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Advocacy and Litigation in Professional Practice

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On June 20, 2002, the Supreme Court of the United States overruled years of settled legal precedent when it declared that the execution of individuals with intellectual disabilities (ID) violated the United States Constitution's Eighth Amendment prohibition against cruel and unusual punishment (*Atkins v. Virginia,* 2002). This decision is the most recent in a line of cases that have been decided over the past 20 years that have changed the legal framework within which professionals who work with individuals with ID must function. As has been the case with most of these legal landmarks, *Atkins* represented the culmination of decades of legal and legislative advocacy on behalf of criminal defendants with ID seeking to bar the imposition of the death penalty in such cases. It had been a long and rocky road in reaching this watershed legal event. Indeed, only 13 years earlier the Supreme Court had ruled that the Eighth Amendment did *not* bar the execution of criminal defendants with ID (*Penry v. Lynaugh*, 1989). What had changed in those intervening years?

THE ROAD FROM *PENRY* TO *ATKINS*

Although 13 years may seem like a long time in the era of the 24 hour news cycle, within the rarified world of Supreme Court jurisprudence, 13 years is tantamount to the blink of an eye. The Supreme Court's decision in *Penry* was a 5 to 4 decision. Of the four dissenters in *Penry*, only Justice Stevens remained on the Court by the time *Atkins* was decided. The two most pro-civil liberties Justices in the dissenting minority, Justices Brennan and Marshall, had long since retired by the time of the *Atkins* decision. Assembling the 6 to 3 *Atkins* majority thus required not simply that

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Justice Stevens maintain his opposition to the death penalty on Eighth Amendment grounds, but also that two Justices from the *Penry* majority—Justices Kennedy and O'Connor—take the extraordinary step of reversing their positions and joining the *Atkins* majority. No one would argue that the Supreme Court had become more liberal, or more favorably disposed toward criminal defendants in the 13 years between *Penry* and *Atkins*—indeed most commentators would argue that the trend was in the opposite direction. What accounts for this change is not simply the vagaries of political appointments and coalition building among Supreme Court Justices. Rather, legal advocates on behalf of criminal defendants with ID, undaunted by their setback in *Penry*, did not relent in their advocacy in the intervening years. Instead, they cannily crafted the legal arguments and the support for those arguments that ultimately carried the day and yielded this landmark victory.

Daryl Atkins was convicted of abduction, armed robbery, and capital murder. The facts of his crime were not in dispute. In the summer of 1997 Atkins and another man, armed with a semi-automatic handgun, abducted a man, robbed him, drove him to an automatic teller machine where they were photographed withdrawing additional money, and then took him to an isolated location where he was shot eight times and killed. The forensic psychologist who testified for the defense concluded that Atkins was mildly mentally retarded, with a full scale IQ of 59. Atkins was sentenced to death, a penalty that was ultimately affirmed by the Virginia Supreme Court.

In justifying its decision to reverse the imposition of the death penalty in Atkins' case, the Supreme Court was compelled to explain what had changed in the 13 years since its decision in *Penry*. Certainly, it was not the plain language of the Eighth Amendment, which had remained unchanged for over 200 years, "Excessive bail shall not be required, nor excessive fines imposed, nor cruel and unusual punishments inflicted." What had changed, in the view of the Court, was the consensus of the American people as reflected in the deliberations of legislators, scholars, and judges. Of particular importance was the fact that in 1989 only two states had expressly prohibited the execution of defendants with ID. By 2002, in contrast, attorneys for Atkins were able to point to 17 states that had enacted such prohibitions. Moreover, even in those states that preserved the practice, only five had executed a defendant with a known IQ of less than 70 in the years since the Court had decided *Penry*. As a result, the Court concluded that "the practice has become truly unusual, and it is fair to say a national consensus has developed against it" (*Atkins v. Virginia*, 2002, p. 316).

Moreover, Atkins' counsel was able to cite significant clinical research that had been published in the years since *Penry* was decided. Indeed, *Atkins* is an object lesson in how the influence between litigation and professional practice is a two-way street. The Supreme Court in *Atkins* cited studies from the field of ID in the areas of self-control, understanding, and suggestibility to bolster their conclusions. This research suggested that the two principal justifications that are typically given in support of capital

punishment—retribution and deterrence—were not applicable to criminal defendants with ID.

The Supreme Court summarized their conclusions in *Atkins* as follows: "Construing and applying the Eighth Amendment in the light of our 'evolving standards of decency,' we therefore conclude that such punishment is excessive and that the Constitution 'places a substantive restriction on the State's power to take the life' of a mentally retarded offender" (*Atkins v. Virginia*, 2002, p. 321). Thus, the legal advocates, citing clinical research, had convinced the Supreme Court to conclude that standards of decency had "evolved," and the resulting interpretation of the Constitution has forever changed the lives of individuals with ID who become entangled in the criminal justice system.

Throughout recent legal history, professional advocacy and litigation have served to open doors for people with ID, as well as providing them with a measure of legal protection that has set them apart from other groups of individuals with disabilities. In *Atkins* this advocacy meant the difference, literally, between life and death for one subgroup of individuals with ID. Yet the *Atkins* decision is simply one very recent and compelling example of the impact litigation can have on the lives of people with ID and the professionals who address their treatment needs. *Atkins* serves as a fascinating case example of the strategies employed by attorneys in persuading the judicial system to take special note of the challenges faced by individuals with ID in American society. These changes can have profound implications for the lives of people with ID, their families, and those who provide services to them.

YOUNGBERG V. ROMEO AND THE RIGHT TO HABILITATION

Although *Atkins* represents a landmark case in the long history of judicial responses to people with ID, its application is, thankfully, limited to a select group of individuals in the criminal justice system. But although *Atkins* is significant in setting limits regarding what government cannot do to people with ID, other cases set the stage for the legal victory enjoyed by criminal defendants with ID in that case. One of the most significant cases in recent years that impacted the rights of people with ID in an institutional setting was *Youngberg v. Romeo* (1982). *Youngberg* established the minimum level of care to which people with ID confined to state institutions are entitled, that is, a standard that must be met or exceeded.

The Youngberg case arose out of a very protracted piece of civil rights litigation brought by people with ID housed at what was then known as the Pennhurst State School in Pennsylvania. Nicholas Romeo was a 33-year-old man with an IQ estimated to be between 8 and 10. He was committed to Pennhurst at the age of 26 years, after his father died. His mother petitioned for Romeo's commitment because she was unable to control his occasionally violent behavior. While at Pennhurst, Romeo was injured on numerous occasions. His mother filed suit on his behalf, claiming that officials at Pennhurst knew or should have known that he was sustaining

these injuries and that they had failed to institute appropriate preventive measures. This failure was characterized as a violation of Romeo's constitutional rights under the Eighth and Fourteenth Amendments. The Eighth Amendment, as we saw in *Atkins*, prohibits cruel and unusual punishment, whereas the Fourteenth Amendment protects an individual's right to personal liberty. In the course of the lawsuit Romeo was transferred from his ward to the infirmary for treatment of a broken arm. While in the infirmary, he was physically restrained on a daily basis. This development resulted in an amendment to the lawsuit, which was revised to allege that Romeo's constitutional rights were violated by the defendants' failure to provide him with appropriate treatment for his mental retardation.

The case was tried to a jury, and Romeo lost. On appeal his lawyers argued that the trial court judge had committed reversible error based on the instructions given to the jury. The appeal ultimately reached the Supreme Court of the United States, which addressed for the first time the rights of individuals with ID confined to state custody. The Supreme Court addressed three issues of historic importance to individuals with ID confined to state custody. First, Romeo claimed that he had the right to safe conditions. Second, Romeo argued that he had the right to freedom from bodily restraint. The third issue, which the Court described as "more troubling," was whether Romeo had the right to adequate habilitation, which the Court defined as the training and development of needed skills. The training Romeo sought was characterized as "minimal" and he left the type and extent of the training mandated by the Constitution to be determined on a case-by-case basis, in light of present medical or other scientific knowledge.

In analyzing these claims the Court began with what it characterized as "established principles." Specifically, citing prior Supreme Court precedent, the Court accepted the proposition that when a person is institutionalized and dependent on the State for his or her care, the State has a duty to provide certain services and care, although the State necessarily has considerable discretion in determining the nature and scope of its responsibilities. In Romeo's case, moreover, his lawyers conceded that no amount of training would have made possible his release from State custody. His needs were described as those for bodily safety and a minimum of bodily restraint. These needs the Court immediately characterized as constitutionally protected liberty interests. The Court then proceeded to dispose of the first two issues presented by the case by concluding that Romeo, and by implication other persons with ID confined to state institutions, had a constitutionally protected liberty interest in having the State provide for him "minimally adequate or reasonable training to ensure safety and freedom from undue restraint" (*Youngberg v. Romeo*, 1982, p. 319).

The Court then proceeded to address how these principles should be applied with regard to the habilitative needs of people with ID confined to state custody in general. It noted that the rights of such individuals to safety from freedom and bodily restraint were not absolute. Rather, these rights must be balanced by certain rights held by the state, such as the need to protect the individual, as well as others, from violence. The Court

therefore stressed that restraint per se was not unconstitutional, and that in order to determine whether an individual's liberty interests had been violated one must determine whether the extent or nature of the restraint or lack of absolute safety was such as to violate the individual's constitutional right to due process.

The Court then proceeded to articulate a test applicable to both Romeo's case, as well as generally to institutionalized individuals with ID:

> [W]e agree that [Romeo] is entitled to minimally adequate training. In this case, the minimally adequate training required by the Constitution is such training as may be reasonable in light of respondent's liberty interests in safety and freedom from unreasonable restraints. In determining what is 'reasonable'—in this and in any case presenting a claim for training by a State—we emphasize that courts must show deference to the judgment exercised by a qualified professional. By so limiting judicial review of challenges to conditions in state institutions, interference by the federal judiciary with the internal operations of these institutions should be minimized. Moreover, there certainly is no reason to think judges or juries are better qualified than appropriate professionals in making such decisions. For these reasons, the decision, if made by a professional, is presumptively valid; liability may be imposed only when the decision by the professional is such a substantial departure from accepted professional judgment, practice, or standards as to demonstrate that the person responsible actually did not base the decision on such a judgment. In an action for damages against a professional in his individual capacity, however, the professional will not be liable if he was unable to satisfy his normal professional standards because of budgetary constraints; in such a situation, good-faith immunity would bar liability (*Youngberg v. Romeo*, 1982, p. 322).

The Court also decided who ordinarily would be qualified to serve in the role of "professional decision-maker." Generally speaking, such professionals should be individuals competent, whether by education, training, or experience, to make the particular decision at issue. Typically, such decisions should be made by individuals with degrees in medicine or nursing, or individuals with appropriate training in psychology, physical therapy, or the care and training of people with ID.

Although *Youngberg* is an important case in setting the constitutional minimum level of habilitation that a person with ID confined to state custody is entitled to, the Court was careful to limit its holding to the facts before it. It did not, for example, address whether, by accepting Romeo for care and treatment, the State could then constitutionally refuse to provide him with "treatment" as that term was defined under State law, rather than simply "habilitation." In addition, the Court brushed upon, but did not expressly decide, the question of whether the "habilitation" to which an individual with ID was entitled required such training as was necessary to preserve the self-care skills he possessed when he first entered

State custody. By addressing the right to habilitation for the first time in its opinion, however, the Court at least set a constitutional limit to the level of neglect the State could permit to exist in its institutions for individuals with ID. As it was doing so, however, forces were at work in society that would render *Youngberg* less relevant to individuals with ID, because fewer and fewer of them would find themselves confined to state custody in institutions.

CITY OF CLEBURNE V. CLEBURNE LIVING CENTER AND THE EQUAL PROTECTION CLAUSE

The conditions at state facilities such as Pennhurst, and legal decisions such as *Youngberg* that effectively criticized these institutions, gave rise to changes in the law through legislation rather than litigation. In 1984, Congress passed the Developmental Disabilities Act (1984). This federal law required the establishment of watchdog organizations in each state that were responsible for protecting the rights of individuals with ID. The Act made it the policy of the federal government to promote the transition of individuals with ID from state run facilities into community settings:

> [T]he goals of the Nation properly include the goal of providing individuals with developmental disabilities with the opportunities and support to (A) make informed choices and decisions; (B) live in homes and communities in which such individuals can exercise their full rights and responsibilities as citizens; (C) pursue meaningful and productive lives; (D) contribute to their family, community, State, and Nation; (E) have interdependent friendships and relationships with others; and (F) achieve full integration and inclusion in society, in an individualized manner, consistent with unique strengths, resources, priorities, concerns, abilities, and capabilities of each individual (Developmental Disabilities Act of 1984, 42 U.S.C. § 6000 (a)(10)).

Although laudable in its effort to set the national agenda for people with ID, much of the language in the Developmental Disabilities Act regarding the goals for people with ID can be described in legalese as "precatory"—words that suggest action, but that lack the "teeth" of an enforcement mechanism. Whatever rights people with ID were entitled to enforce, as of the mid 1980s, arose either out of state law or the language of the U.S. Constitution itself.

As deinstitutionalization took hold as a state policy and practice expedited by federal financing initiatives, however, individuals with ID gradually moved out of institutions and into neighborhoods. As they did so, however, they encountered resistance among local communities. Because a broad statutory mandate prohibiting discrimination against individuals with disabilities by municipalities and private entities did not exist, advocates were once again forced to rely on the somewhat vaguer requirements of the U.S. Constitution. The constitutional bulwark against arbitrary discrimination

by governmental entities is set forth in the Equal Protection Clause of the Fourteenth Amendment, which commands that no State shall "deny to any person within its jurisdiction the equal protection of the laws," and is thus essentially a direction that all persons similarly situated should be treated alike. It was the Equal Protection Clause to which the Cleburne Living Center, which wanted to lease a building for a group home for individuals with ID, had to resort when the City of Cleburne, Texas refused to issue it a special use permit that would allow it to operate (*Cleburne Living Center v. City of Cleburne*, 1985).

In 1980, the Cleburne Living Center (CLC) sought to lease a building for use as a group home for women with ID. CLC planned to house 13 women who would be under the constant supervision of CLC staff. CLC planned to comply with all applicable federal and state regulations. The city informed the CLC that it would have to apply for a special use permit. The city explained to CLC that under the applicable zoning regulations for the site, the proposed group home should be classified as a "hospital for the feeble-minded." Other multiple residence dwellings, such as apartment houses, boarding houses fraternities, and sororities, were not required to apply for such permits. A public hearing was held after which the City Council voted 3 to 1 to deny the special use permit. CLC filed suit in federal court, arguing that the zoning regulation was unconstitutional because it discriminated against people with ID. The trial court ruled in favor of the city. CLC then appealed to the United States Court of Appeals for the Fifth Circuit, which held that the zoning regulation was unconstitutional. As was the case in *Atkins* and *Youngberg*, the matter was then appealed to the United States Supreme Court.

The Supreme Court noted at the outset that without controlling statutory authority from Congress, the Equal Protection Clause itself is a fairly weak weapon against discrimination. Generally, any statute, ordinance, or regulation can survive an Equal Protection challenge if it is "rationally related to a legitimate governmental purpose." Applying this standard, most legislation is found to be constitutional. This general rule gives way only where a statute attempts to classify individuals by such factors as race and national origin. Under these circumstances, the presumption of validity gives way, and the legislation in question will be found constitutional under the Equal Protection Clause only if it is "suitably tailored to serve a compelling state interest." Under this latter test, most challenged legislation is found to be unconstitutional. Thus, unless a person challenging a law can claim that the law perpetuates racial or national origin discrimination, their chances of prevailing in an Equal Protection challenge are very slim.

Other ways of classifying individuals had also been considered by the Court in developing the law of Equal Protection. Gender, for example, was given a special status that fell somewhere between the heightened level of statutory scrutiny applied where laws divided people along racial lines, and the deferential standard applied when race was not an issue. Where a law sought to classify people by gender, the Court had previously held that such laws would violate the Equal Protection Clause unless the gender classification was "substantially related to a sufficiently important governmental

interest." Other classifications, such as age, had been denied any protected status under Equal Protection analysis. Lawyers had come to characterize the three levels of Equal Protection analysis as "strict scrutiny" (race and national origin), "intermediate scrutiny" (gender), and presumptively valid (no protected class at issue).

The question before the *Cleburne* court had never been previously addressed—could an individual's ID status be sufficiently "suspect" that the increased scrutiny applied to legislation that discriminated on the basis race or national origin could be applied, was it more analogous to gender where an intermediate level of scrutiny would be applied, or was it analogous to neither, in which case the government could freely impose this classification with minimal scrutiny? In other words, could people with ID be granted the same protected constitutional status as individuals who were the victims of racial or gender-based discrimination? The determination of whether the City of Cleburne had discriminated against the CLC by requiring it to apply for a special use permit, and then denying the application, hinged upon which level of scrutiny the Court would apply in cases involving laws that treated people with ID distinctly from people without ID.

The Court concluded that classifying people by their ID status could not be considered irrational discrimination akin to racial classifications. Nor could it be deemed a "quasi-suspect" classification such as gender. Rather, the Court held laws that classified people by their ID status were subject to no more protection under the Equal Protection Clause than were laws that classified people by such factors as age. Having reached this conclusion, the Court then easily concluded that the special use permit ordinance was not unconstitutional on its face. But that did not end the inquiry.

The Court also had to consider whether the reasons given by the city in denying the permit were in fact rationally related to a legitimate governmental interest. It easily concluded that in the case of the CLC group home, this minimal standard had not been met. For example, the city argued that the permit should be denied because of the negative attitudes of property owners who lived within 200 feet of the proposed facility. But the Court concluded that irrational fears and prejudices could never support governmental action. Similarly, the city argued that the proposed facility was across the street from a junior high school. But the Court observed that the school itself was attended by 30 students with ID, thus suggesting that this fear too was irrational and not related to a legitimate governmental purpose. The Court thus concluded that the city's action was based on irrational prejudice against people with ID, and that the denial of the application for the special use permit violated the residents' rights under the Equal Protection Clause.

OLMSTEAD V. L.C. AND THE RIGHT TO BE FREE FROM INSTITUTIONAL CONFINEMENT

As the *Cleburne* case clearly illustrates, people with ID could not rely upon the strong constitutional mandate against discrimination enjoyed

by racial minorities and women. By 1990, however, a new statutory enactment, one with "teeth" appeared on the national stage. The Americans with Disabilities Act of 1990 (ADA) was enacted with widespread fanfare as a historic milestone in establishing and enforcing the rights of people with disabilities. Similar legislation had appeared in the past, principally Section 504 of the Rehabilitation Act (1973), but that legislation applied only to programs receiving federal financial assistance. The ADA applied to public and private settings, and included specific commands to administrative agencies to enact regulations that would allow its broad mandate of nondiscrimination to be applied across a wide range of activities in American life. The ADA also provided legal avenues for addressing claims of discrimination both through enforcement by administrative agencies, as well as through private litigation.

Pursuant to the ADA's command, the Attorney General of the United States issued regulations seeking to implement the provisions of Title II, which applied to any "public entity." These regulations included what was called the "integration regulation," which read "A public entity shall administer services, programs and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities" (28 C.F.R. § 35.130(d)). The "most integrated setting" language was further defined as "a setting that enables individuals with disabilities to interact with nondisabled persons to the fullest extent possible" (35 C.F.R. pt. 35, App. A, p. 450). Public entities were required to make "reasonable modifications in policies, practices, or procedures" where necessary to avoid discrimination, unless the public entity could demonstrate that making such modifications would "fundamentally alter the nature of the service, program, or activity" (28 C.F.R. § 35.130(b)(7)).

It was against this legislative backdrop that the Court was required to address a controversy involving two women with ID who went by the pseudonyms L.C. and E.W. (*Olmstead v. L.C.*, 1999). L.C., who had mental illness as well as ID, had been voluntarily admitted to the Georgia Regional Hospital (GRH) in Atlanta in 1992. By May 1993, her condition had stabilized and her treatment team agreed that her needs could be met in community-based programs. She remained hospitalized until February 1996 when she was placed in a community program. E.W. was similarly voluntarily admitted to a psychiatric unit at GRH in 1995. After first trying to discharge her to a homeless shelter (her attorney complained and the plan was abandoned), her treatment team agreed in 1996 that she was ready to be treated in a community-based setting. She remained institutionalized at GRH until 1997.

In May 1995, L.C. brought suit in federal court. She alleged that her rights under the ADA to be placed in an integrated, community-based setting had been violated. E.W. intervened in the lawsuit with an identical claim. The State argued that its failure to place these women in a community-based setting was not discrimination by reason of their disabilities, but, rather that it was unable to implement such placements because of a lack of funding. The State also argued that requiring immediate transfers of patients whose treatment teams had concluded that the patients were ready for such transfers would "fundamentally alter" their

activities, in violation of the public entity's rights under the ADA. The trial court rejected both these arguments and ruled in favor of L.C. and E.W.

The inevitable appeal ensued, and the Eleventh Circuit United States Court of Appeals reversed the trial court's rejection of the State's cost-based defense. It concluded that such a defense may be justified where the expenditure of funds to provide community-based services was so unreasonable, given the demands of the State's mental health budget, that it would fundamentally alter the services the State provides. Once again, the Supreme Court was required to weigh in on this dispute.

Unanimous Supreme Court decisions are relatively rare in hotly contested cases such as *Olmstead*. Generally speaking, a decision is not binding on the parties unless one side can muster five of the Justices to its position. It is not uncommon for some portions of a Supreme Court decision to command the required five votes, and thus become the law of the land, whereas others command less than five, thus becoming little more than miniature law review articles for the enjoyment and befuddlement of legal scholars. The Court's decision in *Olmstead* was thus broken into parts, only three of which commanded a majority of the Court.

The Court was first required to consider whether "undue institutionalization," that is the State's maintaining an individual with ID in an institutional setting where the individual's treating professionals believe that transition to a community-based setting is appropriate, qualifies as discrimination by reason of disability. The Court concluded, with some qualifications, that undue institutionalization was prohibited by the ADA. Its decision reflected "two evident judgments." The first was that institutional placements of individuals who could benefit from community settings perpetuates unwarranted assumptions that such persons are unworthy of participating in community life. Second, confinement in an institution precluded the individual with ID from enjoying everyday life activities, such as family life, social contacts, work options, economic independence, educational advancement, and cultural enrichment.

The Court noted, however, that nothing in the ADA or its underlying regulations mandates the deinstitutionalization of individuals unable to handle or benefit from community settings. The rule ultimately adopted by the Court was reminiscent of its ruling in *Youngberg*, which demonstrated a willingness to defer to professional judgment in matters involving individuals with ID.

> [T]he State generally may rely on the reasonable assessments of its own professionals in determining whether an individual 'meets the essential eligibility requirements' for habilitation in a community-based program. Absent such qualification, it would be inappropriate to remove a patient from the more restrictive setting. Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it (*Olmstead v. L.C.*, 1999, p. 602).

The Court was unable, however, to give clear direction to the lower courts regarding the manner in which courts should address the State's argument

that cost limitations could serve as a defense to the ADA's deinstitutionalization mandate. Four Justices voted in favor of a standard that would have required the lower courts to consider the resources available to the State for individuals with ID, while also considering the needs of others with mental disabilities. A majority of the Justices appeared to believe that the State was entitled to raise as a defense that the expenditure of funds required for deinstitutionalization could represent a prohibited "fundamental alteration" of the State's programs under the ADA. The precise contours of this argument, however, did not command a majority of the Justices, leaving this issue for another case to definitively decide.

THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT—BEYOND HABILITATION

As the discussion of the preceding cases demonstrates, progress for protected populations such as individuals with ID takes time in the world of constitutional jurisprudence. Moreover, the courts appear reluctant to grant this population rights beyond vague references to "minimal progress," "habilitation," and "reasonable accommodation"—all of which depend on the subjective discretion of professionals. The one area where Congress and the courts have required a more particularized effort to enhance the functioning of individuals with ID, and something more than subjective standards of accountability, has been in the area of the education of students from birth to the age of 18. The Individuals with Disabilities Education Act (IDEA) mandates not only that school districts locate and educate students with disabilities, but also requires that these students must make measurable educational progress no matter how severely impaired they may be. Like the ADA, IDEA provides for enforcement of the individual with ID's rights. Unlike the ADA, IDEA sets the standard to which the State is held at a level above that of simple "habilitation."

One of the bedrock principles underlying IDEA is that of "zero reject." Zero reject describes the policy shift toward the view that an appropriate education is the right of all students, regardless of disability status. Thus, students may not be categorically excluded on the basis of a disability. Instead, students eligible for special education services must be provided with appropriate services and aids. The broad scope of special education law is illustrated by the case of *Timothy W. v. Rochester, New Hampshire School Dist.* (1989). That case concerned a severely handicapped child with, among other conditions, severe metal retardation, complex developmental disabilities, spastic quadriplegia, cerebral palsy, and hydrocephalus, which had destroyed a large part of his brain. All of this combined to leave the child in a vegetative state, although there was testimony that he could see bright light, could smile, and responded to touching and talking.

In response to the severe nature to the child's disability, the school district refused to provide any special education services based upon its conclusion that he would not be able to benefit from such services. When the child's parents brought suit, the federal court held that a child with

disabilities did not need to be able to demonstrate an ability to benefit from special education services in order to be eligible. Instead, the school had a duty to provide special education services to every such child, regardless of the severity of the disability or the level of achievement possible for the child. This case illustrates starkly that no child, regardless of the severity of his or her disability, may be denied services under IDEA. Under IDEA all eligible students are entitled to a free appropriate public education (FAPE), which must be composed of a written statement of goals and objectives, as well as the special education and ancillary services needed to help the student attain these goals. This plan is known as an Individualized Education Program (IEP).

Virtually all students with ID are likely to be eligible under the definition set forth under the regulations implementing IDEA. To qualify as a student with "mental retardation" under IDEA requires that the student have "significantly subaverage general intellectual functioning, existing concurrently with deficits in adaptive behavior and manifested during the developmental period, that adversely affects a child's educational performance" (34 CFR § 300.7(c)(6)). Similarly, IDEA makes it clear that all students with ID, not simply those likely to benefit from instruction, must be integrated with nondisabled students to the maximum extent possible. This is called the Least Restrictive Environment (LRE) requirement of IDEA. It sets a much higher standard than the one articulated by the ADA and interpreted by the Supreme Court in *Olmstead*. To the maximum extent appropriate, children with disabilities, including children in public or private institutions or other care facilities, are to be educated with children who are not disabled. Special classes, separate schooling, or other removal of children with disabilities from the regular educational environment should occur only when the nature or severity of the disability of a child is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily (20 U.S.C. § 1412(a)(5)).

The power of the LRE concept is frequently illustrated in the cases that have arisen under IDEA. Neil Roncker was a 9-year-old student classified as trainable mentally impaired ("TMI") (*Roncker v. Walter*, 1983). Neil also had seizures, although his seizures were nonconvulsive and were controlled by medication. Both the parents and the school district recognized that Neil would require some type of restrictive placement but disagreed on the level of restrictiveness. The parents wanted Neil educated in a placement that would expose Neil to his nondisabled peers during gym, lunch, and recess. The district wanted to place Neil in a county school for children with ID.

The court framed the LRE issue under IDEA as follows:

> In a case where the segregated facility is considered superior, the court should determine whether the services which make that placement superior could be feasibly provided in a nonsegregated setting. If they can, the placement in the segregated school would be inappropriate under the Act. Framing the issue in this manner accords the proper respect for the strong preference in favor of mainstreaming while still realizing the

> possibility that some handicapped children simply must be educated in segregated facilities either because the handicapped child would not benefit from mainstreaming, because any marginal benefits received from mainstreaming are far outweighed by the benefits gained from services which could not feasibly be provided in the nonsegregated setting, or because the handicapped child is a disruptive force in the nonsegregated setting (*Roncker v. Walter*, 1983, p. 1063).

The approach to services under IDEA is thus much more hostile to institutional placements than that employed using either constitutional principles or the ADA. It is *presumed* that students with ID should be treated in a mainstream setting unless it can be *proven* that they cannot benefit from such a setting.

Unlike the approach to these issues under the principles of constitutional law, or even those of the ADA, cost is rarely recognized as a defense to providing services for students eligible under IDEA. If a particular program or service is required to provide a disabled child with FAPE, it must be provided, regardless of cost: The Supreme Court has specifically rejected cost as a defense to the provision of services. An illustrative case, *Cedar Rapids v. Garret* (1999), involved a student who was injured when his spinal cord was severed in a motorcycle accident, was ventilator-dependent and required continuous care, including urinary bladder catheterization once a day, suctioning of his tracheotomy tube as needed, being placed in a reclining position for 5 minutes per hour, ambu bagging occasionally while his ventilator equipment was tested, assistance in case of ventilator malfunction, and emergency services in the event he experienced autonomic hyperflexia.

The student's family personally attended to him during kindergarten and used settlement proceeds, insurance and other resources to employ a nurse for the next 4 years. When these funds ran out, the family asked the district to accept financial responsibility for his needs during the school day. The Supreme Court rejected the district's claim that the continuous care required by the student was too costly. Although recognizing that the District may have legitimate financial concerns, the Court concluded that the necessary services were required to provide the student with meaningful access to the public schools. Thus, the District was required to fund the services.

CONCLUSIONS

Although the injustices of the past will continue to linger, litigation by attorneys and advocacy by professionals in the field of ID, working together, have produced much to be proud of in terms of accomplishments over the past three decades. Presumptions in favor of institutionalization are being gradually transformed into presumptions in favor of integration into the community. The execution of criminal defendants with ID has been declared unconstitutional. Although the legal rights of adults with

ID continue to evolve, litigation under IDEA has established that young people with ID, and with other disabilities, have a statutory entitlement to a free appropriate education in the least restrictive environment. This progress will, no doubt, continue. Although the broad contours of the rights of people with ID have been drawn, much remains to be filled in. Issues of cost/benefit in treatment and education will continue to occupy the courts for some time to come. What constitutes adequate progress toward clinical goals remains a hotly debated topic within the legal, educational and clinical communities. As long as people of good may continue to differ on these points, and cannot come to consensus, litigation will remain one avenue of addressing and resolving these disputes.

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