior year (turning age 21) begins to focus on specific post-secondary placement, the IEP team is actively communicating with the Division of Vocational Rehab as well as their state-assigned social worker. Sometimes agencies were also utilized that assist with students with emotional disturbances.

> VR visits our sites several times per year and they are constantly working with the students. They also do on-site assessments. Our district does not do assessments

> for post-secondary placements. These must come from VR. All of our sites have a VR counselor associated with them that consults with the teacher and students several times per year and we are constantly in contact with state case managers regarding students who may need day placement. (Mike)

Another goal area addressed in each student's transition IEP was that of independent living. Mike shared that teachers and administrators assisted families to do some things with living arrangements.

> Typically, our staff will go visit various group homes but most of these homes are a house that might have four or five adults that live there and they have someone that comes in and manages the appointments and makes sure things run smoothly for the adults. (Mike)

When discussing post-secondary eligibility requirements, Mike conveyed the ultimate responsibility for placement after the age of 21 belonged to the individuals and their families or guardians:

> Typically, through the IEP and services rendered throughout the IEP services are we will work with those agencies to help them. Typically, we are hooking up with those agencies and find out what we need. But, typically, it is eligibility and so it is eligibility vs. entitlement. So under IDEA, you are entitled to a free appropriate education; once you go to an agency, you have to meet their eligibility criteria. (Mike)

Mike pointed out how student skill level could affect the type of post-secondary placement. He stressed the impact that inappropriate behaviors could have on not only obtaining placement, but also maintaining the placement.

> If you are looking at once they become a young adult and leave district services, the skillsets we have found to be the most appropriate to go the furthest are the ones who have behaviors under control, behavior management, and they also have attained a level of independence. Areas such as daily living, or independent with self-care such as toileting, they are going to go a lot farther…more doors are open. If a student is unable to toilet themselves, unable to feed themselves; most competitive employers will shut their door immediately. Many sheltered workshops will shut their door because they do not have the staff to support their toileting needs. However, some sheltered workshops are becoming a little better at that. If the person can come with a personal aide, sometimes they will have someone there that will support them. So some of our students who have medical needs can apply through the state or Funding Agency One to have a nurse come once a day to give them that shot, or they may have an aide that shows up at noon to do a feeding tube; to help feed for lunch or go to the bathroom and then that aide would leave. These services are only purchased for that student. (Mike)

Mike conveyed that he was not necessarily knowledgeable of the entry-level criteria for local post-secondary program for students with severe disabilities.

> I cannot say that I have actually seen criteria for those programs that would be for lower functioning adults. My conversations with them varies, so it really depends upon the client and what skills they bring to the table. Often times, behavior and aggression are very much looked down upon. We do have a couple of programs that will bring in a behavior specialist, but if the family cannot afford to have the

behavior specialist on the site at all times then the student is not welcome there. (Mike)

Mike further explained the skills on which the programs concentrated the most were behavior and independence. He shared students who entered day programs often had communication needs and they worked together with the day program so the individuals would be able to continue utilizing their communication systems. For students who were sheltered workshop-bound, the same expectations applied, however they were increased.

> We take those same parameters and then behavior and then bump them up. We want to make sure they can stay on task without behaviors and interact with multiple types of adults, um, without behavior and/or physical outbursts. That they are able to manage the sheltered workshop environment which sometimes can be very noisy and poorly lit. (Mike)

Mike also shared, in general, VR did not like to evaluate or become involved in the evaluative process until the student was approximately six months prior to graduation. If the student was going to require some type of supported employment then the agency may become involved earlier, in combination with state support services. “What are we looking at is the family’s needs and we are collaborating with the state because all of this goes into the family plan as we are starting to support those types of things” (Mike).

As Mike discussed methodologies and strategies utilized by schools, he shared teachers participated in professional development, touring graduation sites, day programs, and sheltered workshops. They also invited guest speakers such as representatives from VR, the state, and local Funding Agency.

> As an administrative group, the effective practice specialists interface with the agencies to maintain current trends. So what is going on out there; so we typically meet with agencies just to find out what has changed, let them know what has changed with us and state agencies. We are all working collaboratively together to know what we need to be doing. (Mike)

Mike further explained that as an administrative group, they collectively interfaced with a local multi-agency coalition. At these meetings, they discussed employment opportunities and various supports that were available. He further stressed that his role as a facilitator revolved around building relationships.

> I meet with other effective practice specialists and assist them in the development of relationships with various organizations. At the teacher level, the teachers know those VR reps very well as they are in constant contact. They understand the various local organizations and they are in-serviced on those things and, as student needs arise, we collaborate with our contacts at those agencies. (Mike)

Amy. Amy is a teacher of Autism for the Midwestern School District. She supervised paraprofessionals who supported students who received Applied Behavior Analysis support in the school setting. She also provided support to the special education and general education teacher. One of Amy's responsibilities was to case-manage and chair her students' IEPs. As students reached the age of 16, Amy and the student's IEP team were charged with writing transition goals. When asked to describe her program and the type of student population she served, she shared her students ranged in age from kindergarten to 10th grade.

> Generally, I have 20-something kids on my caseload. On the continuum of service, we have two different levels. We have direct services, which are kids that receive direct Applied Behavior Analysis (ABA) minutes; we also have support services which are students that do not necessarily need that direct ABA but need, you know, a paraprofessional to support them throughout the day, whether it is behavior problems or just support in the general education classroom or consult services. (Amy)

When asked about how her district's mission statement was implemented throughout the curriculum, she shared the following:

> The biggest thing with ABA is reinforcement and prompting. So it is really kind of looking at what can we do to reinforce - to prompt - it is our teaching method. Do we need to do over hand or model, gesturing within stimulus prompting those types of things? We generally want to be the least intrusive. We want our students to be included in groups and gen education and have that ABA par to support whenever necessary. Least intrusive is what I go by. (Amy)

Amy explained that due to the age of her caseload, she was not directly involved in her student's transition process at the time. She shared that she did not work directly with the transition stakeholders.

> I have three kids at the high school program, as far as that transition piece, you know that we have a transition specialist come in and hone in on where we are going with the goals and we keep working math and the nearest dollar paper pencil type things. At the core, the student needs to know how to greet people, say

> hello, follow directions, you know, be able to speak clearly, so those are the things that I think. (Amy)

When asked about the types of skills on which her program concentrated so students may gain access to varying adult programs, Amy stressed communication and group participation skills.

> I mean I think the biggest things are the communication skills, the ability to sit and complete tasks so task completion, so having, you know, follow directions and keep going and completing things without repeated direct instruction and the ability to be around other people and, kind of, I mean I think that is huge. Sitting at a table and communicating and tolerating other people in your space. I think socialization and communication skills are definitely huge. (Amy)

Amy conveyed that she really did not know too much about the collaborative efforts between her school and the various post-secondary agencies her students might access in the future.

> I don't' really know too much about that. I do think that there needs to be more collaboration and more options and a lot of times kids are exiting and parents want competitive employment and they want this for their kid. Individuals with developmental disabilities need to have the ability to say no, I do not want to do this, and let the natural consequences happen. (Amy)

Melissa. Melissa taught in a high school self-contained program. She worked with students with Intellectual Disabilities and Autism. When describing her program, she stressed its primary focus was on the application of daily living skills. "My program is functional in nature with a focus on independence and daily living skills. My students

also earn elective credits towards their graduation requirements by participating in a community work program two days a week" (Melissa). She shared she implemented the mission of her district, the Midwestern District (pseudonym), by collaborating with other districts. "In collaboration with partner districts, we provide technical education and a wide variety of individualized educational and support services, designed to ensure the student's successful contribution to our community" (Melissa).

Melissa stressed job focus when asked how she implemented the curriculum in her classroom. "I implement this throughout my curriculum by providing hands-on, meaningful activities in my classroom to ensure my students are independent and job-ready so they can obtain and keep employment in their community" (Melissa). She additionally shared that she utilized the Midwestern School District's transition department to facilitate student placement in post-high school programs. "I am responsible for completing all necessary paperwork, setting up observations, setting up meetings, etc. for any student moving on to a post high school transition program. I have minimal contact with subsequent providers" (Melissa). Melissa conveyed that she was not very familiar with the admission criteria for the program for students with severe cognitive disabilities.

> My program focuses on 'soft skills' and independence. We focus on teaching appropriate job behaviors versus specific job skills. I begin talking about transition options at the first year IEP, regardless of the student's age. Specific programs are not usually discussed until the junior year IEP. The main focus of my program is independence. The more independent the student, the more options available. (Melissa)

State Agencies

Harper. Harper was a social worker for the state of Missouri. She served as a state-appointed case manager for many individuals of all ages with developmental disabilities. Her job duties primarily involved helping families and their loved ones to access services, programs, and a multitude of resources that could be available to them through various federal, state, county, and local programs.

> The Department of Mental Health is a state agency and we provide case management services to those with developmental disabilities and/or mental retardation. We fund for services, we monitor the services that we fund, and we meet with families just to make sure that they are getting the services that they need. (Harper)

Harper advised everyone she served had an individual support plan and this plan served as the framework which justified any purchased or accessed services.

> We look at the services we are able to fund for; we look at how to best provide inclusion for the person. But we fund for the services so that the agencies are able to do that and we advocate for our consumers based upon what their ability is and actually try and assist them with planning as to how they are going to meet their goals and that is done through the individual support plan. (Harper)

In order to receive most services offered to individuals with significant disability levels, they must first be identified as having a developmental disability according to the state guidelines. Harper shared her office was responsible for certifying individuals who did indeed possess a developmental disability according to state guidelines.

> We have an assessment department and they evaluate anyone who comes in to our office for services. There is an application that needs to be completed. Our assessment department can request any other data from schools or school records or medical records, even psychiatrists, and use that data to determine eligibility for services. As far as our agency is concerned, it is considered a volunteer agency, so it means that the person can come or leave our agency anytime that they want to. But in order to receive service, they have to be assessed and they have to have a functional limitation that occurred prior to the age of 22, or mental retardation. (Harper)

Harper further shared eligibility had nothing to do with income, medical insurance, or Medicaid.

> They must have mental retardation or a developmental disability that impacts them prior to the age of 22. There is an assessment tool that the state uses to determine eligibility. This assessment evaluates six areas: self-care, mobility, receptive and expressive language, learning, self-direction, and we look at capacity for independent living or economic self-sufficiency. We use the Mocabi, a Missouri assessment tool that that evaluates the level of functioning in these six areas. The receiving funding does not impact eligibility; those two are separate. (Harper)

As Harper discussed the types of functional skills evaluated for program placement, she went back to how program placement was determined in our state. She shared that anyone who attended a day program would have already been evaluated for

employment and it would have been determined that they did not possess the skills necessary at that particular time to be appropriate for sheltered employment.

> So day programs are appropriate for a person who for whatever reason, cognitive functioning, physical disability, and/or behaviors, whatever makes them inappropriate for employment at that point. At the end of high school they [the school system] can do a referral for VR which generates a DESI evaluation. (Harper)

Harper has had consumers (her clients) who have stayed in the school system until the age of 21 to work on independent living skills and employment issues and challenges through the school's post-high school curriculum. Prior to graduation, skills were evaluated and it was determined what type of employment would be most appropriate for the individual. Harper shared how each consumer had an individual person-centered plan which provided the framework, as well as the rationale, for purchased services. The plan discussed the individual's level of functioning and described the supports they required to be safe, along with their likes and their dislikes. "The person-centered plan paints a picture of the person. The individual support plan drives the service. You cannot ask for funding or serviced unless the plan specifies that need" (Harper).

Harper addressed the importance of the case manager being included on the IEP teams. She felt that the case manager should be invited, not only for transition meetings, but as soon as possible throughout the student's school career. The case manager could then experience how the child was developing and share with the parents as they

developed what they wanted for their son or daughter and help them understand that they should want them to reach their potential, whatever that happens to be.

> Just like any kid, one kid may be good in science or math another kid may be good for a technical school. So you want to encourage them to develop their vision and what their expertise has to be whether they have a disability or not. And I see some parents, they see the disability, they do not see the potential the child has. (Harper)

A final question for Harper asked her to address the types of collaborative efforts between school and her agency that would make a smoother transition when determining placement and programming for clients' adult years. Harper stressed the need of all stakeholders, but especially the parents, to focus on independence and skills to promote independence from a very early age.

> Families need to work to develop those skills. But sometimes families say it is just easier if they do it . . . it takes too much time. This impairs the development of their son or daughter . . . their child has the right to develop those skills. The least amount of supports they need, the more opportunities they will have. (Harper)

Common Themes

Shared common themes and/or skillsets emerged as data was sorted, categorized, and coded. Table 3 reflects the common themes, which emerged in the study by the responses from the school and agency interviews. However, out of 21 themes, 11 were shared by five or more interviewees.

Table 3.

Common Themes

Themes	Grace	Celia & Daniel	Barbara	Derek	Lebanon Industries	Nest Step Council	Leisure/ Sport Council	Funding Agency One	Funding Agency Two	Mary Beth	Mike	Amy	Melissa	Harper
Person Centered Plan/Support Plan		x	x	x										x
Ten hour support week			x					x	x					x
Ability to handle change or transitions		x	x											x
Age	x	x	x	x	x	x	x	x	x	x	x	x	x	x
Area of residence as first qualifier	x		x							x	x			x
Attendance (at IEP meetings)		x	x	x						x	x			
Behavior – ability to maintain appropriate	x	x		x	x	x	x	x		x	x	x	x	x
Case management			x				x				x			x
Communication method carried over to adult	x	x	x	x				x	x		x	x		

Table 3. (continued)

Common Themes

Themes	Grace	Celia & Daniel	Barbara	Derek	Lebanon Industries	Nest Step Council	Leisure/ Sport Council	Funding Agency One	Funding Agency Two	Mary Beth	Mike	Amy	Melissa	Harper
Documentation of dev. disabilities				x			x	x	x					
Etiquette, proper manners, politeness, eye to eye contact	x	x	x	x	x		x				x	x	x	x
IEP – presence of agency at meeting			x	x				x		x				
Medicaid waiver –importance of in funding of programs	x	x	x	x				x						x
Observing in schools/ importance of	x	x												
Person Centered Plan	x	x	x	x				x	x					x
Residence type as first qualifier	x	x	x	x			x	x	x					x
Self-care skills & behavior skills, importance especially toilet skills					x	x		x	x					x
Social skills	x	x	x	x	x	x	x	x	x	x	x	x	x	x

Common Themes Explained

Age. When asked if their organization had age requirements for entering or exiting program/services, Mike shared that participants in the public school transition plan had to be at least 18 years of age. Bonnie who served as director of the Leisure/Sport Council explained that most of the programs she facilitated have age restrictions, as well as other determining factors such as area of residence and meeting state developmental disability requirements. Donald advised that the workers in his sheltered workshop ranged in age from 20 to 70, with the minimum age required being 20.

Ability to Maintain Appropriate Behavior. Twelve participants of focus groups express that the ability to maintain appropriate behavior was critical to not only gaining placement in post-secondary programs, but also to maintain placement. Grace, who was the director of the community integration program, stressed that paramount to any other eligibility characteristics or requirements, safety was first. Donald described the difficulties of maintain productive work groups when one of the greatest challenges that their workers face is in the area of behavior management.

Attendance at IEP meetings. When questioned about the importance of agency attendance at school IEP meetings, Celia and Daniel shared that they would like to attend the IEPs from the time the student turns 18. “The development of the pathway for communication and planning is essential” (Celia & Daniel).

Communication Method Carried Over to Adult Program. Celia and Daniel stressed the importance of being able to carry from the school environment the ability to communicate. How to operate varied communication devices and the specifics of who and when the clients utilized them was imperative to know.

Diagnosed Developmental Disability. Larry, who worked in the employment development program, shared that all employees hired had a diagnosed developmental disability. Harper shared that individuals must first be identified as having a developmental disability according to the state guidelines. Harper shared her office was responsible for certifying individuals did indeed possess a developmental disability according to state guidelines. Both Funding Agency One and Two shared that first and foremost, participating individuals had to meet the criteria for being diagnosed with a developmental disability, and the funded agency had the responsibility to ensure that individuals met that qualification.

Etiquette/Proper Manners/Politeness. Barbara was the director of a leisure services program who conveyed that the younger they (children with significant cognitive disabilities) were and the faster they got into a socialization skills class to learn proper etiquette, manners, politeness, eye to eye contact, how to shake a hand, those types of things, would really help them as they progressed and grew older.

Medicaid Waiver. Funding Agency One shared that Medicaid should be applied for as soon as the services were needed. Barb further explained the Sarah Lopez waiver which was usually for individuals that had a significant medical need and bypassed the low income requirement of Medicaid. In some counties there existed what was called a partnership waiver, whereby families could receive up to $12,000 or less. This fund allowed families to not always need or apply for a high needs waiver, such as the Sarah Lopez. With this waiver, citizens could obtain home modifications, therapy services, personal services, and transportation. Most people who participated were over 18, but the purpose of it was to prevent the need for future services. Additionally there was a

Community Supports Waiver, which was $22,000; however, eligibility for this waiver was more restrictive than the partnership waiver.

All interviewees who directly managed programs reported that the funding stream that supported their program was vital to an individual's eligibility. Grace shared, "For a lot of people, funding is an important piece; it is not a requirement, but it can determine their ability to participate" (Grace). Barbara further shared:

> In the past, it was an entitlement. Anyone who graduated from Midwest School District was entitled to go on to a day program or they could go to supported employment. Since the 90s, that money has run dry; sometimes (waiver) slots open up. (Barbara)

Person Centered Plan. Harper conveyed that the Person Centered Plan was the only document that seemed to hold both the day program and the social worker (or funding management) source accountable to somewhat of a degree. All direct adult servicing interviewed shared that they referred to the applicants plan to develop and guide services.

Residence Type. Derek, who managed a leisure program, explained that additional eligibility requirements included that participants must be at least seven years old and must live in their natural home, not a residential facility or group home situation. That residence type could be a service disqualifier.

Self-Care/Behavior Skills. Daniel described that his adult day program sought to align the evaluation with the individual's person-centered plan to determine exactly what barriers were faced to make placement work. For example, someone who, at home, may be able to use the restroom independently, but in the community it may be an entirely

different story that can be overwhelming to a person. The level of supports necessary to participate in a given program were essential to determine. Derek conveyed if they were dealing with an individual who had not been supported in another AHC program, they must rely on communication from the families and schools. They also reviewed documentation from the individual's person-centered plan.

Mike, who was a transition facilitator and assisted students and families in seeking adult placement opportunities explained, "If a student is unable to toilet themselves, unable to feed themselves; most competitive employers will shut their door immediately" (Mike).

Harper summarized how behavior could affect the ability of the agency to deliver services. If the individual was not able to maintain safe/appropriate behaviors, then services were difficult to deliver and it could be determined that current programming was not working and other programs must be sought out. The staff of Lebanon Industries also shared that the ability to maintain appropriate behaviors was an integral part of partaking in their program.

Social Skills. Amy who was a teacher of students with Autism explained that while she taught academics, at the core of her instructional practices was the teaching of appropriate social skills. The ability to follow directions, say hello, greet people, and speak clearly were very important. Derek and Celia who managed an adult day program also shared that they evaluated how program applicants communicated and conveyed their wants and needs, as well as their ability to interact and socialize with their fellow program participants.

Summary of Application Topics

Several adult agencies shared their intake packets with the interviewer. These intake packets detailed the skillsets or characteristics, which were deemed necessary to be evaluated by the individual agencies. In Table 4, I categorized the information the agencies focused upon in their intake packets into a summary of program application questions.

Table 4.

Summary of Program Application Questions

Communication	Mobility	Personal Assistance	Behavior/Social Skills	Task or Activity Participation	Funding
What is primary means of communication?	What types of Adaptive Equipment or Individualized Equipment is Used	Dressing Do they require 1:1 assistance?	Are they hyperactive?	Do they need hand over hand assistance?	Does participant have Medicaid Waiver funds?
Do they know how to contact you in the event of an emergency?	Are there issues affecting safety?	Do they require assistance with dressing?	Are they oppositional or defiant?	Do they need verbal cues?	Type of waiver: Community, Sarah Lopez, Comprehensive or Partnership for Hope
Does the individual have appropriate picture identification?	Are there environmental issues affecting safety?	Bathroom: Do they require reminders to use the bathroom?	May they physically harm themselves?	Do they need physical prompts?	Do they have a diagnosed Developmental Disability?
Do they have emergency contact numbers?	Are there medical issues that might affect safety?	Do they use diapers?	Do they tell the truth?	Will they accept hand over hand prompting?	
Do they know not to leave with strangers?		Dressing: Do they require verbal cues when dressing	Do they need motivation to participate?	Will they interact with staff during activities?	
Do they wear a seatbelt in the car or van?		Eating: Do they require verbal cues?	Do they have a short attention span?	Will they interact with peers during activities?	
Is individual aware of danger near busy streets, parking lot, etc.?		Do they require 1:1 assistance when eating or drinking?	Are they manipulative?		
Can they point out exit signs?			May they physically harm others?		
Do they know where to go or what to do during a tornado, earthquake or fire?			May they stray away from group?		
			Do they curse?		

Summary

This chapter presented the findings based on data gathered for my study. The interviews were comprised of representatives from adult day programs, secondary schools, and adult agencies. They provided the interviewer with their varied perspectives as to the skill factors and characteristics utilized to determine how to service their clients. Both individual and focus group interviews were utilized to gather information for this study.

Chapter Five: Discussion of Results and Summary

The purpose of this study was to identify local-area post-secondary eligibility requirements that might possibly result in attainment of a non-restrictive adult placement for students with severe disabilities. Secondary school and post-secondary school interview responses provided by participants employed by school districts, county and state-funded agencies, and the state of Missouri, who were responsible for assisting families of and individuals with severe developmental disabilities in securing a post-secondary placement, were compared to the Missouri Alternative Frameworks curriculum. This chapter summarizes the responses to my research questions and discusses the implications and resulting transition checklists for both parents and educators. Additionally provided are recommendations for future research.

Research Questions

Throughout this study, I triangulated the responses from school administrators and adult agency personnel with the Missouri Alternative Frameworks.

> The distinctive characteristic of hypotheses in qualitative research is that they are typically formulated after the researcher has begun the study; they are ‘grounded’ (Glaser & Strauss, 1967) in the data and are developed and tested in interaction with them, rather than being prior ideas that are simply tested against the data. (Maxwell, 2013, p. 77)

The journey of interviewing, comparing, and contrasting the responses to my research questions resulted in the creation of two checklists, which I hope will assist both parents and educators in both the collection and provision of pertinent information for families of

students with significant disabilities as they make their transition journey. Two checklists (Appendices F & G) are discussed in more detail later in this chapter.

RQ1: How do the Missouri Alternative Frameworks utilized in secondary programming differ from the eligibility criteria utilized in post-secondary programs?

Don, the executive director of Lebanon Industries Sheltered Workshop shared that employees are required to count and create sets, a skill tested in Alternative Frameworks. The math skills of counting and creating sets directly related to the Alternative Frameworks for Curriculum Development, specifically Show Me Standard Goal 1, alternate process standard number six: "recognize, interpret and make use of patterns in daily living" (MODESE, 2005b, p. 10). Additionally, paying with money is also directly related to the Alternative Frameworks for Curriculum Development Mathematics Show-Me-Standard NO 8.17, making change from $1.00 or less (MODESE, 2005b, p. 28).

Mike, who was an effective practice transition specialist shared that his responsibilities concentrated on transitioning the 18 to 21-year-old students from a practical skills-based curriculum to one that provided a more functional workplace setting. He informed me that no standardized tests were administered during the high school transition period. Celia and Daniel, who comprised the management staff of an adult day program, shared that "the pencil and paper stuff that schools require is not important" (Celia & Daniel). The secondary school routines of checking the weather or completing picture journals did nothing to help individuals be successful in their program. Schools need to stop these routines and provide more real life community experience that requires behavior management in unfamiliar and non-structured environments. The experiences of Mike, Celia and Daniel seemed to agree with research

by Browder and Spooner (2011), from which they concluded that transition-centered learning emphasized the student's future.

Of all of the common themes that emerged from my interviewing, only three responses directly related to the academic nature of the Missouri Alternative Frameworks. The first was the ability to count and create sets, which I discussed previously in this chapter, and the second directly related response spoke to the importance of individuals being able to pay for items and keep track of their money. In my classroom, I call it 'snucker math.' For my students, learning to identify dollar amounts and to be able to keep track of money utilized for their own personal needs to the greatest extent that they can, is a skill they took great pride in. We worked daily on identifying paper money in the classroom. On community outings, students would bring five to ten dollars. They were encouraged to know the dollar amount that they started out with, and then to know the approximate dollar amount they needed to spend on lunch, or whatever item they planned to purchase. Finally, students estimated how much money they should have left in their wallet at the end of the day. Most individuals with severe developmental disabilities received assistance from someone to help them make purchases or participated in the buying of services. The ability to keep track of and manage their money, even to a nearest dollar amount, could be most gratifying and promoted self-determination and responsibility. The positive effect of teaching individuals to participate and determine outcomes on their own behalf teaches them to advocate throughout their entire life (Friend, 2008). My own stepson often went on outings with his day program. He was continually taking money to the program for restaurant outings and even trips to the casino! He loved this, he knew how much he

started out with, and about how much he would probably spend that day. We also asked him to remember where he spent the money and who helped him since this also put into place a level of accountability for those who were assisting him on any given day.

RQ2: How does the post-secondary eligibility process relate to the Missouri Alternative Frameworks Curriculum guidelines?

Of the responses to the 39 summarized questions from adult program applications, only two skills were related to skills that tested in the MAP-A. Both questions required the student to be able to read or recognize environmental print and/or exit signs. The Communication Arts standard three called for students to "read simple text (words/pictures/symbols/objects/actions) consisting of environmental print" (MODESE, 2005a, p. 20). "For example, Flowers, Browder, Ahhgrim, Defezel and Spooner found that teachers reported difficulty in understanding the relationship of alternate assessment outcomes to grade level standards" (Clayton, Denham, Kleinert, & Kearns, 2006, p. 20). None of the application questions asked about math or writing skills. Other than reading signage or creating math sets, no other similarities were noted between the Missouri Alternative Frameworks Curriculum and any program application questions (Appendix I).

Amy, a teacher of students with Autism, conveyed that some of her students had academic goals, especially in math, such as rounding to the nearest dollar. She felt that "at the core", the student needed to know how to greet people, say hello, and follow directions. Her response was consistent with responses received from interviews, since almost all stressed the importance of controlling behaviors, communication, etiquette, and social skills. These responses were consistent with my research, which related that

"Life skills, vocational experiences and social skills should all be included in the IEP transition plan" (Special School District, 2012, pp. i-4).

RQ3: What specific self-care skills and academic skills determine criteria for students with severe cognitive disabilities in post-secondary adult programs in the St. Louis area?

Post-secondary entrance application questions fell mostly into five main categories: communication, mobility, personal assistance, behavior/social skills, task completion/participation, and funding. Common themes across the interviews stressed the displaying of appropriate behaviors, use of proper etiquette, social skills, communication, funding, and geographical area of residence. The focus group from Lebanon Industries shared that the people that they employed must have the ability to work and be a part of a production team; that the focus on the 'soft skills' in the area of behavior management was most critical. In addition, employees must possess the self-care and behavioral skills necessary to perform the job. Adult day program, secondary school personnel, and agency personnel all stressed the importance of the common themes of appropriate behavior, communication skill, etiquette, proper behavior, and social skills. These were common themes amongst all participants.

RQ4: In addition to self-care and academic skills, what other factors determine student placement in post-secondary programs for the severely developmentally disabled within the St. Louis Area?

Age at the time of application, the possession of a Medicaid Waiver, a developed Person Centered Plan, and Residence Type were all common themes amongst interviewees that were not related to self-care and academic skills. Harper, who worked

as a social worker, conveyed the importance of the development of a Person Centered Plan for each individual. This plan served as both the framework and rational for purchased services. The Person Centered Plan was the only document that seemed to hold both the day program and the social worker (or funding management) source accountable, to a degree. From individual program goals to the maintenance and repair of adaptive equipment, the person-centered plan was crucial to the provision of services. The importance of the Person Centered Plan servicing as the focal point from which adult services were delivered agreed with my research, whereby the plan served as the document developed to service as a framework from which eligible individuals receive funding for services and supports from the St. Louis Area Regional Center (Kansas Center for Autism Research and Training, 2014).

Being eligible for state funding was a huge factor in obtaining program placement, as the cost for such programs was substantial and often out of the reach of the families of individuals with severe disabilities. Research concurred that expected adult post-secondary opportunities can be targeted based upon assessment data, IEP team contributions, family beliefs, student preferences, and funding sources (West ,1999). In addition, many programs were funded on a regional tax basis, and therefore only serviced individuals within their geographical area. Furthermore, if an individuals was living in a group home situation, and not in a private family situation, that could inhibit qualification for services intended to provide relief for caring families, and thereby discriminating against individuals placed in some type of custodial care situation.

Implications

Adult Day Program Providers. Adult Day Program providers shared that they would like the opportunity to attend transition IEP meetings, so they could begin to evaluate potential clients for their programs. They explained that it was important to get to know the individuals so providers could begin to determine what support level may look like for their particular programs. Teachers on the front lines working with students and parents directly often do not get to make the direct connection between individual schools and the personnel of day programs. While we might have access to transition administrators, they often are involved with issues that take them away from the everyday transition IEP. It would be helpful if area adult day program personnel contacted area high schools directly and made an effort to establish relationships with local administrators, as well as teachers. Therefore, when IEP invites are prepared and as school personnel are helping parents to learn about area programs, these agencies could be included. As many factors fall into the consideration of the support ratio determined to be necessary to support a client, school personnel could share specific learning styles and strategies regarding behavior needs, safety needs, and feeding or personal care requirements. If funding is not in place by the Division of Mental Health, the individual would have to privately pay for services.

Secondary Transition Curriculum/Secondary Teachers. From their personal experiences, both Celia and Daniel stressed the need for more community-based high school programs.

> You know, sitting behind a desk until you are twenty years old and doing a weather chart, is that really preparing someone for the future? That the keeping of

> routines in place such as discussing the weather at the beginning of each day does just that . . . keeps routines in place. (Celia & Daniel)

Secondary curriculums need to look at how to stop teachers from continuing these academic school routines and gradually prepare transitioning students with more realistic experiences. The mastering of soft skills is crucial, and day program providers stressed that they would like to see the acquisition of soft skills built into the secondary curriculum, as well. Celia and Daniel shared that both parents and students were used to not receiving "natural consequences" when negative behaviors or practices were exhibited. For example, when students drooled in school, adaptations and modifications were made and students could continue to learn; however, when one emits bodily fluid in a public forum, adaptations and modifications do not have to be provided.

One of the most important factors stressed by adult agencies was the ability to communicate. The carry-over from secondary school where students had trained professionals working with them on a regular basis to improve communication skills, as well as to program augmentative devices to keep current with their daily happenings, did not exist in the adult day care setting. A Communication Checklist that secondary teachers can prepare for their students to have available for other professionals who are unfamiliar with how the students communicate their wants and needs, as well as how they share their thoughts and ideas, is provided in Appendix F.

Missouri Alternative Frameworks. Since the Missouri Alternative Frameworks parallels the standards and expectations for general education students only academic related skills are tested. Teachers shared that they often teach students to read or recognize environmental print, or that they teach students to count, make sets, or 'round-

up,' While the Alternative Frameworks provided for accountability for academic skills, (Appendix I), the level of mastery of soft skills was not measured. Additionally, students were tested through grade 11, while often students with significant disabilities remained in the public schools system through the year they turned 21. No level of accountability by means of high-stakes testing was available to these students. These students were not counted in MODESE's facts and figures. The population of students with significant disability who were attending public school during their transition years were not seen as a population of learners targeted for district, school, or teacher accountability.

Students, Families/Guardians. For both the families of students with significant disabilities and the students themselves, the most important themes seemed to revolve around building of a village as early as possible. By seeking and allowing the active participation of as many stakeholders as possible, students and families can broaden their knowledge of how to achieve the most non-restrictive adult placement possible. This is not unlike the typical developing child whose parents began at an early age to develop sports interest or specific skills. Students with significant disabilities also find it helpful to have participated in both school and leisure programs, which were sponsored by some of the same entities who provided opportunities for their adult programming. Some of these included voucher programs that allowed individuals with disabilities and their families' opportunities to choose programs and activities that best met their interests and support needs, presentations/trainings, and workshops. The creation of networking opportunities between recreation agencies, both school and community-based can begin to weave the web of a supportive village of stakeholders.

The myriad of tasks that comprise the building of a supportive village can be both time consuming and overwhelming. A swift Transition Checklist is included in Appendix G. This checklist is not meant to be a comprehensive list; however, it was designed to help families target their efforts towards the achievement of the most non-restrictive post-secondary placement possible for their loved one. The checklist highlights such areas as program funding, age requirements, communication, and behavior.

Recommendations for Further Study

I have several recommendations for future research studies on students with significant disabilities maintaining their most non-restrictive post-secondary adult programming placement. First, I would suggest a written survey to all participants, in order to provide interviewees the opportunity to select responses from a pre-determined answer bank. I would then suggest comparison of those responses to data gained via qualitative interview methods, to provide a more in-depth look into perceptions of current programming.

Future research could also be completed regarding how teachers and administrators were accountable for their curriculum offerings, as well as the learning of students enrolled in their transition programs. Additionally, I would suggest that research be completed via the interviewing and surveying of parents or transitioning students with disabilities (both prior to graduation and post-graduation) regarding not only their understanding of the transition process and its components, but also where they are as a family in securing placement for their loved ones.

The stakeholders, both public and private in the lives of our transitioning students with significant disabilities, do come together to form the framework which services

them. This framework however, begins and ends with each individual family bearing the ultimate responsibility for the care, education, and welfare of the child.

Summary

It is nighttime, my house is still, and quiet; I look up and see my stepson's Cardinal jacket lying over the back of the couch along with some left over popcorn. He spent his day with his volunteer day program at a St. Louis Cardinal's game, and is now bathed and tucked in by his caregiver (who helps us two nights per week). I reflect upon all those who assisted him throughout his day and facilitated the day's experience of attending a professional baseball game. There are the tireless efforts of his dad getting him up, dressed, fed, and loaded onto his waiting ride service to the staff of his day program to his evening caregiver to myself and step-brother, who are always available to feed, clothe, and share our lives with him. I remember the words of one of my interviewees, Barbara, a leisure services director, who advised that "it helps to build the village that supports the child" (Barbara). What a village we've built . . . this village has included so many stakeholders, beginning with secondary school providers to his adult agency providers and his family . . . he is happy and enjoys his life each and every day!

I wish to share with you some of the facts that I have learned, not only about how schools can make a positive difference in the transition of students with severe disabilities to adulthood, but also some lessons I have personally learned as my stepson has made his transition journey. The village we have built for my stepson has been comprised of the same entities from which I conducted my interviews: secondary school providers, adult program providers, and service agencies. They contribute on a daily basis

to not only the transition of students with severe disabilities from secondary school to adulthood, but also to the maintaining of these services throughout their lives.

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Appendix A

Letter to Participants

Lindenwood University

School of Education

209 S. Kingshighway

St. Charles, Missouri 63301

Informed Consent for Participation in Research Activities

Secondary Functional Curriculum Design as it relates to Post Secondary Programming Eligibility Requirements

Principal Investigator: Deborah DiRisio

Telephone: 636-236-6896 E-mail: dad647@lindenwood.edu

Participants: Managers and staff at Post-Secondary Day Program Facilities
Contact Info: Administration at Day Program Facility

You are invited to participate in a research study conducted by Deborah DiRisio. The purpose of this research is to identify adult day program eligibility requirements so as to potentially pinpoint both academic and self-care skills that frame adult day program placement and possibly result in student's placement in the most non-restrictive adult program.

Your participation will involve being interviewed about program eligibility requirements and the identification of academic, social and self-care skills that frame student placement. Program staff will be interviewed about academic self-care and social skills that contribute to students obtaining the most non-restrictive adult placement. Your participation in this study will involve a brief interview that will take approximately 20 minutes to complete.

There are no risks to you as a participant. The results of this study will be published in my dissertation. All of the information will be held confidentially and will be destroyed five years from the completion date of the dissertation. Lastly, the names of the organization, and both administrative and staff members will be anonymous to ensure participants' confidentiality. No management names or staff member names will be used during the writing of the dissertation and the findings. Names will not be utilized in the writing of the data analysis.

Your participation may benefit others by adding to the literature and current information on improving student's ability to obtain the most non-restrictive environment in their adult placement. You will not be penalized in anyway if you choose not to participate. You may also withdraw from this study at any time.

If you have any questions about this research project, please contact me either by e-mail at dad647@lionmail.lindenwood.edu or at 636-236-6896
Thank you for your participation.

Appendix B

Initial e-mail to School Administrators

Lindenwood University

School of Education

209 S. Kingshighway

St. Charles, Missouri 63301

Secondary Functional Curriculum Design as it relates to Post Secondary Programming Eligibility Requirements

Principal Investigator: Deborah DiRisio

Telephone: 636-236-6896 E-mail: dad647@lindenwood.edu

To whom it may concern,

I am conducting a study that involves research on the types of self-care and academic skills that determine the placement of students with severe cognitive disabilities in their post-secondary programs. The specific purpose of this research is to explore the thoughts and perspectives of school administrators, teachers and adult program managers and caregivers to better understand the skill factors that can result in students being placed in most non-restrictive environment in their post-secondary programming. Below is a description of the procedures that will be followed:

1. Identify schools and day programs that service individuals with severe cognitive disabilities in the St. Louis area
2. Interview school building administrators and teachers who are involved in implementing transition plans for students with severe disabilities
3. Interview adult program managers and caregivers who are involved in determining eligibility and daily programming
4. Using Grounded Theory Qualitative criteria I will analyze the interview data and align with the Missouri Alternative Frameworks
5. Identify not only self-care and academic skills but also, other factors that are considered to contribute to individuals obtaining the most non-restrictive adult placement.

I am requesting permission to interview you and member of your staff, the interview will take approximately 20 minutes to complete. There are no risks to participants. The results of this study will be published in my dissertation. All of the information will be held confidentially and will be destroyed five years from the completion date of the dissertation. Lastly, the names of the organization, and both administrative and staff members will be anonymous to ensure participants ‘confidentiality. No management

names or staff member names will be used during the writing of the dissertation and the findings. Names will not be utilized in the writing of the data analysis.

Your organization may benefit others by adding to the literature and current information on improving student's ability to obtain the most non-restrictive environment in their adult placement. You and/or your organization will not be penalized in anyway if you choose not to participate and you may also withdraw from this study at any time.

If you have any questions about this research project, please contact me either by E-mail at dad647@lionmail.lindenwood.edu or at 636-236-6896.

I thank you in advance for your consideration in assisting me with my study.

Thank you,

Deborah DiRisio

Appendix C

Initial e-mail to Adult Day Program Managers

Lindenwood University

School of Education

209 S. Kingshighway

St. Charles, Missouri 63301

Secondary Functional Curriculum Design as it relates to Post Secondary Programming Eligibility Requirements

Principal Investigator: Deborah DiRisio

Telephone: 636-236-6896 E-mail: dad647@lindenwood.edu

To whom it may concern,

I am conducting a study that involves research on the types of self-care and academic skills that determine the placement of students with severe cognitive disabilities in their post-secondary programs. The specific purpose of this research is to explore the thoughts, and perspectives of school administrators, teachers and adult program managers and caregivers to better understand the skill factors that can result in students being placed in a "least-restrictive" environment in their post-secondary programming. Below is a description of the procedures that will be followed:

1. Identify schools and day programs that service individuals with severe cognitive disabilities in the St. Louis area.
2. Interview school building administrators and teachers who are involved in implementing students with severe disabilities transition plan.
3. Interview adult program managers and caregivers who are involved in determining eligibility and daily programming.
4. Analyze the interview data and align with the Missouri Alternative Frameworks.
5. Identify not only self-care and academic skills but also, other factors that are considered to contribute to individuals obtaining the most non-restrictive adult placement.

I am requesting permission to interview you and member of your staff, the interview will take approximately 20 minutes to complete. There are no risks to participants. The results of this study will be published in my dissertation. All of the information will be held confidentially and will be destroyed five years from the completion date of the dissertation. Lastly, the names of the organization, and both administrative and staff

members will be anonymous to ensure participants ‘confidentiality. No management names or staff member names will be used during the writing of the dissertation and the findings. Names will not be utilized in the writing of the data analysis.

Your organization may benefit others by adding to the literature and current information on improving student’s ability to obtain the most non-restrictive environment in their adult placement. You and/or your organization will not be penalized in anyway if you choose not to participate and you may also withdraw from this study at any time.

If you have any questions about this research project, please contact me either by E-mail at dad647@lionmail.lindenwood.edu or at 636-236-6896.

I thank you in advance for your consideration in assisting me with my study.

Thank you,

Deborah DiRisio

Appendix D

Interview Questions

Post-Secondary Providers (Programs after age 21)

1. Please describe your program and the type of population that you serve.
2. What is the organization's mission statement?
3. How is the mission statement implemented throughout the agency?
4. How is eligibility for program placement determined?
5. How does insurance, Medicaid, and or no insurance coverage impact eligibility?
6. What types of functional skills (skills that are important for everyday living) are evaluated for program placement?
7. If there is a regression in a person's skill sets, then is there any kind of step programming services available? Likewise, if a person shows significant growth, then how does your organization meet those needs?
8. What determines the level of service a client receives?
9. Do you have any age requirements for entering or exiting program/services?
10. What factors other than those related to the client's individual skill set determine eligibility? (i.e., residency, age, income)
11. What methodologies or strategies would you recommend to the providers of secondary instruction to assist the client in attaining the most non-restrictive post-secondary (after age 21) placement?
12. In preparing for the transition from high school, what collaboration efforts between school and your organization would make for a smoother transition for both your client and your organization when

determining placement and programming? (i.e., attending IEPs, or student team meetings throughout the school year)

Appendix E

Secondary School Teachers

1. Please describe your program and the type of student population you serve.
2. What is your school's mission and how is this mission statement implemented throughout your curriculum?
3. How is the school involved in students transitioning to adult programs? Do you have direct contact with their subsequent providers?
4. How does the school transition team decide what type of programs the student will seek to gain admission to?
5. How does a students skill level affect the type of program they are admitted to?
6. Are you aware of the admission criteria for the post-secondary programs for those with severe cognitive disabilities? If so, how does your program mesh with those criteria?
7. What types of skills does your program concentrate on so that students may gain access to varying adult programs?
8. At what age does the transition team begin speaking with adult day program personnel about possible student admission?
9. What methodologies and strategies does your program teach to assist the students in maximizing their post-secondary adult program choices?
10. What collaborative efforts exist between your school and the various agencies that are involved in students obtaining post-secondary program placement?

Appendix F

Communication “Quickie” Checklist

for Students with Significant Disabilities

- My signs:
-
- My words:
- When I’m hungry I let you know by:
- When I need to be changed or go to the bathroom I let you know by:
- When I want to talk or have company I let you know by:
- When I want to be left alone I let you know by:
- How to use my communication device:
    - How to turn on
    - How to navigate
    - How to turn off

Appendix G

Transition "Quickie" Checklist
for Students with Significant Disabilities

- Review Age Requirements for Adult Programs in the area you might be interested in (can my child enroll at 18, 19 or 20)

- Does my child exhibit any behaviors that may impact their ability to participate in adult programming (aggression, self-injurious, loud vocalizations etc.)

- Ask school to develop and work on goals to help improve these behaviors

- Communication - Develop a method for your child to convey to those who don't know your them what their wants, needs , likes and dislikes are (see "Quickie" communication checklist)

- Does my child display the etiquette, proper manners, politeness, eye to eye, shake a hand, skills that are important all thru life, if not ask the school to develop goals that help you child develop one or more of these skills

- Medicaid Waiver – Discuss frankly with your Regional Case manager, the funding sources utilized for adult programming in your area. You will want to ensure that you are allowing your child to participate in programs now that will help them gain access to future funding

- Explore how your area of residence affects the types of post-secondary programming available to your child

- Social Skills – if this is an area of need for your child, be sure the school develops transition goals to improve these skills

Appendix H

Carlo DeFlippo
(pseudonyms used throughout this document)
Person Centered Plan
Guardian: Peter DeFlippo
State ID: 000000
Implementation Date: 07/01/2012

Current Living Situation:

Carlo DeFlippo, who prefers to be called Carl, lives with his father, Peter DeFlippo, his stepmother Beth and his stepbrother Matt in a home in St. Louis Missouri. His parents are divorced and he has contact with his mother, who lives out of state, and his sister, though not as much as Carl would like. Beth's son Matt lives with them and they have become positive influences on each other as they spend more time together. Beth and Peter both work full time and it is important for them to have consistent, reliable staff to support Carl while they are working.
People that are important to Carl:

Peter – father
Susie- his mother
Beth – his stepmother
Maria – his sister
Yolanda – his stepsister
Matt – his stepbrother
Shanda Corin – his state case manager
Program Day Staff
Casey – Close Friend

What is important to Carl?

Being able to voice his want/needs and have those attended to respectively
Having Friends
Having adequate warning to coming changes in routine
Being as independent as possible
Being involved in decisions and activities that directly affect him

People Who Know Carl describe him as**:**
Handsome
Self-Advocate
Humorous
Pleasant disposition
Motivated
Hard working
Eager to please

Has a great memory
Able to tell you what day of the week any day would be
Clever

Carlo Likes:

Family
Movies
Structure & Consistency
Private time in his room
Sleeping in on weekends
Going to camp
Cookies and Cake
Doughnuts
Oldies Music
Gym
Playing tricks/Having "Inside Jokes"
Teasing
Laughing
Dressing nicely
Pleasing Dad
Going for Walks
Spending time with his sister Maria
Phone calls from Mom
Immediate responsiveness
Time Alone
Being Clean
Listening to the radio
Going places with Beth
Day Program
Leisure Camp
Playing softball
Parks
Going adventurous places
Shopping at the Mall
Jamie Lee Curtis
Michael J. Fox
Eating at Restaurants
Karaoke- "Hey There Delilah"
Using the switchboard
Praise Physical reinforcement
Deep pressure hugs when he is upset
Cooking Channel
Nintendo Wii system
Casinos
Making Friends

Carlo Dislikes:

Going to the Dentist
Gravy
Babies
Screaming
Sudden Noises
Having his schedule disrupted
Food that is too hot
Others coughing
Others clearing their throat
Not getting attention
Not having his question answered
Trying new things at first
Dad being in the basement
Not being independent
Rules
Mayonnaise
Being made to do things
Schedule changes especially scheduled activities that Carlo has been looking forward or that have been part of his routine for a long period of time

Routine:

Carlo attends the Day Program Monday through Friday from 8:30 to 2:30. Either his father or a respite care provider drops him off each morning. He arrives home via the transportation company and has a snack, spends time alone in his room, eats diner and watches Emeril. On Thursday, Carlo goes to baseball practice. He enjoys watching TV or movies with his stepbrother Matt. His parents are divorced and he has contact with his mother, who lives out of state and sister though not as much as Carlo would like. Beth's son Brandon lives with them and they have become a positive influence on each other as they spend more time together. Beth and Peter both work full time and it is important for them to have consistent, reliable staff to support Carlo while they are working.

Home:

Carlo's weekends vary. He makes plans for the weekend during the preceding week. He plays baseball on Saturday mornings. In the summer, Carlo attends Moon hill Camp. Every Sunday, the family has a family dinner at his home. Carlo has mentioned moving to a new home, but Peter believes that Carlo's resistance to change outweighs his desire to move. Peter has been researching necessary remodeling to accommodate Carlo as both he and his parent age.

While at Day Program:

Carlo has an electric chair that he has used to learn to maneuver independently. Carlo trains in the use of the chair utilizing an obstacle course to improve his maneuvering abilities. Carlo has been involved in volunteering at the Carmel child Development Center where he interacts with the children and assists with their activities.
Carlo is active in the planning of the day. He and the others in his group collaborate to plan a full day of work and fun that everyone can enjoy.
Carlo has been working on his manners while at the center and will continue to do so. He has become good at recognizing when he should not say something inappropriate. He will say "I shouldn't say that at program" or "it's not nice to…" indicate that the knows what proper behavior is and what is not
Carlo will contribute new ideas for activities around the community
Carlo will self-check his seatbelt and notify staff if it is not secured
Carlo will be supported Monday through Friday with On Site Day Habilitation Group in a ratio of 1:3 from 8:30 AM to 3:30 PM
Carlo will bring single dollar bills for his afternoon snack
While at program, staff will monitor Carol's liquid intake, more specifically water intake throughout the day. He will drink 8oz in the morning and8oz in the afternoon, for a total of 16oz for the day. This does not include liquids that are not water.
Carlo brings a water bottle each day to program to facilitate this goal. It can be found in the side of his backpack.

Hopes, Dreams, Wants:

Carlo wants to have an audience. He enjoys entertaining people and being entertained by people, so it is important for him to be surrounded by people who he finds entertaining and who have a good sense of humor. Carlo hopes to remain living with his family. Carlo hopes for his family to receive enough support for him to live with his family the rest of his life. Carlo dreams of learning to operate his electric chair to increase his independence.

Would Like to Try:

Carlo would like to try to have his own email so that he may communicate with his mother, sister and Casey. Casey is moving at the end of the summer and they are both anxious about keeping in touch. Carlo has expressed an interest in Tai Chi, a class offered at a nearby medical center that two other program participants attend.
Carlo enjoys sports and would like to develop that interest, more specifically attending Cardinal's games, visiting the racetrack going fishing or swimming. He has expressed a desire to write a play. He worked on the foundation of the play for a while, but has not worked on the development of the play for some time Carlo changes his mind often about whether he would like to continue this endeavor.

Fears, Concerns:

Carlo is afraid of falling over in his wheelchair; therefore, rocky terrain makes him nervous. In the event that smooth surfaces are not an option, staff should inform Carlo of the impending bumpiness to ease his anxiety.
Carlo's father, Peter, is concerned about Carlo maintaining the same quality of life after Mr. DeFlippo is no longer to directly support Carlo. Carlo must be in an environment where someone will not take advantage of him.

Mobility:

Carlo needs full support for mobility. He is currently training to maneuver to hi electric wheelchair more adeptly, but requires consistency with his practice so that he may retain his skills. He requires 1:1 support while operating his own wheelchair in the community. There is an accessible entrance through the garage into the home. The entrance to the hallway is wide enough to enable Carlo to have access to his bedroom. Staff can use the ceiling lift in the bedroom and avoid the need to manually lift him. An aluminum ramp system and roll shower has been installed, but Carlo uses a shower chair to enable staff and/or family to maneuver him from his room to the shower safely for bathing. Peter has been researching necessary remodeling to accommodate Carlo as both he and his parents age. His two slings were replaced on his lift to provide more support for lifting him. Carlo also needs two new slings due to the possibility of slipping during transfer. Peter is accepting bids for the two slings. Beth is researching the benefits of continued use of the shower chair versus a roll-in tub.

Transportation:

Carlo needs transportation with wheelchair access. Carlo should never be transported home before 3:15PM from the Day Program. Make sure his footrests are locked into place. He must sit up straight in his wheelchair or his legs or ankles will ache. Whenever Carlo uses his electric chair, staff should inform drivers that Carlo needs assistance when getting on and off the van and that it needs to be turned off when in transit. Carlo attends the Day Program Monday through Friday from 8:30-2:30PM. He is dropped off each morning by either his father or a respite care provider. He arrives home via his transportation service.
Medical/Health:

Carlo needs assistance with eating. He requires physical assistance. His food must be fed to him in bite size pieces. He drinks using a straw. If he becomes highly entertained while eating, he will laugh and may choke on his food if he continues to laugh with food in his mouth. Staff should remind Carlo to swallow before laughing too hard. Carlo needs nebulizer treatments when he is outside in hot weather due to the heat and humidity causing breathing difficulties. His nebulizer is sent to camp with him. He has not needed his nebulizer in the last three years, but remains a possibility. Indications that he needs his nebulizer are wheezing and struggling to breathe.
Medications: Carlo takes medications at home. He takes Ducolax, PRN , as decided by his father.

Important information regarding Carlo's Health:

- Monitor his pain. If he begins to experience pain for his hip, his doctor needs to be contacted. Carlo will state when he is in pain.
- The area on his bottom needs to be monitored to decrease excessive pressure from constantly sitting on that side. His wheelchair seating has been adjusted to allow the sore to heal, but monitoring is still important to prevent recurrence.
- Monitor his skin for jock itch and rash due to incontinence and wearing Depends. This is usually an issue twice a year.
- Carlo is frequently constipated. He needs roughage in his diet to make his bowels move. Carlo takes an over the counter suppository every three nights (Ducolax)
- Carlo's doctor said he might be allergic to the antibiotic, Ceclor.
- Carlo is not allergic to animals
- Carlo is awake during dental procedures. He usually has a high fever afterwards and needs antibiotics administers; cool bath, fla7up, and Tylenol. Due to Carlo's tendency to work himself up over dental appointments. Carlo does not advise Carlo until the night before.

Communication:

Carlo communicates verbally and has a wide vocabulary. He understands what is said to him and has an impeccable memory. When Carlo is upset, he will stiffen and sometimes verbalize his displeasure. He will also bite his finger, although this action has decreased over time and mostly happens at home. Carlo should be prompted when change is about to happen, giving him a choice and ask him if he would like to do the activity now or in ten minutes.

Self-Care:

Carlo requires assistance with all things related to his health and hygiene. He is able to verbalize when he is in pain. Carlo needs total assistance with bathing, dressing, wheelchair transfers and changing his depends. Carlo needs a shower every two days. Carlo is always supervised at home because he is unable to respond to emergencies or address his self-care needs. He needs 24 hour protective oversight, but does not need to be within the line of sight.

Legal:

Peter DeFlippo is Carlo's guardian. Carlo declined attendance to his planning meeting despite encouragement form program staff, social worker and step-mom.

Safety:

- Carlo's hip is out of socket. Therefore, it is important that staff ensure that his legs do not cross at the knees when he is in a horizontal position. If there is a

problem with Carlo's hip, indicators are bedsores and protrusion of bone on his bottom.

- Make sure Carl's cushion is properly inflated The support from the cushion is important both to Carlo's comfort and to his health as an improperly inflated cushion causes hip pain or sores
- Make sure Carlo is completely moved back in this chair. Throughout the day, staff should check for sliding and help him adjust if he has slid down in his chair. Carlo will state "I want to sit up" when he is uncomfortable and knows he has slid
- Carlo's chair should never be at0 degrees, every hour Carlo should be tilted to a different position
- Carlo uses his wheelchair for his mobility needs at all times. It is maintained and monitored for repairs.
- Carlo's heels are sensitive and need monitoring for skin breakdown due to pressure exerted to the back of the foot while in his wheelchair. He has a hell cup in one shoe and gel pad in the other that has solved the problem. His father monitors for further issues regarding his heels.
- Carlo uses an electric wheelchair at his day program. Staff monitors his usage of the chair. He needs enough room to maneuver safely. He has not mastered using his chair in small or tight spaces. He does not use his electric chair at home due to spatial conditions. Staff will create an obstacle course to assist Carlo in mastering the use of his chair.
- Monitor Carl's body temperature and breathing during extreme weather conditions
- Carlo does not perspire and always needs an air conditioner. He is heat sensitive
- Carlo's hip is out of joint, so there can be no pressure put on his feet or legs
- Carlo must wear sunscreen and a hat, located in his backpack, whenever he goes out into the community

In Order to Support Carlo, it is good to know:

- He must have an appropriate amount of support available for him to be as independent as possible
- There must be variety in his day
- He must have consistent attendant care staff that is properly trained
- Carlo must have an accessible bedroom
- Carlo keeps a notebook containing a brief summary of Carlo's daily activities and any additional information for Mr. DeFlippo

Family Needs:

The DeFlippo family is currently bids to install two slings to provide more support for lifting him and reduce the risk of slipping during transfer. Beth is researching the benefits of continued use of the shower chair versus a roll-in tub. An aluminum ramp system and roll shower have been installed, but Carlo uses a shower to enable staff and/or family to maneuver him from his room to the shower safely for bathing. Peter has been researching necessary remodeling to accommodate Carlo as both he and his parent age. The DeFlippo

family needs continued funding for Day Program, Respite and transportation to maintain Carl's current quality of life.
Respite:

Carlo receives respite care through the Regional Center, the hours of which vary based on CI program hours and the schedules of Mr. and Mrs. DeFlippo.

Outcomes:

Outcome #1: Carlo helps plan and participate in opportunities and meaningful activities

Action Steps:

- Carlo will help plan his itinerary with his group
- Carlo will help plan both volunteer and leisure activities in which he has interest
- Staff will collaborate with Carlo to plan these activities
- Carlo will explore new activities such as Tai Chi, Aqua Therapy and Bowling
- Carlo will continue with current interests such as volunteering at a Daycare and writing his play
- Carlo will complete an ongoing journal

Timeline: 07/01/2014-06/30/2015
Responsible Parties: Day Program Staff

Outcome #2: Carlo develops relationships and has appropriate conversations with his

peers and staff.

Action Steps:

- While in group, Carlo will have conversations and share his ideas with others in his group
- Staff will assist Carlo with developing various topics that he can draw upon to engage in conversation with others in his group
- Carlo will talk with peers using appropriate communication skills (no yelling, screaming or teasing etc.)
- Carlo will establish an email to maintain and enhance communication with his mother, sister and Casey
- Staff will assist Carlo in sending emails to his mother, sister and Casey

Timeline: 07/01/2015-006/30/2015
Responsible Parties:
Day Program Staff

Outcome #3: Carlo practices maneuvering his electric wheelchair to develop skill in tight

spaces

Action Steps:

- Mr. DeFlippo will maintain the functionality of the electric wheelchair for Carlo's use at program
- Carlo will practice maneuvering his chair once each week
- Staff will create obstacle courses for Carlo to practice maneuvering his wheelchair in tight spaces

Timeline: 07/01/2014-06/30/2015
Responsible Parties:
Day Program Staff

Outcome #4: Carlo communicates information about his day through a communication

book

- Mr. DeFlippo will provide a notebook for staff to record Carlo's daily activities
- Staff will record Carlo's daily activities in the notebook
- Any additional information about program will be put in the book

Timeline: 07/01/2014-06/30/2015
Responsible Parties:
Day Program Staff

Outcome #5: Carlo is healthy and safe.

Action Steps:

- Service Coordinator will request bid for two additional slings for ceiling lift to decrease risk of fall
- Service Coordinator will request bid for roll-out tub
- Carlo's wheelchair will never be at 0 degrees
- Staff will reposition Carlo's wheelchair every hour to ensure comfort and prevent sores
- Timeline: 07/01/2014-06/30/2015
- Responsible Parties:
- Day Program Staff

Appendix I

Sample Alternate Performance Indicators

Alternate interpretation of the Show-Me Standard: *Students will acquire essential receptive and expressive communication skills by:*
Alt CA-3: reading and/or attending to nonfiction works and informational material.
Sample Alternate Performance Indicators
(For a full list, refer to the Alternate Grade-Level Expectations for the content area)
WP4.1 Identify the most important parts of a short text
IL1.2 Identify purpose of resources
IL2.2 Identify key words to find information
IL3.1 Recognize important information
RD1.2 Understand print tells story by attending to and/or reading story
RD1.10 Match pictures to printed words to show printed words represent objects or pictures of objects
RD1.16 Understand punctuation has meaning
RD2.3 Discriminate final sounds of single-syllable words
RD3.1 Demonstrate letter/sound relationships (individual letters and letter clusters)
RD3.8 Use invented spelling to demonstrate understanding of some word sounds
RD3.13 Confirm reading of a word by looking at its parts
RD4.2 Read simple text (words/pictures/symbols/objects/actions) consisting of environmental print
RD5.1 Use base words (e.g., common roots, homophones, homographs)
RD5.6 Use context clues to learn new vocabulary
RD5.11 Use meaningful parts to determine word meaning
RP1.2 Preview text and/or pictures
RP1.7 Set a purpose for reading
RP2.1 Attend to the reading of the story and to the pictures
RP2.6 Visualize (e.g., What does something in the story or article look like?)
RP3.2 Question to clarify understanding: who, what, when, where, and why?
RP3.8 Draw conclusions (e.g., Why did something in the story happen?)
RP4.1 Identify similarities between text ideas and own experiences
RP4.6 Analyze the relationships between text ideas and the real world
RC1.1 Locate title
RC1.7 Identify parts of books
RC4.2 Match information in text (read to student as needed) with pictures or charts
RC4.6 Analyze text features in newspapers and magazines to clarify meaning
RC5.1 Match ideas in text with words/pictures/symbols/objects/actions
RC5.7 Identify simple cause and effect relationships
RC5.11 Make requests/choices in response to information gathered
RC6.2 Follow a simple pictorial or written direction (e.g., icons on a cake mix)

(MODESE, 2005, p. 20).

Vitae

Deborah DiRisio graduated from Lebanon High School in Lebanon, Indiana in 1976. In 1980, she graduated from The College of Mount St. Joseph, Cincinnati, Ohio with a Bachelor of Arts degree in Elementary and Special Education. During the following years, she was employed by St. Catharine of Sienna School, Cincinnati, as an elementary math and science teacher. She then embarked on a career in professional property management spanning over 12 years. She managed both commercial and residential properties in Connecticut, New York, and Chicago. In 1998, she returned to work as an educator, employed by Special School District, Town and Country, Missouri. In May of 2004, she received her Masters of Science Degree in Education Administration from Lindenwood University. Her anticipated graduation date for her Doctorate in Instructional Leadership is December, 2014. She worked as a teacher of the Multiply Handicapped for nine years and today works as a teacher of students with Learning Disabilities and Autism. She also currently serves as teacher of the Multiply Handicapped students who are a part of an after school program which services students who attend non-public schools.