

Growing Up With Disabilities: Education Law and the Transition to Adulthood

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> Susan G. Clark & Timothy Lillie
> The University of Akron

Abstract: The field of disability studies uses a social model or social construction model for much of its theoretical basis at present. The social model exists concurrently and, to some extent, is seen as replacing a civil rights approach. The authors propose that while the social model is very useful in understanding the nature of disability and should continue as a valuable theoretical underpinning, the civil rights model is better understood when educators are engaged in teaching children with disabilities what their rights are and how to exercise them. This is especially the case when considering students who are very cognitively impaired. An outline of the three most relevant US laws is given, along with information that is necessary for effective advocacy, whether by individuals with disabilities themselves or their families or friends.

People with disabling conditions have long been viewed from perspectives generally reflecting the belief that the proper reaction to disability is cure or, at the very least, control over such people (see Triano, this issue). Brendtro, Brokenleg, & Van Bockern (1990) have described how, at different times, and in different cultures, disability (in their example, troubled youth) has been viewed and treated as something that is a societal problem, rather than a different way of living, until very recently. In the United States, for various reasons having to do with early eugenics efforts or merely societal discomfort with disability in the public view, States have demonstrated a long and in some cases continuing history of discrimination and oppression toward people with disabilities (Brief of Morton Horwitz, 2000), based on a medicalized view of deviance or disability.

Two models

We believe that (as a result of work in the field of disability studies and related areas, founded on the social construction model) there are currently two viable, if not completely compatible, ways of looking at disability and the need for disability rights. The first, of course, relies on the social model (see: Berger & Luckman, 1967; Barnes, Mercer & Shakespeare, 1999). Parents, professionals, and people with disabilities who are new to the disability rights arena might understand this model as explaining the lack of services and rights for people with disabilities as merely a result of the social attitudes that people have. When the attitudes change, services and rights will be seen as entitlements for people with disabling conditions and will naturally and normally follow. Abberly (1987) notes that the concept of oppression is useful here because using that term helps us to understand how social forces have been (consciously or

unconsciously) gathered to discourage individuals with disabilities from exercising their rights. In Abberly's view, this oppression is the result of historical workings, is not natural, and therefore can be changed by societal action. The social model fits the experience of many people with disabling conditions (especially "hidden" ones) very well and has, therefore, become prominent in the field. We believe it to be an extremely useful way of perceiving people with disabilities.

The other model, that exists concurrently with the social model is the civil rights view of disability. Jane West (1991) described this model for people with disabilities with regard to the Americans with Disabilities Act of 1990 (ADA). She maintains that people with disabilities are particularly disadvantaged even by reference to disadvantaged minority groups in general. This law (ADA), in her view, has helped people with disabilities self-identify, begin to exert some influence over how they are labeled and, therefore, beginning to change attitudes. The law, in this case, is the vehicle necessary for changing the social construction of disability. Indeed, use of the law can be seen as very helpful in empowering those with disabilities who may be outside the American mainstream, whether because of minority status or because they live in rural communities, or both (NCOD, 1997). Richard Scotch, in 1989, described the disability rights movement at least in part by its relationship to Federal authority, including Federal civil rights and related laws. The civil rights approach has a long and honorable history when advocating for appropriate services. However, the most important reason for taking the civil rights (law-related) model as important is that the social model does not adequately explain the situation of very seriously disabled people. While Bogdan & Taylor (1992) and Ferguson, Ferguson, & Taylor (1992) remind us that people with severe disabilities can benefit from an approach that includes social construction, and story-telling (of their own stories, in their own words) as a means of understanding the experience of people with severe disabilities, Watson (1996) has argued that social construction and qualitative studies have not been able to explain the social and other exclusion of very cognitively disabled people. This leads us to propose that for the purposes of teaching students with disabling conditions to learn how to exercise their rights, an emphasis on the civil rights approach, with its reliance on law to establish and maintain appropriate and effective services and rights for people with disabilities is preferable to the social model.

We believe that, given the culture of the schools (see Kruse & Lillie, this issue) in the United States, this model will be the most useful one, at least in the short run. Students with disabilities (and their families and allies) who are receiving services in the schools under the provisions of the Individuals with Disabilities Education Act Amendments of 1997 (IDEA) (however flawed it may be) are used to receiving services, sometimes with a fight, as an entitlement. However, upon graduation from high school or aging out of the IDEA protections, students and their families and allies experience a set of laws based on eligibility and limited service, not entitlement. The IDEA has provided the opportunity for schools and states to inform students of their rights (under IDEA), as a way of promoting self-determination and the exercising of adult responsibilities. In order to do this, students, professionals, family members and other allies must be familiar with the laws and how they operate to protect the rights of people with disabilities. The balance of this paper is devoted to providing an outline which we hope will be useful for disability advocates and others who are seeking ways to take control over their own lives.

The law

The 1990s reflected widespread growth in business and industry, an unprecedented level of international cooperation in world trade markets, and a commensurate demand that employees be skilled and adaptable to rapid change as the United States continued its evolution from a manufacturing-based to an information-based economy. In part, global competition directed national attention toward the skills, abilities, and competence of students leaving high schools and entering the world of work. Education reforms brought on by increased public scrutiny of the outcomes of public education sought to continue America's economic edge and workforce preparedness by heightening graduation requirements, learning standards, and skill proficiencies of students.

Federal lawmakers enacted a notable series of reform legislation to enhance all students' achievement and transition to employment such as the Goals 2000: Educate America Act (Goals 2000, U.S. Department of Education, 1994) which set increased academic standards, and the School-to-Work Opportunities Act (STWOA, 1994) which requires career awareness and exploration. These reforms recognized the problems in obtaining an adequate education to prepare students for the world of employment.

Students with special educational needs were not excluded from these reform efforts.

In 1997, Congress reauthorized the Individuals with Disabilities Education Act (IDEA) which targets improvements in the education of only students with disabilities. The IDEA requires that educators have high performance and achievement expectations of these students. By providing students with disabilities greater access to the general education curriculum with an emphasis on meaningful progress, and by requiring educators to plan for the transition to adulthood, the IDEA intends that students with disabilities leave school prepared for post-secondary education, self-sufficiency, and employment. Yet, students with disabilities leaving the school system and the guarantees of special education law in which others generally make decisions for them often learn that in the adult world, there are no coordinated service systems for persons with disabilities designed to be responsive wholly to needs and preferences of individuals they serve.

This article explains the legal requirements to address the preparation of students with disabilities for the transition to adulthood, distinguishes the similarities and differences between the laws; and makes clear the challenges of implementing these legal guarantees.

Review of Literature

A longitudinal study of typical adolescents found that young adults left high school unprepared for the realities of work and the many interpersonal challenges posed by no longer being in school (Amundson & Borgen, 1996). The range of developmental issues they faced included uncertainties about their work and their relationships. The former students reported that their post-high school transition was hindered by relationship problems, career confusion, financial difficulties, unemployment, lack of job satisfaction, lack of educational opportunities, lack of support, and difficulties adjusting to post-secondary education.

The primary recommendation of the authors was to engage students in career counseling designed to engender competence. This expanded view of career counseling recognizes the

developmental needs of young people, the influence of social and economic changes, and the importance of making decisions based on personal and career competence. These findings, among other sources addressing post-school unpreparedness, helped spawn national attention to the need to better prepare students for the world outside of school. Although Amundson and Borgen's study did not examine the challenges facing students with disabilities, the findings inform disability advocates of the need for a concerted, systematic effort to address the dilemma of transitioning students with disabilities from school to the adult world.

The need to have students with disabilities leave high school prepared to live, work, and learn as adults has been scrutinized for years by researchers (Blackorby & Wagner, 1996; Halloran & Simon, 1995; Johnson & Rusch, 1993; Wagner et al., 1991; Roessler et al., 1990; McAfee, 1988). Post-school employment statistics reflect poor outcomes for a large portion of students with disabilities (Phelps & Hanley-Maxwell, 1997). One study found that only 28% of young adults with mental retardation who had been out of school for one year were competitively employed (SRI International, 1991).

As reported in the United States Code Congressional and Administrative News, students with disabilities have been moving from high school into adult life with varying degrees of success (1990). "Some go to college, some enter vocational training programs, while others enter the work force, and some qualify for vocational rehabilitation services. Unfortunately, others will exit our nation's schools into nothing" (pp. 1731-32). Without a systematic plan to provide applied learning experiences to students with disabilities concerning their career planning and rights as students and adults, "Years of special education will be wasted while these individuals languish at home, their ability to become independent and self-sufficient placed at a significant risk" (pp. 1731-32).

Section 504 of the Rehabilitation Act of 1973

Section 504 is a short provision of the labor statute, The Rehabilitation Act of 1973, which provides for federally-assisted rehabilitation programs for persons with disabilities. This civil rights law also requires nondiscrimination in educational institutions that receive federal funding. The law means to "level the playing field" by eliminating barriers to adults' or students' full participation in educational institutions receiving federal funds. It requires equal opportunity and access to the programs, services, and benefits of the institutions to which it applies. Section 504 is remarkably brief:

No otherwise qualified handicapped individual in the United States . . . shall solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subject to discrimination under any activity receiving federal financial assistance (Section 504, 29 U.S.C. 794(a)).

There are three components that must be met for a person with a disability to be entitled to the protections of Section 504. First, an adult must be employed, or a student enrolled, in an educational institution that receives federal funds (henceforth "recipient" institution). This institution may be public or private, religious or governmental so long as one or more of its programs or activities receive federal funds directly or indirectly, in whole or in part. Second, an

adult or student must have a disability as per the definition of disability under Section 504. Lastly, the person must be qualified to perform or receive the services of the institution. Once these three requirements are met, a person is eligible for the protections of Section 504. Importantly, institutions serving school-aged students have the responsibility to locate and identify qualified students who may have disabilities. The same is not true for students in post-secondary institutions or employees of covered entities. In those cases, the individual is responsible for informing the employer or the institution of the disability.

Eligibility. A person with a disability under Section 504 has one or more physical or mental impairments that substantially limit one or more major life activities, has a record of such an impairment, or is regarded by others as having such an impairment. Physical impairments include physiological disorders or conditions, disfigurement, or anatomical loss. Mental impairments include conditions such as mental retardation, emotional or mental illness, or specific learning disabilities. The mere presence of an impairment does not establish eligibility. The impairment must limit substantially a major life activity, either permanently or temporarily, such as walking, breathing, speaking, learning, or working, although there is no written requirement that the disability adversely effect educational performance.

The statute also protects those who have a record of such impairment. This component of the definition includes two groups of individuals: those who had an impairment at one time, but have since recovered (e.g., history of emotional or mental illness, drug addiction, alcoholism, or cancer); and those who have been misclassified as having an impairment (e.g., persons erroneously labeled mentally retarded or mentally ill) (Yell, 1998). The third part of the definition includes individuals who have a physical or mental impairment that does not limit substantially a major life activity, but who are treated as if the impairment does limit substantially major life activities. This group of persons represents, for example, those who have recovered from drug or alcohol addiction and who are treated as if they were engaging currently in drug or alcohol use.

Next, not only must the Section 504 definition of disability be met, eligibility is contingent upon the person being "otherwise qualified" for the job or for the educational program. Students in recipient schools are considered otherwise qualified if they are of the age of students without disabilities served in the school. Virtually all school-aged students meet the "otherwise qualified" criteria.

In contrast, students or employees in post-secondary educational recipient environments are otherwise qualified if they meet the academic, technical, or performance requirements of the program or job with or without reasonable accommodation. The Supreme Court reviewed this statutory requirement in *Southeastern Community College v. Davis* (1979). The College denied a student with a hearing disability admission to a nursing program on the grounds that she was not qualified to participate in the program. The student sued the school claiming that Section 504 promised her an equal educational opportunity to participate and because she had met the grade requirement and could read lips, she was entitled to have access to the program. The Court held that Section 504 was not violated, and instead, found that legitimate physical qualifications (i.e., hearing) may be essential to participation in particular programs. The ruling held that the ability to understand speech without reliance on lip reading was an essential performance function of a nurse and was necessary for patients' safety.

The Individuals with Disabilities Education Act

The IDEA represents the most significant federal law protecting the educational rights of students with disabilities between the ages of birth and 21 so long as doing so is not inconsistent

with state law or a court order. However, unlike Section 504, the IDEA is not a civil rights statute. It is an education act passed by Congress to provide federal funds to assist states and school districts to guarantee to eligible students with disabilities the procedural and substantive rights to a free appropriate public education (FAPE), which is different than a FAPE under Section 504. The IDEA attempts to ensure that parents will participate in educational decision making by providing an inclusive definition of parent. Under the IDEA, parents are expected to protect the rights of their children and to act for them. Parents have the right to fully understand the IDEA, including all procedural due process rights. In contrast, the students generally are passive recipients of these rights and aforementioned special education and related services through the decision making of others.

Eligibility. Unlike the inclusive definition of disability under Section 504, to be eligible for the protections of the IDEA, a student must have a disability that falls within one or more of thirteen categories of disability: autism, deaf-blindness, deafness, hearing impairment, mental retardation, multiple disabilities, orthopedic impairments, other health impairments, emotional disturbance, specific learning disability, speech or language impairments, traumatic brain injury, or visual impairments, including blindness. Should a disability be identified, eligibility is dependent upon the student's need for special education and related services. A team of persons knowledgeable about the disability, any evaluation results, the child, and the school curriculum and district resources including the parent, and student, if appropriate, devises a written individualized education plan (IEP) that lists all the student's identified needs and services and commits the district's resources to its implementation. Although consensus among IEP team participants is the goal for any decision making, because school officials are obligated under the law to provide special education, if the team is not in agreement, school officials must make the decision for the team. Parents are then free to challenge the school officials' decisions through the due process procedures enumerated in the IDEA.

The Scope of the IDEA. Because the IDEA is a public education law, its reach does not extend to the workplace or to post-secondary education environments. Also unlike Section 504, the IDEA is not an equal educational opportunity statute; rather, it requires that students with disabilities be provided full educational opportunity to meet their needs. Full educational opportunity provides that eligible students with disabilities have the right to a FAPE. A FAPE is defined as special education and related services provided at public expense that meets the substantive and due process requirements of the IDEA and its implementing regulations and is in conformity with the IEP.

A FAPE under the IDEA differs from a FAPE under Section 504. While Section 504 precludes any barriers to equal participation, the IDEA requires affirmative action in meeting the individual needs of students. The equal opportunity mandate of Section 504 requires that students with disabilities have the same opportunities, the same education, the same services as those received by students without disabilities. The IDEA requires students with disabilities be given an education that is appropriate to their unique needs, allowing them to make progress in a meaningful individualized education program. Students protected under Section 504 are entitled to an integrated environment. Students protected under the IDEA are entitled to an education in the least restrictive environment that allows them to participate, to the maximum extent appropriate, with students who do not have disabilities. Section 504 requires a plan for accommodation. The IDEA requires an IEP which commits the school district's human and financial resources to the provision of specialized instruction necessary for a student with disabilities.

Section 504 has no requirement that students with disabilities assume their own rights under the Act or be prepared for employment, post-secondary education, or other activities after leaving high school. Again, Section 504 requires only that students with disabilities have the same opportunities as students without disabilities. Therefore, federal initiatives such as the School-to-Work Opportunities Act, the Job Training and Partnership Act, vocational education, and vocational rehabilitation are critical program opportunities for students with disabilities protected by Section 504. Students with disabilities under the IDEA may receive benefit from the career awareness and exploration mandates of these laws, but more significant is the fact that a FAPE under the IDEA includes preparing students with disabilities for employment and independent living. Thus, the IDEA asserts legal entitlements for students with disabilities concerning their transition to adulthood.

Preparing Students with Disabilities for Adulthood

The IDEA was strengthened in 1997 because the improvements in the quality and nature of education for secondary students with disabilities brought on by federal and state reform initiatives were significantly less than the improvements made for students without disabilities. Students with disabilities in high schools were found to have proportionately higher failure and drop-out rates and more behavioral problems than students without disabilities (Benz & Halpern, 1987). In one study, young adults with disabilities experienced lower employment rates, lower participation in post-secondary education, and lower satisfaction with their adult lives while parents reported worrying about the uncertainty of their children's futures and what the transition from high school would bring (Whitney-Thomas & Hanley-Maxwell, 1996).

Transition services are coordinated activities identified by the IEP team to promote the matriculation of students with disabilities into post-secondary education, vocational training, competitive or supported employment in integrated settings, continuing and adult education, independent living, group home residence, or community participation, depending on the students' needs. The purpose of transition planning under the law is to infuse a longer-range perspective into the IEP process and to help students better reach their potentials as adults (Tucker & Goldstein, 1992). The IDEA requires educators to prepare students for employment, independent living, and to assume and exercise the rights accorded to their parents when they reach the age of majority.

Transition

Many students with disabilities require more individualized and proactive planning and services to achieve appropriate career outcomes because of the nature and extent of their disabilities. Indeed, the additional obstacles they may encounter when accessing services, employment, or entering and participating in other aspects of adult life require a systematic plan of instruction to ensure that the students are prepared. Congress intended that public schools provide students with disabilities any services needed to facilitate their transition from school to post-school activities and school officials legally are responsible for the provision of all the services that constitute a FAPE, including transition planning for adulthood.

In order to facilitate its goals, the IDEA requires that students with disabilities of any age be invited to assist the parents, educators, and other interested experts in identifying their needs for transition to adulthood. The law stipulates that transition services are to be built upon the student's expressed needs, interests, and preferences and so students are to be included in these transition meetings. This provision is an indication that self-advocacy and self-determination are necessary components of a special education although educators and parents are used to a system in which they hold the key decision making roles.

The transition requirements will necessitate negotiation between teacher, parent, and the student where each brings to the meeting their ideas and goals which are melded by consensus into a plan that suits the student's needs (Battle, et al. 1998). Importantly, the regulations state that if the student is unable to attend the meeting, school officials are obligated to take other steps to ensure that the student's preferences and needs are considered. The IDEA regulations further strengthened the student's role in the process by adding that beginning no later than age fourteen, a statement of transition services needs must be included in the IEP and must focus on the student's course of study, whether vocational or advanced placement college preparatory curriculum. Preparing students with disabilities for post-secondary education is one of the reasons Congress requires transition services under the IDEA.

Evidence suggests that high school students with learning disabilities often enter post-secondary settings with little knowledge of their disability and how it affects their learning (Brinckerhoff, Shaw, & McGuire, 1993). Brinckerhoff (1994) found that about one-half of the students in a disability intervention program at Boston University remembered something about having an IEP, but only a few knew what it was designed to do or even what the acronyms and abbreviations contained in it meant.

With so few students reporting an understanding of their disabilities or their needs, they are unprepared for advocacy of their own rights as adults. Furthermore, the responsibility for ensuring students' disability rights shifts from school officials to the students themselves when they reach adulthood. Students involved in a study by Greenbaum, et al. (1995) indicated that post-secondary institutional barriers to success for them most often involved "a lack of understanding and cooperation from faculty and administrators, including discrimination because of the disability" (p. 468). Social skills, job-seeking skills, teamwork, problem-solving strategies, collaboration, communication and organization skills, career assessment, self-regulation (Battle et al., 1998, Zimmerman, 1989), skills to monitor progress, and more should be included in the transition plan, if needed.

Clearly, the skills needed by all persons engaged in successful post-secondary school endeavors need to be deliberately planned and students given ample experiences learning them, but few secondary school programs place a major emphasis on teaching the social skills or self-advocacy that are necessary for academic success (Skinner, 1998). Formalized transition policies addressing the move to post-secondary education are not widely prevalent in high schools (Gartin et al., 1995). Gartin identified three instructional components essential to any transition to post-secondary education - psychosocial adjustment (e.g., self-advocacy, problem solving), academic development (e.g., career awareness, in-class accommodations, study/research skills), and college and community orientation (e.g., career choices, disability services in colleges) - as essential elements of the transition to post-secondary education. Consequently, the decision making IEP transition team must recognize and plan for the challenges these students may face in post-secondary educational environments. Model high school programs demonstrate that skills needed by students to successfully communicate their academic strengths and weaknesses and to tactfully request accommodations can be taught (Durlak, Rose, & Bursuck, 1994; Van Reusen & Bos, 1994).

Self-advocacy is the ability to recognize and meet the needs specific to one's own disability without compromising the dignity of one's self or others (Spector, Decker, & Shaw, 1991; Brinckerhoff, 1992). Students demonstrate self-advocacy when they show an understanding of their disabilities, when they have awareness of their legal rights, and when they manifest

competence in communicating their rights and needs to those in positions of authority (Skinner, 1998).

Beginning no later than age 16, IEPs must state the services needed to facilitate, in a coordinated way, the movement of students with disabilities from school to the adult world. The two years between the required statement of needs no later than age fourteen and this services statement enables the decision making IEP team to plan, organize, and generate resources the student will need when the plan is implemented at age 16. The transition statement must include any interagency responsibilities or linkages necessary for implementation irrespective of who will pay for or deliver them. (One thing is certain: parents are not to pay for them; a FAPE is free.) If these links are needed, the IEP decision making team must include at least one representative of another agency, vocational, community, or business, who is concerned with the provision of services to students with disabilities, who has a legitimate educational interest in the student, and who is likely to be responsible for providing or paying for transition services. The IDEA requires such cooperative relationships between school officials, the student, parents, employers, adult human service agencies (e.g., Bureau of Vocational Rehabilitation, U.S. Department of Housing and Urban Development), and transportation agencies. As the student's needs for services and supports become known, services from each agency can be arranged and included into the planning, especially for students who will not be eligible for vocational rehabilitation services. Success will depend, in part, on the ability of the educators to effectively collaborate with others. Should the transition service provider fail to provide the services, the school district assumes responsibility to reconvene the team and reassess the plan.

The IDEA also establishes a goal of independent living, although it does not guarantee that all students with disabilities, in fact, will attain self-sufficiency (Rowley Case, 1982). Students, especially those with physical, severe, or profound disabilities, may need instruction, related services, and community experiences to assist them to acquire daily living skills. Consequently, public school officials may not overlook the matter of planning for independent living for all students with disabilities that may need assistance in learning independence, including those who have been academically successful.

A student's academic success in high school, due in part to the special education received, should not be a barrier to receiving whatever transition services that may need to be equally successful in college, including instruction in daily living skills. A case from South Dakota illustrates the point (*Yankton School District v. Schramm*).

Parents of a daughter with cerebral palsy sought transition services to aid her move from high school to independent living at college. In March, 1996, when the student turned age 16, she requested a specially designed driver's education course, an opportunity to learn self-advocacy skills, and instruction in cooking and cleaning needed for independent living. The requests were included in the IEP with the parents identified as service providers for nearly all the needed instruction. School officials then moved to dismiss the student from special education in June, claiming that the young woman was in need of related services - transition services constituting a type of related service and not special education - thus making her ineligible. At the due process hearing initiated by the parents, the hearing officer found that transition services were a type of special education and the student was deemed eligible. The regulations pursuant to IDEA 1997 address this very issue and state clearly that transition services may be special education if provided as specially designed instruction or related services.

Planning for independence and daily living also requires consideration of housing arrangements and community supports for some students. Without doubt, transition should include planning

for income support such as Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI), if needed. Eligibility for income support is dependent on the disability, which must affect the ability to work or participate in substantial, gainful activity. Social Security regulations consider a minor student to have a disability if its effects limit the ability to function independently, appropriately, and effectively in an age-appropriate manner. The impairment must be of comparable severity to that which would disable an adult.

For a student under the age of 18, income eligibility considers a portion of the parent's income. For those over age 18, only personal income is taken into account to determine eligibility (Gordon v. Shalala, 1995). The benefits from SSI and SSDI may include Medicaid health benefits. Parents and students must be aware of the availability of these services, particularly in planning for the transition to adulthood. While it is possible that these income benefits may be eliminated or reduced when a student with a disability moves into the work world, all or a portion of the income and health benefits may be retained if proper and thorough planning is done prior to the student beginning to work.

When considered as a comprehensive plan to move students with disabilities into post-secondary schooling, community living, or employment, transition must necessarily include all the elements of an independent adult life including how to manage a budget, how to obtain legal or medical assistance, how to spend leisure time, and how to set goals and work toward them. Perhaps the first place to begin is by providing the student with applied instruction in how to run the IEP team meeting to address personal needs and goals.

Congress intended that transition services be planned over time and delivered to students, at no cost to them, so that the outcomes of their special education lead to productive adult lives. A FAPE is substantively more important than paperwork. One example of the importance of the legal right to transition service over the proper paperwork is a case from the Tenth Circuit Court of Appeals. In this case, the parents of a student with a disability sued the school district because the IEP did not contain the required transition statement. The parents alleged that this omission constituted a failure to provide FAPE. The court, however, distinguished between a statement of transition services on the IEP and the actual delivery of those services. The record included numerous reports from the parents, teachers, and the student attesting to the fact that, although the IEP lacked the necessary statements, the student did receive the services agreed to by the team. The court concluded that the student had benefitted from those services and was thus receiving a FAPE (Urban v. Jefferson County School District, 1996). Nonetheless, in another court, or where the record is not as clear, the failure to include a transition statement could result in a denial of FAPE.

Transfer of IDEA Rights

While parents retain all rights to direct the education of their minor children, when those children reach the age of legal adulthood, the IDEA permits an adult student to exercise those rights once afforded exclusively to the parent. Under the IDEA, a state legislature may opt to enact a law that provides for the legal transfer of IDEA rights from the parent to a student with a disability who has reached the state's legal age of majority. Forty-six states designate 18 as the age of majority; two states use age 19; and two states, age 21. One state statute provides that persons with mental retardation remain as permanent minors unless they are interdicted formally by a court of domicile.

Table 1

The Age of Majority for Youth

Age State

18 Alaska Arizona Arkansas California Missouri Connecticut
Delaware Florida Georgia Montana Hawaii Idaho Illinois
Indiana Iowa Kansas Kentucky Louisiana Nevada Maine
Maryland Massachusetts N. Hampshire Michigan Minnesota New Jersey
New Mexico N. Carolina N. Dakota Ohio Oklahoma Oregon
Rhode Island S Carolina S. Dakota Tennessee Texas Utah
Vermont Virginia Washington W. Virginia Wisconsin Wyoming
Washington, D.C.
19 Alabama Nebraska
21 Colorado Mississippi Pennsylvania

Once the age of majority is reached or a formal interdiction is made, presumably, adult students then exercise their IDEA rights in their own best interests. This legislation is optional for the states. Should a state decline the opportunity to enact such a law, the student's parents retain the rights accorded to them by the IDEA and they continue to make educational decisions on behalf of their children. To date, no states have moved to enact transfer of rights legislation (personal communication, Zirkel, 1999).

If a state opts for the transfer of rights, school officials must write a statement into the IEP, at least one year before the age of majority is reached, to indicate that the student and parent have been informed of the transfer. The rights that transfer to the student include all rights conferred upon parents by the IDEA (see Table 2).

Table 2

Rights that Transfer to Adult Students Upon Reaching the Age of Majority

The right to examine their own educational records and to obtain a copy of their own IEP or educational records

The right to attend all meetings, including IEP meetings, concerning their own identification, evaluation, and placement; and provision of FAPE

The right to have their concerns and the information that they provide considered in the development and review of the IEP

The right to be regularly informed of their progress toward the IEP annual goals and the extent to which that progress is sufficient to enable the adult student to achieve the goals by the end of the school year

The right to obtain an independent educational evaluation if they disagree with the school district's evaluation results

The right to prior written notice, in their native languages, of the district's proposal to change or refusal to change their identification, evaluation, or placement; or the provision of FAPE; if this notice is not an initial referral for evaluation, the right to obtain a copy of the school district's procedural safeguards, and the right to sources for the adult student to contact and obtain legal assistance in understanding the IDEA

All procedural safeguards including the right to present all complaints related to their own identification, evaluation, or placement; or the provision of FAPE, including mediation as a complaint resolution option (the adult student must adhere to the school district's procedures requiring them to provide notice concerning any complaint [must include their name, address, name of school, a description of the nature of the problem, facts relating to the problem, a proposed resolution]); this includes the right to due process hearings, including requirements for

disclosure of evaluation results and recommendations; state appeals, if applicable; and civil actions and the right to attorney fees

The right to a copy of the procedural safeguards upon initial referral for evaluation, upon each notification of an IEP meeting, upon reevaluation, upon filing a due process complaint

The exercise of these rights under the law transfer from the responsibility of the parent to the child who has attained the age of majority and remains in the school placement or is incarcerated in an adult, juvenile, federal, state, or municipal correctional institution.

The successful transfer of rights does not imply, however, that parents no longer have a role in decision making concerning the education of the adult child. Indeed, the statute begins with a list of findings made by Congress that over 20 years of research and experience have demonstrated that the education of students with disabilities can be made more effective by strengthening the opportunities for parents to provide meaningful input and participation in their children's education. The statute requires that upon transfer of IDEA rights all required prior written notices (e.g., meeting dates, conference participants, evaluations) be given to both the adult student and the parent.

Furthermore, after the age of majority is reached, case law demonstrates that all procedural safeguards continue to be in effect entitling the parent to all rights to due process proceedings. In the first case, prior to the IDEA Amendments of 1997, the district court was asked to determine if procedural safeguards (e.g., prior notice to parent, stay-put) were required before the state ended a residential placement for an adult student based only on the student's consent (*Mrs. C. v. Wheaton*). The State of Connecticut Department of Children and Youth Services had placed the student with functional retardation and learning disabilities in a private school. When the student turned age 22, the state successfully acquired the student's consent to terminate the placement. The parents, however, sued on the basis that neither they, nor the surrogate, were given notice of the change; nor was a team meeting held to discuss the termination. The district court found that stay-put and the other safeguards were not applicable.

On appeal, the Second Circuit Court found that the statute and the regulations of the special education law contemplated that procedural safeguards applied. The parents were entitled to prior notice because the state could not terminate placement unless consent was informed. The court went on to state that consent without adherence to the procedural safeguards of the statute was ineffective.

In the second case, adjudged in 1997, a federal district court ruled that the parent was entitled to prior notice of a change in program even though the student had been tried, convicted, and incarcerated as an adult. Mere incarceration as an adult did not thwart the IDEA's procedural safeguards to parents.

Additionally, parent participation in the student's educational program can be continued by school officials issuing an invitation to the parents to attend all decision making conferences, as educators may invite to a meeting any individuals who are knowledgeable about the child.

Hence, parents may continue to attend and participate in all IEP conferences or meetings at which the student's placement, program, evaluation, or FAPE are to be discussed, reviewed, or revised, even if the student does not want parental involvement.

Furthermore, a 1982 decision from the Second Circuit Court of Appeals held that the parents of an adult student had standing to maintain a federal IDEA lawsuit under New York state law, as did the 18 year-old. Hence, this student who reached the age of majority and who was not incapacitated or incompetent, was found to be able to represent his own interests in court for an IDEA claim, along with his parents (*Vander Malle v. Ambach*). As this court suggested, perhaps

its decision would have been different if 18-year old had been adjudged incapacitated or incompetent.

While the transfer of rights facilitates IDEA's intention that students play an active role in their own education, there are two circumstances that prevent transfer. The first is the matter of incompetence. The second, which will be considered initially, is in the case where a student, who is otherwise competent to make basic life decisions, lacks the capacity to give fully informed consent regarding educational planning and programming.

The doctrine of informed consent, which applies to every competent adult, is to promote self-determination and rational decision making (Levy, 1998). Evidence of a cognitive or mental disability does not by itself disqualify a person from exercising this right. Since the capacity to make decisions varies from person to person and decision to decision, a careful individualized assessment of capacity should be made. The ability to absorb and process information is a product not just of skills in abstract reasoning, but of the manner in which information is communicated. Capacity is a relative concept and may vary depending on the type of decision to be made.

For example, a person may have the capacity to choose a residence or apply for a job, but be unable to make complex financial decisions. Under the IDEA, fully informed consent is understood as a voluntary agreement in writing that the adult student understands the activity to be conducted for which consent is required, the activity must be described, and any records to be disclosed must be listed as well as the names of those who will be privy to the records. Hence, if a student with a disability does not, cannot, or will not comprehend why consent is needed, the purposes of the activity, its consequences, or its implications, perhaps the student lacks the capacity to give informed consent in that area.

It is especially important for the adult student to be fully informed as consent may be revoked at any time. In the case of lack of capacity, states may opt to create procedures to appoint the parent to act on behalf of the adult student, or if the parent is not available, another individual. The standard for appointing such a guardian will vary state to state. Each state must, therefore, establish procedures to obtain fully informed consent for any student of majority age who lacks the capability to make responsible educational decisions, but who is not declared incompetent. The second IDEA provision that prevents transfer permits parents to retain all their rights if the adult student is declared incompetent under state law. Determined by a court of law, incompetence is a legal finding that a person lacks the capacity to make informed decisions about themselves or their education in every aspect of their lives. There is no consensus on the standard of proof required for a finding of incompetence. Some states require a showing of clear and convincing evidence. Once a court has made a finding of incompetence, its overriding concern is determining what is in the best interests of the individual, not what represents the individual's wishes.

Incompetence is a finding of last resort and differs from a finding of a lack of capacity. A lack of capacity is much narrower in scope than competency. It focuses on specific problems in a particular area of decision making. Hence, most students with disabilities will be fully competent and able to give informed consent. Some will be competent, but lack the capacity to make decisions about their education and the exercise of their rights under the IDEA. Others may be incompetent in all aspects of their lives.

Case law and the transfer of rights provision of the IDEA Amendments of 1997 make clear that once students with disabilities reach the age of majority, they have the legal right to give informed consent concerning their educational programs if they have the capacity to do so. The

transfer of rights to adult students is not without precedent. The Family Education Rights and Privacy Act (FERPA, 1974) is a federal law designed to protect the privacy of student educational records. Once students, with or without disabilities, reach the age of 18, all FERPA rights transfer from the parent to the adult student. Consequently, adult students assume the rights once afforded to their parents including the right to inspect and review their educational records, contest that which is contained in them, and prevent their release without permission. The IDEA provision to transfer rights merely aligns the disability law with FERPA.

Conclusion

Until a school-aged student reaches the age of majority, minors are presumed to lack the maturity and judgment necessary to make many decisions affecting their lives (e.g., minors cannot marry or get a tattoo without parent permission). Parents, guardians, and even educators are afforded legal rights to act on behalf of these minors, presumably, in their best interests. Thus, school-aged students, including those with disabilities, generally have been relegated to essentially passive roles, leaving others to make important and fundamental decisions for them and their lives. Section 504 and the IDEA require that teams, which may or may not include the students, make the educational decisions affecting them.

Importantly, how and what minor students with disabilities learn about their rights and personal responsibilities through their passive experiences in decision making will not reflect an accurate understanding of their adult rights or responsibilities once they leave the school setting unless the promise of transition planning is made reality. Adult students bear the responsibility to inform the student services office, the instructor, or their employer of their disability needs in post-secondary environments since there is no obligation under the law for these institutions to seek out individuals with disabilities for service.

With the IDEA Amendments of 1997, the expectation that students' involvement in their own educational planning has been strengthened through transition requirements and the transfer of rights provision. All young adults, but especially those with special needs, must become their own advocates. The transfer of rights is an indication of Congress' desire to empower students to take responsibility for the outcomes of their education and particularly in planning for their lives beyond school.

Thus, astute educators who espouse advocacy for students with disabilities will ensure that these young adults have an understanding of their educational rights under Section 504 and the IDEA. Individuals with disabilities, including those with the most severe disabilities, generally are capable of engaging in gainful employment, and the provision of individualized vocational rehabilitation services and education can improve their ability to become gainfully employed. They, too, must learn of their rights under the laws that protect their opportunities to obtain gainful employment in integrated settings and be active participants in their own rehabilitation programs, including making meaningful and informed choices about the selection of their vocational goals and objectives and the vocational rehabilitation services they receive.

Individuals with disabilities and their advocates are full partners in the process of growing into adulthood and its subsequent responsibilities with respect to education choice and program implementation. Ultimately, all students should communicate their goals and view professionals and families as their consultants in making their life choices. Self-determination means that persons with disabilities have the freedom, authority, support, and responsibility for their own lives, including the outcomes of their education. These principles are inherent in the federal laws that protect their rights to become productive citizens.

In sum, a few recommendations included in this paper are included in table form below along with a rationale (see Table 3).

Table 3

Recommendations

Age 14: Transition Planning

Required to prepare students for independent living, post-secondary education, supported or competitive employment

First time student attendance required at IEP; students are to be invited to share their interests, preferences, and needs; should be able to describe their strengths and limitations

Must address student's course of study (e.g., vocational, advanced placement, college prep)

Indication that self-advocacy and self-determination are necessary components of a special education, a FAPE

Enables IEP team to plan curriculum, organize services, and generate resources the student will need when the plan is implemented at age 16

Students have equal opportunity to participate in school-wide initiatives such as School-to-Work projects

Students have a need to know how their disability affects their learning, performance, and behavior

Age 16: Transition Statement

Identifies any interagency responsibilities or linkages necessary for implementation of the transition plan

Includes agency, business or other community representatives, transportation needs

Students need to know the accommodations necessary for success in the classroom and work environment, including social skills, job-seeking skills, teamwork, problem-solving strategies, collaboration, communication and organization skills, career assessment, self-regulation, skills to monitor progress

Age 16 to Program Completion

Modify IEP transition services as needed to accommodate student needs including psychosocial adjustment (e.g., self-advocacy, problem solving), academic development (e.g., career awareness, in-class accommodations, study/research skills), and college and community orientation (e.g., career choices, disability services in colleges)

All students have independent living needs including how to manage a budget, how to spend leisure time, how to set goals and work toward them, how to obtain legal or medical assistance

Students are entitled to know their rights and what services they will need as adults under the Section 504 and ADA; they must know how to exercise those rights

Students and families need to know about adult services and systems so that they can gain access to the services (e.g., SSDI, SSI, Medicaid)

If Authorized by State Law, One Year Before the Age of Majority

Include statement on IEP that parent IDEA rights will transfer to the adult student in one year (if state permits such transfer)

If student lacks the capacity to give informed consent, parent may seek a finding of incompetence in a court of law or, if state law so provides, parent may use state IDEA procedures to retain those rights

Students must have the capacity to give fully informed consent for rights to transfer

Students must be fully informed of the meaning of these rights under the IDEA and their responsibility for exercising them

Age of Majority

IDEA rights transfer to student if permitted by state law; parents and student notified of the transfer

After transfer, parents continue to receive required notices as identified in the procedural safeguards

Parents may continue to attend all IEP meetings if invited by the student or school officials

Parents may seek due process if necessary concerning the transfer

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