


2010

Preparing a Student With a Disability and Their Family for Transition Into Adulthood

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PREPARING A STUDENT WITH A DISABILITY
AND THEIR FAMILY FOR TRANSITION INTO ADULTHOOD

A Thesis

Presented to

The Graduate Faculty

Central Washington University

In Partial Fulfillment

of the Requirements for the Degree

MEd. Master Teacher

by

Katherine Matwiczak-Weber

July 22, 2010

ABSTRACT

PREPARING A STUDENT WITH A DISABILITY AND THEIR FAMILY FOR TRANSITION INTO ADULTHOOD

by

Katherine Matwiczak-Weber

July 2010

As a student with a disability makes the transition from high school to adult life, together the student and the family are faced with decisions and challenges outside the support of the school system. There are certain time lines and criteria that need to be fulfilled in order to make the change successful as well guarantee the student's rights and entitlements both financially and vocationally from the federal government and other community based systems. Transition-focused educators have long advocated for a vision of post-school life for the young adult with a disability that includes community and social interactions in addition to supported employment and self-dependency. The purpose of this project was to learn more about community based as well as federal financial supports and responsibilities for the young adult with a disability who is unable to make this transition and life-impacting choices without additional support. The rationale is to use current information available as a springboard for discussions as well as future support for educators, families and others to further assist this special population with intellectual disabilities transition into a safe and successful social life of their community.

ACKNOWLEDGMENTS

The author would like to express sincere gratitude to the memory of her mother for life's lessons of self-determination, patience and humor. Her spiritual support, the value of family and a mother's love will be carried on to the author's children, who give her meaning and sustenance.

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BRIEF

CENTRAL WASHINGTON UNIVERSITY

Graduate Studies

Final Examination of

Katherine Matwiczak Weber

B.A., City University, Bellevue, WA

for the Degree of

Master of Education

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EDCS 598	Issues & Policies in Schools	3	S. Nourse	Summer, 2009
EDF 503	Philosophy of Education	3	S. Schmitz	Summer, 2009
EDSE 512	Ed. Rights-Individual Rights	3	D. Fennerty	Fall, 2009
EDF 510	Research and Development	4	D. Shorr	Fall, 2009
EDCS 513	Creative Teaching	3	S. Nourse	Winter, 2010
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CHAPTER I

INTRODUCTION

Background

When one thinks of the word transition in the broad sense certain commonalities seem to appear. For example in literacy, transition is used to describe a sentence or phrase to connect a thought. In the field of sports, transition means a change in the process from defensive to offensive plays. Another example, in music the word transition is defined as movement from one key note to another. However, in education transition is described as the connection between different times within a student's educational years, for example the changes a student makes from elementary to middle school or the movement into high school. Nonetheless, one of the most important transitions a student undergoes in their schooling years is the passage from high school to adult responsibilities and full community involvement. Metaphorically, transition is the bridge between the security and structure offered by the public school system to the opportunities and risks of adulthood.

Most children learn about adult life through observation and participation in family, social and even school-related events and experiences (Korpi, 2008). During these formative years the student absorbs this information and structures his / her own understanding of social expectations as well as their role in society. However, a student with disabilities may be at a significant disadvantage in this process. For example, a student's cognitive disability may limit the ability to interpret or acquire crucial information as successfully as age appropriate peers. The Department of Social and Health Services (2010) for the state of Washington defines a "developmentally delayed disability results in substantial limitations to an individuals' adaptive functioning." This lack of ability to perform adequately in meeting social expectations such as

career choices, independency and self-reliance can be considered quite different from critical life skills such as self-advocacy, communication and problem solving. These concepts are difficult to consider for the developmentally delayed student. It is for that reason generally the parent of the student choose to limit the student's social experiences, which are meant to protect him when in actuality this protection will curb the child's knowledge and understanding of the world in which he lives (Korpi, 2008).

Typical teenagers transitioning into high school frequently have conversations with each other and their parents regarding their social and academic goals and aspirations after leaving high school. This discussion has been going on for decades. On the other hand, this dialogue seldom involves young adults with a developmental disability when it comes to the future planning. Parents of a student with a disability and the student with themselves still continue to have dreams of a lifetime- being self-sufficient, having a personal career and a group of social friends while living a life of independency. This journey for most adolescents and their family is full of joys, challenges and career paths from which to choose. At the same time, as severe levels of conflict and stress may not be inevitable, the transition to young adult is nonetheless considered a challenging period of family adjustment for which there is little preparation (Spring B., & Rosen, K., 2002). It could be even more difficult for one to imagine this transition for the disabled teenager who has been enabled and protected throughout their younger years to a time when independence, self-advocacy and self-reliance are expected. This change is stressful for any parent yet, "it has been demonstrated that the stress levels of parents of children with disabilities are typically higher than those of parents on non-disabled children" (Lessenberry & Rehfeldt, 2004).

Addressing the many challenges associated with transition for the disabled student will require a much larger support system than the typical teenager and advocacy for the student and the family as well. Successful transition planning is a lifelong process in which the student with a disability, the family, and the community come together to develop and act upon a plan that will lead to a successful adult life. For this reason, transition planning has become a significant part of Federal laws protecting the rights of the disabled. In 1975 Congress enacted into public law, the Education for All Handicapped Children Act (EAHCA) referred to as Public Law 94-142. The intention of this law was that all handicapped children from age 3 through 21 would have a right to a free appropriate public education (FAPE) in the least restrictive environment (LRE) and to establish a process by which each state and local educational agencies would be held accountable for providing educational services for all handicapped children (U.S. Department of Education, Office of Special Education and Rehabilitation n.d.). Furthermore, the educational services provided by individual states had to be in compliance with requirements of the EAHCA.

In 1990, amendments to P.L. 94-142 changed the name of the Act to the Individuals with Disabilities Education Act (IDEA). This new legislation redefined some fundamental vocabulary and terminology. For example, the term “handicapped” was changed to “disability.” The purpose for this change in expression was to utilize “people first language.” People first language would use the term “student with a disability” rather than “disabled student” (Yell, 2006). A second crucial decision was that a student diagnosed with autism or traumatic brain injury was identified as a distinct disability entitled to the law’s benefits. Finally, the 1990 amendment also stipulated that an individual education plan (IEP) for each student with a disability contains a statement of needed transition services for the student by the time they reach the age of 16. This statement of

transition services are those educational and community services that will help the student prepare for life after high school (Yell, 2006).

Though significant advances within special education legislation had taken fifteen years to be addressed from the initial 1975 law, Congress felt that little focus was spent on translating research into practice and too much emphasis was being placed on paperwork and legal requirements (Yell, 2006). So once again the law was adjusted in 1997. This alteration strengthened the role of the parent in the student's educational planning, encouraged teachers and parents to resolve differences with a variety of options, addressed language concerning the discipline of a student with a disability and lastly restructured the content and members of the official IEP.

This (IEP) was defined in IDEA as "a written statement for a child with a disability that is developed, reviewed, and revised in accordance with requirements of the law" (Wrights Law, 2010). The IEP is created as a planning process which school personnel and parents work together to develop a map of special education, related services (i.e. speech / language, technology) and a transition component in a written document that will result in a meaningful benefit for the student. Members required in the development of an IEP for a student at age 16 include the student's parent or guardian, a special education teacher, a general education teacher, a district representative (who is qualified to supervise the provisions of special education, knowledgeable of general education curriculum and understands the availability of resources in the school), a person who can interpret the instructional implications of the student's specific evaluation results (i.e. school psychologist) and most importantly, the student. Discretionary participants would be those that provide related services such as a speech and language therapist,

occupational therapist, a representative from the outside agency that will offer transition services, and other persons at the judgment of the parent or the school (Yell, 2006). Components within the written document of the IEP describe how the student learns, how the student best demonstrates the learning, and how teachers along with other service providers need to ensure the progress of the student. Though IDEA requires a minimum of eight specific components be present in an IEP, individual states have the freedom to require additional information.

Following is a brief list of what IDEA requires within the IEP according to the textbook, *The Law and Special Education*, by Mitchell Yell (2006):

- The present levels of performance, both academically and functionally, of the student with a disability
- Measurable annual goals, academically and functionally including short term objectives for the student who takes an alternative assessment
- A statement of progress the student is making in achieving the goals and when the progress will be reported to the parent
- Special Education services and other related services (Speech/Language, Transitional, etc.) program modifications and or supports for school personnel
- An explanation of the extent to which the student will or will not be in the classroom with non-disabled peers
- Accommodations that will be provided to the student with a disability to enable them to progress appropriately in general education classrooms, district and state-wide assessments or an explanation as to why the student will not be assessed
- A starting date and ending date of the services being offered and a statement with the frequency, location and duration of each service
- A statement that the Individual Education team determined appropriate prior to the student turning 16 years old of needed transition services and post-secondary goals relating to education, employment, job training, and when/where appropriate independent living skills

While the principle behind IDEA is to allow individual states freedom to submit a plan according to their personal mandates that meet or exceed the federal requirements for special education, there are specific elements for each student that must be provided such as FAPE, LRE, the identification and evaluation process and what is commonly known as Procedural Safeguards. This booklet explains the heart of the IDEA principal and is designed to protect the interests of the student with a disability. A major safeguard within this statute is advising the parent and student to the transferring of rights from the parent to the individual student not later than one year before the student reaches the age of majority (National Dissemination Center for Children with Disabilities n.d.).

Depending upon individual states within the United States, the age of majority is considered the age at which a young adult is able to retain full and legal responsibility for themselves. For example, a student could choose to drop out of school at eighteen, thus becoming ineligible for any transition services they are entitled to until the age of twenty-one. In a state such as Washington that has elected to transfer educational decision making rights at the age of majority (18), a student becomes responsible for his / her educational program. The student is the primary decision maker, not the parent for making such choices as a change in placement or denying special education services. These types of decisions, if uninformed, could ultimately affect the quality of life for the student after high school. Therefore, parents need to be equal partners in the transitional planning of their child with a disability.

Parents are critical members of the IEP team that guides the child with a disability through every stage of the educational process. In order to assure that their student with a disability receives an appropriate public education in the least restrictive environment, parents

need to be aware of the laws that ensure equal opportunities and govern special education (National Dissemination Center for Children with Disabilities, n.d.). Procedural Safeguards is a written document that explains these rights; it is the check and balances of the IDEA system. Informed parents who are aware of the legal rights and services are empowered to be involved and monitor their child's ongoing progress through school (Austin, 2000). Many parents and students who are not properly informed have missed out on numerous quality services to which they are entitled.

It is with this misinformed premise that the special education teacher within the secondary environment has the responsibility to be educated with current mandates in the district, the state and federal guidelines. The special education teacher should be the informative link between community services, federal funding and vocational programs that the disabled student is entitled to. It is imperative for teachers to support students' career development (Levinson & Palmer, 2005).

As stated earlier, at an annual IEP meeting for the high school student with a disability, it is mandatory that transition is addressed with an explanation of a course of study intended for the student who is 16 years of age (Office of Superintendent of Public Instruction, Washington State, n.d.). Included within this course of study are goals for post-secondary employment, independent living, and continued education. Following these guidelines for the developmentally disabled student, a focus is put on independent living and supported work environments. Unfortunately, it is common practice to simply inform parents and hand them a stack of pamphlets with resources to read on their own and fit together a puzzle that starts the necessary steps for transition. Since the student's entry into the school system, parents have learned to negotiate various aspects of

the child's education through the IEP (Korpi, 2008). However, parents who have learned to navigate through the system and be effective advocates for their student will find the processes, philosophies and funding mechanisms are completely different in the world of adult programs and services (Korpi, 2008). Unlike special education services, there is no law that mandates adult services or programs, consequently the support from the school system fades away, leaving the parents with challenging decisions and complicated choices that are not prioritized. Schools must give more focus, in both time and resources, to preparing non-college track students for work or post-secondary training (Levinson & Palmer, 2005)

Project Purpose

The purpose of this project was to develop a handbook that will inform teachers, the student, the parent and other members of an IEP team of the rights and entitlements for the disabled student as they transition out of high school into the community as a young adult. It is the intention of the author to collect relevant facts, competency requirements, and combine this information into a simplified handbook that is easy to read and understand, and includes time lines and resources. Informing the participants will allow them to make quality decisions concerning life-altering choices and transitions that are important for the student. Steve Riggio, a parent of a young adult with special needs, was quoted by Rubin and Aduroja (2005) in the Chicago Tribune as saying that "the availability of programs after high school was like going from a cruise ship to a dinghy." School district personnel may genuinely need additional time to navigate the school system, as well as the other resources, effectively and to identify other avenues of support, particularly for a process they have never provided before (Korpi, 2008).

Project Limitations

The scope of this project is limited to the secondary school population of developmentally disabled students within Washington State. Specifically the student, parent and team members involved within the annual IEP addressing the transition of the student into post-secondary services and adult programs.

Definition of Terms

Accommodations: (National Dissemination Center for Children with Disabilities. Retrieved July 5, 2010, from www.nichcy.com)

Define a description or alterations of services that allow a disabled student to complete tasks, academic or non-academic as non-disabled students. Example: allowing the student with a writing disability to orally answer questions or use a word processor.

Age of Majority: (Office of Superintendent of Public Instruction Washington State. Retrieved July 5, 2010, from, www.k12.wa.us)

Regardless of disabilities, students are considered adults and are competent to make their own decisions at age 18, unless there is a court appointed guardian. Example: students have the right to make their own educational, medical decisions and sign their own consent forms.

Cognitive: (Merriam-Webster Dictionary. Retrieved July 10, 2010, from www.merriam-webster.com)

A term defining the process of acquiring intelligence and increasingly advanced thought and problem solving ability.

Education for All Handicapped Children's Act (EAHC): (Wrightslaw Special Education Law and Advocacy. Retrieved July 10, 2010, from www.wrightslaw.com)

A law passed in 1975 by federal legislation holding state and local educational agencies accountable while offering opportunities in education for handicapped children and adults through specific requirements of a free appropriate education, in the least restrictive environment.

Free, appropriate, public education (FAPE): (Office of Superintendent of Public Instruction, Washington State. Retrieved July 10, 2010, from www.k12.wa.us/specialed/).

When determined eligible the special education student is entitled to an appropriate educational / vocational program that they will benefit from, not the best or most probable available.

Functional: (Office of Superintendent of Public Instruction, Washington State. Retrieved July 10, 2010, from www.k12.wa.us/specialed/)

Defined as every day living skills or tasks that contribute to the success of an individual to adulthood, skills may be grouped into different categories such as self-care, recreational / leisure, communication / social, vocational that are important for community participation.

Individual with Disability Act (IDEA): (Office of Superintendent of Public Instruction, Washington State. Retrieved July 5, 2010, from www.k12.wa.us/specialed/).

Refers to federal law ensuring services for a child with a disability. IDEA governs how states and public agencies provide services and are held accountable for students from early childhood until age 21.

Individualized Education Act (IEP): (Office of Superintendent of Public Instruction, Washington State. Retrieved July 3, 2010, from www.k12.wa.us/special/).

A mandated written document of the Individuals with Disability Act (IDEA) that requires school districts to develop a unique educational program for a student who meets federal and state requirements of a disability. Refers to a team effort (student, parent, school district, discretionary service members, teachers) collaboratively creating the document to service the student in the most appropriate means.

Least Restrictive Environment (LRE): (Office of Superintendent of Public Instruction, Washington State. Retrieved July 10, 2010, from www.k12.wa.us/specialed/)

Refers to a student with a disability having opportunities to be educated with non-disabled students, ensuring that education for all can be achieved and benefited.

Modification: (Office of Public Instruction, Washington State. Retrieved July 4, 2010, from www.k12.wa.us/specialed/).

Refers to a change in what is being taught or the expected learning of the student with a disability. Example: modifying an assignment, making the content easier for the disabled student to understand.

CHAPTER II

REVIEW OF RELATED LITERATURE

Two of the most critical periods in the education of the child with special needs are during early intervention (birth to three years of age) and when they are preparing to transition out of high school (Korpi, 2009). These two periods steer the beginning of the educational years and the ending, when the student is transitioning from high school to independent adulthood. Many parents develop strong advocacy skills in the beginning of the instructive years in order to obtain educational services that best meet the needs of their child with a disability. As the child moves through the system parents begin to relax with the standardization of the educational arrangement as each year progresses. Yet, the time passes quickly and suddenly the parents find themselves in un-chartered waters and the support of the classroom environment for twelve years is about to diminish. When the student reaches the end of the education period parent advocacy is still vital. The transition can be more efficient and successful for the young adult with a disability when the change occurs during the parents' lifetime and when the parents are still actively involved in the decision making (Morgan, 2008). Experts such as Jeff M. McNeff M.D., director of the Center for Children with Special Needs at Children's Hospital and Regional Medical Center in Seattle, say parents with a student with special needs face all the typical issues parents must confront in preparing teens for the transition to adulthood, but their preparation takes more foresight, time and effort (Gensheimer, 2005). Research studies indicate parenting children with disabilities increases stress in the areas of everyday management and concerns about the future of children when the parents are no longer able to care them.

According to The President's Committee for People with Intellectual Disabilities (PCPID) of 2003 it is estimated there are seven to eight million Americans of all ages who experience mental retardation or intellectual disabilities. Intellectual disabilities and mental retardation were considered synonyms through the amendment of Americans with Disabilities Act of 2003. Intellectual disabilities affect about one in ten families in the USA (U.S. Department of Health and Human Services, Administration for Children and Families n.d.). It is for this reason that parents of a child with a disability need to be continuously involved and informed by the special education school support team throughout the educational years as well as post-secondary. The evidence is clear and consistent that when schools and families work together, student learning and outcomes improve (Henderson, 2010).

A common misconception of the school system about parents is that they have learned to rely on the educational structure for support or are experiencing too much stress to acknowledge the importance of transition as the child moves into adulthood. Parents of a child with a disability experience a disproportionately greater level of stress relating to their child than did those of a child without disabilities (Dyson, 1997). The parents' stresses have a relationship with aspects concerning family functioning as well as social interactions that lack external support. Research of Richard Hastings in May of 2004 emphasized the importance of multiple measures of social support. Evidence suggests that standard service models such as social care management, support teams in education as well as medical, most likely help to reduce parental stress (Hastings, 2004).

Another misconception about parents is that they do not care. This mistaken belief suggests parents are too busy to realize specific time factors and responsibilities as the

student matures. In actuality, most parents care a great deal and would like to support each other as well as the professional efforts, but they need some leadership to guide them. Parents of a disabled child indicated in a study by Milan Wang in 2004 that the parent would have to undertake less advocacy actions if professionals engaged in partnership with families to help obtain quality services for the child. Teachers and school personnel must continually examine the preconceptions about parents and recognize that new ways must be discovered to include parents in the child's education (Grossman, 1999). This partnership can begin by showing parents the members of the support teams such as social, educational and medical value their disabled child. It is a trust building event that takes time and patience.

These roles of families, schools and support teams in the development of the child or youth with an intellectual disability can be very complex. Family- related risk factors such as the lack of community support, uninformed decisions, and lack of direction for information available to parents play an important part in decision making factors for the disabled child (Cogan, 2004). Families have the potential to be the greatest source of positive influence and support for the youth in the transition out of the educational system into adulthood. Skills parents need to possess besides advocacy include understanding their child's disability, knowing how to obtain resources and recognize their rights as supported by research (Wang, 2004). For families or parents to be active partners with the educational system in addressing these issues, they must be informed of the rights and responsibilities to which they are entitled to within Federal government directives. The Office of Special Education and Rehabilitation Services offers their mission statement, "To provide leadership to achieve full integration and participation of people with

disabilities by ensuring equal opportunities and access to excellence in education, employment and community living.” (U.S. Department of Education n.d.). These opportunities that are presented for leisure times as well as employment offer avenues that provide meaningful use of time, gives structure to daily activities and builds personal confidence for the young disabled adult.

Parents have likely learned new ideas for self-support independently from a variety of sources such as magazines, books, the Internet, conferences, and possibly the most useful, other parents. Throughout their experiences, parents are urged to communicate and be actively involved with professionals who work closely with disabled children. Children’s medical and / or educational teams are able to assist parents with current research-based information and options. It is the extension of the IEP team concept that began during the educational years for the disabled student now as they move into adulthood that the support and information gradually transition to the local community, state, and federal agencies.

The education of all children, whether disabled or not, must prepare them for the future and participation in society. Parents, educators and other support members must work together to create and implement new possibilities that will be relevant to the new reality of the student with a disability’s passage into adulthood. This requires a break with the traditional thinking of the team to shift the focus of their interactions from *dis-*ability to ability of the student. This change is essential for successful transition of the student into the community (Korpi, 2008). The 1990 changes to the Individual with Disabilities Act (IDEA) demonstrated Congress’s recognition that special education should make a difference in the lives of a student with a disability even after their school

years. The underlying theory of IDEA is that the student with a disability will move forward into adult life, living a productive and independent existence with individual capabilities. This speculation challenges the consistency and worries regarding the child's security and safety becoming key issues for parents during this time (Austin, 2000). Schools need to re-examine their support role given to the parents of a disabled youth in the transition program. The quest remains to develop new programs or avenues of communication that encourage the participation of parents, provide them with support and acknowledge they are invaluable members in the transitional intervention of the child.

It is with this thought in mind that IDEA mandated during the transition process the school system will co-ordinate with social agencies to arrange for the provisions of whatever services are determined by the IEP team to be appropriate for the student's individual needs. For example, schools will have to interact with the Department of Social and Health Services (including Department of Vocational Rehabilitation and Department of Developmental Disabilities) and other agencies that are responsible for coordinating transitional / adult services for the disabled student. Therefore, it is important while under the provision of IDEA the student and parent plan accordingly, assure community services are in place, and responsibilities / rights are understood. The following topics provide the parent and student information and sources that will enable them to effectively advocate for future planning and opportunities.

Legal Issues

Just as it is important for a typical teenager transitioning to adulthood, adolescents with developmental disabilities have certain responsibilities they are required to fulfill to the best of their ability. It is essential that the student have the legal documents that will be needed for them to participate in the activities of adult life, including obtaining employment (Korpi, 2008). It is necessary all legal documents and issues are addressed and kept current to protect the rights of the student before and after they become a legal adult. Examples would be an original birth certificate and social security card that are kept in a secure place. If the student is lacking a social security card this is a time to apply for one. Also vital at this time is for every young adult, disabled or not, to have a state issued identification card such as a driver's license or individual state identification card. It is important for the disabled young adult to have the legal documents needed to participate in everyday activities such as getting a job, traveling, or even cashing personal checks. Washington State currently requires two primary documents for those who are under the age of eighteen to obtain an official identification card. A certified birth certificate and an affidavit of the custodial parent or legal guardian are required (Washington State Department of Licensing n.d.). An original birth certificate and social security card that are typically kept in a safe place cannot be used daily. This would constitute having a non-driver pictured state identification card being accepted for the young disabled adult as a legal identification to carry when needed for proof of residency.

Guardianship

Though guardianship is an intense decision with serious implications both for and about the student identified as having a developmental disability, the concept of

guardianship has received little emphasis in the literature of special education (Payne, & Stilington, 2008). IDEA directs that at least one year prior to reaching the age of majority, both parents as well as the student be notified of the shifting of responsibilities. All parties must understand all rights recognized by parents will be transferred to the student. In a study by Turnbull and Turnbull (2001), it is suggested that an individual with developmental disabilities likely will require ongoing support such as social, financial or decision making from others to experience a quality life. The Council of Exceptional Children's Division on Mental Retardation or Developmental Disabilities cited their concerns that the age of majority required by IDEA may "lead to a circumstance where parents and family members will feel compelled to obtain guardianship or other legal decision-making status over the son or daughter when they might not otherwise do so." (Lindsey, Wehmeyer, & Martin, 2001) This legal arrangement occurs when an individual, the petitioner, requests that a court appoint a guardian to have the authority to make decisions for another when it is documented the individual is not capable of such independence (Perkins, M, Law Office n.d.).

Washington state transfers rights to students at the age of eighteen (Revised Code of Washington 26.28.010). A student is granted such liberties as the right to vote, to marry, to consent to medical treatments, and / or sign contracts. It is the developmentally disabled student that lacks the cognitive ability to recognize these decisions, acknowledge options or even distinguish long term consequences of their decisions. For this student, guardianship or some form of formal representation by an advocate is appropriate. The decision regarding guardianship must be considered by the IEP team members but most importantly the parents. It is pertinent for instructional and support agency members to

be aware of the vast alternatives to and options within the guardianship process (Payne, & Stilington, 2008). Education concerning this important matter could be presented in such forms as a Transitions Topics Night sponsored by schools in collaboration with community service providers and members of the judicial system.

Selective Service Registration

All young men are required to register for Selective Service, this must happen within thirty days of their eighteenth birthday. If they are between the ages of eighteen through twenty-five and living in the United States, it is the law that they register regardless of disability (Selective Service System n.d.). If a draft were to be instituted, the young men's documented disability could / would prevent him from serving in the military (Selective Service System).

Voters Registration

A disabled young adult may need assistance when exercising the right to vote. As citizens of the United States, they are eligible to vote in all elections once they turn eighteen years of age. Exercising this right to vote is an opportunity in which family and community members can encourage and assist with the self-advocacy of the young adults with disabilities.

Under Washington state law, only a state court may declare a person mentally incompetent and unable to exercise the right to vote. These specific decisions are made on a case-by-case basis by a Superior Court Judge. It is not an assumption that because developmentally delayed adults are protected under guardianship due to cognitive or mental capacity they are ineligible to vote (Washington Secretary of State n.d.).

Financial Support

Developmentally disabled young adults have aspirations and expectations for their futures and employment very similar to those of their non-disabled peers. Due to their intellectual disabilities their limitations to support themselves independently vary significantly. Individuals within this category will need financial support from family, financial planning agencies as well as federal assistance. Public financial support for the intellectually disabled in the United States grew from 2.3 billion in 1955 to 82.6 billion in 2004 and the federal government emerged during this period as the principle provider of such financial support (Braddock, 2007).

Parent groups such as the Association of Retarded Citizens (Arc) and professional groups such as the American Association on Mental Retardation and Council for Exceptional Children advocate quite extensively for advancements in special education, community services and institutional reform. Federal Medicaid funding and other state as well as community services have been brought forth with the growing advocacy of parents, educators and other professionals such as legal practices. Though these advisory groups have definitely brought awareness about the necessity of financial support, this reflection offers a positive implication to the responsiveness of the U.S. government. It is interesting how much still remains questionable and undone for this population. Family support programs receive only a small fraction of the extensive funding available in the field today. Inequitable distributions to states, communities, families and individuals are considered through studies (Braddock, 2007).

A study by Braddock (2007) found that “in 1978, federal financial commitments first surpassed state spending – just seven years after Congress authorized the

Intermediate Care Facility / Mental Retardation program (ICF/MR) an amendment to Medicaid and three years after the enhancement of the federal role in education through public law 94-142.” The rapid growth of students identified with developmental disabilities plus other categories such as autism and brain injuries since the law was enacted in 1975 significantly affected federal funding and the relationships between state and federal agencies in governing financial distributions. U.S. Department of Education reported in 2004 those with developmental delays claimed an increase in numbers from none reported in 1995 to 304,975 students reported in 2004. Given the overall growth within the educational system, assistance for students transitioning onto adulthood is just as important as when they were supported by their parents, an IEP, and the school system.

The Department of Developmental Disabilities (DDD) located in each state is the primary governmental support agency and is responsible for providing services for people with significant cognitive disabilities. Determination of specific eligibility is based upon intelligence testing and / or adaptive life skills scales. The majority of these tests are done by the school psychologist before the students’ aging out of the school system, or the parents have the option of having a private professional conduct the assessments. The results of these tests will allow the proper procedures to occur so as to register each individual student properly.

The Department of Vocational Rehabilitation (DVR) service is a federal and state sponsored program that works in partnership with the community and local businesses to develop employment training and opportunities for persons with disabilities (Department of Social and Health Services n.d.). The eventual goal for most post-secondary students,

whether they are leaving a special education program or a four-year college, is eventually to find a job. As a division of DSHS, DVR offers programs that are designed specifically for the individual needs and disability of each student. There are opportunities that are available in supported work environments that offer reasonable accommodations that the disabled adult is entitled to under Americans with Disability Act, but in order to seek protection under the amendment the worker / student must reveal the disability to the employer. The DDD assists individuals and their families, helping them to obtain services and support based on individual preferences, capabilities, and needs, which promote everyday activities, routines, and relationships common to most citizens (U.S. Department of Social and Health Services n.d.). Programs through this agency include but are not limited to alternate living arrangement, community protection services, companion homes, dental services, employment and day care, group homes and community based services. Eligibility is determined by the Washington State definition of a developmental disability (Washington State Department of Social and Health Services n.d.). The federally funded program also has a health insurance program for low-income families who cannot otherwise afford the costs. Adults with disabilities, who are unable to support themselves fully, also fall under this protection (Washington State Department of Social and Health Services n.d.). Though most family health plans stop when the young adult leaves school or after 18 years of age. If the young adult is not a full-time student, parents need to be advised to contact their individual health insurance companies. Some health care provision plans continue coverage for adults with a documented disability.

The Social Security and Supplemental Income disability programs are the largest of several federal programs that provide assistance to people with disabilities. The Social Security program makes monthly payments to people with low-income and limited resource to allow them to work and support themselves. The amount of money that the disabled young adult receives monthly depends upon the state in which they reside and the income / resource of the family members living in their household. Social Security has certain criteria that must be met by young adults to be considered disabled. For example, students must not be earning more than \$1000.00 a month in 2010 and this amount will change yearly according to economic structure. To be considered, “students must have a physical or mental condition or a combination of conditions that have severe functional limitations and the condition must have lasted or be expected to last more than twelve months” (U.S. Department of Social Security Administration n.d.).

Disabled young adults have lower or no incomes to support themselves yet have health insurance responsibilities higher than those of the general public. Therefore, their financial future and well-being can be susceptible to defenselessness due to lack of ability to take care of themselves. It is important to note the majority of services for the disabled are dependent upon the availability of funding through government support, consequently policy needs to continue to pay extra attention to financial support of the chronically ill and disabled, enabling this population to have opportunities for a quality and productive life within society.

Need for Significant Adult Support

In order for a successful transition from school to adult services to take place one must develop a strong component that allows close contact between team members of the

support team concerned about the well-being of students with disabilities. A student with a disability needs a team who can encourage, advocate, and research, and most importantly be aware of all the services available within the immediate community as well as state / federal programs.

It is a mission of transition- focused educators to advocate for a vision of post-school life for their students with developmental disabilities. The support services include preferred community and social activities in addition to employment and continuing lifetime support and stability. Social and community outcomes are critical to young adults' quality of life, yet the second National Longitudinal Transition Study (2009) found that students with disabilities are less likely to participate in community activities after leaving school. Youth with developmental disabilities who have exited the public school system often experience isolation and limited social interactions due to lack of interactions with peers. Next to the family, the school is generally considered the most important influence on students' lives, with students spending a majority of the formative years within this community. In this environment students spend more than one-third of their lives learning important lifetime skills such as trust, expecting to be cared for by people other than immediate family, while taking on the job of trying to learn. Next to home, school team members put forth the greatest influence on how students see themselves and their abilities, not their disabilities.

Educators commonly believe that the maximum success of students with disabilities begins with the team working together to achieve goals that are in the best interest of students. The expectations are consistent when it comes to information and support on both sides. As life-long learners the educators' responsibility is to keep up to

date with support services available within the immediate community, informing the parents, and involving the student to be a self-directed learner willing to take active participation in their transition into adulthood.

A study conducted by Eisenman (2009) reported that families and young disabled adults were satisfied with current community and social situations offered. Yet, as noted in other studies, families may lack knowledge and community resources as they move from the school system into more limited arena of adult services (Aveno, 1987). Research emphasizes the significance of consistent assistance including multiple measures of social support; need to make the transition of school services to adulthood successful. Activities and services must be coordinated with each other and the process must focus on results that address functionality and quality of life for the individual disabled adult. Working together in a collaborative effort, the professionals, the parents and the student will determine what services need to be available, when they need to be in place. Planning ahead for each of these areas can greatly assist in the preparing for life after high school. Korpi (2008) suggests that “even parents who have learned to navigate the special education system and be effective advocates for the younger children will find that the processes, philosophies, and funding mechanisms are completely different in the world of adult programs and services, as well as post-secondary education and employment.”

The complexity of this period in time is that parents have a fine line that needs to be observed. They want to advocate as much as they can for the well-being of their child yet the young adult has a need to be actively involved within the transition process to the extent that they are capable of understanding. The roles of the special education teacher as well as other personnel all play a key role in the transition of the children with

developmental disabilities. In the past educators have specifically focused on academic instruction. However since the enactment of the new amendments of IDEA the education has expanded to factors important for adult living. During the last couple of years of high school, special education training specifically works on goals and objectives for the young adult to self-advocate and gain independence. The student is taught social safety and skills that will allow him/her to reach the highest level of individual independence that they are capable of. Nonetheless, this is where the dilemma arises when the parents must learn to balance their dreams and expectations with the wishes of the young adult. Parents need tools and information that will allow them to include the young adult in the important decision making. The parents need to understand the child's individual disability, their learning styles, limits of their functional capability, cognitive awareness and then be able to challenge the child to act upon his/her fullest potential. Experts agree that the most important thing parents can do is to let go of their child and let them experience success as well as failure on their own. "No matter how complex the special need is, children will be striving for a state of independence. They want just like all adolescents want – independence," reports Dr. Jeff Neff director of the Center for Children with Special Needs Children's Hospital and Regional Medical Center in Seattle (Gensheimer, 2005)

Providing services and programs to help individuals with an intellectual disability has led to a new understanding of the disability. Professionals are able to identify strengths and abilities while not focusing on the disability itself. Listening to student and families' ideas for the future is critical in the team members' individual roles. The team will be able to determine how much support is needed at home, in school, post-secondary

and community as well.. Developing creative ways for the students to communicate their preferences and interest is fairly new to the school system. This new approach gives a realistic picture for an individual child with disabilities, it also gives the realization that this can change as the student grows, learns and adapts to the new social environment.

Building bridges and developing connections between school, community agencies, families and professionals is the most important component in successful transition planning. Each individual on the team has a significant part in the future of a child with a disability, it is a matter of relaying information to one another, communicating needs and, most importantly supporting in the success of individual student's passage into a safe and secure adulthood. While this can be challenging, families can find encouragement in the words of Dr. Neff of Seattle Children's Hospital, "In over 40 years of pediatric practice, I am just overwhelmed with awe at the strength, resilience and insights of families with special needs." (Gensheimer, 2005).

While a variety of information about students / people with special needs seems to focus on a certain type of disability, parents and support teams should discount the specific disability label and continue to review topics or information relating to the individual student. In the course of examining the issues, the team will discover much of the information is appropriate to people with a wide range of disabilities. For example, a text offering information on social skills for a student with autism would still be useful to the student, parent, and teacher of one with many other types of a disability such as a developmental disability.

The quality of information and its intricacy can be overwhelming for everyone on the individual students' support team to understand. But as the team works together

determining relevance to the individual student, quality based decisions can be made that will assist the young adult to become a productive member of society. Guiding the teenager with a disability through the transition from school to adult life will be a positive and rewarding experience with effective communication and knowledgeable advocates working together and sharing the responsibility.

CHAPTER III PROCEDURES

While there are many research models available that provide information with specific details and longitudinal studies that quantify as well as qualify the categorical aspects of a study, the author chose a historical approach. This research technique allowed the author to review data and articles written in the past, draw conclusions that affect studies on the present as well as the future. Although the author had some understanding of the area being explored, it seemed invalid to simply rely on existing knowledge. The purpose of the author's research was to use a logical approach to be an effective communicator with the final outcome of producing a quality product. This artifact will reflect originality, using a variety of sources to be authentically planned and developed. It is the author's personal experience through transition IEP's and attempts to inform parents of the developmental disabled students, it is apparent that current information was lacking and that it could be delivered in a more organized manner. Therefore a need for an informational booklet was deemed a useful tool for transitional students as well as their parents.

Criteria for Research

Before beginning the research the author needed to be clear of the outcome intended; to produce a handbook that parents and special need students can read and easily follow concerning relevant services and responsibilities for the transitioning young adult. The author researched various informational concepts and found different printed resources useful. One intention was to examine personal opinions and experiences of persons / parents who have witnessed the lack of information readily available to them. Authors of these books wrote personal journeys as their

teenager transitioned out of high-school into adulthood. This provided a sound source on background information and offered a personal touch to the research product.

A secondary source the author chose for information was Central Washington University's journal-article database. It permitted the author to make comparisons between sources and allowed citing and quoting current researched based information. In doing so the author was able to vary the sources and retract pertinent knowledge from educational institutions, governmental bodies as well as psychological references.

Once the research process was established certain criteria needed to be met that allowed authenticity. For example, online journal articles needed to begin with abstract, certain references needed to be cited in the external and personal sources, and research had to support the need of the authors' project. Researching articles with abstracts allowed the author some time-consuming advantages. The author searched for key words and phrases relevant to the interest of the project to identify potential resources. By incorporating keywords through the indexed search engine, the author highlighted the pivotal topics and was able to make informed judgments about the appropriateness of identified literature.

Implementation

As the pamphlet is completed to the satisfaction of the committee it is the intent of the author to have it readily available to parents and the student during annual IEP meetings. It will be used as a reference guide with time lines that parents can refer to when they need to initiate certain legal procedures, apply for state / federal funding and start proceedings for adult services concerning independent living and / or supported employment for the disabled young adult.

It is the intent of the author's booklet to have a transition planning process that represents an opportunity to be stress free and allow pro-activeness to be favorable for the parent. The successful collaboration of professional information that is collected will offer services, support, and funding to provide a strong foundation for family members to make well-informed decisions and at the same time gain access to additional resources.

CHAPTER IV

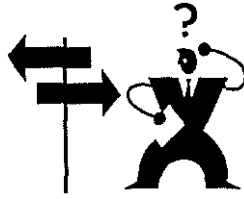
THE PROJECT

The intent of this handbook is to provide a brief explanation of information and current issues so that families and members within the Individual Education Plan process can design an effective and successful transition plan for a student with a developmental disability. The hope is to assist the special teenager and their families develop realistic goals that support the student's unique interests and skills compatible with community support. The handbook provides essential information and resources as well as added community support to help the team make knowledgeable and quality decisions following specific timelines and federal guidelines that will prepare the student with a disability to transition into adulthood.

Guidelines for Transition into Adulthood



**Kathie Weber
Kentlake High School**



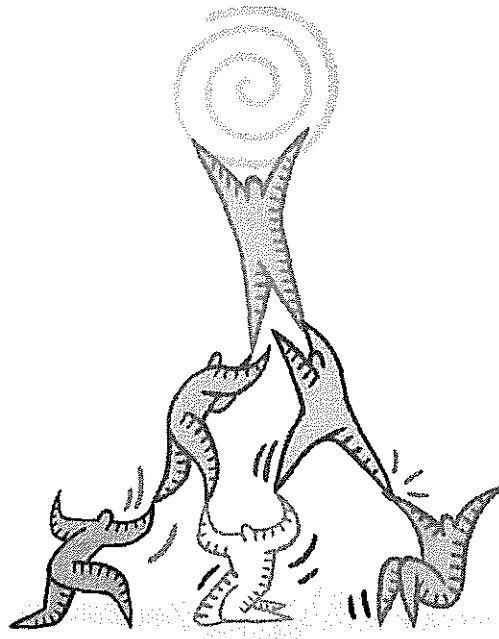
Introduction:

When the young adult with disabilities reaches the end of their educational program, parent as well as student advocacy is essential. As the student begins to transition from the school setting a complete new world of opportunity must be investigated in order for the student to have access to the supports enabling them to have a productive and safe adult life.

The following is an overview of specific programs and timelines including proper identification, financial support, supported work / career programs, and legal provisions. This informational packet is not an inclusive list but rather an introduction of information workable for parents to start the transition necessities in an organized system.

Notes

Financial and Health Insurance Support



Social Security:

1-800-882-1213

www.socialsecurity.gov

To initiate the process for SSI parents are urged to set up an appointment when the student turns eighteen. At eighteen the decision regarding benefits is based on the disabled young adult's financial assets alone – excluding any income from the family. This is an essential moment for the parent to be outspoken for the welfare of the disabled young adult.

Supplemental Security Income provides financial support to persons with a documented disability that stops them from obtaining *substantial, gainful, employment*. Social Security law requires that part of the monthly stipend be used for essential needs, such as rent, so it is advised parents charge a monthly fee for rent and supply a receipt for such.

While receiving monthly stipends SSI will allow the adult to meet monthly basic needs the better acknowledgement is that the recipient will be eligible for Medicaid benefits. Medicaid is the primary source of payment for all adult services. It will provide not only health benefits but also direct payments for living expenses, day programs, transportation and even long-term job coaching.

Notes

Medicare:

www.dshs.wa.gov (follow link for health benefits)

Medicaid is a health care program for people with low income and limited assets. It is a federal health insurance program for people 65 or older or people who have been getting social security disability benefits for two years. Because children, even those with disabilities, do not get Social Security disability benefits until they turn 18, no child can get Medicare coverage until he / she is 20 years old.

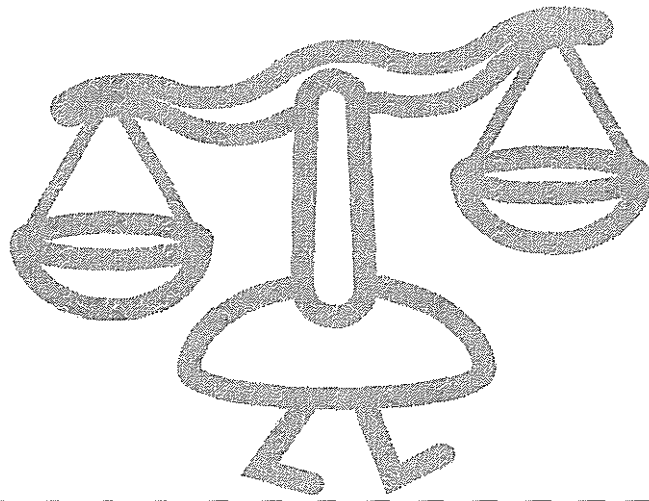
Notes

Other Health Insurance:

Even though most health insurances stop when the typical young adult leaves school or becomes an adult at eighteen years of age, parents should contact their health care provider and find out if the provider continues coverage with a documented disability prior to eighteen years of age and for how long after the fact.

Notes

Legal Needs and Documentations



Washington State Identification Card

www.dol.wa.gov

A state identification card offers a valid identification for the disabled student who most likely will not be obtaining a driver's license. If the card is obtained when the student is a minor (under 18 years of age) less documentation is needed to prove identity. In the state of Washington the parent or guardian will need to accompany the student to sign an authorization affidavit. The parent or guardian will need to show documents proving their identity (i.e. state issued driver's license, passport) and proof they are the legal parent or guardian of the student (i.e. birth certificate, legal documents of adoption)

Notes

Guardianship

Adults with special needs may require extra support and structure to successfully handle their legal affairs. If the young adult's disability impacts their ability to make decisions or leave them vulnerable to influences, guardianship is recommended as the best way to protect them throughout adult life.

It is recommended to apply for legal guardianship of the disabled young adult before they turn 18 years of age. It is advisable to start the process several months before the student turns 18 so that the process will be completed by their 18th birthday.

How to apply:

This is a legal process; the parent can hire an attorney to assist in the process. As with any legal services there is a fee, but under additional support services in the back of this handbook are two different supports offering assistance for free or a fee based upon financial ability. Both the King County Bar Association and / or Northwest Justice Project offer resources and support concerning guardianship.

Additionally The Arc of King County offers assistance and resources that will assist the parent with frequent questions and opportunities. This is a very complex and important experience that should be thought through thoroughly and effectively.

Notes

Selective Service

www.sss.gov

All young men are required to register for Selective Service within 30 days of the 18th birthday. Having a disability does not exempt them from the registration. If a draft were instituted, the young adult's documented disability could exempt them from being required to serve. Young adults may register online at the Selective Service website or by using the Selective Service postcard available at any U.S. Post Office.

Notes

Voter Registration

www.secstate.wa.gov

One responsibility that the disabled adult may need is extra assistance with exercising their right to vote. In the United States all citizens are eligible to vote once they turn 18 years of age. The disabled young adult should have some familiarity with the process through participation in school elections and social study classes. Exercising the

right to vote is an opportunity for the family to encourage the young adult with special needs to put forth self-advocacy and some independence.

Notes

Employment



Division of Vocational Rehabilitation (DVR)**1-800-637-5627**www.dshs.wa.gov/dvr

*The Division of Vocational Rehabilitation counselor should be invited to the student's annual IEP meeting before graduation.

The Division of Vocational Rehabilitation (DVR) provides employment services and counseling to individuals with disabilities who want to work, but because of a physical, sensory and / or intellectual disability they may experience barriers to gain full employment. A DVR counselor provides assistance to develop a customized plan and services designed for the individual. The young adult needs to be prepared to discuss their disability and how it impacts their ability to work. But that their personal interests and choices are important in helping the counselor design their employment goals.

Other support and assistance DVR offers:

- Counseling and Guidance
- Assessment Services
- Independent Living Services
- Assistive Technology Services
- Training and Education
- Job-related Services

Notes

Other Supports



Division of Developmental Disabilities (DDD)**1-800-314-3296**www.dshs.wa.gov (type in search DDD services)

DDD services offer a wide range of lifetime services ranging from family support, community support, and residential services. DDD services are dependent upon eligibility that the person meets the definition of a developmental disability as defined in Washington State law. As defined by RCW71A.10.020 (3) the definition of a developmental disability is:

- Mental Retardation
- Cerebral Palsy
- Autism
- Another neurological or other condition closely related to mental retardation or that requires treatment similar to that required for individuals with mental retardation

Which:

- Originated before 18 years of age
- Continued or can be expected to indefinitely
- Results in substantial limitations to individuals intellectual and / or adaptive functioning.

Notes

ADDITIONAL SUPPORT



Disability Rights Washington (DRW)

315 Fifth Avenue South, Suite 850

Seattle, WA 98104

(206) 324-1521 or 800-562-2702

www.disabilityrightswa.org

- This is a non-profit organization that protects the rights of people with disabilities. It offers free advocacy advice, community education, training, and legal services.

Notes

Do-it at the University of Washington

(Disabilities, Opportunities, Internetworking, and Technology)

4545 15th Avenue NE

University of Washington, Box 355670

Seattle, WA 98195-5670

Voice / TTY: (206) 685 – DOIT (3648)

www.washington.edu/doit

- DO-IT is a national award winning program that mentors youth with disabilities as they pursue academics and careers. The program promotes the use of technology to maximize the independence, productivity, and participation of people with disabilities. They provide an extensive list of disability resources on their web page.

Notes

King County Bar Association Lawyer Referral Service

1200 5th Ave Suite 600

Seattle, WA 98101

(206) 267-7100

www.kcba.org

- This program offers low income persons to volunteer attorneys. Clients are screened for financial eligibility, merit and program priorities.

Notes

Northwest Justice Project (NWJP)

401 Second Avenue South, Suite 407

Seattle, WA 98014

(206) 464-1519

New Client Intake Line: (888) 201-1014

www.nwjustice.org

- Northwest Justice Project offers many helpful materials and resources about special education, including forms, on their website. Some material is available in Spanish.

Notes

The Arc of King County (Chapter of The Arc of Washington)

(Advocates for the Rights of Citizens with developmental disabilities)

233 Sixth Avenue North

Seattle, WA 98109

(206)364-1613

www.arcofkingcounty.org

- The Arc provides referrals, literature, publications from the Office of Superintendent of Public Instruction (OSPI) and works with schools and parents in a team setting to teach both parties how to work together. They also work with disabled adults to become active members within their community

Notes

Washington Pave

(Parents are Vital in Education)

6316 South 12th Street

Tacoma, WA 98465

Voice / TTY (800) 572-7368 or (253) 565-2266

www.wapave.org

- PAVE provides information and support to families on a variety of issues, including special education, Individualized Education Program (IEP), and transition from high school to adulthood. They assist parents in advocating for the child's education through newsletters, workshops, and one on one support.

Notes

CHAPTER V

SUMMARY, CONCLUSIONS, AND RECOMMENDATIONS

Summary

Studies clearly indicate that special education students and their parents are in dire need of emotional and informational support during the transitional time of post secondary high school into young adulthood. Research has shown how important current information is needed for legal matters such as guardianship and official identification well before the student turns eighteen years of age. Other matters needed to be considered are future employment, independent living and financial stability for the developmental disabled young adult.

Developmentally delayed students need their parents and other devoted, caring adults to guide them through these crucial decision making periods. Concerned adults have the ability to influence the special need student through nearly every important decision as they transition out of the high school environment. These personal relationships require extensive communication between not only the parents, but care takers, teachers, medical specialists, and governmental agencies as well. Effective communication and collaboratively working together is vital for the positive development of the secondary transitional passage to occur.

One of the best practices is for all parties to be pro-active and prepared to meet critical timelines within the students' transition period. The author's task has been to investigate and research to create a handbook that will assist parents and special education teachers in the ability to access not only local agencies, but state and federal support groups to ensure support entitled to the disabled adult. The intention of the

booklet is not only to make available financial support to the young adult, but also to allow the parents to contact local parent groups for guidance and support as they enter into the new time span of their growing child.

The intended handbook will allow parents to have access to local governmental agencies with current addresses or e-mails, plus give a brief definition of each entitlement that the student is awarded according to federal guidelines.

Conclusion

It has been common practice as witnessed by the author that current procedures informing parents of all the legalities needed to be complete prior to the child turning eighteen. This process has been a painstaking experience not only for the parents but special education teacher as well. Insufficient information, lack of guidance and inability to complete necessary worksheets has left parents completely overwhelmed in the process. This has happened so much so that parents choose to ignore the importance of these legal matters and continue to stay in the comfort zone they have become accustomed to through the educational years of the disabled child.

Recommendations

The population of special need students has been overlooked in many ways during the history of events for special education. Since the passing of the amendment of IDEA 2004 pertaining to special need students, several changes have taken place in and out of the classroom environment. In order for the parents of the special need student to be aware of the current legislation and community responsibilities, the author has developed this handbook in which current information and critical timelines need to be addressed.

It should be common practice for the specialists, teachers, and medical advisors involved to stay current with federal legislation as well as support opportunities as they occur for this special population. In doing so, present practices and up to date services can to be restructured in the handbook, keeping it an organized and well calculated process with positive results to occur within the transition time span.

The parents and the special education team will need encouragement to continually seek out new information through local, state and federal agencies. This knowledge can be found through local support agencies as well as parent support groups. The current handbook in this project will provide a guideline to follow which indicates protocol, procedures and a simple explanation of such entitlements.

It is the intention of the author to share the handbook with other special education teachers at the secondary level as well as middle school. This collaborative process will allow professional development and ideas to be shared. The author will also give opportunity for parents to share input on the handbook. Giving each group opportunity to voice the effectiveness and organization of the handbook will enhance the product. In doing so, hopefully the IEP process addressing transition for the special need student will be more organized, less stressful and have the possibility to be enjoyed and celebrated as intended for parents and student together.

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