

Government, Law and Policy Journal



A Publication of the New York State Bar Association
Committee on Attorneys in Public Service, produced in cooperation with the
Government Law Center at Albany Law School

Civil Rights and Disabilities Law



The Committee on Attorneys in Public Service

2013 Annual Meeting Program and Awards for Excellence in Public Service



Tuesday, January 22, 2013

Hilton New York

1335 Avenue of the Americas (53rd-54th Sts.)

Supreme Court Update

(9:00 a.m. – 12:15 p.m.)

Social Media and Legal Ethics

(2:00 p.m. – 4:30 p.m.)

2013 Awards for Excellence in Public Service Reception

(5:30 p.m. - 7:00 p.m.)

2013 Honorees:

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Hon. Judy Harris Kluger

Deborah Liebman

Committee on Attorneys in Public Service:

Catherine A. Christian, Chair

Awards Committee Chairs:

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Message from the Chair

By Catherine A. Christian

I am very proud to be a lawyer. I am a member of a profession that allows me the opportunity to perform public service every day. I have been fortunate to have found a career that has brought me professional fulfillment. My membership in NYSBA has contributed greatly to that fulfillment. I immediately said yes when President Seymour James asked me to Chair the Committee on Attorneys in Public Service (CAPS). The majority of my career has been spent as a prosecutor in the New York County District Attorney's Office and the Office of the Special Narcotics Prosecutor for the City of New York. When I became President of the New York County Lawyers' Association (NYCLA) in 2007, I received a congratulatory letter from John Buonora, who was the President of the Suffolk County Bar Association. John was then the Chief Assistant District Attorney in the Suffolk County District Attorney's Office. John wrote: "I have always believed that more prosecutors should be made aware that they are part of the larger family of lawyers represented by bar associations and that all lawyers have much more in common than some might think." I have frequently repeated John's comments to my colleagues and to other public sector attorneys.



As a member of the NYSBA House of Delegates, Executive Committee and past member of the Nominating Committee, I know that public sector attorneys are a much needed voice in discussions about policies and issues that are central to NYSBA's priorities, including recommendations for legislation that affect the practice of law in New York State. Much of my professional development as a lawyer has been obtained through the activities I have engaged in as an active bar association member. I have been fortunate that all three of my bosses, Robert M. Morgenthau, Cyrus Vance Jr. and Bridget Brennan, have supported my work as a bar leader. I encourage other public sector employers to be equally supportive of their attorneys' bar association activities.

I am honored to serve as Chair of CAPS and am looking forward to continuing the CAPS mission to serve New York public service attorneys lawyers by promoting the highest standards of professional conduct and competence, providing a network system to bring together public service attorneys to further their common interests, and highlighting the exceptional work done by public service attorneys.

The Committee is working on a number of initiatives and programs that will interest public service attorneys for 2012-2013. In September we had a well-received Citation

for Special Achievement in Public Service Program. This year the program was a luncheon held in New York City at NYCLA. The Subcommittee on Awards and Citations, co-chaired by Donna Giliberto and Terri Egan, originated the Citation award during 2008. The subcommittee solicited nominations for the citations, reviewed all nominations received, and identified the most worthy nominees. The subcommittee then presented a list of finalists to the full CAPS committee from which the citation recipients were chosen. Our 2012 Citation winners were Jonathan Darche, an assistant district attorney in the Queens County District Attorney's Office, and Karen Freedman, Executive Director of Lawyers For Children, Inc. Our guest speakers were *Times Union* reporters Casey Seiler and Jimmy Vielkind. Both gave an informative and interesting presentation on covering the passage of the landmark marriage equality legislation.

The Honorees for the 2013 Awards for Excellence in Public Service are the Honorable Carmen Beauchamp Ciparick, Honorable Judy Harris Kluger, and Deborah Liebman. The awards will be presented at a reception on Tuesday evening, January 22, 2013 at the New York State Bar Association Annual Meeting in New York City.

Our Subcommittee on Ethics, co-chaired by Hon. James McClymonds and Steve Krantz, will be working on updating the *Ethics in Government* publication and will continue to review the Rules of Professional Conduct and the rules most relevant for the public service attorney.

Our Subcommittee on the Administrative Law Judiciary co-chaired by Hon. James F. Horan and Hon. Elizabeth H. Liebschutz organized with the NYSBA Committee on Continuing Legal Education a Fall 2012 CLE Program, *Administrative Hearings Before New York State Agencies*. The program was held on November 27 in Manhattan and December 5 in Latham.

We have created a new Subcommittee on Outreach to Law Schools and Law Students. The subcommittee is tasked with providing law students with information about various public sector attorney positions, practical advice about securing positions and introducing the students to the various career opportunities available in local, state and federal government. CAPS members will participate in upcoming NYSBA career events at law schools.

Please join CAPS during 2012-2013 at one or more of our events. I invite you to join CAPS and meet other public sector attorneys and other members of the bar represented in NYSBA Committees and Sections.

Finally, a big thank you to Rose Mary Bailly for her continued dedication and tireless work as editor-in-chief of the *Government, Law and Policy Journal*. Rose Mary has assembled a stellar group of authors and informative articles for this issue dedicated to disability issues and law.

Editor's Foreword

By Rose Mary K. Bailly

Bridgit Burke, Esq., Professor and Co-Director of the Civil Rights and Disabilities Law Clinic, and my colleague, graciously agreed to be the Guest Editor for this issue of the *Government, Law and Policy Journal*. The thirtieth anniversary of the Civil Rights and Disabilities Law Clinic at Albany Law School is an excellent opportunity for celebration and a perfect time to examine the influence of disability law on individuals, families and government. She has assembled an outstanding group of experts who do just that. We are grateful to Bridgit and her authors for highlighting the range of issues in disability law.

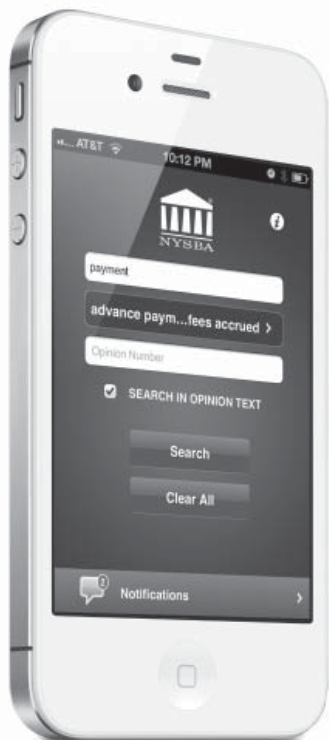
I would like to especially thank our Executive Editor for 2012-2013, Stefen Short, Albany Law School, Class of 2013, for his professionalism and enthusiasm. He and his Albany Law School colleagues, Laura Bomyea, Edward DeLauter, Katharine Fina, Evamaria Kartzian, Craig Mackey, Dave Schreiber, and Katie Valder, all members of the Class of 2013, worked extremely hard to help create



this issue. My thanks also to the staff of the New York State Bar Association, Pat Wood, Megan O'Toole, Lyn Curtis and Wendy Harbour, for their help, expertise and most especially their patience. And last, my thanks to Patty Salkin, now Dean of Touro Law Center, for her inspiration.

Finally, I take full responsibility for any flaws, mistakes, oversights or shortcomings in these pages. The errors are entirely my own. Your comments and suggestions are always welcome at rbail@albanylaw.edu or at Government Law Center, 80 New Scotland Avenue, Albany, New York 12208.

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Guest Editor's Foreword

By Bridgit Burke

This issue celebrating the thirty years of the Civil Rights and Disabilities Law Clinic (Clinic) at Albany Law School highlights the relevance of disability law to a wide range of legal practices, government entities and the lives of over 36 million Americans.¹ Each of the authors in this edition has made significant contributions to this area and many of them began their careers at the clinic. In the first article, Nancy Maurer, Esq. and I relay how the Clinic has influenced the lives of law students, clients and the law.



"[T]his issue explores many of the ways in which the dynamic nature of law and policy [for individuals with disabilities] play out."

Public education in the United States has played a significant role in addressing the disadvantages and discrimination faced by individuals with disabilities. Given the significance of education, several of the authors have examined the federal and state laws that provide for a free appropriate public education for individuals with disabilities. Lauren Mechaly, Esq. examines special-education advocacy in New York City, Rosemary Queenan, Esq. looks at the need for a change in the standard used to determine when to provide extended school year services for identified students, and Tara Moffett, Esq. reveals for us the interplay between the foster care system and the Individuals with Disabilities Education Act.

While great strides have been made in moving individuals out of institutional settings and into the community, New York still provides services to many individuals in institutional setting. Certainly there have been improvements in the care and treatment of individuals with disabilities in institutional settings. However the incidence of abuse and neglect in these institutions is incredibly disturbing. It is critical that we have a vigorous oversight system and that we find new ways to ensure that the system addresses preventing abuse and holding abusers accountable for their actions. Sheila Shea's article, *The Mental Hygiene Legal Services at 50: A Retrospective and Prospective Examination of Advocacy for People with Mental Disabilities*, demonstrates that Mental Hygiene Legal Services

has played an important role in ensuring that individuals in an institution have a voice. Jennifer Monthie's article, *New York Reforms Its System of Protection for Vulnerable Individuals*, explores the development of the Justice Center, the government agency which will be established over the next year to oversee all of the New York State government agencies that serve individuals with disabilities in an institutional setting.

New York officials have expressed a commitment to serving more individuals in the community and fewer in institutionalized settings. However, to achieve this objective, the health care systems in New York will need to find new ways to serve individuals in need of supports. Edward Wilcenski and Tara Anne Pleat's article explores tax incentives available for individuals with disabilities. Michael Mule provides some very valuable information about accommodations required under the Americans with Disabilities Act, particularly with respect to communication with individuals who are deaf and hard of hearing. Finally, Thomas Benjamin looks at those who become disabled while working in the workers' compensation system.

The areas of law and policy touched by matters relevant to individuals with disabilities are too vast to explore all of them in a single issue. However, this issue explores many of the ways in which the dynamic nature of law and policy in this area play out. I hope that readers will begin to appreciate the omnipresent and complex nature of this area of practice and the important ways in which attention to this area will influence people's lives.

Endnote

1. 2010 American Community Survey; Disability Statistics, www.disabilitystatistics.org. (36 million captures only adults who are not living in an institutional setting; therefore, the actual number is far greater.).

Professor Bridgit Burke has been a part of Albany Law School's clinical program since 1994 and has served as the Director of the Civil Rights and Disability Law Clinic since 2000. In 2011 she accepted the Clinical Legal Education Association's Award for Excellence in a Public Interest Case, for the work students have done on behalf of individuals with developmental disabilities under her supervision.

Professor Burke is the interim Co-Director of Albany Law School's Law Clinic and Justice Center with Professor Nancy Maurer.

Albany Law School's Civil Rights and Disabilities Law Clinic: Thirty Years of Education and Experience

By Nancy Maurer and Bridgit M. Burke

Thirty years ago I sat behind a partition in a "study room" on the third floor of Albany Law School preparing for the inaugural semester of the Civil Rights and Disabilities Law Clinic.¹ I became interested in the field in the late '70s, in part because this was the new frontier in civil rights. The Rehabilitation Act of 1973 prohibited discrimination against people with disabilities by recipients of federal financial assistance. The Education for All Handicapped Children Act of 1975 guaranteed to all children—regardless of severity of disability—the right to a free and appropriate public education. Regulations implementing these statutes were being adopted just as I graduated from law school. The Developmental Disability Assistance and Bill of Rights Act established a national system of Protection and Advocacy for people with disabilities. There was much to be done.



Nancy Maurer

its kind in the nation.⁴ The Clinic is also part of the New York State's federally mandated system for providing Protection and Advocacy (P&A) for people with Developmental Disabilities.⁵ In 1975, Congress passed the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) in response to atrocities that had come to light in state-run institutions for people with disabilities.⁶



Bridgit M. Burke

Willowbrook in Staten Island was perhaps the most notorious of these facilities and was the subject of news exposés and on-going litigation.⁷ Also, in 1977, New York established the Commission on Quality of Care for the Mentally Disabled (now the Commission on Quality of Care and Advocacy for Persons with Disabilities, CQC) as the state's response to the atrocities. In 1980, Governor Carey designated the CQC to be the P&A agency in New York.⁸ The CQC, in turn, entered into contracts with legal services offices and public interest law organizations around the state to perform the important P&A functions.

It is in this context that as a young "P&A" staff attorney at the CQC, Nancy Maurer, proposed developing a clinic at Albany Law School. A law school clinic would involve law students in representing clients under experienced attorney/faculty supervision as part of the legal educational program. It would bring a new dimension to our P&A system—the training of a new generation of lawyers knowledgeable about disability rights. CQC Chair Clarence J. Sundram supported the program: "Our concern had been there were relatively few lawyers coming out of law school knowing much about disabilities and the law." He further cautioned that "[a]ttorneys often don't want to get involved in these areas because, No. 1, they don't know much about it, and No. 2, their clients can't afford to pay their fees."⁹

The newly formed clinic would address these issues by fulfilling two interrelated missions: first, it would enhance the students' legal education by integrating the learning of substantive law with the development of legal and professional skills and exploration of the values associated with the practice of law; and second, it would provide legal representation to individuals with developmental disabilities. Since the fall of 1983, Albany Law School has continuously served both its educational and client service missions.

As I got down to work in my makeshift office, developing my first syllabus for the classroom component of the course, gathering materials, and drafting petitions for student practice, I could not have imagined that 30 years later the Clinic would still be here serving both law students and clients. The Clinic, in fact, has thrived as an experiential course in which law students learn law, skills, and values of the legal profession while representing real clients under attorney/faculty supervision. At the same time, despite progress, the field of disability law continues to be both cutting edge and vital to protecting and advocating for the rights of people with disabilities.²

This volume of the *Government, Law and Policy Journal* celebrates the work and legacy of the Civil Rights and Disabilities Law Clinic. The articles in this edition were written primarily by Clinic alumni—an important part of that legacy. In this article we highlight a few of our cases, clients, and students, as we reflect on the impact the Clinic has had on law students' education, individual client's rights, and the development of law and policy affecting people with disabilities.

I. Creation of the Civil Rights and Disabilities Law Clinic

Established in 1983, Albany Law School's Civil Rights and Disabilities Law Clinic (Clinic) was one of the first law school clinics to teach law students through the representation of individuals with disabilities,³ and it is the third longest continuously running clinical program of

In 1984, the Clinic moved from the small study room where the inaugural semester was prepared to the basement of a state office building across the street from the law school. There, despite limited budgets, make-shift office space, and hand-me-down furniture,¹⁰ the Clinic flourished.¹¹ By 1990, Albany Law School began to invest more fully in clinical legal education. The office space was given a makeover, and clinical “instructors” were recognized as clinical “professors.” In 2001, the Clinic moved to the current location—a state of the art law office shared with the five other in-house clinics: Health Law, Family Violence Litigation, Introduction to Litigation, Low-Income Taxpayer, and Domestic Violence Prosecution Hybrid.¹² Collectively, these clinics and an extensive field placement program¹³ became the law school’s award winning Law Clinic and Justice Center.¹⁴

As proposed thirty years ago, the Clinic was designed to assist students in developing competencies in 1) substantive knowledge of law and procedure, 2) practical legal skills including interviewing, counseling, negotiating, writing, and trial advocacy, and 3) professional ethics and values. This would be accomplished through student participation in classes, simulations, and supervised client representation including individual and small group conferences with the “instructor.” Students were expected to work approximately 10 hours per week on cases and attend a two-hour weekly class. They earned 2 pass/fail credits.¹⁵

We continue to use the same basic educational format of supervised client representation, along with classes and case reviews combining substantive law, skills and professionalism. Today we also focus intentionally on diversity, cultural competence, judgment, and professional identity. Students now participate in the Clinic for up to 6 graded credits/per semester.¹⁶

In the nearly thirty years since the Clinic first opened its doors, approximately 400 students have participated in and contributed to the representation of over 1,600 clients on matters ranging from special education rights to claims of discrimination in housing, employment or access to services, and protection of family rights. The Clinic has been engaged in matters that have had a significant impact on individual clients as well as groups of clients and the development of the law.¹⁷ In the course of representing clients, law students have appeared in a variety of administrative forums and in just about every level of state and federal courts including the United States District Court,¹⁸ United States Second Circuit Court of Appeals,¹⁹ New York State Supreme Court,²⁰ New York Supreme Court, Appellate Division,²¹ and the New York Court of Appeals,²² as well as various lower courts.²³ In one long-standing clinic case, students assisted in the preparation of briefs before the United States Supreme Court.²⁴

II. Integration of Education with Client Representation and Development of the Law

The Clinic united Albany Law School’s interest in enhancing its clinical legal education options for law students with its goal of serving the community and assisting individuals who might otherwise not have access to the justice system. At the same time, the Clinic would leave its mark on disability law and train a cadre of future lawyers capable of representing clients with disabilities into the future. As originally conceived, the Clinic captured much of what we still try to do thirty years later—prepare our students “for intelligent, creative and ethical participation in the legal profession by offering opportunities to develop habits of critical analysis, understanding of theory, acquisition of professional skills, a deep commitment to justice and service, and an appreciation of the dignity and responsibility that accompany membership in the profession.”²⁵

A. The Impact of the Clinic Experience on Law Students

Students who have participated in the Clinic have had a significant role in the development of disability rights law. Many of them have gone on to practice in the field and many have contributed to the law in other ways. They have all seen the impact they, as lawyers-to-be, can have on the lives of their clients. They have learned from their professors, clients and colleagues. The clinic experience, coupled with their reflection on the experience, has helped shape their professional identity. While Clinic graduates go on to varied careers, they all enter practice with a greater awareness of disability law, the biases and discrimination that impact individuals with disabilities, and the contributions that individuals with disabilities make. They also develop an understanding of the power of the law in a real world context and their role in the legal profession.²⁶

In its first few years, the majority of the Clinic’s clients were children with disabilities and their families seeking to enforce a child’s right to free and appropriate public education. The Individual Disability Education Act (“IDEA,” then known as the Education for All Handicapped Children Act) was still fairly new. The United States Supreme Court had just decided *Rowley v. Board of Education* interpreting the IDEA mandate to furnish all children with disabilities with a free and appropriate public education.²⁷

In 1984, the Clinic was asked to assist A.T., a medically fragile five-year-old boy with multiple severe disabilities, in a hearing to challenge his school district’s proposed change in his educational program and placement.²⁸ A.T.’s family care provider, parents, teachers, physicians and others who educated and cared for him, believed that he would be irreparably harmed if he were removed from the unique specialized school setting that offered the inter-related services he required. For two years, law students

participated in fact investigation, negotiation, case planning, client and witness interviewing, two lengthy special education impartial hearings (lasting seven and five days respectively) and administrative appeals, and finally an action in United States District Court.

The case was ultimately resolved in A.T.'s favor when the Court decided that the school district had "failed to offer [A.T.] an educational program that was reasonably calculated to enable him to receive educational benefits."²⁹ The Court noted the school district's failure to give "serious consideration to the opinions of those most knowledgeable about [A.T.]"³⁰ and found that "such failure was in contravention of the procedural requirements of the [IDEA]."³¹

In 1985–86, as a law student in the Clinic, Sheila Shea '86, worked on A.T.'s special education case. Sheila, the daughter of a New York State Supreme Court judge and the sister of a boy with severe disabilities, was profoundly impacted by her experience in the Clinic. While planning and strategizing for the case and preparing briefs and witness testimony, she saw how her own family influences could be used to inspire a meaningful legal career.

The Clinic gave me a vision of what I could do with a law degree. It was like a light came on. I was able to put both of these important influences together at the clinic. I found a way to be a lawyer and have a profession that benefits people with disabilities. The traditional law school curriculum didn't lend itself to that understanding. I didn't know what could be possible until I had the clinic experience.³²

After graduation, Shea worked in private practice briefly. When an opening came up at Mental Hygiene Legal Services, she jumped at the chance to practice disability law. "Where else can you have such an impact on real people and policy? You are a voice for the vulnerable.... it is inspiring."³³ She has been with Mental Hygiene Legal Services for twenty five years and for the last five years has been the Director of the Mental Hygiene Legal Services in the Third Department. Her article in this volume looks at the changing role of Mental Hygiene Legal Services in advocating for clients with mental disabilities.³⁴

As Sheila Shea was graduating, others joined the Clinic and their experience in the Clinic had a similarly profound impact. Joe Connors '88 signed on in the fall of 1986, and for all intents and purposes, (except for a four-year stint at Monroe County Legal Services) he never left. He, too, attributes his development and identity as a lawyer to his experience in the Clinic.³⁵ Joe, now Director of the Law Clinic & Justice Center's Health Law Clinic, has vivid memories of his first client. "Her birthday was April 15, and she hated having a birthday associated with tax day." He learned about "client-centered" representation from representing her and advocating for her goals. Her school

district had not found an educational program for her and she had been at home without an educational program until the Clinic intervened and negotiated a settlement with her school district.

As a clinical professor, Joe Connors finds that the biggest impact on students is the inspiration derived from the guided practice experience. Students "take away the success stories" from their time in the Clinic. They must tell a client's story and apply general principles of law to practice. They see it come together. Joe, himself, was able to make connections as a Clinic student and meet a community of advocates and lawyers who would help him land his first law job with Monroe County Legal Services. After four years in practice, he was able to come back to practice in the Clinic, first as a staff attorney, and ultimately as a professor.

Students in the Clinic learn more than law and skills. They also develop important life lessons about what it means for a person to have a disability. The answers are variable and depend on context and perception. As Clinic alumnus Edward Wilcenski '95 recalls:

During my tenure at the Clinic I represented a young girl with Asperger's Syndrome. This was over 15 years ago. At that time, Asperger's was an unfamiliar term, and autism had not yet become as widely recognized a disability as it is today. I remember struggling to understand the nature and scope of this particular disability, as it can manifest itself in such subtle ways. It was the perfect introduction to the idea that the term "disability" belies simple definition and can mean different things in different contexts...³⁶

Edward Wilcenski's firm specializes in estate planning and special needs trusts for people with disabilities. His article regarding the ABLE Act, a type of tax-deferred account for people with disabilities, is also included in this edition. Developing an understanding of disabilities and how they impact clients is an important competency for lawyers given the huge numbers of people who are impacted by them. In 2010, nearly 12 percent of the population in the United States was identified as having a disability.³⁷

Bridgit Burke '89, like Sheila Shea and many other law students over the years, was drawn to the Clinic because of her family's experiences.

My brother was diagnosed with schizophrenia as a young adult, and my mother spent a fair amount of her time, when I was growing up, as a parent advocate for her son and other individuals with disabilities. While I came to law school thinking that I wanted to practice family law,

my experience in the Clinic showed me that there are many ways that lawyers can serve their communities.³⁸

After graduation, Professor Burke did practice family law for a brief time; however, she quickly was drawn back into public interest work, working for four years in legal services.

For the last seventeen years, my passions have brought me back to the Civil Rights and Disability Law Clinic. My students have learned many lessons beyond the substantive law that I teach. These lessons have included important skills, such as communication, brief writing, oral advocacy, negotiations, problem solving and tenacity. My students have also developed their instincts for critical professional values such as client centered representation, self-reflection and social responsibility. Most importantly the students learn how to exercise professional judgment.

Regardless of the career path Clinic graduates take, they are able to apply lessons learned from their disability rights clinic experiences: tenacity in advocating for a client or cause, self-reflection to enhance continued learning, collaboration and the importance of drawing on the experiences of others. Michael O'Leary '07 reports, for example, that he relies on the lesson in "tenacity" learned in the Clinic to his job as Assistant Comptroller at the Office of New York State Comptroller:

At one point, Professor Burke called me into her office and asked me about one of my cases. I had been turned away by a couple of agencies [when seeking information for a client], and I was getting frustrated. She told me that I was too easily taking "no" for an answer, and that I needed to keep pushing. If the answer was not directly in front of me, I needed to get creative. If I was turned away the first time I called, I needed to call again. And again. It was a very critical meeting, but it motivated me to stop accepting what [the agencies] were telling me so quickly, and continue to push. That lesson in tenacity has served me well in my career.³⁹

We attempt to impress upon the law students that there are many lessons to be drawn from experience in practice, and that it is essential that students and practicing lawyers spend time reflecting on their experiences to make the most of them. It is through reflection that we continue to learn from experience.⁴⁰ Justin Myers '07, now in private practice, continues to benefit from the skill of reflection as a means of improving his practice and judgment:

The Civil Rights and Disabilities Law Clinic taught me that the most successful advocates not only achieve the client's goal, but do so in a way that ensures the client's dignity throughout the representation. Although clients may have similar legal issues, a cookie-cutter approach often fails to take client's unique values into consideration. Just as important as giving thought to the client's experience, the Clinic instilled the importance of routine self-reflection. Honest self-reflection is a humbling process that reminds me that the "practice" of law always contains short-comings, and always leaves room for improvement.⁴¹

Clinic students also learn from each other and even from prior students. On occasion, Clinic graduates will return to the Clinic to share lessons learned and new found expertise and assist the current students in representing Clinic clients. Five years after he graduated, Edward Wilcenski '95 had a chance to assist in the preparation of an oral argument on behalf of his former client. As a Clinic student in 2001, Michael Krenrich⁴² '02, was preparing to argue before the Appellate Division on behalf of a client who had been challenging a guardianship petition for twelve years. He prepared diligently, spending hours each day researching, working and reworking his argument.⁴³ Edward Wilcenski had successfully argued a related case before the Appellate Division when he participated in the Clinic, and he was familiar with the client and case history.⁴⁴ He assisted in Michael's preparation taking on the role of "judge" in practice oral arguments. Our client, again, received a favorable Decision.⁴⁵

Similarly, Clinic law students have drawn on the work of prior students and faculty and earlier clinic cases to advocate for the rights of their clients. In 1989, Clinic Professor Connie Mayer (now Associate Dean for Academic Affairs) and her Clinic students represented an employee "ombudsman" of the New York State Office of Mental Retardation and Developmental Disabilities in the New York State Supreme Court and were successful in establishing the independence of the office of the Ombudsman in an institutional setting.⁴⁶ Over 20 years later, in 2011, two of the Clinic students were able to rely on that case to support their efforts on behalf of institutionalized clients.⁴⁷

Recently the law students participating in the Clinic have had opportunities to develop professional relationships with parents, clients, experts and lawyers by collaborating for the freedom of their clients who remain in the institutional setting. Students have seen institutions from the inside, providing them a unique perspective on the impact of health care policies which support institutionalization and stifle the development of community living. As they are poised to begin their careers, many in the public sector, they have observed that the administrators in

institutions where their clients live benefit from working collaboratively with advocates to identify problems and implement solutions. This lesson of collaborative reform is one that can benefit students who move on to do civil rights advocacy and students who work in the public sector.

As a Clinic student, Michael Mulé '05 was able to arrange for his client's mother to have Spanish interpretation when communicating with the staff at the institution on critical issues related to her son's care. He recalls the experience of working with the families and the clients:

My most memorable experience was talking to the Spanish-speaking mother of my client and realizing that she did not understand the treatments, medications and services that were being provided to her son who had been placed at a youth psychiatric facility. In the Clinic, I learned how to deal with these difficult moments and work together with my clients to come up with solutions to the issues they were confronting.⁴⁸

Michael is now with the United States Department of Justice investigating discrimination complaints in the Civil Rights division. Upon graduation, he received the 2005-2007 Hanna S. Cohn Equal Justice Fellowship, during which he developed a project at the Empire Justice Center in Rochester, New York, devoted to the rights of non-English speaking individuals to translation.

B. Impact on Disability Law

The work that the law students have done in the Clinic has not just shaped the professional lives of the students, but has also shaped disability law. The law students have raised awareness of the rights of individuals with disabilities, allowed courts to clarify those rights, and improved the systems that serve their clients through policy and regulatory reform. For example, the court's decision in the case Sheila Shea worked on as a student illustrated the importance of involving people who know a child best in making educational decisions, and supported damages to reimburse families for costs when their children's rights are denied.⁴⁹ The Clinic representation of a client whose home-based Medicaid services were terminated without notice led to the development of new procedural protections for other individuals in need of home-based services under the Medicaid waiver program.⁵⁰

The case that drew the most attention from the public and media was *Neale v. Community Hospital of Schoharie*.⁵¹ Dianne Neale sought assistance from the Clinic after being terminated from her hospital job due to epilepsy. Dianne Neale and her seizure disorder received quite a bit of attention with an article in the *New England Journal of Medicine*⁵² and a parody used in season three of *Seinfeld*.⁵³ As director of the Clinic, Professor Mary Lynch and her

students filed an employment discrimination case in 1989 on behalf of Ms. Neale before the enactment of the American's with Disabilities Act.⁵⁴ The unusual notoriety of the case aside, the work of the students and the professors who supervised them drew attention to the impact a seizure disorder can have on a person's life and the need for reasonable accommodations in the workplace.

For the last decade, the law students have been representing individuals residing in an institution. The Clinic was first drawn to this work when it was learned that the Capital District Developmental Services Office opened a residential adolescent unit without any educational supports for the students.⁵⁵ In addition to the impact that this work has had on the individuals represented by the Clinic, the work has resulted in important systemic reform. The law students, and their partners, have successfully advocated for the development of statewide discharge planning procedures, clarification of P&A investigation authority in New York, and reforms to the systems designed to protect the most vulnerable populations from abuse and neglect. In 2011, the Clinical Legal Education Association recognized this work of the clinic with the Excellence in a Public Interest Case or Project award. Clinic alumna, Jennifer Monthie '05, is now a staff attorney with Disability Advocates, Inc., and Clinic partner in advocacy on behalf of clients in institutions.⁵⁶ She discusses some of the recent reforms to the system of care for individuals in institutional settings in her article in this volume, *New York Reforms Its System of Protection for Vulnerable Individuals*.

C. Impact on Clients

The work of the students has also had a lasting impact on the clients of the Clinic. Years after his representation of his first client, Joe Connors heard from her parents that she continued to fight for her independence as she challenged her need for a guardian.

The client that Michael O'Leary represented tenaciously ten years ago was a woman with a developmental disability. She was served with papers to terminate her parental rights. In the papers, the county claimed that her MR diagnosis made her an unfit mother. Michael O'Leary and several other law students in the Clinic successfully advocated for the client's ability to keep her children. Ten years later the client remembers those students with gratitude:

I think of those students often. My children ask me about that time and I tell them how hard we had to fight to get them back. Those students were there for me-whatever I needed. They were there even if I just needed to talk. I thank God for the Clinic.⁵⁷

The work with institutionalized clients has given the clients greater quality of life, independence and autonomy, and has insured greater oversight to address abuse and neglect in the institutions. Many of these clients are cur-

rently supported in their community and no longer need to live in the restrictive institutional setting because of the law student's representation.⁵⁸

III. Conclusion

It is rewarding to know that the legacy of the Clinic will continue with each successive group of students. As one alumnus expressed:

The Clinic was the first time I ever witnessed and played a role in harnessing the power of the law to actually make a difference in someone's life.... I learned the value of using my gifts to be a part of something that helped people and solved problems that people really needed help solving.⁵⁹

Whether or not our graduates end up practicing disability law, their experiences in the Clinic will have shaped their professional identity and ultimately be relevant to any legal practice. Articles in this volume on topics such as special education law, accommodations required by the Americans with Disabilities Act, workers' compensation, tax planning, Medicaid waivers, and protections of vulnerable populations illustrate the breadth of disability law and the varied and complex ways in which disability rights issues arise.

As we write this article we are inspired by a recent recognition that individuals with disabilities can be strong and heroic. Olympic athlete Oscar Pistorious, who raced the world's best on prosthetic legs, was universally cheered.⁶⁰ However, our work is not finished. Given that individuals with disabilities still have lower employment rates,⁶¹ higher incidents of poverty,⁶² and are more likely to be victims of a crime,⁶³ it would be a mistake not to recognize that lawyers are still needed to focus on changes in society and the enforcement of law.

Alumni looking back on their clinical experience may feel that they changed the world for one individual, or they may feel that they learned lessons about how to reform the legal system. We are assured that our law students who are just starting their professional careers are prepared for the hard work ahead. "[In the Clinic] I learned how to use the law to achieve progressive victories for people who are otherwise unrepresented or underrepresented."⁶⁴

Endnotes

1. In the beginning the Clinic was called the Disabilities Law Clinic. Eventually the name was changed to the Civil Rights and Disabilities Law Clinic to reflect the civil rights nature of the cases that were being handled by the Clinic.
2. Nancy Maurer's reflection.
3. *Albany Law School's Law Clinic Legal Assistance for Disabled*, THE COLONIAN, Sept. 23, 1985, at 18.
4. In 1975 Maryland School of Law started its Disability Rights Clinic, and Loyola Law School has been educating students in its Disability Rights Legal Center since 1977.
5. The Protection and Advocacy (P&A) System is a "network of congressionally mandated," legal advocacy offices. Each state has a P&A agency with the authority to provide legal representation to people with disabilities. The system prioritizes representation which (1) involves monitoring, investigating and remedying adverse conditions in institutional settings and (2) is aimed at a client's desire for inclusive education, financial entitlements, health care, housing and employment. *About P&A/CAP Network*, NATIONAL DISABILITY RIGHTS NETWORK, <<http://www.napas.org/en/about/paacap-network.html>> (last visited Sept. 12, 2012).
6. See Developmentally Disabled Assistance and Bill of Rights Act, Pub. L. No. 94-103, 89 Stat. 486 (1975); Developmental Disabilities Act of 1984, Pub. L. No. 98-527, § 142, 98 Stat. 2662, 2679-80.
7. In 1972 Geraldo Rivera started a series of exposes that were aired on ABC News which focused on Willowbrook, the largest state-run institution for individuals identified as mentally retarded. When Geraldo Rivera went into the institution he found that the wards were filthy and overcrowded. The residents were not being educated or trained. Some did not have clothing; they were exposed to diseases and forgotten. *About NDRN: Our History*, NATIONAL DISABILITY RIGHTS NETWORK, <<http://www.napas.org/en/about/about-ndrn/26-our-history.html>> (last visited Sept. 12, 2012). The conditions in this facility were challenged in *N.Y. State Ass'n for Retarded Children v. Carey*, 393 F.Supp. 715 (E.D.N.Y. 1975); see also *N.Y. State Ass'n for Retarded Children v. Carey*, 551 F.Supp. 1165 (E.D.N.Y. 1982), *aff'd in part and rev'd in part*, 706 F.2d 956 (2d Cir. 1983), *cert. denied*, 464 U.S. 915 (1983). See also *N.Y. State Ass'n for Retarded Children v. Rockefeller*, 357 F. Supp. 752 (E.D.N.Y. 1973). This litigation resulted in widespread reforms to the institutions in New York and around the country. For video clips from the original expose and a reflective look back on Willowbrook, see *About NDRN: Our History*, NATIONAL DISABILITY RIGHTS NETWORK, <<http://www.napas.org/en/about/about-ndrn/26-our-history.html>> (last visited Sept. 12, 2012). On Nov. 2, 2012 Albany Law School's Government Law Center and the Clinic hosted *Willowbrook: Fulfilling the Promise*, a conference to examine the history of the Willowbrook litigation, the impact it had on the system of care, and the current challenges facing the system.
8. In 1977, in response to the inhumane conditions in institutional settings, New York created the Commission on Quality of Care (now the Commission on Quality of Care and Advocacy for Persons with Disabilities), a state agency responsible for independently investigating complaints of abuse or neglect within state-operated facilities. See MHL § 45.01 (Consol. 2008). The federal government created the Protection and Advocacy system to safeguard the human and civil rights of individuals with disabilities in 1984. 42 U.S.C. §§6000-09, repealed by Developmental Disabilities Assistance and Bill of Rights Act of 2000, 42 U.S.C. §15043(a)(2)(A) (i)).
9. John Caher, *Trial Gives Law Students On-the-Job Experience*, ALBANY TIMES UNION, Mar. 8, 1989, at Main Section.
10. At one point, clinic student workspace was furnished with old library carrels rescued from the curb.
11. In the early years of clinical education, it was not unusual for the offices to be in the basement or another out-of the way location. See Marjorie Anne McDiarmid, *What's Going on Down There in the Basement: In-House Clinics Expand Their Beachhead*, 35 N.Y.L. SCH. L. REV. 239, 274-75 (1990).
12. For several years, we offered a Securities Arbitration Clinic as well. In the Domestic Violence Prosecution Hybrid clinic, full-time faculty worked closely with select District Attorneys' offices in teaching and training law students in Domestic Violence prosecutions.
13. *Albany Law Clinic & Justice Center: The Clinics*, ALBANY LAW SCHOOL, <<http://www.albanylaw.edu/cjc/clinics/Pages/default.aspx>>

- (last visited Sept. 13, 2012). The Field Placement Clinic offers over 150 possible externships in various areas of law practice including criminal defense and prosecution, public interest advocacy, government law, science and technology, and judicial chambers. Law students work directly with supervising attorneys in the field and receive classroom instruction from adjunct faculty and indirect supervision from full-time faculty in the clinic. *Id.*
14. Over the last several years, the Center for Law and Justice and faculty have received multiple awards from local, state and national organizations including: Clinical Legal Education Association's Award for Excellence in a Public Interest Case (2011); New York State Bar Association Angelo T. Cometa Award "recognizing excellence in lawyer referral and service which advances access to justice" (2010); Albany Family Court Children's Center Award (2008); New York State Department of Health chose Albany Law School Health Law Clinic Cancer Services Program as an Innovate Project (2008); New York State Developmental Disability Planning Council Community Leader of the Year Award (2007); New York State ARC's Hodgson/Jacobs Law Award for "demonstrating outstanding commitment to improving the lives of individuals with developmental disabilities" (2006); New York State Bar Association Denison Ray Criminal Defender Award (2006); American Bar Association Judy M. Weightman Memorial Public Interest Award Finalist (2005); The Shanara Gilbert Award from the Association of American Law Schools (AALS) (2005); Greater Upstate Law Project Award for Fair Hearing of the Month (2004); Legal Aid Society of New York 2004 Pro Bono Award for "outstanding service" to Legal Aid clients for work on clemency for battered women (2004); New York State Developmental Disabilities Planning Council Community Leader of the Year Award (2003); Black, Latino, Asian and Pacific American Association Appreciation of Dedication to Diversity (2000); New York State Bar Association Pro Bono Service Award (1999); Legal Aid Society of Northeastern New York Distinguished Service Award (1998); NOW's "Making Waves Award" for work on behalf of women (1997); New York State ARC's Hodgson/Jacobs Law Award for "outstanding interest and commitment to disability law" (1995); IIWDA Certificate of Merit—First Case to Enforce Provisions of the ADA (09/1992); Legal Aid Society of Northeastern New York Distinguished Service Award (1987), and Parent Network Center Certificate for Merit presented to the Civil Rights & Disabilities Law Project at Albany Law School (1987). *Albany Law Clinic & Justice Center: Awards Received by the Clinic & Justice Center*, ALBANY LAW SCHOOL, <<http://www.albanylaw.edu/cjc/news/awards/Pages/Clinic-Awards.aspx>> (last visited Sept. 13, 2012).
 15. Proposal for DD Law Clinic, Albany Law School (1983) (on file with the authors). In the early years of the Disabilities Law Clinic, clinic courses were included in the limit of 4 "co-curricular credits" that could be counted toward graduation. *Id.*
 16. During this period, the number of clinical credits students may carry toward graduation requirements increased from four (which included "co-curricular credits") to 20 clinical credits.
 17. The Civil Rights and Disability Law Clinic addressed a wide variety of disability rights issues including the right to special education program and services, entitlement to supplemental security income, social security disability benefits, Medicaid or other benefits, and the right to be free from discrimination based on disability in housing, employment, and access to public accommodations or services under state and federal law.
 18. *Taylor v. Bd. of Educ. of Copake-Taconic Hills Cent. Sch. Dist.*, 649 F.Supp. 1253 (N.D.N.Y. 1986); *Sargent v. Bowden*, No.88-CV-337, 1991 WL 214074 (N.D.N.Y. Oct. 18, 1991); *Russman v. Bd. of Educ. of the Enlarged City Sch. Dist. of Watervliet*, 945 F.Supp. 37 (N.D.N.Y. 1995); *Hannigan v. Bd. Of Educ. of Brunswick Cent. Sch. Dist.*, No. 95-CV-1435 (FJS), 1997 WL 10971 (N.D.N.Y. Jan. 9, 1997); *Bethlehem Cent. Sch. Dist. v. Doe*, 961 F.Supp. 31 (N.D.N.Y. 1997).
 19. *Doe v. Pfrommer*, 148 F.3d 73 (2d Cir. 1998); *Russman v. Sobel*, 85 F.3d 1050 (2d Cir. 1996).
 20. *Albany Law Sch. v. Office of Mental Retardation & Dev. Disabilities*; *Ziobrowski v. Office of Mental Retardation & Dev. Disabilities*, 145 Misc.2d 728 (N.Y. Sup. Ct., Albany Co. 1989).
 21. *In re Janet L.*, 200 A.D.2d 801, 606 N.Y.S.2d 431 (3d Dep't 1994), *lv. dismissed*, *lv. denied*, 83 N.Y.2d 941, 615 N.Y.S.2d 869, 639 N.E.2d 409 (1994); *In re Janet L.*, 287 A.D.2d 865, 731 N.Y.S.2d 299 (3d Dep't 2001); *Albany Law School v. Office of Mental Retardation & Dev. Disabilities*, 81 A.D.3d 145 (3d Dep't 2011).
 22. *Albany Law Sch. v. Office of Mental Retardation & Dev. Disabilities*, 19 N.Y.3d 106, 945 N.Y.S.2d 613 (2012).
 23. *Id.*
 24. *Bd. Of Ed. Of Enlarged City Sch. Dist. of the City of Watervliet v. Russman*, 521 U.S. 1114 (1997). The clinic was involved for over ten years in representing Colleen Russman, a child with disabilities who sought support services from her school district so that she could attend the school she would have attended but for her disabilities—a private sectarian school. Over the years, students participated in administrative hearings, appeals, federal court litigation and motions, and ultimately a writ for certiorari in the U.S. Supreme Court. All the while, the law surrounding special education and First Amendment evolved and changed. The experience for students and the benefits (as well as drawbacks) of handling big cases in the clinic are described in Nancy M. Maurer, *Handling Big Cases in Law School Clinic, or Lesson from My Clinic Sabbatical*, 9 CLIN. L. REV. 897 (2003).
 25. *Mission Statement*, ALBANY LAW SCHOOL, <www.albanylaw.edu/about/pages/mission.aspx> (last visited Sept. 13, 2012).
 26. While most of the clients of the Clinic are living with lifelong disabilities, Thomas G. Benjamin '05 explores how the law responds to an individual becoming disabled due to an accident at work in *Injured on the Job: The Fear of Future Expenses*, which is included in this volume.
 27. *Bd of Educ. of the Hendrick Hudson Cent. Sch. Dist. v. Rowley*, 458 U.S. 176 (1982) (The court defined "appropriate" as a program of special education and related services that were "...reasonably calculated to enable the child to receive educational benefits." As interpreted, schools were not required to provide the best program or to even maximize a student's potential, but had to provide at least an appropriate education). This issue of appropriate education continues to inspire scholarship and debate. Three articles in this volume address issues of special education: Tara Moffet '99 discusses the needs of students in foster care in *Intersections Between Foster Care and the IDEA—How to Bridge the Gap between Systems on Behalf of Students with Disabilities*; Rosemary Queenan discusses the standard used to determine when twelve month programming is needed for a student in the article *Repairing the Extended School Year Regression Standard in New York to Individualize the Need for Special Education Services*; and Lauren Mechaly '09 discusses the special case of special education in New York City in her article *Special Education Advocacy in New York City*.
 28. *Taylor v. Bd. of Educ. of Copake-Taconic Hills Cent. Sch. Dist.*, 649 F. Supp. 1253 (N.D.N.Y. 1986).
 29. *Id.* at 1258.
 30. *Id.* at 1255.
 31. *Id.* at 1258.
 32. Interview by Author with Sheila Shea (July 3, 2012).
 33. *Id.*
 34. Ms. Shea's article is entitled *The Mental Hygiene Legal Service at 50: A Retrospective and Prospective Examination of Advocacy for People with Mental Disabilities*.
 35. On a 1990 "Survey of Disability Law Clinic Graduates," Joe stated, "I'm hooked. The DLC was the springboard for what has been and promises to continue to be a rewarding career serving individuals with disabilities." The survey was sent to clinic graduates as part of an effort to establish a source for case referrals for clients with disabilities that the clinic could not serve. In exchange for free training through the New York State Bar Association, attorneys would accept a pro bono case. Survey of Disability Law Clinic Graduates (1990) (Surveys on file with the authors).

36. Email from Edward Wilcenski to author (July 31, 2012) (on file with author).
37. Cornell University's Disability Statistics Website provides outstanding statistical information on topics such as the prevalence, employment rate, education, and income of disability in the United States. *Disability Statistics*, CORNELL UNIVERSITY: EMPLOYMENT AND DISABILITY INSTITUTE, <<http://www.disabilitystatistics.org/reports/acs.cfm?statistic=1>> (last visited Sept. 13, 2012).
38. Bridgit Burke's reflections.
39. Email from Michael O'Leary to author (July 30, 2012) (on file with author) (responding to a request to some of our former students about what they remember most about their clinical experience).
40. See generally DONALD SCHON, *THE REFLECTIVE PRACTITIONER: HOW PROFESSIONALS THINK IN ACTION* (1983).
41. Email from Justin Myers to author (July 18, 2012) (on file with author).
42. Michael Krenrich is now an attorney with the New York Attorney General's Office.
43. *CRDLP Student Argues Before the Appellate Division*, *THE ISSUE*: ALBANY LAW SCHOOL, Sept. 2001, at 1.
44. *In re Janet L.*, 200 A.D.2d 801, 606 N.Y.S.2d 431 (3d Dep't 1994), *lv. dismissed*, *lv. denied*, 83 N.Y.2d 941, 615 N.Y.S.2d 869, 639 N.E.2d 409 (1994).
45. *In re Janet L.*, 287 A.D.2d 865, 731 N.Y.S.2d 299 (3d Dep't 2001).
46. *Ziobrowski v. Office of Mental Retardation & Dev. Disabilities*, 145 Misc.2d 728 (N.Y. Sup. Ct., Albany Co. 1989).
47. See Danny Hakim, *For Disabled Care Complaints, Vow of Anonymity was False*, *N.Y. TIMES*, Nov. 11, 2011.
48. Email from Michael Mulé to author (July 31, 2012) (on file with author). Michael's article, *Ensuring Effective Communication with Deaf and Hard of Hearing Individuals*, is included in this volume.
49. *Taylor v. Bd. of Educ. of Copake-Taconic Hills Cent. Sch. Dist.*, 649 F.Supp. 1253, 1255, 1259 (N.D.N.Y. 1986). See, e.g., *W.G. v. Bd. of Tr. of Target Range Sch. Dist. No. 23*, 960 F.2d 1479, 1484 (9th Cir. 1992) (citing *Taylor* regarding importance of parental involvement in educational decisions); Allan G. Osborne, *Remedies for a School District's Failure to Provide Services Under IDEA*, 112 WELR 1, 8 (1996) (citing *Taylor* regarding damages).
50. *Caffrey v. Wing*, No. 95-CV-0599 (N.D.N.Y. May 2, 1995). The regulations detailing these new protections can be found at N.Y. COMP. CODES R. & REGS. tit. 14, §633.12 (2012).
51. *Neale v. Cmty. Hosp. of Schoharie Cnty.*, 89-CV-753 (1989).
52. Venkat Ramani, *Audiogenic Epilepsy Induced by a Specific Television Performer*, *NEW ENG. J. MED.*, July 11, 1991, at 134-35, available at <<http://www.nejm.org/doi/full/10.1056/NEJM199107113250218>>; see also *Woman Says Mary Hart's Voice Triggers Seizures*, *PRESCOTT COURIER*, Mar. 17, 1992, at 3A, available at <<http://news.google.com/newspapers?nid=886&dat=19920317&id=z29LAAAIAIAJ&sjid=q30DAAAIAIAJ&pg=4982,3957126>>.
53. *Seinfeld: The Good Samaritan*, Season 3, Episode 20 (NBC television broadcast Mar. 4, 1992).
54. A number of the other law school clinical professors worked on this case, most notably Professor Laurie Shanks.
55. In response to the Clinic's complaints, the agency hired a teacher for a few of the students and arranged for the other students to attend public or private schools in the Capital District. The adolescent unit has now closed largely in response to the Clinic's calls to move the residents into community settings with appropriate supports.
56. In 2005, the Clinic began to share the P&A grant we received from CQC with Disability Advocates, Inc. (DAI). This arrangement has allowed us to share resources and expertise to the benefit of our clients. Our partnership has also involved engaging in litigation to clarify the access that contract P&A entities have to otherwise confidential information when investigating the abuse or neglect of an individual with a disability. This partnership has made it possible for students in the Clinic to observe and participate in strategy sessions with multiple seasoned attorneys. Witnessing a room full of lawyers with many diverging opinions reach consensus helps the students develop their own professional identify and professional confidence. In the fall of 2011, the students in the Clinic worked with Jennifer Monthie, Tim Clune, and Cliff Zucker from DAI, and the law firm of Patterson Belknap Webb and Tyler (this firm and the attorneys from this firm, Chris Jackson and Brian Lasky, have generously participated in this case pro bono), on a brief for an appeal before the New York Court of Appeals regarding P&A access to client records. See *Albany Law School v. Office of Mental Retardation & Dev. Disabilities*, 19 N.Y.3d 106 (2012).
57. Author interview with Michelle Husband (July 2012).
58. Renee Hebert '03 discusses the Office of Persons with Developmental Disabilities newest program aimed at supporting community living in *The Waiver of the Future*.
59. Email from Scott Goodspeed '99 to Bridgit Burke (July 16, 2012) (on file with author).
60. Each semester at least one class is devoted to cultural competence and abelism. We are keenly aware that the commonly believed stereotype is that individuals with disabilities are always in need of assistance and often deserving of pity. Further, since our clients in the clinic are in crisis, or they would not be seeking the clinic's assistance, the experience could potentially reinforce this misguided stereotype. Therefore, throughout the semester, we highlight examples that refute the stereotype, and in this class in particular, we celebrate the humor, creativity, intelligence, strength and diversity of individuals with disabilities.
61. *Disability Statistics*, CORNELL UNIVERSITY: EMPLOYMENT AND DISABILITY INSTITUTE, <<http://www.disabilitystatistics.org/reports/acs.cfm?statistic=1>> (last visited Sept. 13, 2012).
62. *Id.*
63. ERIKA HARRELL, U.S. DEP'T OF JUSTICE, *CRIMES AGAINST PERSONS WITH DISABILITIES, 2008-2010 STATISTICAL TABLES* (2011), available at <<http://bjs.ojp.usdoj.gov/content/pub/pdf/capd10st.pdf>> (National Crime Victim Survey from 2008-2010 of non-institutionalized civilian households in the United States).
64. Stefen Short '13, end of semester reflection (May 2012).

Professor Nancy Maurer established the second in-house clinic at Albany Law School in 1983. Since that time she has served multiple times as the Director of the Law School's Law Clinic and Justice Center, the Director of the Field Placement Program, Co-Chair of the New York State Bar Association Committee on Issues Affecting People with Disabilities, and Chair of the board of directors for Disability Advocates.

Professor Bridgit M. Burke has been a part of Albany Law School's clinical program since 1994 and has served as the Director of the Civil Rights and Disability Law Clinic since 2000. In 2011 she accepted the Clinical Legal Education Association's Award for Excellence in a Public Interest Case for the work students have done on behalf of individuals with developmental disabilities under her supervision.

Currently Professors Maurer and Burke are the interim Co-Directors of Albany Law School's Law Clinic and Justice Center.

Special Education Advocacy in New York City

By Lauren I. Mechaly

Students with disabilities are protected by federal and state regulations to ensure that they receive appropriate educational services. This article will provide a general overview of the services available to students with disabilities, as well as the laws in place to protect them. The article will specifically illustrate how these laws are enforced in New York City.



I. Federal and State Law

A. The Individuals with Disabilities Education Improvement Act

In 2004, President George W. Bush signed into law the Individuals with Disabilities Education Improvement Act (IDEA).¹ The spirit of the law was to provide students with disabilities a free appropriate public education (FAPE)² by introducing higher standards for programs and personnel across the country. The purpose of the IDEA is “to ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living....”³

As defined under the law, FAPE “means special education and related services” that are provided at public expense and under public supervision and direction which meet the identified standards and include an appropriate program that is provided in conformity with the student’s Individualized Education Program (IEP).⁴ This education must be provided by the local educational agency (LEA),⁵ such as the New York City Department of Education, and must be provided in the least restrictive environment (LRE).⁶ The law defines the LRE as the setting that provides the student with the greatest opportunity to interact with his or her non-disabled peers. In other words, a student with a disability should only be placed in a special education program to the extent that he or she could not make meaningful progress in a general education environment, i.e., without special education services and support.

The IDEA sets forth procedural and substantive guidelines to ensure that the LEA provides a FAPE to students with disabilities. The Second Circuit has determined that “a school district fulfills its substantive obligations

under the IDEA if it provides an IEP that is ‘likely to produce progress, not regression’” and if the IEP affords the student with an opportunity greater than mere “trivial advancement,”⁷ in other words, one that is likely to provide some “meaningful” benefit.⁸ The IDEA does not require the LEA to develop an IEP that maximizes the potential of a student with a disability;⁹ students are entitled to the Honda, not the Cadillac.

B. Regulations of the Commissioner of Education

In New York State, the Commissioner of Education issued Regulations to further govern the education of students. Parts 200 and 200.1¹⁰ specifically regulate the education of students with disabilities, and provide stringent guidelines within which the LEA must operate in developing and implementing a student’s special education program. The Regulations also provide procedural and substantive guidelines to ensure that the LEA provides a FAPE to students with disabilities.

C. Definitions

In order to fully understand the federal and state regulations governing special education, there are certain terms of art that must be defined and explained.

First and foremost, New York State Education Law defines a student with a disability as a student under the age of twenty-one who, as a result of a physical, mental or emotional disability, can only receive an appropriate education through a special education program.¹¹ A special education program may include special classes, resource room, related services, or direct instruction, to name a few.

In order to identify and secure an appropriate special education program, a multidisciplinary team of individuals must convene on an annual basis to develop the student’s IEP.¹² When the student is in preschool, this multidisciplinary team is called the Committee on Preschool Special Education (CPSE). When the student transitions to kindergarten and until he turns twenty-one,¹³ the team is referred to as the Committee on Special Education (CSE). An IEP meeting, or CSE meeting as it may be referred to outside of New York City, is held to review the results of any recent evaluations or progress reports, and to determine the student’s present levels of performance for purposes of developing new annual goals and, where appropriate, short-term objectives for the upcoming year. The team will also review the student’s related services and determine whether the services should be continued, modified, or terminated based upon the student’s progress during the school year. The substance of the IEP will be discussed in greater detail below.

The CPSE and CSE teams should consist of individuals who are intimately familiar with the student's needs, such as the classroom teacher, related service providers, and any medical or other professionals associated with implementing the student's program. The parent is a mandatory member of both the CPSE and the CSE. There must also be a district representative present at the meeting. Very often, the school psychologist is qualified to serve as the district representative. The parent is also entitled to a parent member, someone who has a child with special needs of his or her own and can advocate for the parent and assist the parent in making decisions regarding the student's program.

II. The Individualized Education Program

Of course, a special education program encompasses a wide range of services. Related services include physical therapy, occupational therapy, speech and language or audiology services, psychological services, special transportation, health services, and various other supports and services that can be provided to a student with a disability. The program may also include a resource room or tutoring, or specially designed instruction such as a modified curriculum. A student's IEP should be reasonably calculated to ensure educational benefit.¹⁴

A. Classifications

A student with a disability must be classified by the CPSE or CSE. Classification may dictate the type of program that is recommended. At the CPSE level, there is only one classification, which is preschool student with a disability. At the CSE level, there are thirteen classifications for a student with a disability.¹⁵ Some classifications are very narrowly tailored to a particular disability, while others may be appropriate for a wide range of students. The classifications include: Autism; Deafness; Deaf-blindness; Emotional Disturbance; Hearing Impairment; Learning Disability; Intellectual Disability; Multiple Disabilities; Orthopedic Impairment; Other Health Impairment; Speech or Language Impairment; Traumatic Brain Injury; and Visual Impairment including Blindness.¹⁶

B. Staffing Ratio

Once the classification is determined, the CPSE or CSE will determine a staffing ratio, which is the number of students to the number of teachers and paraprofessionals, if any, in the classroom.¹⁷ For example, a 12:1:1 program is comprised of twelve special education students, one special education teacher, and one classroom paraprofessional. A more restrictive setting would be a 6:1:1 or a 12:1:4, while a lesser restrictive setting would be a 12:1, which is a classroom without a paraprofessional. The least restrictive special education classroom is a Co-Teach Classroom, which is an integrated setting comprised of general and special education students, as well as general education and special education teachers. The CPSE or

CSE may also determine that while the student requires related services, he or she could make progress in a general education setting.

C. Transition Services

Transitional support services are provided for in a student's IEP and are to aid in the transition from special education to general education.¹⁸ Specifically, when a student is declassified by the CPSE or CSE, and it is determined that the student no longer requires special education services, related services and/or other supports shall be put in place to assist the student in transitioning from the special education setting.

D. Extended School Year

If the student has a tendency to exhibit regression over breaks or the summer months, extended school year services (ESY) may be considered.¹⁹ Designed to assist in the maintenance of skills the student learns during the school year, ESY is available under the IDEA²⁰ and offered pursuant to the student's IEP. In addition to regression and recoupment, whether the IEP team will determine that ESY is appropriate will depend upon a number of factors, including but not limited to the student's behavioral and physical impairments, his or her rate of progress, and the availability of resources. The IEP team will also consider the parents' ability to provide the necessary structure and consistency at home. ESY cannot be limited to particular disabilities or types of services. ESY is not "summer school." It is a two-month program that is implemented in July and August to prevent any regression over the summer months and to avoid the loss of skills achieved from September to June.²¹

E. Annual Goals and Short Term Objectives

While the classification, staffing ratio, and related services illustrate the student's overall program, the annual goals and short term objectives dictate what skills the student will be working on over the course of the school year. The IEP must include academic and functional goals that are meaningful and measurable and relate to meeting the student's needs.²² The IEP must explain how the goal will be measured, how frequently it will be measured, and the success rate which will constitute progress or mastery of the goal. Examples of how the goals will be measured are teacher or provider reports, classroom observations, and daily data collection. The IEP must also include how frequently progress reports will be prepared.

For all preschool students with disabilities, short term objectives and benchmarks must be included on the IEP. At the CSE level, short term objectives and benchmarks are only included on the IEP if the student is an alternate assessment student. The short term objectives are included as immediate steps to be measured in the student's progress towards the annual goals.

F. Related Services

As indicated, related services are included on the student's IEP to address areas of deficit such as fine motor, gross motor, and language and communication skills.²³ The related services are mandated by duration, frequency, and group size. For example, a student who is nonverbal may benefit from daily speech and language on a one-on-one basis, while a student who can communicate but lacks social skills may benefit from two sessions per week in a group. Typically, sessions are 30 to 45 minutes. The sessions can be provided as "push-in," meaning the therapist goes into the classroom to provide the service, or as "pull-out," meaning the service is provided in a separate location. The mandate should be consistent with the student's needs, and whether the service is push-in or pull-out will be reflected on the IEP. In certain circumstances, the CPSE or CSE may recommend home-based services as well.

The related service providers are responsible for developing the goals that are included on the following school year's IEP for the student's related services. Goals are developed based upon the student's progress over the course of the school year, and should identify any lack of progress toward the existing goals. The student's goals should be consistent with his or her present level of performance, which should reflect the student's current strengths and weaknesses across all domains.

Very often, students with disabilities require additional support on the school bus. Special Education transportation is a related service under the law. For example, a student may require limited travel time, a lift bus, a transportation paraprofessional, or an air-conditioned bus. With a note from the student's pediatrician, the CPSE or CSE must accommodate the student's needs with regard to transportation to and from school.

Oftentimes a classroom paraprofessional is not sufficient for a student with disabilities, and a one-on-one paraprofessional may be assigned. This may happen when a student has a medical need and requires a health paraprofessional, exhibits aggressive or violent behaviors and requires a crisis management paraprofessional, or simply has delays significant enough to warrant one-on-one assistance throughout the course of the school day.

G. Behavior Intervention Plan

If a student with a disability exhibits maladaptive behaviors which interfere with his or her ability to learn, such behaviors must be addressed and memorialized on the student's IEP. An IEP shall "consider the use of positive behavioral interventions and supports, and other strategies, to address that behavior" if the child's behavior impedes his or her learning or that of others.²⁴

A behavioral intervention plan (BIP) is developed based upon the results of a functional behavioral assess-

ment (FBA), which is conducted to identify the student's target behavior as well as the "contextual factors that contribute to the behavior."²⁵ The BIP includes "a description of the problem behavior...hypotheses as to why the problem behavior occurs and intervention strategies that include positive behavioral supports and services to address the behaviors."²⁶

H. Transition Plan

The IEP that is in place when the student turns fifteen must include a transition plan.²⁷ The plan should reflect the student's strengths and weaknesses, and should include appropriate post-secondary goals. The transition plan should be implemented until the student ages out of CSE, and in place to transition the student to independent community living. For example, the transition plan should address money management, time management, employment, and daily living skills.

I. Implementation

There shall be no delay in implementing a student's IEP. The IEP shall be implemented within 60 days of the initial referral, or within 60 days of the referral for review. If the student will be placed in a private school, the IEP must be implemented within 30 days. The LEA must ensure that each student identified as a student with a disability has an IEP in place at the beginning of the school year. A child's IEP must be implemented on the beginning of the school year.²⁸ Implementation of the IEP includes placement in an appropriate program designed to meet the student's unique educational needs. Failure to timely implement a student's IEP is a violation of his or her right to a FAPE.

It should be noted that every LEA should have a policy in place to locate, identify and evaluate public school students with a disability. This principle, referred to as "child find," ensures that students with delays have available to them a FAPE. The LEA should also work with private schools to ensure that students parentally placed in non-public schools have the same support available. Failure to identify a child with a disability is also a denial of a FAPE.

III. Placement in Private School

In general, the IDEA assigns responsibility for equitable participation to the LEA where the private school is located.²⁹ Each LEA must spend an amount equal to a proportionate amount of Federal funds made available under the IDEA to meet its obligations to parentally placed private school children with disabilities.³⁰ The same does not apply to students who have been parentally placed as a result of the LEA's failure to provide a FAPE in the public school.

A. State-Approved Non-Public Schools

The CSE has the ability to place a school age student in a state-approved non-public school if the CSE agrees that the public school available to the student is inappropriate to meet his or her needs.³¹ The CSE may issue a Nickerson Letter,³² or may defer the student's case to the Central Base Support Team (CBST).

1. Deferral to CBST

In New York City, if it is determined that the public school cannot provide an appropriate educational environment, the CSE may defer the child to the CBST for placement in a state-approved non-public school (NPS).³³ If the case is deferred to the CBST, the case worker assigned to review the student's case will compile a list of NPS placements that may be appropriate for the student based upon his or her recent IEP and evaluations. The schools will review the student's profile and arrange an interview with the student and parent. If the school and the parent agree that the placement is appropriate, the CBST will approve funding and the student will be enrolled.

2. Nickerson Letter

The court has held that the LEA must "take all actions reasonably necessary to accomplish timely evaluation and placement in appropriate programs of all children with handicapping conditions."³⁴ If a student in New York City does not receive a placement recommendation within thirty days of the review meeting that established the student's program for the upcoming year,³⁵ a Nickerson Letter³⁶ must be issued to authorize tuition funding for an NPS.³⁷ This passes the burden on to the parent to find an appropriate school for the student with an available seat.

B. Private Schools

1. Ten Day Letter

If a parent decides to unilaterally place the student in a private school (i.e., does so without the support or approval of the LEA), the parent may be entitled to tuition reimbursement (see below). However, the parent must advise the LEA of the decision to place the student in the private school within ten business days prior to the removal.³⁸ Failure to do so may not only affect the tuition reimbursement case from a financial perspective, but will also impact the case from an equities perspective. The letter should address the parent's concern with the public school, and with the LEA's inability to provide the student with a FAPE. In practice, this letter puts the LEA on notice that the parent is alleging a violation of the student's rights, and provides the LEA with an opportunity to cure the violation.

C. Funding

If the parent is seeking tuition reimbursement from the LEA due to a unilateral placement in a private school,

the student shall continue to receive special education and related services that he or she would have received in the public school. The Supreme Court has held that "IDEA authorizes reimbursement for the cost of special education services when a school district fails to provide a FAPE and the private-school placement is appropriate, regardless of whether the child previously received special education or related services through the public school."³⁹

Despite the unilateral withdrawal of their child from the public school, parents may be entitled to tuition reimbursement for failure of the LEA to provide a FAPE.⁴⁰ The factors a parent must prove in such a case, hereinafter referred to as the "*Burlington* factors," include 1) the public school placement is inappropriate; 2) the private school placement is appropriate; and 3) the equities favor the parent.⁴¹ There are two sources of funding available to parents who unilaterally place their child in a private school setting—Carter funding and Connors funding.

The Supreme Court unanimously held that if a public school fails to provide an appropriate education to a student with a disability, and the student receives an appropriate education in a private placement, the parents are entitled to be reimbursed for the child's education.⁴² Through this "Carter funding," the Supreme Court has created the ability to unilaterally place a student in a private school, and to seek reimbursement through the impartial hearing process.

The Northern District in New York identified that a conflict arises between a student's right to FAPE and the state's approval process "when a parent does not have the financial means to front the cost of a non-approved private school. Without external support, the child would have no chance at what has already been determined to be his or her opportunity to receive an appropriate education."⁴³ The Court held that if the *Burlington* factors have been met, and if a parent can demonstrate that he or she is unable to afford unilateral placement in a private school, "the public school must pay the cost of private placement immediately."⁴⁴ Through this "Connors funding" the court created the ability for parents to unilaterally place a student in a private school and seek prospective payment.

IV. Impartial Hearing Office and Office of State Review

New York State is one of the few states that maintains a two-tier system for special education proceedings. If the LEA denies a child's right to FAPE, the parent's recourse is to request an impartial hearing by filing a Request for Due Process.⁴⁵ This administrative proceeding, held before an Impartial Hearing Officer ("IHO"), sets forth any and all violations alleged against the LEA,⁴⁶ and requests certain relief for the student for the LEA's failure to provide a FAPE. The statute of limitations under federal and state law is two years.⁴⁷

A decision by an IHO must be made on substantive grounds based on a determination of whether or not the child received a FAPE.⁴⁸ Under the IDEA, if a procedural violation is alleged, an administrative officer may find that a child did not receive a FAPE only if the procedural inadequacies (a) impeded the child's right to a FAPE, (b) significantly impeded the parents' opportunity to participate in the decision making process regarding the provision of a FAPE to the child, or (c) caused a deprivation of educational benefits.⁴⁹ Also, an IHO is not precluded from ordering the LEA to comply with IDEA procedural requirements.⁵⁰ It should be noted that the burden of proof rests with the LEA, except when a parent is seeking tuition reimbursement for a unilateral placement.⁵¹

During the pendency of the impartial hearing, the parent has the right to invoke stay-put, meaning that the last agreed upon IEP will be in place during the pendency of the proceeding.⁵² For kindergarten placement, the conflict arises whether to implement the child's preschool IEP during the pendency of the proceeding, and place the child back in a preschool program, or to withdraw the child from the public school system and unilaterally place him or her in a private school for the kindergarten year. In *Burlington*, the court recognized the conflict parents face between maintaining their child in an inappropriate placement and finding the funding for a private school. Accordingly, the court held that a unilateral withdrawal from school prior to an administrative hearing did not waive the child's right to such an equitable remedy at the end of the review process.⁵³

V. Discipline

Unfortunately, a student's behaviors are not always appropriately addressed, and maladaptive behaviors exhibited result in disciplinary action against the student. When a student with a disability is removed from his or her current educational program for disciplinary reasons, he or she is placed in a temporary educational placement, or interim alternative educational setting ("IAES"). While placed in this interim program, the student shall continue to receive educational services pursuant to his or her IEP.⁵⁴ The parent must be notified of any change in placement, including placement in an IAES, or a disciplinary change in placement due to a suspension.⁵⁵

VI. Suspensions and Disciplinary Changes in Placement

If a student "is insubordinate or disorderly or violent or disruptive, or [his or her] conduct otherwise endangers the safety, morals, health or welfare of others," he or she may be suspended.⁵⁶ A student may be suspended for five school days by the trustees or board of education, a district superintendent, or a building principal with authority to suspend.⁵⁷ During the suspension, the student shall be placed in an appropriate IAES.⁵⁸

In the event that a suspension of more than five days is imposed, a superintendent's hearing must be conducted, either by a superintendent of schools or by a hearing officer so designated, to determine whether the student shall be suspended for an extended period of time.⁵⁹

If a student with a disability is subject to a disciplinary action, a manifestation review must be conducted to determine whether the conduct is a manifestation of the student's disability.⁶⁰ Such review shall be conducted no later than ten days following: (1) a superintendent's decision to change the student's placement to an IAES; (2) an Impartial Hearing Officer's decision to place a student in an IAES; or (3) the imposition of a suspension that constitutes a disciplinary change in placement.⁶¹ The parent has an absolute right to attend the manifestation determination review, and should be invited to the meeting in writing on the day of the decision to change the student's placement to an IAES.⁶²

The manifestation review meeting will determine whether the student's behavior was "caused by or had a direct and substantial relationship to the student's disability; or...was the direct result of the school district's failure to implement the IEP."⁶³ Under either circumstance, the student's behavior is deemed a manifestation of his or her disability and, except under limited circumstances, the student shall return to his or her original placement.⁶⁴ Further, if any deficiencies in the IEP were discovered as a result of this review, said deficiencies must be remedied.⁶⁵

The parent who disagrees has a right to challenge the school district's decision regarding the placement or with the determination of the manifestation team, and may request an expedited impartial hearing.⁶⁶

A procedural violation for disciplining a student with a disability will not automatically invalidate the determination of a manifestation team,⁶⁷ while a failure to produce evidence regarding the district's compliance with the procedures for conducting a manifestation determination review may not uphold the determination of the team.⁶⁸

If the student charged with a violation of the school district's code of conduct had not yet been identified as a student with a disability, the parent may request a manifestation determination review, a functional behavioral assessment, or any other protection set forth under the law. However, the school district must have had knowledge that the student was a student with a disability before the behavior occurred. This "basis of knowledge" can be determined through prior writings from the parent to the school expressing a concern of the student's education; a previous request for an evaluation; or the classroom teacher's concern regarding a pattern of behavior exhibited in the classroom.⁶⁹ If, however, the parent had previously refused an evaluation, refused services, or it was determined that the student was not disabled, the student

will not be considered a student with a disability for purposes of the pending disciplinary action.

VII. Special Needs Planning

Parents with special needs children should also be advised that there are certain estate planning tools available to them to ensure the best protection for their children in the future. A consultation with an attorney who specializes in the field is highly recommended.

Endnotes

1. 20 U.S.C. §§ 1400 *et seq.*
2. 20 U.S.C. § 1412(a)(1); 18 N.Y.C.R.R. § 200.4(c)(5); 20 U.S.C. § 1400(d)(1)(A); *Schaffer v. Weast*, 126 S.Ct. 528, 531 (2005); *Frank G. v. Bd. of Educ.*, 459 F.3d 356, 371 (2d Cir. 2006).
3. 20 U.S.C. § 1400(d).
4. 20 U.S.C. § 1401(9).
5. 20 U.S.C. § 1401(19).
6. N.Y. Education Law § 4410 (EDL); 20 U.S.C. § 1412(a)(5)(A); 34 CFR § 300.114; 8 N.Y.C.R.R. § 200.6(a)(1).
7. *Cerra v. Pawling Cent. Sch. Dist.*, 427 F.3d 186, 195 (2d Cir. 2005), citing *Walczak v. Florida Union Free Sch. Dist.*, 142 F.3d 119, 130 (2d Cir. 1998).
8. *Mrs. B. v. Milford Bd. of Educ.*, 103 F.3d 1114, 1120 (2d Cir. 1997).
9. *Bd. of Educ. v. Rowley*, 458 U.S. 176, 197 n.21, 199 (1982); see *Grim v. Rhinebeck Cent. Sch. Dist.*, 346 F.3d 377, 379 (2d Cir. 2003); *Walczak*, 142 F.3d at 132.
10. 8 N.Y.C.R.R. § 200.
11. EDL § 4401.
12. It should be noted that prior to entering preschool, the student may have an Individualized Family Service Plan (“IFSP”) which is developed for the Early Intervention program, or birth to age three.
13. A student with a disability is entitled to a FAPE until the end of the school year during which he turns 21, or until he receives a high school diploma, whichever happens first. EDL § 4401(1); EDL § 3202; 8 N.Y.C.R.R. § 200.1(zz); see also 8 N.Y.C.R.R. § 200.4(a)(5)(iii) and 8 N.Y.C.R.R. § 200.13(c).
14. 20 U.S.C. § 1400 *et seq.*
15. 8 N.Y.C.R.R. § 200.1(zz).
16. *Id.*
17. 8 N.Y.C.R.R. § 200.6.
18. 8 N.Y.C.R.R. § 200.1(ooo).
19. 34 C.F.R. § 300.106.
20. *Id.*
21. It should be noted that the preschool school year runs from September to August, while the school age school year runs from July to June.
22. 8 N.Y.C.R.R. § 200.4(d)(2)(iii).
23. 8 N.Y.C.R.R. § 200.4.
24. 20 U.S.C. § 1414 (3)(B)(i) (2012).
25. 8 N.Y.C.R.R. § 200.1(r).
26. 8 N.Y.C.R.R. § 201.2(a).
27. 8 N.Y.C.R.R. § 200.1(fff); 200.4(ix).
28. 8 N.Y.C.R.R. § 200.4(e)(i-ii).
29. 34 C.F.R. § 300.132(a); 20 U.S.C. § 1412(a)(10)(A)(i).
30. 34 C.F.R. § 300.133(a); 20 U.S.C. § 1412(a)(10)(A)(i)(I)-(II).
31. The Practitioner should be aware that the Senate and Assembly recently passed bills S.7722A and A.10722A which amend §§ 4402 and 4404 of the Education Law. The legislation is now pending before Governor Cuomo. The bills requires the CSE to consider the educational impact of the differences between the student’s school and home environments, as well as the impact that the family background may have on the his or her ability to receive a FAPE. The bill also provides that unless the CSE amends or modifies the IEP, the school district must provide tuition reimbursement. A parent’s request for reimbursement must be granted or denied within ninety days, and if granted, the parent must be reimbursed within thirty days from the date the request was granted.
32. See, *infra*, Section III (A)(2). A “Nickerson Letter” entitles a child to non-public day school programs at the expense of the New York State Education Department. See New York City Department of Education, *Recommendations Timeline*, <<http://schools.nyc.gov/Academics/SpecialEducation/SEP/determination/timeline.htm>>.
33. New York State Education Department, *Approved Private, Special Act, State Operated and State Supported Schools in New York State*, (June 30, 2010), <<http://www.p12.nysed.gov/specialed/privateschools/>>.
34. *Jose P. v. Ambach*, 669 F.2d 865, 867 (1982).
35. 18 N.Y.C.R.R. § 200.4(e); EDL § 3206-c.
36. This document was named for Eugene P. Nickerson, the Judge appointed to hear the case in the United States District Court for the Eastern District of New York.
37. The reader should note that only schools on the state-approved list will accept Nickerson Letters as a source of funding. For placement in private schools not on the list, the parent must consider “Carter” funding and “Connors” funding, discussed later in the article.
38. 20 U.S.C. § 1412.
39. *Forest Grove School District v. T.A.* 557 U.S. 230 (2009). It is important to remember that a child with a disability who has been parentally placed in a private school does not have an individual right to receive special education and related services that he or she would receive if enrolled in a public school (34 CFR § 300.137; 20 U.S.C. § 1412(a)(10)(A)).
40. *Burlington School Committee v. Department of Education*, 471 U.S. 359 (1985).
41. *Id.*
42. *Florence County School District Four, et al. v. Carter* 510 US 7 (1993).
43. *Connors v. Mills*, 34 F.Supp.2d 795 (N.D.N.Y. 1998).
44. *Connors*, at 805.
45. 18 N.Y.C.R.R. § 200.5(i); 20 U.S.C. § 1415(b)(7), 1415(c)(2); 34 CFR § 300.508.
46. The statute of limitations in these cases is 2 years.
47. 20 U.S.C. 1415(b)(6)(B); 8 N.Y.C.R.R. 200.5(j)(1)(i).
48. 20 U.S.C. § 1415(f)(3)(E)(i).
49. 20 U.S.C. § 1415(f)(3)(E)(ii); see also 8 N.Y.C.R.R. § 200.5(j)(4).
50. 20 U.S.C. § 1415(f)(3)(E)(iii).
51. EDL 4401(1)(c).
52. 20 U.S.C. § 1415; 18 N.Y.C.R.R. § 200.5(m).
53. *Burlington*, at 370.
54. 34 C.F.R. § 300.530(d).
55. 8 N.Y.C.R.R. § 201.7.
56. EDL § 3214(3)(a).

57. 8 N.Y.C.R.R. § 201.7(b); EDL § 3214(3).
58. The length of the suspension may not exceed the length of suspension that would be imposed on a non-disabled student for the same behavior.
59. 8 N.Y.C.R.R. § 201.2(q).
60. 8 N.Y.C.R.R. § 201.4(a); 30 C.F.R. § 300.530(e); 20 U.S.C. § 1415(k)(1)(E).
61. *Id.*
62. 8 N.Y.C.R.R. § 201.4(b); 20 U.S.C. § 1415(k)(1)(H).
63. 8 N.Y.C.R.R. § 201.4(c).
64. 8 N.Y.C.R.R. § 201.4(d); 34 C.F.R. § 300.530(f).
65. 8 N.Y.C.R.R. § 201.4(e).
66. 20 U.S.C. § 1415(k)(3)(A); 34 C.F.R. § 300.532(c); 8 N.Y.C.R.R. § 201.11(3)-(4); *see also* *Coleman v. Newburgh Enlarged City Sch. Dist.*, 503 F.3d 198, 201-02 (2d Cir. 2007) and New York State Education Department, State Review Officer Decision 11-034, at 8 (May 16, 2011), <http://www.sro.nysed.gov/decisionindex/2011/11-034.pdf>.
67. *Fitzgerald v. Fairfax County Sch. Bd.*, 556 F. Supp. 2d 543, 551 (E.D.Va. 2008); *Farrin v. Maine Sch. Admin. Dist. No. 59*, 165 F. Supp. 2d 37, 51 (D. Me. 2001); *A.C. v. Bd. of Educ.*, 553 F.3d 165, 172 (2d Cir. 2009); *Matrejek v. Brewster Cent. Sch. Dist.*, 471 F. Supp. 2d 415, 419 (S.D.N.Y. 2007) *aff'd*, 2008 WL 3852180 (2d Cir. 2008); *SRO Decision 11-034*, *supra* note 66, at 9.
68. New York State Education Department, State Review Officer Decision 10-028 (May 7, 2010), <http://www.sro.nysed.gov/decisionindex/2010/10-028.pdf>; *SRO Decision 11-034*, *supra* note 66.
69. 8 N.Y.C.R.R. § 201.5(b).

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Repairing the Extended School Year Regression Standard in New York to Individualize the Need for Special Education Services

By Rosemary Queenan

I. Introduction

The Individuals with Disabilities Education Act [hereinafter “IDEA”], formerly known as the Education for All Handicapped Children Act,¹ is a federal statute that is intended to provide eligible children with disabilities a right to “have available to them a free appropriate public education [hereinafter “FAPE”] that emphasizes special education and related services designed to meet their unique needs”² and ensures “equality of opportunity, full participation, independent living, and economic self-sufficiency for individuals with disabilities.”³ As part of this mandate, courts have recognized that school districts may be required to provide special education and related services beyond the typical 180 day school year because for some children with disabilities, “breaks in the educational program”⁴ during the summer months stand “in the way of the attainment of some of [their] objectives[.]”⁵ These services are known as extended school year [hereinafter “ESY”] services.⁶



the degree of the child’s impairment, the rate of the child’s progress, the child’s behavioral and physical problems, and the availability of alternative resources.⁹ This article identifies two of the main criticisms of the recoupment/regression standard; first, the standard imposes various hardships on parents of children with disabilities, and second, applying a standard that focuses on regression alone does not adequately assess each individual child’s need for ESY services. It then argues that applying a multi-factored standard would provide a more comprehensive analysis of the child’s needs for continued summer services and would lessen some of the challenges placed on parents of children with disabilities.

II. School Year Eligibility Under the IDEA

There are two basic requirements for eligibility for school-year special education and related services under IDEA. The student must be evaluated to determine whether he or she has a disability that falls within a list of thirteen categories specified in the IDEA.¹⁰ The categories include physical impairments, mental, emotional and cognitive impairments as well as other more general categories.¹¹ The student must also be in need of “special education and related services” as a result of the disability.¹²

Once a student is deemed eligible, the school district must provide the student with a FAPE. In *Hendrick Hudson District Board of Education v. Rowley*, the Supreme Court defined a FAPE as

special education¹³ and related services¹⁴ which (A) have been provided at public expense, under public supervision and direction and without charge, (B) meet the standards of the State educational agency, (C) include an appropriate pre-school, elementary, or secondary school education in the State involved, and (D) are provided in conformity with the individualized education program required under section 1414(a)(5) of this title.¹⁵

The Court also established the following two-part test for FAPE: (1) whether the state has complied with the procedural requirements under the statute and (2) whether the Individual Education Program [hereinafter “IEP”] for the particular student is “reasonably calculated to enable the child to receive educational benefits.”¹⁶ The FAPE mandate does not require the provision of educational services

“[A]pplying a multi-factored standard would provide a more comprehensive analysis of the child’s needs for continued summer services and would lessen some of the challenges placed on parents of children with disabilities.”

In New York, ESY services are provided based on the single criterion of whether ESY services are necessary to prevent “substantial regression.”⁷ As applied, this standard, also known as the regression/recoupment standard, requires proof that the student has lost a skill that he or she has mastered and that it would take an inordinate amount of time for the student to regain that skill or, alternatively, that there is a reasonable basis for regression.⁸ Some jurisdictions employ an alternative to the regression/recoupment standard when determining whether ESY services are necessary and instead have applied a multi-factored standard that evaluates, *inter alia*,

that would “maximize each child’s potential ‘commensurate with the opportunity provided other children.’”¹⁷ However, the IDEA requires “that the education to which access is provided be sufficient to confer some educational benefit upon the handicapped child.”¹⁸ A FAPE must also be “tailored to the unique needs of the handicapped child by means of an [IEP],”¹⁹ a document that is prepared and reviewed annually by the Committee on Special Education [hereinafter “CSE”], also known as the IEP team, for the particular student.²⁰

III. The Standard for ESY Services

Although the IDEA does not expressly refer to ESY services, the federal regulations require that school districts “must ensure that [ESY] services are available as necessary to provide FAPE....”²¹ Neither the statute nor the regulations specify the standard for determining whether ESY services are necessary. However, the federal regulations provide that “a public agency may not (i) limit extended school year services to particular categories of disability; or (ii) unilaterally limit the type, amount or duration of those services.”²²

The states that receive funding under the IDEA are authorized to establish “rules, regulations and policies” related to the Act so long as they “conform to the purposes of the statute.”²³ As such, many states have used various standards for determining whether ESY is necessary including, but not limited to: (1) no single criterion;²⁴ (2) emerging skills;²⁵ (3) the nature and severity of the impairment; (4) the ability of the parents to provide an educational structure at home;²⁶ and (5) recoupment/regression.²⁷

In New York, ESY is determined by whether the child “require[s] a structured learning environment of up to 12 months duration to prevent *substantial regression*.”²⁸ “Substantial regression” is defined as

a student’s inability to maintain developmental levels due to a loss of skill or knowledge during the months of July and August of such severity as to require *an inordinate period of review*²⁹ at the beginning of the school year to reestablish and maintain IEP goals and objectives mastered at the end of the previous school year.³⁰

The initial determination of whether ESY services are necessary for a particular child is made by the IEP team during the process of developing an IEP for the student.³¹ The IEP team typically includes the Chair of the school district’s Committee on Special Education, at least one special education teacher, at least one of the student’s general education teachers (if the child is participating in a regular education environment), the student’s parent(s) and a volunteer parent representative.³²

IV. Criticisms of the Substantial Regression Standard

A. Obstacles Faced by Parents of Children with Disabilities

New York’s application of the regression standard presents various obstacles for parents of children with disabilities, which conflict with the statute’s intent to “ensure that the rights of children with disabilities and parents of such children are protected....”³³ As the standard is applied in New York, many parents are faced with the impossible choice of allowing their child to regress to justify the need for ESY services, or providing some support to their child themselves, which many parents are ill equipped to do without special education training. Some courts, including the Third Circuit, have recognized that this presents “a serious problem” and that “Congress [likely did not] intend[] that courts present parents with the Hobson’s choice of allowing regression (hence proving their claim) or providing on their own what their child needs to make meaningful progress.”³⁴

School districts may provide ESY services based on the school or an independent evaluator’s expert opinion of a “reasonable basis” for regression. However, this application of the standard may result in potential conflicts of interest between the school district, which may have a financial interest in limiting ESY eligibility,³⁵ and the child’s service providers, who represent the child’s interest, but are often employees of the school district. Even if the service provider believes the child would benefit from ESY services, his or her opinion may be influenced by external factors. In the event that the parents seek the opinion of a publicly provided independent evaluator,³⁶ that evaluator’s opinion may be less credible if his or her assessment of the child was limited and/or he or she is less familiar with the child.³⁷

Further, most parents are at a significant disadvantage when compared to school districts in terms of gathering evidence that ESY services are necessary as school districts have “better access to records and witnesses, greater expertise, superior knowledge of the availability of educational services in the district, and greater influence on decisions made by the IEP team.”³⁸ This power imbalance was acknowledged by Justice Ginsburg in her dissent in *Schaffer v. Weast*, a case in which the Court held that in an administrative hearing where the student’s IEP is being challenged, the party seeking the relief bears the burden.³⁹ Justice Ginsburg, in her dissent, concluded that, for “policy considerations, convenience and fairness,”⁴⁰ the burden should be on the school district because “the school district is...in a far better position to demonstrate that it has fulfilled [its statutory] obligation than the disabled student’s parents are in to show that the school district has failed to do so.”⁴¹ “[E]ven in the rosiest of scenarios,” any procedural protections afforded by the statute do “not

begin to impart to the average parent the level of expertise or knowledge that the school district possesses as a matter of course.”⁴² Although the IDEA requires parents to participate in the IEP process and decisions about their child’s placement and services, “many school professionals do not see parents as true partners in such complex decisions.”⁴³

The fact that parents are unfamiliar with and/or unable to navigate the regression standard also facilitates more arbitrary ESY determinations by the school district.⁴⁴ To apply the standard more objectively, school districts should be required to record evidence of regression by tracking the student’s progress during the school year as well as after any breaks in service, including weekend and holiday breaks. Although the New York state and federal regulations provide specific requirements for the IEP, including a “statement of the child’s present levels of academic achievement and functional performance,” and a “description of the child’s progress toward meeting [his or her] annual goals,”⁴⁵ there is no requirement to conduct an ongoing assessment of regression.⁴⁶ To the extent that the school is determining whether ESY is necessary to provide a FAPE based on a finding of substantial regression, school districts should be required to utilize a more methodical evaluation of the student’s progress to justify its findings.

Parents who disagree with the school district’s ESY determination may decide unilaterally to place their child in a summer program and seek reimbursement for the expenses of the program by way of a request for an impartial due process hearing challenging the school district’s determination.⁴⁷ However, many parents forgo the opportunity to challenge the school district’s determination and defer to the school district because they lack the expertise in the area of education. Parents also avoid challenging the school district’s determination informally (during the IEP meeting) or formally (via a due process hearing), as they often feel “denigrated in their relationships with school personnel, who are in positions of power.”⁴⁸ Empirical research reinforces this perception, finding that “middle class parents are those who most often proceed to a...hearing.”⁴⁹ Many low income parents—who are more likely to have children with disabilities⁵⁰—are less likely to challenge a determination of the school district through a due process hearing because many do not have the “knowledge or resources to bring successful claims against the district.”⁵¹ As a result, the power imbalance between the school district and the parent with respect to special education decisions related to their children perpetuates because parents have less knowledge and resources to challenge the school district’s determination.

Parents may also feel that a challenge to a determination is futile, given the length of the administrative review process and the time sensitivity in resolving an issue related to ESY services. Once a parent files a request for a

due process hearing, the school must convene a meeting with the parents and other members of the IEP team to discuss the due process complaint.⁵² If the complaint is not resolved, the complaint will proceed to a due process hearing conducted by an impartial hearing officer appointed by the school board.⁵³ If the parents disagree with the decision of the hearing officer, that decision may be appealed to the state review officer [hereinafter “SRO”] at the State Education Department.⁵⁴ The SRO decision may be appealed to the New York State Supreme Court or federal district court.⁵⁵ Because the regulations allow for some flexibility regarding the time allotted for the hearing process, a simple matter may be resolved in two months, but a more complicated case may take closer to a year to resolve.⁵⁶ Given that the initial determination of ESY services is typically made during the spring, a challenge to that determination will likely not be resolved until well after the summer and far into the subsequent school year.

B. New York’s Regression Standard Falls Short of the FAPE Mandate

Under the IDEA, a child’s FAPE must be “tailored to the unique needs of the handicapped child” by way of the IEP.⁵⁷ Relying on regression as the *sole* criterion for ESY services is not the most effective way to guarantee a FAPE that provides an educational benefit. Because the standard focuses only on skills accumulation and regression, whereas a student’s progress and capacity to learn can be influenced by a host of factors depending on the severity and nature of his or her disability, the standard may not adequately assess the child’s ability to obtain a meaningful educational benefit without continuous service beyond the typical school year. A single criterion approach also cannot accommodate the vast range of disability challenges, the divergence of educational characteristics⁵⁸ and the variation among children with disabilities “in their degree of impairment, their recovery time from regression,” and the individual potential and abilities of each child.”⁵⁹ As the purpose of a FAPE is to provide meaningful educational benefit,⁶⁰ looking solely at the skills lost and the time needed to regain that skill, regardless of the type of disability or any unique learning attributes associated with that particular disability, is not likely to accomplish that goal.

In *Rowley*, the Supreme Court explicitly declined “to establish any one test for determining the adequacy of educational benefits conferred upon all children covered by the Act.”⁶¹ Other courts have agreed that substantial regression should not be the “only factor” in determining eligibility and have cautioned against “converting what should [be] a multifaceted inquiry into application of a single, inflexible criterion.”⁶² In *Johnson v. Indep. Sch. Dist.*, the Tenth Circuit noted that the IEP team should consider various factors, including the degree of the child’s impairment, the ability of the parents to provide educational structure at home, the child’s vocational needs, the rate of

the child's progress, the child's behavioral and physical problems, and the ability of the child to interact with non-disabled children.⁶³ Some courts have focused on whether the "child benefits meaningfully within his potential from instruction under a proper IEP over a regular school year" and whether "the benefits accrued to the child during the regular school year will be significantly jeopardized if [the child] is not provided [ESY]."⁶⁴

V. Repairing New York's Regression Standard

There is some validity to evaluating regression to determine whether ESY services are necessary. Regression indicates an inability to maintain a skill or skills, which may interfere with the child's overall ability to benefit from his or her educational program, particularly, if, as is often the case with disabled children, it takes the child an inordinate period of time to regain that skill or skills. However, regression, alone, is not a meaningful measure of the child's need for ESY services because it fails to recognize that there are other indicators that a break in instruction for children with certain disabilities will greatly impact the child's ability to obtain an educational benefit under the IDEA. Given the wide range of disabilities, a multi-factored standard that considers the nature and/or severity of the child's disability, the degree of progress toward the IEP goals and objectives⁶⁵ and whether the student's skills are emerging for the particular student and a summer break would interfere with the student's progress⁶⁶ would also allow for a more individualized approach to reviewing the child's needs. For example, an ESY analysis would include whether a particular student is on the verge of learning a key skill, such as reading, and whether a break in service during the summer months would cause significant obstacles for that student in terms of mastering that skill, both of which would be integrated under the emerging skills criterion. As a student's "needs are necessarily determined in reference to goals,"⁶⁷ an ESY analysis should also include an assessment of whether the child has reached the particular goals set for that student during the school year, and whether the absence of continued services would further thwart that student's ability to reach those goals. Evaluating various criteria would provide a more comprehensive assessment of the need for ESY services that is more consistent with the statute's intent to provide services that are "reasonably calculated to enable the child to receive educational benefits" and "gauged in relation to the child's potential."⁶⁸

A multi-factored standard could also address some of the challenges faced by parents of children with disabilities. Evaluating evidence related to some of the more objective criteria, such as the nature and degree of the impairment, or the degree and progress toward mastering the IEP goals, which is more readily attainable by parents, would provide parents with more access to the process of seeking ESY services. This would accomplish the statute's intent to "ensure that the rights of children with disabilities and parents of such children are protected."⁶⁹

VI. Conclusion

Although there are valid reasons to consider whether there is a reasonable basis for regression when determining whether ESY services are necessary to provide a FAPE to children with disabilities, such a determination should not be based on a regression alone. The Act and regulations admittedly provide various procedural protections to parents, but the standard remains inequitable because it presents various challenges to parents of children with disabilities who are seeking ESY services and therefore, does not accomplish the statute's goal of "ensur[ing] that the rights of children with disabilities and parents of such children are protected."⁷⁰ Applying regression as the sole criterion also does not adequately assess the other factors that might be more effective in adequately determining whether continued services are necessary for the child to obtain an educational benefit. Exploring a more comprehensive, multi-factored, standard that considers the degree and nature of the child's disability, the child's progress toward mastering his or her IEP goals, and whether the child's skills are emerging, would provide a more balanced assessment of the child's need and would provide more access to the process of determining whether ESY services are necessary.

Endnotes

- 20 U.S.C. §§ 1401 et seq.; Alan G. Osborne, Jr., *Can Section 1983 Be Used to Redress Violations of the IDEA? An Update*, 230 WELR 453, n.1 (2008). The IDEA was previously named the Education for All Handicapped Children Act (1975) and was renamed in 1990. See Education of the Handicapped Act Amendments of 1990, Pub. L. No. 101-476, §§ 901(a)(1)–(3), 104 Stat. 1103 (codified as amended at 20 U.S.C. § 1400(a) et seq.).
- 20 U.S.C. § 1400(d)(1)(A).
- 20 U.S.C. § 1400(c)(1).
- Battle v. Commonwealth of Pa.*, 629 F.2d 269, 275 (3d Cir. 1980), *on remand*, 513 F. Supp. 425 (E.D. Pa. 1981).
- Id.* at 281 (finding that "the inflexible application of a 180 day maximum prevents the proper formulation of appropriate educational goals...").
- See 34 C.F.R. § 300.106 (referring to "Extended school year services" in title of section).
- N.Y. Comp. Codes R. & Regs. tit. 8, § 200.1(eee) (N.Y.C.R.R.).
- Id.* § 200.1(aaa); see also *Cordrey v. Euckert*, 917 F.2d 1460 (6th Cir. 1990); THOMAS F. GUERNSEY & KATHE KLARE, *SPECIAL EDUCATION LAW* 134 (3d ed. 2008) ("[W]here there is no such empirical data available, need may be proven by expert opinion based upon a professional individual assessment."); *Application of Child with a Disability*, SRO dec. no. 93-28 (1993).
- Johnson v. Indep. Sch. Dist.*, 921 F.2d 1022, 1027 (10th Cir. 1990); *Polk v. Cent. Susquehanna Intermediate Unit 16*, 853 F.2d 171, 182 (3d Cir. 1988); *Reusch v. Fountain*, 872 F. Supp. 1421 (D. Md. 1994) *supplemented by* CIV. A. MJG-91-3124, 1994 WL 794754 (D. Md. Dec. 29, 1994); *Lawyer v. Chesterfield Cnty. Sch. Bd.*, 19 IDELR 904 (E.D. Va. 1993); see also discussion *infra* at Section IV B.
- 20 U.S.C. § 1401(3)(A)(i).
- The thirteen categories include: autism, developmental disability, specific learning disability, intellectual impairment, emotional and/or behavioral disability, speech and language disability, deaf-blind, visual impairment, hearing impairment, orthopedic or

physical impairment, other health impaired (including attention deficit disorder), multiple disabilities, and traumatic brain injury. 20 U.S.C. § 1401(3)(A)(i); 34 C.F.R. 300.8(a).

12. 20 U.S.C. § 1401(3)(A)(ii).
13. “Special education” is defined as “specially designed instruction, at no cost to parents, to meet the unique needs of a child with a disability, including instruction conducted in the classroom, in the home, in hospitals and institutions, and in other settings....” 20 U.S.C. § 1401(29).
14. Related services are “transportation, and such developmental, corrective, and other supportive services...as may be required to assist a child with a disability to benefit from special education....” 20 U.S.C. § 1401(26). Examples of “related services” include “speech language pathology and audiology services, interpreting services, psychological services, physical and occupational therapy....” 20 U.S.C. § 1401(26).
15. Bd. of Educ. of Hendrick Hudson Cent. Sch. Dist. v. Rowley, 458 U.S. 176, 188 (1982) (quoting 20 U.S.C. § 1401(9)(A)–(D)).
16. *Id.* at 206–07 (emphasis added).
17. *Id.* at 198 (quoting the district court’s opinion); see also M.M. v. Sch. Bd. of Miami-Dade Cnty. of Fla., 437 F.3d 1085 (11th Cir. 2006).
18. *Id.* at 200. What constitutes “some educational benefit” has been the subject of debate among various courts. Although some courts have found that even the most minimal of educational benefit would satisfy the FAPE requirement (see, e.g., Weiss v. Sch. Bd. of Hillsborough Cty., 141 F.3d 990, 997 (11th Cir. 1998); Gregory K. v. Longview Sch. Dist., 811 F.2d 1307, 1314 (9th Cir. 1987)), other courts have determined that “Congress intended to afford children with special needs an education that would confer meaningful benefit.” Polk *ex rel.* Polk v. Cent. Susquehanna Intermediate Unit 16, 853 F.2d 171, 184 (3d Cir. 1988), *cert. denied*, 488 U.S. 1030 (1989); Bd. of Educ. v. Diamond, 808 F.2d 987, 991–92 (3d Cir. 1986); Doe v. Smith, 879 F.2d 1340, 1341 (6th Cir. 1989); see also Cypress-Fairbanks Indep. Sch. Dist. v. Michael F., 118 F.3d 245 (5th Cir. 1997).
19. *Rowley*, 458 U.S. at 181; 20 U.S.C. § 1401(9)(D).
20. 20 U.S.C. §§ 1414(d)(1)(A)–(B); 8 N.Y.C.R.R. § 200.3 (2012). The IEP team typically includes a representative of the local education agency, the child’s regular education teacher, the child’s parent or guardian and the child’s special education teacher or special education provider. 20 U.S.C. 1414(d)(1)(B); 8 N.Y.C.R.R. § 200.3(a).
21. 34 C.F.R. 300.106(a)(1); 34 C.F.R. 300.106(a)(2) (“Extended school year services must be provided only if a child’s IEP Team determines, on an individual basis, in accordance with §§ 300.320 through 300.324, that the services are necessary for the provision of FAPE to the child.”); *Armstrong v. Kline*, 476 F. Supp. 583 (E.D. Pa. 1979), *remanded sub nom.* *Battle v. Commonwealth of Pa.*, 629 F.2d 269, 280 (3d Cir. 1980), *on remand*, 513 F. Supp. 425 (E.D. Pa. 1981) (finding “the inflexibility of the [school’s] policy of refusing to provide more than 180 days of education to be incompatible with the Act’s emphasis on the individual.”).
22. 34 C.F.R. 300.106(a)(3)(i)–(ii).
23. See 20 U.S.C. § 1407(a)(1); Sch. for Language & Comm. Development v. New York State Dep’t of Educ., 2006 WL 2792754, at *5 (Sept. 26, 2006) (noting that the New York State Department of Education “possesses the authority to enact policies to ensure compliance with the IDEA, provide such policies are consistent with its objectives and guidelines.”); *Taylor v. Vermont Dep’t of Educ.*, 313 F.3d 768, 777 (2d Cir. 2002) (“‘States are responsible for filing in the numerous interstices within the federal Act through their own statutes and regulations.’” (quoting *Burlington Sch. Comm. v. Dep’t of Educ.*, 736 F.2d 773, 785 (1st Cir. 1984))).
24. See, e.g., *Johnson ex rel. Johnson v. Indep. Sch. Dist.*, 921 F.2d 1022, 1027 (10th Cir. 1990) (adopting the Fifth Circuit’s broad standard that includes “whether the benefits accrued to the child during the regular school year will be significantly jeopardized if he is not provided an educational program during the summer months.”).

The court also noted that

The list of possible factors [including] the degree of impairment, the degree of regression suffered by the child, the recovery time from this regression, the ability of the parents to provide the educational structure at home, the child’s rate of progress, the child’s behavioral and physical problems, the availability of alternative resources, the ability of the child to interact with nonhandicapped children, the areas of the child’s curriculum which need continuous attention, the child’s vocational needs, and whether the requested service is extraordinary for the child’s condition, as opposed to an integral part of a program for those with the child’s condition. *Id.* at 1031 n.9.

25. See, e.g., *Reusch v. Fountain*, 872 F. Supp. 1421, 1435 (D. Md. 1994) supplemented by CIV. A. MJG-91-3124, 1994 WL 794754 (D. Md. Dec. 29, 1994) (listing the relevant factors noted in the Montgomery County, Maryland, County Public Schools guidelines, including “the nature and severity of the disability, the student’s IEP objectives, the severity of past or projected regression, and the rate of recoupment[.]” and noting that “[t]hese factors are not exclusive of other factors and all factors relevant to the students [sic] individual needs should be considered.”).
26. See, e.g., *Alamo Heights Indep. Sch. Dist. v. State Bd. of Educ.*, 790 F.2d 1153, 1158 (5th Cir. 1986) (considering “whether the benefits accrued to the child during the regular school year will be significantly jeopardized if he is not provided an educational program during the summer months” in determining whether the extended school year services are necessary).
27. See, e.g., *D.D-S. v. Southold Union Free Sch. Dist.*, 2011 WL 3919040 (E.D.N.Y.) (finding child was not in need of ESY because no evidence was produced to show that the child’s regression was “atypical.”); *Rettig v. Kent City Sch. Dist.*, 539 F. Supp. 768, 778 (N.D. Ohio 1981), *aff’d in part vacated in part on other grounds*, 720 F.2d 463 (6th Cir. 1983) (finding that parents must show “significant regression of skills or knowledge”). Some consider whether “benefits accrued during regular school year will be significantly jeopardized” if he or she is not provided with ESY services. *Alamo Heights Indep. Sch. Dist. v. State Bd. of Educ.*, 790 F.2d 1153, 1158 (5th Cir. 1986).
28. 8 N.Y.C.R.R. § 200.1(eee) (2012) (emphasis added); see e.g., *D.D-S. v. Southold Union Free Sch. Dist.*, 2011 WL 3919040 (E.D.N.Y. 2011).
29. In interpreting an “inordinate period of review,” courts and hearing officers have deferred to the guidelines established by the New York State Education Department’s Office of Special Education:

A student is eligible for a twelve-month service or program when the period of review or reteaching required to recoup the skill or knowledge level attained by the end of the prior school year is beyond the time ordinarily reserved for that purpose at the beginning of the school year. The typical period of review or reteaching ranges between 20 and 40 school days. *As a guideline for determining eligibility for an extended school year program, a review period of eight weeks or more would indicate that substantial regression has occurred.* *D.D-S. v. Southold Union Free Sch. Dist.*, 09-CV-5026, 2011 WL 3919040, at *16 (E.D.N.Y. Sept. 2, 2011) (emphasis in original).

See also *id.* (noting that “while no court in the Second Circuit has expanded on what constitutes an ‘inordinate period of review,’ SROs in New York have consistently applied the standard articulated by the New York State Education Department’s Office of Special Education...” (quoting *Extended School Year Programs and Services Questions and Answers*, www.p12.nysed.gov/specialed/finance/2011QA.pdf) (emphasis added); Application of a Student

- with a Disability, Appeal No. 08-078, at 21-22, *available at* <<http://www.sro.nysed.gov/decisionindex/2008/08-078.pdf>>; Application of a Child with a Disability, Appeal No. 07-089, at 8 n.3, *available at* <http://www.sro.nysed.gov/decisionindex/2007/07-089.pdf>; Ty v. New York City Dep't of Educ., 584 F.3d 412 (2d Cir. 2009).
30. 8 N.Y.C.R.R. § 200.1(aaa) (emphasis added). The New York State Education Department Regulations also provide that students *must* be considered for 12-month special services and/or programs to prevent substantial regression if they are students:
 - whose management needs are determined to be highly intensive and require a high degree of individualized attention and intervention and who are placed in special classes;
 - with severe multiple disabilities, whose programs consist primarily of habilitation and treatment and are placed in special classes;
 - who are recommended for home and/or hospital instruction whose special education needs are determined to be highly intensive and require a high degree of individualized attention and intervention or who have severe multiple disabilities and require primarily habilitation and treatment;
 - whose needs are so severe that they can be met only in a seven-day residential program; or
 - who are receiving other special education services and who, because of their disabilities, exhibit the need for a twelve-month special service and/or program provided in a structured learning environment of up to twelve months' duration in order to prevent substantial regression. *See Extended School Year Programs and Services—Questions and Answers*, NYSED.GOV (last visited June 19, 2012), <<http://www.p12.nysed.gov/specialed/applications/2012ESY-qa.htm>>.
 31. 20 U.S.C. § 1414(d).
 32. *Id.* § 1414(d)(1)(B); 34 C.F.R. 300.321(a); N.Y. Educ. Law § 4402; 8 N.Y.C.R.R. § 200.3 (2012).
 33. 20 U.S.C. § 1400(d)(1)(B).
 34. *Polk*, 853 F.2d at 184; *see also Johnson*, 921 F.2d at 1027-28 (citing *Polk*, 853 F.2d at 184); *Cordrey v. Euckert*, 917 F.2d 1460, 1470 (6th Cir. 1990) (citing *Polk*, 853 F.2d at 184) (stating that parents and amici objected to the recoupment/regression standard on the grounds that it is “too narrow and unfair” and works particularly harsh results where parents have provided an extended school year to their child on their own. These parents would be forced either to allow their child to regress without an ESY (thus empirically proving his need for one) or to provide on their own what they believe their child needs to make reasonable progress and is entitled to by the Act.). *Id.*
 35. Cost considerations may not be used to deny FAPE, but are “relevant when choosing between several options, all of which offer an ‘appropriate’ education.” *Guernsey & Klare*, *supra* note 2 at 40; *Deal v. Hamilton County Bd. of Educ.*, 392 F.3d 840, 859 (6th Cir. 2004) (“[T]he school district may not, as it appears happened here, decide that because it has spent a lot of money on a program, that program is always going to be appropriate for educating children with a specific disability, *regardless of any evidence to the contrary of the individualized needs of a particular child*”); *Clevenger v. Oak Ridge Sch. Bd.*, 744 F.2d 514, 516-17 (6th Cir. 1984).
 36. 8 N.Y.C.R.R. §§ 200.5(g)(1), 200.1(z).
 37. *See, e.g., N.B. v. Hellgate Elementary Sch. Dist.*, 541 F.3d 1202, 1212 (9th Cir. 2008) (finding it “reasonable for the hearing officer to rely on the testimony of [school district personnel] because they “had observed [the child’s] school performance” while the parents’ “witnesses based their opinions predominantly upon file reviews.”).
 38. Joanne Karger, *A New Perspective on Schaffer v. Weast: Using a Social-Relations Approach to Determine the Allocation of the Burden of Proof in Special Education Due Process Hearings*, 12 U.C. DAVIS J. JUV. L. & POL’Y 133, 189 n.251 (citing Brief of Petitioners at 45-50, *Schaffer ex rel. Schaffer v. Weast*, 546 U.S. 49 (2005) (No. 04-698), 2005 WL 1812490 (listing advantages school districts have over parents)); *see also Oberti v. Bd. of Educ. of Borough of Clementon Sch. Dist.*, 995 F.2d 1204, 1207 (3d Cir. 1993) (noting the school district’s greater access to information, better control over witnesses and greater expertise.).
 39. *Schaffer*, 546 U.S. at 49. Although the Court’s decision resolved a circuit split on the burden issue, the “Court declined to address the question of whether states, on their own, could adopt legislation or regulations assigning the burden to the school district.” Karger, *supra* note 38, at 138. Subsequently, New York enacted legislation assigning the burden of proof to the school district, except in tuition reimbursement cases. N.Y. EDUC. LAW § 4404(1).
 40. *Schaffer*, 546 U.S. at 63 (Ginsburg, J., dissenting).
 41. *Id.* at 64. In *Weast*, the Court assigned the burden of proof in an IEP challenge to the party seeking relief, typically the parents of the subject child.
 42. *Weast v. Schaffer ex rel. Schaffer*, 377 F.3d 449, 458 (4th Cir. 2004).
 43. COLIN ONG-DEAN, *DISTINGUISHING DISABILITY* 115 (2009).
 44. *See Diane Browder & Frances Lentz, From Extended School Year Services: From Litigation to Assessment and Evaluation*, 14 SCH. PSYCHOL. REV., No. 2, 188 (1985).
 45. 8 N.Y.C.R.R. § 200.4; *see also* 34 C.F.R. 300.20(a)(1), (3)(i).
 46. *See Browder et al., Determining Extended School Year Eligibility: From Esoteric to Explicit Criteria*, 13 J. OF THE ASS’N FOR PERSONS WITH SEVERE HANDICAPS, No. 4, 235-43 (1988) (finding, based on a case analysis of ESY in Pennsylvania, that there was “very minimal documentation of skill regression...even though this was the established policy for ESY eligibility”).
 47. 20 U.S.C. §§ 1415(b)(7), 1415(c)(2); 34 C.F.R. 300.508, 200.5(i); N.Y. EDUC. LAW § 4404(1); 8 N.Y.C.R.R. § 200.5(j).
 48. Joanne Karger, *A New Perspective on Schaffer v. Weast: Using a Social-Relations Approach to Determine the Allocation of the Burden of Proof in Special Education Due Process Hearings*, 12 U.C. DAVIS J. JUV. L. & POL’Y 133, 154 (2008) (citing David M. Engel, *Law, Culture, and Children with Disabilities: Educational Rights and the Construction of Difference*, 1991 DUKE L.J. 166, 188 (1991)); Pamela Pruitt Garriott et al., *Teachers as Parents, Parents as Children: What’s Wrong with this Picture?* 45 PREVENTING SCH. FAILURE 37, 42 (2000); Alan Gartner & Dorothy Kerzner Lipsky, *Beyond Special Education Toward a Quality System for All Students*, 57 HARV. EDUC. REV. 367, 378-79 (1987).
 49. Karger, *supra* note 48, at 156.
 50. *Id.* at 155 (citing Mary Wagner et al., *Characteristics of Students’ Households in The Children We Serve: The Demographic Characteristics of Elementary and Middle School Students with Disabilities and Their Households*, 28 (Rep. of the Special Educ. Elementary Longitudinal Study (SEELS) Prepared for the Office of Special Educ. Programs, U.S. Dep’t of Educ., Sept., 2002), *available at* http://seels.net/designdocs/SEELS_Children_We_Serve_Report.pdf (last visited Jun. 29, 2012) (finding “one-third (36%) of students with disabilities lived in households with incomes of \$25,000 or less, compared with 24% of children in the general population.”); *see also* Sandra M. DiIorio, *Comment: Breaking IDEA’s Silence: Assigning the Burden of Proof at Due Process Hearings and Judicial Proceedings Brought by Parents Against a School District*, 78 TEMP. L. REV. 719, 734-36 (2005).
 51. Karger, *supra* note 48, at 156.
 52. 20 U.S.C. § 1415(f)(1)(B)(i); 34 C.F.R. 300.510(a)(2); 8 N.Y.C.C.R. § 200.2.
 53. 20 U.S.C. §§ 1415(f)(1)(A), (f)(3), 34 C.F.R. 300.510(b); *id.* §§ 300.511(b), (c)(3); N.Y. EDUC. LAW § 4404(1); 8 N.Y.C.R.R. §§ 200.2(b)(9), 200.5(j)(3)(i)-(ii).
 54. 20 U.S.C. § 1415(g); 34 C.F.R. 300.514(b); N.Y. EDUC. LAW § 4402(2); 8 N.Y.C.C.R. § 200.5(k).
 55. 20 U.S.C. § 1415(i)(2)(A); 34 C.F.R. 300.514(d); N.Y. EDUC. LAW 4404(3); 8 N.Y.C.R.R. § 200.5(k)(3).

56. 8 N.Y.C.R.R. § 279.2; 200.5(j)(3)(xiii); Application of a Child with a Disability, Appeal No. 01-064 (hearing officer's verdict issued less than two months after the impartial hearing request), available at <<http://www.sro.nysed.gov/decisionindex/2001/01-064.htm>>; Application of a Child with a Disability, Appeal No. 00-024 (reviewing a decision issued nine months after the original hearing request), available at <<http://www.sro.nysed.gov/decisionindex/2000/00-024.htm>>. See also Mary A. Lynch, *Who Should Hear the Voices of Children with Disabilities: Proposed Changes in Due Process in New York's Special Education System*, 55 ALB. L. REV. 179, 185-86 (1991).
57. Bd. of Educ. of Hendrick Hudson Cent. Sch. Dist. V. Rowley, 458 U.S. 176, 181 (1982).
58. Battle v. Commonwealth of Pa., 629 F.2d 269, 280 (3d Cir. 1980) (citing *Armstrong*, 476 F. Supp. at 588-90, *remanded sub nom. Battle v. Commonwealth of Pa.*, 629 F.2d at 269 (3d Cir. 1980), *on remand*, 513 F. Supp. 425 (E.D. Pa. 1980)).
59. *Battle*, 629 F.2d at 280 (citations omitted).
60. *Rowley*, 458 U.S. at 202; Mrs. B. v. Milford Bd. of Educ., 103 F.3d 1114, 1120 (2d Cir. 1997).
61. *Rowley*, 458 U.S. at 202.
62. *Johnson v. Indep. Sch. Dist.*, 921 F.2d 1022, 1031 (10th Cir. 1990) (finding that no single criterion could be used to determine ESY eligibility); see also *Lawyer v. Chesterfield Co. Sch. Bd.*, 19 IDELR 904, 907 (E.D. Va. 1993) (finding that

[R]egression is not the only factor in determining eligibility for ESY and noting that the court should also consider the child's rate of progress, the child's behavioral or physical problems, the availability of alternative resources, the areas of the child's curriculum that need continuous attention and the child's vocational needs);

Cordrey v. Eukert, 917 F.2d 1460 (6th Cir. 1990); *Reusch v. Fountain*, 872 F. Supp. 1421 (D. Md. 1994), *supplemented by* CIV. A. MJG-91-3124, 1994 WL 794754 (D. Md. Dec. 29, 1994) (quoting *Johnson*, 921 F.2d at 1031; *Alamo Heights*, 790 F.2d at 1158)).
63. *Johnson*, 921 F.2d at 1027.
64. *Alamo Heights*, 790 F.2d at 1158; *Johnson*, 921 F.2d at 1028; *Reusch*, 872 F. Supp. at 1435.
65. These annual goals form the basis of determining whether the child is making progress under the IEP. See 20 U.S.C. § 1414(d)(4)(A)(i).
66. See, e.g. *Reusch v. Fountain*, 872 F. Supp. 1421 (D. Md. 1994), *supplemented by* CIV. A. MJG-91-3124, 1994 WL 794754 (D. Md. Dec. 29, 1994).
67. *Battle*, 629 F.2d at 276 (citing *Armstrong v. Kline*, 476 F. Supp. at 603).
68. *Rowley*, 458 U.S. at 207; *Polk v. Cent. Susquehanna Intermediate Unit 16*, 853 F.2d 171, 182 (3d Cir. 1988).
69. 20 U.S.C. § 1400(d)(1)(B). See also *Rowley*, 458 U.S. at 183 n.6 (noting "Congress' effort to maximize parental involvement in the education of each handicapped child").
70. 20 U.S.C. § 1400(d).

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Intersections Between Foster Care and IDEA Services—How to Bridge the Gap Between Systems on Behalf of Students with Disabilities

By Tara Moffett

Children in foster care are sometimes called our forgotten children.¹ They lack stability in their homes, in their education, and, without careful planning, they may leave the child welfare system without the skills necessary to become independent members of society. Tragically, the very system designed to protect children in foster care often creates the obstacles to successful outcomes. Children end up in the foster care system for a variety of reasons, from prenatal exposure to alcohol or drugs, parental abuse, neglect, abandonment, exposure to domestic violence, and family crisis and health issues. According to the Child Welfare Information Gateway Foster Care statistics, in September 2010, there were an estimated 408,425 children in foster care in the United States.² Regardless of the reasons they enter, they are disproportionately identified as children with disabilities as compared to the general population. They are often bereft of a consistent and well-informed adult to advocate for them, and they frequently move from one school to another due to the instability of the foster care system itself.

In an effort to curb the long term effects of foster care on children growing up in the system,³ Congress passed the Fostering Connections to Success and Increasing Adoptions Act of 2008 (“Fostering Connections Act”), which underscores the importance of permanency planning and stability, including family connections and education planning, for children in care.⁴

Children under age 4 make up 31% of the foster care population nationally, yet while in care, many infants and toddlers fail to receive critical medical and educational interventions that they need to combat high rates of developmental, emotional, and behavioral problems.⁵ Building on this unfortunate legacy, more than half the children in care (260,558) are between the ages of 5 and 17, which would make them “school aged” in most states across the nation.⁶ It is undisputed that positive school experiences can enhance a child’s overall health and well-being, prepare them for successful transitions to adulthood, and increase the likelihood of being self-sufficient, employed, and economically stable.⁷



I. The Problem—Challenges Facing Children in Foster Care

School success is directly related to and can lead to employment, housing, improved health, and life expectancy.⁸ Historically, children in foster care lack educational stability, which undermines their academic performance and contributes to school failure.⁹ The National Conference of State Legislatures reported in 2003 that school-aged foster children had “high rates of grade retention; lower scores on standardized tests; and higher absenteeism, tardiness, truancy and dropout rates” as compared to the general school population.¹⁰ Students in foster care have lower rates of graduation (around 50%) compared to the 70% graduation rate for students in the general population.¹¹ Of the foster care children who do graduate from high school, either with a GED or a diploma, only 20% pursue higher education.¹² Considering that 75% of school-aged children in foster care are performing below grade level expectations, the fact that as many as fifty percent of children in care leave school without a diploma is unfortunately not surprising.

The highly transitory nature of foster care is a contributing factor to poor educational outcomes for children in care.¹³ In a 2005 national study, the average consecutive stay in the foster care system was just over twenty-nine months.¹⁴ While in care, children have been frequently relocated by the child welfare agencies, often with little to no regard given to their educational stability. On average, a child in foster care moves to a new foster placement one to two times per year.¹⁵ With each relocation, in addition to the potential loss of academic credit, children in foster care are uprooted from their schools, their friends, their teachers, and their community. For every educational placement change, it can take anywhere from 4-6 months for the student to recover his or her stride academically.¹⁶

Stability in a child’s life fosters academic success. For children in foster care, who lack essential stability in their homes, their communities, and in their schools, the legacy of the foster care experience may extend beyond their time in care. According to the National Association of School Psychologists, aside from the academic adjustment, it can take children anywhere from six to eighteen months to regain a sense of security and control following a change in setting.¹⁷ School change interferes and interrupts social development and experience as the child has fewer opportunities to develop strong and lasting peer relationships.¹⁸ Children facing relocation lose ties not

only with their family and community, but they lose their friends, their teachers and their school.¹⁹ It is not surprising that children in foster care tend to perform lower than their peers academically. One study quantified the impact, establishing that youth in foster care who were relocated four or more times by sixth grade lost one year of educational progress.²⁰ Without strong advocacy and support for a consistent and appropriate education, children in the child welfare system face a bleak future.

A. 2008—The Fostering Connections to Success and Increasing Adoptions Act Is Passed

In 2008, Congress passed the Fostering Connections Act to address the multiple obstacles foster children face. Among its important provisions to foster stability, as a major goal it placed a focus on the importance of education stability.²¹ For the first time, federal law required child welfare agencies to consider the proximity of out-of-home care to a child's school whenever remaining in the original school was determined to be in the child's best interest.²²

The child welfare agency's case plan must provide for the educational stability of the child while in foster care, including:

(i) assurances that each placement of the child in foster care takes into account the appropriateness of the current educational setting and proximity to the school in which the child is enrolled at the time of placement; and

(ii)(I) an assurance that the State agency has coordinated with appropriate local education agencies...to ensure that the child remains in the school in which the child is enrolled at the time of placement; or

(II) if remaining in such school is not in the best interests of the child, assurances by the State agency and the local educational agencies to provide immediate and appropriate enrollment in a new school, with all of the educational records of the child provided to the school.²³

The law became effective immediately on October 7, 2008.

For students with disabilities, the need for educational stability presents an added dimension that requires close scrutiny and consideration.²⁴ To analyze the educational stability question properly on behalf of a child with a disability who is in foster care, child welfare agencies need to understand the complex infrastructure of the Individuals with Disabilities Education Act (IDEA) and how it is implemented on a district-by-district level (there will be variations between school districts, even if they are served by the same county's social services agency).²⁵ For foster

care children with disabilities, the appropriateness of the educational program in the current school (or in another school) and whether the school can serve the student's education interests and needs (including special education) is an important consideration for the best interest analysis by the child welfare agency.²⁶

B. New York's Response to the Fostering Connections Act from 2008-2012

New York State has approximately 26,000 children in foster care.²⁷ Approximately seventy percent of the children in care in New York are school-aged²⁸ and more than half (approximately 62%) are located in New York City.²⁹ Children placed in foster care experience frequent relocation in a variety of settings, shuttling between family members, foster care families, group homes, and residential placements.³⁰ With every change, children in foster care not only face changes in their caregivers, but risk losing all ties to teachers, friends, and their communities. As a result, looking at the cohort of children in the foster care system as a subgroup, they are far more likely to become high school dropouts as well.³¹

Following enactment of the Fostering Connections Act, Senator Velmanette Montgomery introduced a bill in the New York State Senate to amend the social services law, education law, and the Family Court Act, to incorporate the major provisions of the Fostering Connections Act into State law.³² The bill, introduced in September 2009, was referred to the Children and Families Committee on January 6, 2010, but was never reported out.³³ Despite recognition that New York had to comply with the Fostering Connections Act in order to continue receiving federal funding, the first conforming change in New York appeared in the social services regulations, amended by emergency action, on March 20, 2011, four years after the federal law mandates.³⁴

As part of the permanency planning, New York regulations now require the county agency to make a "best interest" determination regarding the school of attendance.³⁵ Specifically, the regulations provide as follows:

When it is in the best interests of the foster child to continue to be enrolled in the same school in which the child was enrolled when placed into foster care, the agency with case management, case planning or casework responsibility for the foster child must coordinate with applicable local school authorities to ensure that the child remains in such school. When it is not in the best interests of the foster child to continue to be enrolled in the same school in which the child was enrolled when placed into foster care, the agency...must coordinate with...local school authorities where the foster child is placed in order that the foster child is

provided with immediate and appropriate enrollment in a new school; and the agency with...responsibility for the foster child must coordinate...to ensure that all of the applicable school records of the child are provided to the new school.³⁶

Additionally the regulations were amended to reflect that children in the foster care system must attend school full-time unless they have a medical condition.³⁷

C. The Response of the New York State Education Department

In New York, a child's right to free public education is grounded in a determination of his or her residence. For children in foster care, while their residence continued to be the district where they first came into care (N.Y. Education Law §3202(4)) and consequently that district remained fiscally responsible for their education, in the district where they were placed, it became the policy of the New York State Education Department (NYSED) that once placed in foster care, the district where the child was relocated became responsible for the child's education. Consequently, whether a child was relocated five or fifty miles from his or her home school district, once moved outside the district's boundaries, the school district where the child was relocated became responsible for the child's education.

In 2012, without any change in law or regulation, NYSED issued a memorandum (#01-2012) that recognizes, for the first time, the rights of children in the foster care system to remain in their home school districts when determined to be in their interest to do so.³⁸ According to the memo, local district residency requirements no longer serve as a barrier to maintaining a child in foster care in his or her school district of residence and is entitled to remain,

in the same school in which the child was enrolled when placed into care, or the school most recently attended, [and that] the school district in which such school is located should maintain enrollment for the duration of the child's placement in foster care or until a subsequent best interest determination is made.³⁹

This represents a complete reversal of over 15 years of education law and guidance from the department.

II. The Implications of the Fostering Connections Act

The Fostering Connections Act⁴⁰ was an important step towards providing educational stability for children in foster care.⁴¹ The challenge in full implementation of the law in New York requires coordination and cooperation between our courts, child welfare agencies, and school districts. As a result of the Fostering Connections

Act, in addition to planning for the student's eventual transition out of care, the law requires child welfare agencies to develop and plan for ensuring the educational stability of the child while in foster care, taking into consideration the appropriateness of the child's current educational setting as well as the proximity of the child's foster placement to the school where the child was enrolled at the time of placement into care.⁴² State and local education agencies have a vested interest in the educational outcomes of foster care children, yet the challenges faced by these children (including the role of biological parents, juvenile courts, attorneys, foster parents, or agencies, etc.) may be foreign terrain for these stakeholders. There is no federal law that requires education agencies to help implement and achieve Fostering Connection Act outcomes, yet educational stability for children in foster care cannot be achieved without the cooperation of schools and the state education agency.

A. Obstacles to Full Implementation of the Fostering Connections Act

The focus on education issues in child welfare accountability is a relatively new direction for child welfare agencies, which requires an agency mind-shift to place a greater emphasis on educational progress for children in care. School districts are often unfamiliar with the ins and outs of foster care and child welfare services and policy; therefore there is a steep learning curve on the opposite end to be able to recognize and appreciate the competing interests which must be balanced by social service programs. Limited fiscal resources between child welfare and educational agencies present another potential barrier when fiscal responsibility is not expressly assigned within the statute for education-stability related supports, such as transportation. Both child welfare staff and staff in the education system need to undergo a crash course in understanding how the other's system and policies work, so they can identify potential issues to children in both systems and develop practical approaches to meeting these challenges. Foster care parent recruitment in the local communities is a critical component of the ability of agencies to support and maintain children as close to their home and community as possible. And finally, the absence of a dispute resolution mechanism and definitions for key principles under this policy ("best interest" and "reasonable transportation," just to name a few) leaves unanswered which agency or decision-maker has the final say when there is an interagency difference of opinion in providing for children in care.

Children who are "awaiting foster care placement" are entitled to the protections of the McKinney-Vento Act,⁴³ including the right to continue in their present school placement, if it is in their best interest.⁴⁴ The term "awaiting foster care placement" is not defined in the federal law. New York does not have a formal definition of this term; however, it is generally given to mean a child who has been removed from his or her parents' home and

has not yet been placed in a foster home.⁴⁵ If the student has not yet been placed in a foster home, then his or her right to educational stability, including transportation to and from their temporary housing back to their school district of origin, is protected under McKinney-Vento.

The Fostering Connections Act creates a McKinney-Vento-like system of rights for students in foster care who do not meet the definition of “awaiting foster care placement” by allowing for students to remain in their original or “home” school district, or if appropriate, for their transfer and immediate enrollment into another school district.⁴⁶ The key difference between the two acts is the agency designated to assist the student in the school selection process. Under McKinney-Vento, the Local Educational Agency (LEA) is responsible for assisting homeless children in making the school selection and arranging for either continued attendance or immediate enrollment elsewhere. Under the Fostering Connections Act, it is the child welfare agency which takes on this role and is responsible for considering the best interest of the child’s educational interest when making a living placement decision.⁴⁷ There are many possible factors which can be considered, some of which include the child’s and parents’ preferences, the expected length of time in care, the age, grade and maturity level of the child, social adjustment, educational needs of the child, and the appropriateness of the current school program to meet those unique needs.⁴⁸ If the child welfare agency determines that continuing in the present school is not in the child’s best interest, then the agency must work with the LEA to ensure that the student is immediately and appropriately enrolled in the new school, without delay.⁴⁹

B. Transportation—Who Is Responsible?

Critically absent in the Fostering Connections Act is a clear mandate designating the responsibility for transporting children in foster care to enable them to continue in their prior school district regardless of their location. Foster care maintenance payments (FCMP) are costs associated with maintaining a child in a foster care placement.⁵⁰ These maintenance payments *may* be used to cover items such as food, clothing, shelter, personal incidentals and “reasonable travel for the child to remain in the school in which the child is enrolled at the time of placement.”⁵¹ The Fostering Connections Act allows child welfare agencies to use those funds to pay for “reasonable travel for the child to remain in the school where the child is enrolled at the time of placement” into care.⁵² However, it does not provide a mandate to do so.

What constitutes “reasonable travel” to maintain educational stability is left undefined in the Fostering Connections Act. Therefore, it is up to each child welfare agency to determine what would be appropriate cost parameters, distance, and length of travel.⁵³ In June 2012, New York State’s Office of Children and Family Services and the State Education Department formed a task force to “explore” transportation responsibilities. However, there

remains no determination of how transportation will be funded.⁵⁴ While LEAs and local departments of social services (LDSS) are encouraged to collaborate to ensure students in foster care are provided with transportation,⁵⁵ the mechanism and dispute resolution system when there is no agreement has not been defined, leaving this vulnerable population without assurances that they can get from their living situation to their home school.

III. Individuals with Disabilities Education Act

Add to the complex factors that contribute to the poor outcomes for children in foster care the fact that a disproportionately large percentage of children in care are also children with disabilities entitled to special education.⁵⁶ As recognized in the legislative history of the Individuals with Disabilities Education Act, for children with disabilities, special education is essential to enable them to meet academic standards.

In order to provide students with disabilities access to education, the federal law includes a complex set of procedural safeguards that provide for individual evaluations, annual reviews, and development of an individualized education program (IEP). Depending on the nature and severity of a child’s disability, the student may be placed in a highly specialized educational program which is designed to meet that student’s individual and unique special education needs. When considering the impact that educational disruption has on any child, the impact can be especially profound when the disruption requires a change in placement for a child with a disability.

In every case, the parent, a critical member of the decision making team, plays a central role in the development and review of a child’s IEP. For children placed in foster care homes, the parent is often left on the sidelines, sometimes forgotten altogether.⁵⁷ While federal law defines “parents” to include foster parents,⁵⁸ where such definition is consistent with state law, in New York, the child’s parent remains the decision maker unless the child is deemed a ward of the state, which under New York law includes only those children whose parental rights have been terminated.⁵⁹

In every case, the laws affecting the rights of children with disabilities are complicated and, for parents, effective advocacy often presents a major challenge. For children with disabilities in the foster care system, the challenges their parents face are daunting and sometimes insurmountable. In every case, however, when a child’s permanency plan provides for the child’s reunification with the parent, a major focus for the parent to prepare for the child’s return needs to be on the development of effective advocacy skills on behalf of their child in school.

Studies show that between 30-40% of the children in foster care are entitled to special education and related services,⁶⁰ a rate significantly higher than the 12% average in the general student population.⁶¹ For children in foster

care, the evaluation and placement process is often complicated by the difficulties in distinguishing between the effects of disability and the impact of child abuse, neglect, and instability.⁶²

Access to a consistent advocate or caretaker who knows the child and is familiar with educational rights for children with disabilities is frequently absent in the case of children in the foster care system. Since parents play a pivotal role in securing services for children with disabilities, the absence of someone to champion the educational needs of the child in foster care is a stumbling block which can preclude or delay access to special education services.

Under the IDEA, the parents play a critical role in their child's education from referral, planning, programming, and determining when their child will enter and exit the educational system.⁶³ At the outset, parental consent is needed to authorize an initial evaluation for a student suspected of having a disability, before any educational decision is made.⁶⁴ After an eligibility determination is reached, the parent must provide consent, once again, to permit the initial provision of special education services.⁶⁵ What is often surprising is that the IDEA does not provide a means to override a parent's refusal to consent for services, even where the district and the child welfare agency agree the child's need for special education services is paramount. Yet, if a parent refuses or fails to give consent for the child to receive special education services, the decision is final.⁶⁶

Moreover, if, at any time after the initial provision of special education services, the parents revoke consent in writing for continued services, the District must stop all services to the student and provide written notice to the parents advising them of the impact of their decision.⁶⁷ In the event that a parent disagrees with the IEP team regarding a program, recommendation, or service, the parent has certain due process rights to challenge the school district's decision, including the right to request an impartial hearing or mediation.⁶⁸ The child will remain in "pendency" while the dispute is resolved, which can mean without services if the dispute relates to the initial classification or service recommendation.

New York's definition of "parent" includes birth or adoptive parent, a legally appointed guardian or relatives acting in the place of a birth or adoptive parent, or a surrogate parent.⁶⁹ Children in foster care who are wards of the state in New York⁷⁰ are limited in their ability to access the special education system until a surrogate parent is appointed.⁷¹ New York's educational regulations provide only three exceptions to an initial evaluation for children who are in the care and custody of the state and are not residing with their parents. The LEA may proceed with the evaluation,

- (1) [when] the school district cannot discover the whereabouts of the parent

despite reasonable efforts to do so; or (2) [when] the rights of the parents...have been terminated in accordance with State law; or (3) [where] the rights of the parent to make educational decisions have been subrogated by a judge in accordance with State law and the person the judge appoints to represent the student gives consent.⁷²

New York state law does not provide authority for judges to limit parents' right to exercise their educational decision-making for their children in foster care, despite recognition in the state regulations that it may be necessary in some cases to limit or restrict a parent's decision-making authority while a child is placed in care.⁷³

If a parent refuses to grant consent to evaluate his or her child, LEAs may, but are not required, to initiate due process to override lack of consent.⁷⁴ However, now that the regulations are permissive (instead of mandatory as they were prior to the 2004 reauthorization of IDEA), this option is rarely used. Even if the district did secure consent to conduct an initial evaluation, there is no law which allows the LEA to implement special education services recommended by the committee absent parental consent.

As identified above, if the child does not reside with his or her parent (while in the foster care system) and despite reasonable efforts, the parent cannot be found, the regulations provide for the appointment of a surrogate parent, who will be empowered to make all special education decisions on the child's behalf, including whether to accept special education services.⁷⁵ Following the required notification, the CSE/CPSE will determine, within a reasonable time following the student's referral to the committee for an evaluation, whether to appoint a qualified "surrogate" parent for the child who will make all other special education decisions, including whether special education services will begin. The role of a surrogate parent is to make decisions regarding the child within the education system related to special education and to ensure that the rights of the student are protected. A surrogate parent is afforded the same rights and responsibilities as accorded to the parent and represents the child in all matters related to: screening, evaluation, access to early intervention and preschool services as well as school-aged special education supports and services, placement decisions, transition planning, and graduation.⁷⁶ The person selected and appointed by the board of education must have no interests which would conflict with his or her allegiance to the child, should be knowledgeable about the programs and the student's need to adequately represent the child and cannot be "officers, employees or agents of the local school district or State Education Department or any other agency involved in the education or care of the student."⁷⁷ The caseworker assigned to the foster care child's case by the welfare agency cannot serve as a surrogate parent, given the potential conflict between the

agency's goals and the needs of the child. In New York, a foster parent (who is only tangentially referenced in the state regulatory definition of "parent") may act as the parent⁷⁸ if he or she is appointed to serve as a surrogate parent by the school district's board of education.⁷⁹ New York also recognizes the authority of a "person in parental relationship" appointed by a parent to act in his or her place on behalf of the child.⁸⁰ Following title 15-A of the General Obligations Law, parents may temporarily assign their parental rights to another individual in the event that they have died, are ill, imprisoned, institutionalized, or have abandoned or deserted their child, if they are living outside the state or their whereabouts are unknown.⁸¹ A parent may appoint a foster care parent to serve as his or her child's "person in parental relation" which would eliminate the need for the foster parent's appointment as the surrogate parent. It is essential that the child welfare agency and caseworker understand and explain to the parent and the foster parent these issues and limitations, so there are no misconceptions when it comes to who makes the educational decisions for the child. Nothing in the law or regulations precludes a parent from inviting a foster parent to attend and participate as a person with knowledge or special expertise about the student.

If the CSE/CPSE determines that the child qualifies for special education support and services, the committee will develop an individualized education program (IEP) which will serve as the vehicle for the student's educational program. The IEP reflects the individual needs of the student, as determined by the committee made up of educators, evaluators, related service providers, parents, and the district representative.⁸² Although not a mandated IEP team member under state or federal law, a child welfare caseworker can participate if invited by the parent or the school district as a person who has knowledge and special expertise regarding the child.⁸³ Often the child's welfare agency caseworker has a wealth of information regarding the student's health and welfare and can offer insight into permanency planning, which is a relevant factor that may impact services or placement recommendations under the IDEA. In the event the caseworker is unable to attend a CSE/CPSE meeting, collaboration with the school district, the parent, and foster care providers is essential to allow the child welfare agency to remain informed about school needs and issues, which could conversely factor into decisions about school stability under the Fostering Connections Act.⁸⁴

IV. Lessons Learned and Next Steps

Over the past eight years, the growing recognition that our children in foster care have paid the price for gaps in the system has resulted in key legislation that could turn the tide towards achieving better outcomes for this vulnerable population. Permanency planning, as envisioned by the Fostering Connections Act, provides a critical opportunity for interagency collaboration to

benefit all children in the foster care system. Educational stability can help ground children in foster care while issues beyond his or her control are being handled through proper channels. Moreover, when the plan is for a child to return to his or her parents' care, the child welfare agency can focus its efforts on preparing the parents to effectively resume their role as the primary advocate for their child's well-being. School districts can help reinforce the significant role that parents play, even while their child may be in the care of the child welfare system.

New York's Office of Children and Family Services and the State Education Department must reach consensus on what are the critical factors in reviewing whether remaining in the present school or relocation to another is in the "best interest" of the child in foster care. To ensure that a child's transition is as smooth as possible, OCFS and NYSED must also come to agreement on best practices and how to use the existing infrastructure within each organization to serve the interests and to meet the needs of the children in foster care. Another key step is to establish a mutually agreeable interagency dispute mechanism, so that systems are not in contest with one another when the child's interests should receive their collective focus. And the state needs to set aside funding in the budget for transportation for children in the welfare system, which will increase the likelihood that children are able to maintain the constancy of their education notwithstanding the circumstances which resulted in their placement into care.

The building blocks to serve as the foundation for better outcomes are in place. Now it is up to the state's agencies to develop the appropriate structure to deliver on the promise of a better future for our children in care.

Endnotes

1. Fostering Connections to Success and Increasing Adoptions Act of 2008, 154 CONG. REC. H8304-01 H8313 (daily ed. Sept. 17, 2008) (statement of Rep. McDermott).
2. CHILD WELFARE INFO. GATEWAY, FOSTER CARE STATISTICS 2010, 1 (2012), <<http://www.childwelfare.gov/pubs/factsheets/foster.cfm>>.
3. See generally LEGAL CTR. FOR FOSTER CARE & EDUC., FOSTER CARE AND EDUCATION Q AND A: THE LINK BETWEEN EDUCATION AND PERMANENCY (2009), <http://fosteringmediaconnections.org/wp-content/uploads/2010/08/ABA_edpermanencylink.pdf>. Educational instability has been linked to higher rates of homelessness, unemployment, and incarceration. *Id.* at 1.
4. Fostering Connections to Success and Increasing Adoptions Act of 2008, Pub. L. No. 110-351, 122 Stat. 3949 (codified as amended in scattered sections of 42 U.S.C.).
5. NAT'L WORKING GRP. ON FOSTER CARE AND EDUC., EDUCATION IS THE LIFELINE FOR YOUTH IN FOSTER CARE 1, 5 (2011), <<http://www.casey.org/Resources/Publications/pdf/EducationalOutcomesFactSheet.pdf>>.
6. *Id.* at 1.
7. Sara Munson & Madelyn Freundlich, *Educating Children in Foster Care: State Legislation 2004-2007*, NAT'L CONFERENCE OF STATE LEGISLATURES 1 (2008), <http://www.ncsl.org/print/cyf/foster_care_education.pdf>.

8. Amy Reichbach & Marlies Spanjaard, *Guarding the Schoolhouse Gate: Protecting the Educational Rights of Children in Foster Care*, 21 TEMP. POL. & CIV. RTS. L. REV. 101, 102 (2011).
9. Steve Christian, *Educating Children in Foster Care*, NAT'L CONFERENCE OF STATE LEGISLATURES: CHILDREN'S POLICY INITIATIVE 1 (2003), <<http://www.ncsl.org/Portals/1/documents/cyf/cpieducate.pdf>>.
10. *Id.*
11. Amy Reichbach & Marlies Spanjaard, *Guarding the Schoolhouse Gate: Protecting the Educational Rights of Children in Foster Care*, 21 TEMP. POL. & CIV. RTS. L. REV. 101, 102 (2011).
12. NAT'L WORKING GRP. ON FOSTER CARE AND EDUC., EDUCATION IS THE LIFELINE FOR YOUTH IN FOSTER CARE 1, 5 (2011), <<http://www.casey.org/Resources/Publications/pdf/EducationalOutcomesFactSheet.pdf>>.
13. NAT'L COUNS. ON DISABILITY, YOUTH WITH DISABILITIES IN THE FOSTER CARE SYSTEM: BARRIERS TO SUCCESS AND PROPOSED POLICY SOLUTIONS 25 (2008). In a 2005 national study, the average consecutive stay in foster care was just over 29 months.
14. *Id.*
15. *The Implementation of the Fostering Connections to Success and Increasing Adoptions Act: Hearing Before the Subcomm. on Income Sec. and Family Support of the Comm. on Ways and Means*, 111th Cong. 30 (2009) (statement of Kathleen McNaught, Assistant Dir. for the Center on Children and the Law).
16. Rebekah G. Hope, *Foster Children and the IDEA: The Fox Guarding the HenHouse*, 14 (2008), <http://works.bepress.com/cgi/viewcontent.cgi?article=1000&context=rebekah_hope>.
17. *Id.* (citing 1991 National Association of School Psychologists report referenced in Linda Jacobson, *Moving Targets*, EDUCATION WEEK, Apr. 4, 2001).
18. Sara Munson & Madelyn Freundlich, *Educating Children in Foster Care: State Legislation 2004-2007*, NAT'L CONFERENCE OF STATE LEGISLATURES 4(2008), <http://www.ncsl.org/print/cyf/foster_care_education.pdf>.
19. Judith M. Gerber & Sheryl Dicker, *Children Adrift: Addressing the Educational Needs of New York's Foster Children*, 69 ALB. L. REV. 1, 9 (2005).
20. Sara Munson & Madelyn Freundlich, *Educating Children in Foster Care: State Legislation 2004-2007*, NAT'L CONFERENCE OF STATE LEGISLATURES 4(2008), <http://www.ncsl.org/print/cyf/foster_care_education.pdf>.
21. 42 U.S.C. §671(a)(16); *see also* Amy Reichbach & Marlies Spanjaard, *Guarding the Schoolhouse Gate: Protecting the Educational Rights of Children in Foster Care*, 21 TEMP. POL. & CIV. RTS. L. REV. 101, 102 (2011).
22. Fostering Connections to Success and Increasing Adoptions Act of 2008, Pub. L. No. 110-351, 122 Stat. 3949 (codified as amended in scattered sections of 42 U.S.C.).
23. 42 U.S.C. §§675(1)(G)(i)-(ii).
24. 42 U.S.C. §675(1)(G)(i); *see also* LEGAL CTR. FOR FOSTER CARE AND EDUC., FOSTER CARE & EDUCATION ISSUE BRIEF: HOW THE IDEA AND THE FOSTERING CONNECTIONS ACT CAN WORK TOGETHER TO ENSURE SCHOOL STABILITY AND SEAMLESS TRANSITIONS FOR CHILDREN WITH DISABILITIES IN THE CHILD WELFARE SYSTEM 5-6 (2012), <http://www.americanbar.org/content/dam/aba/publications/center_on_children_and_the_law/education/issue_brief_IDEA2012.authcheckdam.pdf> [hereinafter FOSTER CARE & EDUCATION ISSUE BRIEF].
25. 42 U.S.C. §675(1)(G)(i); *see also* FOSTER CARE & EDUCATION ISSUE BRIEF at 5-6.
26. It is important to note that the determination of which special education or related services the student requires and where the student will be placed to receive those services is a decision made by the CSE/CPSE and not the child welfare agency.
27. Cara Chambers & Erika Palmer, *Educational Stability for Children in Foster Care*, 26 TOURO L. REV. 1103, 1104 (2011).
28. N.Y. STATE OFFICE OF CHILDREN AND FAMILY SERVS., 2012 NEW YORK STATE CHILD AND FAMILY SERVICES PLAN FY 2010-2014 ANNUAL PROGRESS AND SERVICES REPORT 41 (2012), <<http://www.ocfs.state.ny.us/main/reports/>>. 2011 data analysis identifies the following statistics—Children under age 2 account for nearly one fifth of new entries (21.2%); children ages 2-5 (13.2%); ages 6-9 (9.6%) and ages 14-17 (40.4%). *Id.*
29. Cara Chambers & Erika Palmer, *Educational Stability for Children in Foster Care*, 26 TOURO L. REV. 1103, 1104 (2011).
30. NAT'L WORKING GRP. ON FOSTER CARE AND EDUC., EDUCATION IS THE LIFELINE FOR YOUTH IN FOSTER CARE 1, 3 (2011), <<http://www.casey.org/Resources/Publications/pdf/EducationalOutcomesFactSheet.pdf>>.
31. *Id.* at 2.
32. S. 6185, 232d N.Y. Leg. Sess.
33. *See* S. 6185 Actions report, *available at* http://assembly.state.ny.us/leg/?default_fld=&bn=S06185&term=2009&Summary=Y&Actions=Y&Text=Y.
34. N.Y. STATE OFFICE OF CHILDREN AND FAMILY SERVS., ADMINISTRATIVE DIRECTIVE: NEW REQUIREMENT REGARDING EDUCATIONAL STABILITY OF FOSTER CHILDREN 3 (2012) [hereinafter Administrative Directive 3].
35. N.Y. Comp. R. & Regs. tit. 18, §430.11(c)(1)(1) (N.Y.C.R.R.).
36. *Id.*
37. *See* NAT'L ASS'N OF CHILD WELFARE ADM'RS, HOW STATES ARE IMPLEMENTING THE FOSTERING CONNECTIONS ACT 2, <<http://www.napcwa.org/Legislative/docs/NY.pdf>>.
38. Memorandum from Ken Slentz to District Superintendents, Superintendents of Public Schools & Charter School LEA Administrators on Education Stability Guidance: NYSED Field Memo #01-2012 (June 2012), *available at* <<http://www.p12.nysed.gov/accountability/homeless/docs/FMedStabilityGuidance.pdf>> [hereinafter Memo on Education Stability Guidance].
39. *Id.* at 28-29.
40. Fostering Connections to Success and Increasing Adoptions Act of 2008, Pub.L. No. 110-351, 122 Stat. 3949.
41. N.Y. STATE OFFICE OF CHILDREN AND FAMILY SERVS., ADMINISTRATIVE DIRECTIVE: NEW REQUIREMENT REGARDING EDUCATIONAL STABILITY OF FOSTER CHILDREN 3 (2012) [hereinafter Administrative Directive 3].
42. Cara Chambers & Erika Palmer, *Educational Stability for Children in Foster Care*, 26 TOURO L. REV. 1103, 1104 (2011).
43. The McKinney-Vento Homeless Assistance Act (the McKinney-Vento Act) guarantees a variety of rights and services to children who are homeless, designed to increase the school enrollment, attendance, and educational success of children who do not have a fixed, regular, and adequate nighttime residence. 42 U.S.C. §§11301-11432. Under the McKinney-Vento Act, states and local educational agencies (LEAs) must have systems in place to provide for the continuing educational stability of children who are homeless. Children who are homeless have the right to school selection, including the option of remaining in the school of origin (typically the school where the student last attended), or attending the local school district where they are temporarily housed. If the homeless student elects to enroll in the school district where he or she is temporarily housed, he or she is entitled to immediate enrollment, even without the required documentation typically required. 42 U.S.C. §11432(g)(3)(C)(i). In addition, the McKinney-Vento Act provides for transportation for the students to and from the school they designate, regardless of whether their living situation is located in another district. 42 U.S.C. §11432(g)(1)(j)(iii).
44. 42 U.S.C. §11434a(2)(A)-(2)(B)(i).
45. Cara Chambers & Erika Palmer, *Educational Stability for Children in Foster Care*, 26 TOURO L. REV. 1103, 1104 (2011).

46. *Id.* at 1110.
47. See N.Y. STATE OFFICE OF CHILDREN & FAMILY SERVS., INFORMATIONAL LETTER: EDUCATIONAL STABILITY OF FOSTER CHILDREN (June 13, 2012) [hereinafter Informational Letter]; see also Memo on Education Stability Guidance. The Office of Children and Family Services, the State Education Department, and the Office of Court Administration in New York are trying to reach consensus on a collaborative decision-making approach to determine how best to make decisions related to school selection.
48. Memo on Education Stability Guidance, at 3.
49. 42 U.S.C. §675(1)(G)(ii).
50. 42 U.S.C. §675(4)(A).
51. *Id.*
52. *Id.*
53. U.S. DEP'T OF HEALTH AND HUMAN SERVS.: ADMIN. FOR CHILDREN AND FAMILIES, GUIDANCE ON FOSTERING CONNECTIONS TO SUCCESS AND INCREASING ADOPTIONS ACT OF 200820 (July 9, 2010), <http://www.scf.hhs.gov/programs/cb/laws_policies/policy/pi/2010/pi1011.htm>.
54. There are alternative funding sources, provided that children in foster care meet certain qualifications. Children who meet the definition of "homeless" under McKinney-Vento (including those awaiting foster care placements) have the unequivocal right to transportation funded through the education system. 42 U.S.C. §11432(g)(1)(j)(iii). In New York, funding for homeless transportation is set forth in education statute. N.Y. Education Law §3209(4)(d). Additionally, New York's social service law has provisions to fund transportation for purposes of school stability for homeless children. N.Y. Social Services LAW §350-j (SSL).
55. Informational Letter; see also Memo on Education Stability Guidance.
56. Margaret Ryznar & Chai Park, *The Proper Guardians of Foster Children's Educational Interests*, 45 LOY. U. CHI. L.J. 147, 148-49 (2010) (identifying that children in foster care receive special education at a rate of roughly five times that of the general school population).
57. To this day, there remains confusion among caseworkers, school officials and parents as to the continuing role of the child's parent, regardless of placement in foster care. What is clear is that the child welfare caseworker is not authorized to serve in the role of "parent," therefore this issue needs to be addressed early on to ensure that the appropriate individuals receive notice of meetings, have access to the child's educational records, and are in a position to represent the interests of the child.
58. Pursuant to the IDEA, a "parent" is defined as:

A natural, adoptive or foster parent of a child (unless a foster parent is prohibited by State law from serving as a parent); a guardian (but not the State if the child is a ward of the State); an individual acting in the place of a natural or adoptive parent (including grandparent, stepparent, or other relative) with whom the child lives, or an individual who is legally responsible for the child's welfare; or except as used in sections 1415(b)(2) and 1439(a)(5), an individual assigned under either of those sections to be a surrogate parent. 20 U.S.C. §1401(23).
59. 8 N.Y.C.R.R. §200.1(ii)(1).
60. NAT'L COUNCIL ON DISABILITY, YOUTH AND DISABILITIES IN THE FOSTER CARE SYSTEM: BARRIERS TO SUCCESS AND PROPOSED POLICY SOLUTIONS 9 (2008), <www.ned.gov/publications/2008/02262008>.
61. *Id.*; see also Steve Christian, Educating Children in Foster Care, NAT'L CONFERENCE OF STATE LEGISLATURES: CHILDREN'S POLICY INITIATIVE 1 (2003), <<http://www.ncsl.org/Portals/1/documents/cyf/cpieducate.pdf>>. Research suggests that the high rate of classification and disability among children in foster care is likely due to the early exposure of physical and emotional trauma such as parental abuse, neglect, abandonment, or lack of appropriate medical and prenatal care and then subsequent changes in home and school once children are placed into the foster care system.
62. Rebekah G. Hope, *Foster Children and the IDEA: The Fox Guarding the HenHouse*, 14 (2008), <http://works.bepress.com/cgi/viewcontent.cgi?article=1000&context=rebekah_hope>.
63. Margaret Ryznar & Chai Park, *The Proper Guardians of Foster Children's Educational Interests*, 45 LOY. U. CHI. L.J. 147, 159 (2010) (identifying that children in foster care receive special education at a rate of roughly five times that of the general school population).
64. 20 U.S.C. §1414(a)(1)(D)(k)(I).
65. 20 U.S.C. §1414(a)(1)(D)(i)(II).
66. 20 U.S.C. §1414(a)(1)(D)(ii)(III).
67. 34 C.F.R. §§300.9, 300.300(b)(4); 8 N.Y.C.R.R. §§200.5(b)(5)(i)-(iv).
68. 20 U.S.C. §§1415(b)(5), (6).
69. See 20 U.S.C. §1401 (defining parent to include an individual assigned to serve as a surrogate parent); 34 C.F.R. §300.519(a)-(b) (requiring LEAs or Districts to assign a surrogate parent to protect the rights of a child if no parent can be identified or found, if the child is a ward of the state or if the child is an unaccompanied youth); see also 34 C.F.R. §300.300(a)(2); 8 N.Y.C.R.R. §200.1(ii)(1).
70. 8 N.Y.C.R.R. §200.1(kkk)(1-3) (A "ward of the state" is a child under the age of twenty-one who has been placed or remanded, freed for adoption, who is in custody of the Commissioner of Social Services or the Office of Children and Family Services, or who is a destitute child.).
71. 8 N.Y.C.R.R. §200.5(n).
72. 8 N.Y.C.R.R. §§200.5(b)(6)(i)-(iii). New York's Education Regulation mirrors the provisions under IDEA. See 20 U.S.C. §§1414(a)(1)(D)(iii)(II)(aa)-(cc).
73. N.Y. Family Court Act §1101 *et seq* (FCA).
74. 34 C.F.R. §300.300(c)(1)(ii); 8 N.Y.C.R.R. §200.5(b)(3).
75. 8 N.Y.C.R.R. §200.5(n)(3).
76. 8 N.Y.C.R.R. §200.5(n)(3)(iv).
77. 8 N.Y.C.R.R. §§200.5(n)(2)(i)-(iii).
78. 8 N.Y.C.R.R. §200.1(ii)(2).
79. 8 N.Y.C.R.R. §200.5(n)(3)(v).
80. N.Y. Educ. Law §3212.
81. N.Y. General Obligations Law §§5-1552; 5-1115 (GOL).
82. 34 C.F.R. §300.321; 8 N.Y.C.R.R. §200.3(a).
83. 34 C.F.R. §300.321(a)(5); 8 N.Y.C.R.R. §200.3(a)(1)(ix).
84. See FOSTER CARE & EDUCATION ISSUE BRIEF.

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The Mental Hygiene Legal Service at 50: A Retrospective and Prospective Examination of Advocacy for People with Mental Disabilities

By Sheila Shea

The year 2014 will mark the fiftieth anniversary of the establishment of the Mental Health Information Service (MHIS),¹ which in 1986 became the Mental Hygiene Legal Service.² Upon its creation in 1964, the Service was a “novel experiment” to protect and ensure the rights of patients in psychiatric facilities.³



Following its establishment, one commentator observed that the Service represented “history’s first genuine legislative concern with providing *effective* legal safeguards for persons sought to be committed to psychiatric hospitals”⁴ (emphasis in original). Almost fifty years later, the Service’s basic core function—to study and review the admission and retention of all patients and residents—remains unchanged.⁵ Over time, however, the mandate of the Service significantly expanded in response to case law and legislative enactments.⁶

The Service now operates as a dedicated legal advocacy program providing a broad range of protective legal services and assistance to individuals with mental disabilities not only in psychiatric hospitals, but any facility where services for mentally disabled individuals are rendered.⁷ MHLS constituents include mentally ill and developmentally disabled individuals, persons alleged to be incapacitated and in need of the appointment of guardians, incapacitated criminal defendants and those acquitted of crimes by reason of mental disease or defect, and sex offenders alleged to be in need of civil management. This article explores the origins of the Service, the scope of its current responsibilities and a prospective examination of the challenges ahead.

I. The Past

Few mental patients read the Bill of Rights. The immediate problems which they are unable to bear seem remote from the honored stricture: “No person...shall be...deprived of life, liberty or property without due process of law.” Yet the whole problem of admission of the mentally ill to hospitals is tied to the question of depriving a citizen of his personal liberty.

—Mental Illness and Due Process⁸

The creation of MHIS was the centerpiece of efforts to reform commitment procedures for mentally ill persons in New York State. The tentative beginnings of that effort came in 1959 when the then Commissioner of the New York State Department of Mental Hygiene sought comments from the Presiding Justices of the Appellate Divisions concerning a legislative proposal to amend the Mental Hygiene Law. The Justices, in turn, asked for advice on the proposal from the Association of the Bar of the City of New York and the New York State Bar Association. The Special Committee to Study Commitment Procedures of the Association of the Bar of the City of New York was formed and, in cooperation with Cornell Law School, began an intensive study of New York’s civil commitment scheme.⁹

The Special Committee completed its study in January of 1962 and its findings were published in the seminal volume, *Mental Illness and Due Process*, published by Cornell University Press. Five principles served as the foundation for the special committee’s analysis of commitment procedures in New York and formed the basis for the committee’s formulation of proposed legislation. Those five principles were:

1. Every person with serious mental illness needs some care and in many cases must go to a hospital, even if he does not want to.
2. Mental hospitals are not prisons but they do, by force on body or mind, deprive the patients of some freedom.
3. Rapid, noncompulsory admission to mental hospitals is good for most patients and helps in allowing effective treatment and early release.
4. When a person must be sent to a mental hospital against his will, he should not be treated like a criminal or be tried and convicted of being sick. Procedures for his admission are only stepping stones to treatments.
5. Any person hospitalized against his will is entitled to watchful protection of his rights, because he is a citizen first and a mental patient second.¹⁰

At the time of the Special Committee’s study, New York had seven legal procedures, one voluntary and six involuntary, for admission to a psychiatric hospital. Most people alleged to be mentally ill were admitted to the hospital under section 74 of the former Mental Hygiene

Law (MHL).¹¹ By operation of section 74, an individual could be hospitalized upon the filing of the certificate of two doctors with a petition and court order committing the patient. The person could then be hospitalized for up to sixty days without any additional process. Retention of the person for an indeterminate period after the initial sixty day admission simply required the hospital director to file a certificate with the County Clerk. Upon that filing, the court order for hospitalization became final and the person could be retained for an indeterminate period until discharge.¹²

Upon examination of the practices and procedures associated with the civil commitment scheme at the time, the Special Committee made several findings, among them that:

Although the statute contemplated notice to the allegedly mentally ill person and a hearing where requested, written notice was infrequently served on the person and hearings were rarely held. The Committee observed that under statutory scheme at the time, notice could be dispensed with if it would be “ineffective or detrimental to the person” and the judge was *required* to dispense with notice if the examining physicians stated in writing that notice would be detrimental.¹³

When hearings did take place, the allegedly mentally ill person was rarely represented by counsel and determinations were based on insufficient evidence. A passage from *Mental Illness and Due Process* describes the “somber reality” of a commitment hearing from the era at Bellevue Hospital in New York City:

In the corridor outside, the patients who have requested a hearing, dressed in pajamas and hospital bathrobes, wait in a straggly gray line to present their protests against being “sent away.” A psychiatrist reads to the judge the physician’s report setting out the initial observations and recommendations of the need for care. Most patients, when called into the courtroom, talk up their “defense”; their stories are sometimes rambling and incoherent, sometimes only a pitiful pleas to go home. There is no regular representation of the patient’s rights.... The judges can and do try to explore the patient’s side of the case, but often they must make a decision on the grave issue of liberty with little more than scant evidence.¹⁴

Once a person was committed by court order, whether after a hearing or without one, the period of hospitalization was largely at the discretion of the hospital. The patient was discharged if and when the hospital director

certified that the person (a) had recovered; (b) was not mentally ill; or (c) while not recovered could be cared for at home without detriment to public welfare, or injury to the patient.¹⁵

The Special Committee recommended reform of the statutory scheme and urged adoption of a “medical model” for admission with enhanced due process protections. The Committee’s preference for the medical model of admission was derived, in part, from its observation that prompt hospitalization and immediate medical attention can be of critical importance in the treatment of mental illness and because a medical model of admission was thought to avoid the stigma of criminality which was associated with the judicial process at the time.¹⁶

To ensure that the patient’s due process rights were protected, the first recommendation of the Special Committee was that a new agency be created, independent of the Department of Mental Hygiene, to be the guardian of patient rights. That new agency, initially referred to by the Special Committee as the “Mental Health Review Service,” became the “Mental Health Information Service” (MHIS), an arm of the Judiciary, with the enactment of the Service’s original enabling statute in 1964. An MHIS was established for each of the four Appellate Division Judicial Departments and began operations in 1965.¹⁷

The original functions, powers and duties of MHIS were as follows:

1. To study and review the admission and retention of involuntary adult patients.
2. To inform such patients and in proper cases others interested in the patient’s welfare about procedures for the patient’s admission and retention and his rights to have judicial hearing and review, to be represented by legal counsel and to seek independent and medical opinion.
3. In any case before a court, to assemble and provide the court with all relevant information on the patient’s case, hospitalization and right to discharge, if any, including information from which the court may determine the need, if any, for the appointment of counsel for the patient or the obtaining of additional psychiatric opinion.
4. To perform services for voluntary patients and informal patients similar to those required under (1) and (2) as may be requested by the patient or someone on the patient’s behalf.
5. To provide such services and assistance both to patients and their families and to the courts having duties to perform relating to the mentally ill and alleged mentally ill as may be required by a judge or justice and in accordance with regulations of the Presiding Justice of the Appellate Division of each Judicial Department.¹⁸

By design, the Service was to remedy the phenomenon of the “forgotten man,” emblematic of individuals confined to back wards and “living the regular, monotonous life of the patient without hope of release.”¹⁹ The Service would ensure that when hearings were demanded, there would be an opportunity for a full presentation of the facts upon which the court would make an informed judgment.²⁰ As one commentator observed in 1971, “because of MHIS’s investigation and reporting functions, the Service may be likened to a civil commitment ombudsman.”²¹

In the ensuing years, the rights afforded to individuals committed to psychiatric hospitals were enhanced which, in turn, gave rise to a fundamental transformation of the Service from ombudsman to legal representative. The evolution of the Service into a dedicated legal advocacy organization is thoroughly discussed in a 1980 study undertaken by the Commission on Quality of Care for the Mentally Disabled [CQC] entitled, *Strengthening Patient Advocacy: A Review of the Mental Health Information Service*, authored by then CQC Chairman Clarence Sundram.²² As Mr. Sundram explained in 1980, seminal court decisions such as *Baxtrom v. Herald* (inmates whose sentences are about to expire must be accorded the same rights as civil patients),²³ *People ex rel. Rogers v. Stanley* (patients have the right to counsel in civil commitment proceedings),²⁴ and *People v. Lally* (defendants acquitted by mental disease of defect had the same rights as civil patients),²⁵ had a profound impact on the Service and the mental hygiene system as a whole. The courts’ articulation of new rights and remedies for persons subject to commitment forever changed the advocacy needs of these individuals. Statutory amendments followed seminal case law and the result was an expansion of the responsibilities of the Service.

A full explanation of the evolution of the Service’s functions, powers and duties is beyond the scope of this article, but suffice it to say that the most prominent expansion of the Service’s workload resulted from the recodification of the MHL in 1972. Following the 1972 recodification, MHIS was to interview and advise patients of their legal rights, regardless of their age or legal status. MHIS jurisdiction was also, for the first time, extended to alcoholism facilities and facilities for developmentally disabled individuals.²⁶ As a result, the mandated workload of the Service was estimated to increase from 14,000 to 67,000 patients.

Initially, only the MHIS for the Second Department employed staff attorneys. The other Departments were staffed with mental health information “officers” and assistants.²⁷ Following the 1966 Court of Appeals right to counsel decision in *People ex rel. Stanley*, guidelines were adopted which permitted the First Department MHIS to assume the role of the patients’ counsel in civil commitment proceedings. Indeed, the MHIS First Department was required to represent patients whom it recommended for discharge, subject to the right of the patient to hire

counsel of her own choosing.²⁸ By the 1980s all four departments had followed suit. As noted by Mr. Sundram in the 1980 CQC report:

These procedures for the First Department had critical implications for the operation of the Service. First, a more traditional lawyer-client role for MHIS emerged in those cases where it was recommending discharge. Secondly, it emphasized the court service role where MHIS disagreed with the client, and in such cases alternative legal representation was to be provided to the client. In this latter situation, the potential conflict between the roles of the legal representative and court aide were recognized. However, the ethical dilemma for the Service in gathering confidential information as a client representative and later using this information to support the hospital’s position in its capacity as court aide was not resolved.²⁹

The foregoing observations echoed concerns that had been previously expressed in a 1973 Assembly Ways and Means Committee report which stated that “it is difficult to reconcile the MHIS’ responsibility to make a report to the court for its use in rendering an objective determination and at the same time represent the patient in the role of advocate.”³⁰ Thus, in its 1980 report, CQC recommended that the Service’s reporting function be eliminated and the mission of MHIS be otherwise refined in response to the changing legal landscape and significantly increased demand for legal services to establish, protect and vindicate the legal rights of mentally disabled individuals.³¹ In 1986, the MHIS was renamed the Mental Hygiene Legal Service and the agency evolved into a multi-faceted legal advocacy program providing a broad range of protective legal services and assistance to mentally disabled individuals.³²

II. The Present

Giving Voice to the Vulnerable

—Honorable Gail Prudenti³³

The present mission of the Service is to ensure that the liberty interests of its constituents are not restricted to any extent greater than is absolutely necessary for their protection and the protection of others.³⁴ The Service also strives to protect property interests and seeks to advocate in a manner which enhances and improves the quality of life enjoyed by its constituents whenever possible.

The mandated activities of the Service are statutorily prescribed by article 47 of the MHL and further defined by uniform regulations of the Presiding Justices of the Ap-

pellate Divisions.³⁵ Section 47.03 of the MHL enumerates the core functions and responsibilities of the Service as follows: to study and review the admission and retention of all patients or residents, including the person's willingness and the facility director's determination as to the suitability of the person's status; to inform patients, residents and others of the procedures for admission and retention, and to the legal right to a judicial hearing, counsel and independent medical opinion; and to provide legal services and assistance to patients or residents and their families with respect to admission, retention, care and treatment. The Service is also authorized to take any legal action it deems necessary to safeguard patients or residents from abuse and mistreatment, which may include investigating any such allegations. In 2007, its jurisdiction was expanded to represent sex offenders in article ten civil management proceedings.³⁶

Pursuant to its enabling statute, MHLS provides legal services and assistance to its constituents under articles 9, 10, 15, 29, 33, 79, and 80 of the MHL,³⁷ to prisoners under sections 402 and 508 of the Correction Law,³⁸ to incapacitated criminal defendants and those found not responsible who are committed to treatment facilities under article 730 and section 330. 20 of the Criminal Procedure Law, to individuals who are the subject of guardianship proceedings under article 81 of the MHL and article 17-A of the Surrogate's Court Procedure Act (SCPA), and to patients who are confined in facilities under sections 251 and 353.4 of the Family Court Act.

The Service is a small state agency with a large task. In 2011, for example, there were approximately 145,000 MHL article 9 and 15 admissions and legal status conversions at inpatient facilities for mentally disabled individuals. These admissions do not always result in judicial commitment hearings, but in 2011 alone, there were in excess of 21,000 judicial proceedings of various types commenced which involved MHLS constituents and were handled by the Service.

The Service has additional duties and responsibilities with respect to the quality of care and treatment and to protect the civil rights of patients, generally. Among the functions undertaken by the Service consistent with its mandate are:

- to remedy conditions of confinement where abuse and mistreatment has occurred, investigate allegations of abuse and mistreatment and other incidents, and ensure that corrective action is taken to protect patients from harm;³⁹
- to monitor and take action to ensure that treatment is otherwise being rendered in compliance with applicable laws, including, but not limited to ensuring that patients are not improperly restrained or secluded;⁴⁰
- to ensure that patients are afforded adequate and appropriate treatment and safe discharge plans;⁴¹

- to ensure that non-English speaking patients and residents are afforded appropriate services;⁴²
- to enforce the Americans with Disabilities Act (ADA) and implementing regulations, to ensure that deaf individuals receiving services for a mental disability are afforded access to sign language interpreters, that individuals with physical disabilities are afforded proper accommodations and that mentally disabled individuals are otherwise afforded appropriated community integration opportunities;⁴³
- to ensure that facilities are complying with New York's health care proxy and do-not resuscitate statutes;⁴⁴
- to ensure that mentally retarded and developmentally disabled persons receive therapeutic and efficacious medical treatment and proper consent for such treatment where necessary, as well as engaging in a mandatory review of a guardian's decision to withdraw or withhold life-sustaining treatment from a mentally retarded ward;⁴⁵
- to protect the rights of involuntarily retained patients and residents to refuse or receive appropriate treatment;⁴⁶
- to ensure that patients and residents are treated in the least restrictive environment consistent with their clinical needs;⁴⁷
- to ensure that the statutory provisions with respect to a patient's right to maintain his or her own money and personal property are followed;⁴⁸
- to maintain communication and visits with persons outside of the facility and to ensure that patients and residents may access their clinical records;⁴⁹
- to ensure that regulations are followed before patients or residents are permitted to be served with legal process in a mental hygiene facility.⁵⁰

Thus, MHLS, in the exercise of its representational role, has been at the forefront in advocating patient liberty interests,⁵¹ in protecting patient privacy interests⁵² and challenging aspects of the state statutory commitment schemes where procedural due process deficiencies are identified.⁵³ In addition, the Service annually receives and addresses thousands of inquiries and complaints by patients, family, friends, facility staff and others concerning care and treatment.

On a frequent and consistent basis, MHLS attorneys and officers find themselves in correctional facilities, secure treatment facilities, inpatient psychiatric wards, alcoholism and substance abuse facilities, veteran's hospitals, community residences, day treatment programs, nursing homes, intensive care units, and private homes, addressing constituent concerns.

At any one time, MHLS staff could be selecting a jury for commitment hearing conducted pursuant to articles 9, 10 or 15 of the MHL or section 330.20 of the Criminal Procedure Law or reviewing a guardian's decision to withhold or withdraw life-sustaining treatment from a mentally disabled individual. On any given day, MHLS staff may be conducting an investigation as the court evaluator or counsel in a guardianship proceeding, while a colleague argues a case in the Appellate Division or Court of Appeals, while still another staff member offers a presentation at a local hospital to explain the legal rights of patients.

Whether engaged in judicial or "non-judicial" advocacy, much of the work of the Service will never find its way into a judicial decision or published report. In psychiatric hospitals and developmental centers, MHLS attorneys and officers negotiate on behalf of its clients in a manner which may lead to a client's discharge or abbreviated detention without the need for judicial intervention.⁵⁴ MHLS staff similarly advocate to promote and protect the liberty and property interests of individuals in community-based facilities.

While representing individuals with diminished capacity, MHLS attorneys are ethically required to maintain a conventional attorney-client relationship as far as reasonably possible.⁵⁵ Challenges abound, however, as it is difficult on the one hand to advocate for the wishes and preferences of a person who may be acutely psychotic, or to know how to best represent the interests of a client unable to communicate, on the other. In order to perform its functions, MHLS attorneys and officers must be able to display a "healthy measure of humility, awe and humor" as they adapt conventional professional responsibilities to sometimes unconventional clients and circumstances.⁵⁶

III. The Future

We hope the effects of this study will be felt for many years, years which we trust will mark a brighter future in the care of the mentally ill.

—Mental Illness and Due Process⁵⁷

The legacy of the Service as well as its future is the product of its personnel, many of whom are career employees. The attorneys, officers and administrative staff of MHLS, while diverse in backgrounds, are motivated and inspired by a singular purpose to be a voice for the vulnerable now and in the future.⁵⁸ The Service was not without its critics at its inception, who feared the agency would have counter-therapeutic effects,⁵⁹ and today inevitable tensions continue at the interface of law and psychiatry. Nor is the Service immune from criticism related to the manner in which it exercises its mandate or deploys its resources. Nevertheless, going forward, the fundamental objectives of the agency appear inviolate. Indeed, the constitutionality of New York's medical model of admis-

sion and retention continues to depend in large part upon the viability and ability of the Service to carry out its functions, powers and duties,⁶⁰ and the mission of the agency has been expanded to ensure the right to counsel in a variety of civil proceedings.⁶¹

To understand the challenges of the future, past is prologue. As it was in 1986, the mental health system is now undergoing rapid and dramatic changes relative to the management, design and structure of state agencies operating or overseeing programs for vulnerable persons.⁶² While it is foreseeable that the agency's core functions will continue unaltered, MHLS attorneys and officers may be called upon to advocate in non-traditional ways. For example, and with greater regularity, the Service may be advocating to establish or maintain the eligibility of its constituents to receive essential services, as opposed to interposing objections to care and treatment. No doubt the agency will also have a greater role to play in health care advocacy. These are functions and duties that were little emphasized at the Service's beginnings, which are now central to its mission.

Another important challenge going forward for the Service relates to how it delivers advocacy services. The Service pioneered the establishment of offices in or near psychiatric hospitals and developmental centers, bringing advocacy services directly to the patients and residents of facilities. To enable the Service to perform its on-site legal advocacy function, MHLS is to be afforded access "at any and all times" to facilities for mentally disabled individuals.⁶³ While the Service maintains offices in dozens of state and municipal psychiatric hospitals and developmental centers throughout New York State, many of these facilities are being closed in favor of smaller, community-based facilities. As an example, in 1978, there were approximately 16,447 institutional beds in developmental centers throughout New York State which were operated by the Office of Mental Retardation and Developmental Disabilities (OMRDD).⁶⁴ Today there are currently fewer than 2,100 developmental center beds. By contrast, approximately 31,900 beds now exist in the community.⁶⁵ Reaching its constituent populations remains a priority for the Service, and will require innovation by the agency to ensure that the needs of mentally disabled individuals for legal advocacy and oversight are met, regardless of where they are served.

IV. Conclusion

The motivation of the staff of MHLS is inevitably drawn from the life stories and experiences of the people served by the agency who display tremendous grace, courage and resiliency in the course of their daily lives. Dramatic changes in the service delivery system will not lessen, and more likely, will accentuate the need for strong legal advocacy on behalf the Service's constituents now and in the future.

Endnotes

1. 1964 N.Y. Laws ch. 738.
2. 1985 N.Y. Laws ch. 789.
3. Raj K. Gupta, *New York's Mental Health Information Service: An Experiment in Due Process*, 25 RUTGERS L. REV. 405, 410 (1970-1971) [hereinafter *An Experiment in Due Process*].
4. *Id.*
5. N. Y. Mental Hygiene Law § 47.03(a) (MHL).
6. See, e.g., *People ex rel. Rogers v. Stanley*, 17 N.Y.2d 256, 270 N.Y.S.2d 573 (1966); *People ex rel. Woodall v. Bigelow*, 20 N.Y.2d 852, 285 N.Y.S.2d 85 (1967) (right to counsel in involuntary civil commitment proceedings); *In re Buttonow*, 23 N.Y.2d 385, 297 N.Y.S.2d 97 (1968) (services of MHIS extended to voluntary patients); 1970 N.Y. Laws ch. 996 (services of MHIS extended to incapacitated defendants and those found not guilty by reason of mental disease or defect); *Rivers v. Katz*, 67 N.Y.2d 485, 504 N.Y.S.2d 74 (1986) (patients entitled to a hearing and counsel prior to being subjected to involuntary medication); 1992 N.Y. Laws ch. 698 (services of MHLS extended to persons alleged to be incapacitated in article 81 guardianship proceedings); 1994 N.Y. Laws ch. 560 (services of MHLS extended to individuals subject to assisted outpatient treatment proceedings); 2007 N.Y. Laws ch. 7 (services of MHLS extended to sex offenders subject to civil management proceedings); 2010 N.Y. Laws ch 111 (MHLS given responsibilities with respect to management of patient funds).
7. MHL § 47.01; MHL § 1.03(6).
8. THE SPECIAL COMMITTEE TO STUDY COMMITMENT PROCEDURES OF THE ASSOCIATION OF THE BAR OF THE CITY OF NEW YORK IN COOPERATION WITH CORNELL LAW SCHOOL, MENTAL ILLNESS AND DUE PROCESS: REPORT AND RECOMMENDATIONS ON ADMISSION TO MENTAL HOSPITALS UNDER NEW YORK LAW 13 (1962) [hereinafter MENTAL ILLNESS AND DUE PROCESS].
9. *Id.* at 15. The Special Committee included judges, the Commissioner of Mental Hygiene, a law school dean, the director of a state hospital and several practicing lawyers. One member of the Special Committee, Simon Rosenzweig, Esq., would later be appointed as one of the original MHLS directors for the First Department.
10. MENTAL ILLNESS AND DUE PROCESS at 14–15.
11. *Id.* at 51, 106–107; *An Experiment in Due Process* at 411.
12. *Id.*
13. MENTAL ILLNESS AND DUE PROCESS at 116–17.
14. *Id.* at 7.
15. *An Experiment in Due Process* at 413, n. 36; N.Y. MHL § 87 (1964). The patient's remedy also included a rehearing and review by jury if one was requested within 30 days of certification. See *In re Coates*, 9 N.Y.2d 242, 213 N.Y.S.2d 74 (1961).
16. MENTAL ILLNESS AND DUE PROCESS at 22; see also Note, *The New York Mental Health Information Service: A New Approach to Hospitalization of the Mentally Ill*, 67 COLUM. L. REV. 672, 673 n.9 (1967).
17. MENTAL ILLNESS AND DUE PROCESS at 22; 1964 N.Y. Laws ch. 738.
18. N. Y. MHL § 88 (1964).
19. MENTAL ILLNESS AND DUE PROCESS at 19.
20. *Id.* at 21.
21. *An Experiment in Due Process* at 415.
22. Mr. Sundram currently serves a Governor Andrew Cuomo's Special Advisor on Vulnerable Persons.
23. *Baxstrom v. Herold*, 383 U.S. 107 (1966).
24. *People ex rel. Rogers v. Stanley*, 17 N.Y.2d 256, 270 N.Y.S.2d 573 (1966).
25. *People v. Lally*, 19 N. Y.2d 27, 277 N.Y.S.2d 654 (1966).
26. 1972 N.Y. Laws ch. 251; see Memorandum from Murphy to the New York State Assembly Ways and Means Committee entitled *The Mental Health Information Service: A Program Review and Suggestions for Reform* (July 31, 1973) (unpublished) [hereinafter *Program Review and Suggestions for Reform*].
27. State Commission on Quality of Care for the Mentally Disabled, Clarence Sundram, Chairman, *Strengthening Patient Advocacy: A Review of the Mental Health Information Service*, p. 18 (1980) [hereinafter *Strengthening Patient Advocacy*].
28. *Id.*
29. *Id.* at 18.
30. See *Program Review and Suggestions for Reform* at 12.
31. *Strengthening Patient Advocacy*, at iv–v.
32. 1985 N.Y. Laws ch. 789.
33. Gail Prudenti, *Giving Voice to the Vulnerable*, N.Y.L.J., Jan. 24, 2011, p. 9, col. 3.
34. *Id.*
35. N.Y. Comp. Codes R & Regs. tit. 22, §§ 622, 694, 823, 1023 (N.Y.C.R.R.).
36. 2007 N.Y. Laws ch. 7.
37. MHL art. 9 (civil admission and retention to psychiatric hospitals); MHL art. 10 (sex offender civil management); MHL art. 15 (civil admission and retention in developmental centers); MHL art. 29 (general provisions relating to in-patient facilities); MHL art. 33 (rights of patients); MHL art. 79 (admission and retention in veteran's hospitals); MHL art. 80 (surrogate decision making for patients who lack capacity).
38. Commitment of mentally disabled individuals in local and state correctional facilities.
39. See, e.g., *Hirschfeld v. N.Y.C. Health and Hospitals Corp.*, 07-CV-1819 (co-counsel with New York Civil Liberties Union and Kirkland and Ellis LLP); *Mental Hygiene Legal Serv. v. Maul*, 36 A.D.3d 1133, 827 N.Y.S.2d 777 (3d Dep't 2007), *lv. to appeal den.*, 8 N.Y. 812 (2007).
40. See, e.g., *Mental Hygiene Legal Serv. v. Cuomo*, 195 A.D.2d 189, 607 N.Y.S.2d 179 (3d Dep't 1994).
41. See, e.g., *Koskinas v. Boufford*, 80 N.Y.2d 684 (1984); *Mental Hygiene Legal Service v. Maul*, 10 Misc. 3d 348, 803 N.Y.S.2d 399 (S. Ct. Franklin Co. 2005) *aff'd*. *Dix v. Maul*, 38 A.D.3d 972, 831 N.Y.S.2d 564 (3d Dep't 2007).
42. See, e.g., *W.G. v. Morris*, 95-CV-2106 (co-counsel with Disability Advocates, Inc.).
43. See generally 42 U.S.C. §§ 12131 *et seq.*; *Olmstead v. L.C. ex rel Zimring*, 527 U.S. 581 (1999); 14 N.Y.C.R.R. § 527.4; 14 N.Y.C.R.R. § 633.4.
44. See, e.g., *In re Leonard B.*, 164 Misc. 2d 518, 625 N.Y.S.2d 809 (Sup. Ct. Albany Co. 1995), *mod. and affirmed*, *Finn v. Leonard C.*, 221 A.D.2d 896 (3d Dep't 1995).
45. See generally, MHL art. 80; Surrogate's Court Procedure Act § 1750-b (SCPA).
46. See, e.g., *N.Y.C. Health and Hospitals Corp. V. Stein*, 70 Misc.2d 944, 335 N.Y.S.2d 461 (S. Ct. N.Y. Co. 1972); *Rivers v. Katz*, 67 N.Y.2d 485 (1986); *J.S. v. Morris*, 95 Civ. 0117 (co-counsel with Disability Advocates, Inc.).
47. See, e.g., *Kesselbrenner v. Anonymous*, 33 N.Y.2d 161 (1973); *McGraw v. Wack* 220, A.D. 2d 291, 632 N.Y.S.2d 135 (1st Dep't 1995); *Bernstein v. Pataki*, 233 F.Appx. 21 (2d Cir. 2007).
48. See, e.g., *State v. Muller*, 179 Misc. 2d 980, 686 N.Y.S.2d 652 (Ct. Cl. 1990), *aff'd*, 280 A.D.2d 923, 719 N.Y.S.2d 916 (4th Dep't 2001), *lv. to appeal den.*, 96 N.Y.2d 715 (2001).
49. See, MHL §§ 33.05, 33.07, 33.16.
50. See, *Mental Health Info. Servs. v. Schenectady County Dept. of Social Servs.*, 128 Misc.2d 282, 488 N.Y.S.2d 335 (Sup. Ct. Albany Co. 1985).
51. See *Rivers v. Katz*, 67 N.Y.2d 485 (1986).

52. See *Hirschfeld v. Stone*, 193 F.R.D. 175 (S.D.N.Y. 2000) (co-counsel with Legal Aid Society); *Miguel M. v. Barron*, 17 N.Y.3d 37 (2011).
53. See, e.g., *Ritter v. Surlis*, 144 Misc. 2d 945, 545 N.Y.S.2d 962 (Sup. Ct. Westchester Co. 1988); *In re David B. and Richard S.*, 97 N.Y.2d 267 (2002); *Harkavy v. Consilvio*, 7 N.Y.2d 607 (2006), *MHLS v. Cuomo*, 785 F. Supp. 2d 205 (S.D.N.Y. 2011).
54. *An Experiment in Due Process* at 488.
55. N.Y. Rules of Professional Conduct: Rule 1.14.
56. Stanley S. Herr, *Representation of Client with Disabilities: Issues of Ethics and Control*, Vol. XVII Review of Law and Social Change (1989-90) 609, 650.
57. *Mental Illness and Due Process* at viii-ix.
58. Gail Prudenti, *Giving Voice to the Vulnerable*, N.Y.L.J., Jan. 24, 2011, p. 9, col. 3.
59. *Strengthening Patient Advocacy* at 10.
60. *Project Release v. Prevost*, 551 F. Supp. 1298 (E.D.N.Y. 1982), *aff'd*, 722 F.2d 960 (2d Cir. 1983).
61. MHL § 9.60, 81.10(c).
62. Clarence Sundram, *The Measure of a Society: Protection of Vulnerable Persons in Residential Facilities Against Abuse and Neglect*, < <http://www.governor.ny.gov/assets/documents/justice4specialneeds.pdf> > (last visited Oct. 16, 2012).
63. MHL § 47.03(d).
64. Now known as the Office for People with Developmental Disabilities (OPWDD).
65. *Office for People with Developmental Disabilities, 2012 Interim Report*, < www.opwdd.ny.gov/sites/default/files/documents/interim_RPT_2012_Final.pdf > (last visited June 12, 2012).

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Ms. Shea is a member of the New York State Bar Association (NYSBA), the Elder Law Section and serves on the Committee on Issues Affecting People with Disabilities. She edits the chapters on "Rights in Facilities" and "Individual Rights and Discrimination: The Deaf and Hard of Hearing" for the NYSBA publication, *Representing People With Disabilities*. She is married to Professor Alex Y. Seita of Albany Law School and has three children.

The NYSBA Family Health Care Decisions Act Information Center

The NYSBA Health Law Section has a web-based resource center designed to help New Yorkers understand and implement the Family Health Care Decisions Act—the law that allows family members to make critical health care and end-of-life decisions for patients who are unable to make their wishes known.

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Family Health Care Decisions Act Information Center

New York's Family Health Care Decisions Act (FHCDA)¹ establishes the authority of a patient's family member or close friend to make health care decisions for the patient in cases where the patient lacks decisional capacity and did not leave prior instructions or appoint a health care agent. This "surrogate" decisionmaker would also be empowered to direct the withdrawal or withholding of life-sustaining treatment when standards set forth in the statute are satisfied.

The key provisions of the FHCDA became effective on June 1, 2010.

The FHCDA Information Center is a project of the NYSBA Health Law Section. It is designed as a resource for all persons – including health care professionals, health care attorneys, advocacy groups, policymakers and members of the public – who are seeking information about the FHCDA.

- Summary of Key Provisions of the FHCDA (PDF)
- Text of the FHCDA (PDF)
- Legal Journal Articles about the Family Health Care Decisions Act
- Frequently Asked Questions
- (Including Q&A's added or revised on September 9, 2010)
- FHCDA List Serve
- Related Laws and Regulations
- NYS Department of Health Materials
- Dear Hospital CEO Letter (NYS Dept. of Health, June 1, 2010) (PDF)
- Dear Nursing Home Administrator Letter (NYS Dept. of Health, June 1, 2010) (PDF)
- Deciding About Health Care: A Guide for Patients and Families (NYS Dept. of Health, 2010) (PDF)
- AIDS Institute Fact Sheet: The FHCDA and AIDS/HIV (PDF)
- When Others Must Choose: NYS Task Force on Life and the Law (1992)
- Information about Model Hospital and Nursing Home FHCDA Policies and Forms
- Information about MOLST – Medical Orders for Life-Sustaining Treatment
- Surrogate Decision-Making for Incapable Adult Patients with Mental Disabilities: A Chart of the Applicable Laws and Regulations (PDF) (Revised as of March 2, 2011)

www.nysba.org/fhcda

New York Reforms Its System of Protection for Vulnerable Individuals

By Jennifer Monthie

New York State's system for protecting its most vulnerable citizens has been publicly attacked over the last year. The abuse and neglect of vulnerable New Yorkers, particularly individuals with developmental disabilities, has called into question the state's ability to protect individuals within its care. This criticism has fueled the state to re-examine the entire system of care for people with disabilities, hold public hearings exploring abuse and neglect, and pursue extensive legislative reform. This is not the first time in New York's history that public criticism has resulted in the state making major reform to its system of care for individuals with disabilities. In fact, New York's current model was created after public exposure of abusive and neglectful conditions at the state's facilities for individuals with developmental disabilities.



The History of Abuse and Neglect in New York—The Formation of the Current System

In the 1970s Congress drew public attention to the care of individuals with disabilities through a series of public hearings and launched a federal response to abuse and neglect of individuals with disabilities.¹ Among the original catalyst for reform for abuse and neglect were the horrible conditions at a New York State facility located in Staten Island, Willowbrook State School. Willowbrook, a state-operated facility for children with intellectual and developmental disabilities, became known to the public when its atrocities and abuses were exposed in a 1972 news report by journalist Geraldo Rivera.² The infamous and horrifying stories that came out of the Willowbrook scandal focused public outrage on New York State's system of care for individuals with disabilities. A series of governmental investigations revealed deplorable conditions at the facility, including severe overcrowding, unsanitary facilities, and physical and sexual abuses of residents by employees of the facility.³ One report to Congress described over 200 children crammed into a single room with three to four staff, covered with their own feces, naked or in rags, and banging their heads against the wall.⁴ Unfortunately, the conditions of Willowbrook were alarmingly common in facilities around the United States.⁵ Then newly elected Governor Hugh Carey called the terrible conditions at Willowbrook unworthy of New York State and embarked on a process of overhauling the state's system of care to individuals with disabilities.⁶

In 1977, New York State dismantled the state agency that delivered services to individuals with disabilities, the Department of Mental Hygiene, and created three separate state agencies to serve New Yorkers with disabilities: The Office of Mental Health (OMH); the Office of Mental Retardation and Developmental Disabilities later renamed the Office for People with Developmental Disabilities (OPWDD), and the Office of Alcoholism and Substance Abuse Services (OASAS).⁷ These three state agencies still serve New Yorkers with disabilities today.

The legislation also created the Commission on Quality of Care, later renamed the Commission on Quality of Care and Advocacy for Persons with Disabilities (CQC-APD).⁸ CQC-APD was charged with the responsibility to provide independent oversight of the three state agencies, "for the purpose of offering the Governor and Legislature...informed, yet impartial, advice and recommendations to ensure that service recipients receive the highest quality of care."⁹

The federal government also took action to address the abuse and neglect of vulnerable individuals with disabilities by enacting the Developmental Disabilities and Bill of Rights Act ("DD Act") for citizens with developmental disabilities.¹⁰ The DD Act enumerated a "Bill of Rights" for individuals with intellectual and developmental disabilities living in residential facilities including: appropriate treatment and services, appropriate medical and dental care, limitations on the use of physical restraint, prohibition of the excessive use of chemical restraint, and permission to close relatives to visit their loved ones without notice.¹¹ To ensure the protections of individuals with disabilities receiving state services, the federal government required that each state create a Protection and Advocacy (P&A) agency to "pursue legal, administrative and other appropriate remedies to ensure the protection of the rights of people with disabilities."¹² In 1980, CQC-APD was designated as New York State's federal P&A agency and continues to serve in this role today.¹³

New York Times Series "Abused and Used"

In 2011, New York State's system of care for individuals with disabilities once again came under public scrutiny with the publication of a series of articles led by the *New York Times*. The *Times* articles reported repeated and widespread abuse and neglect of individuals with developmental disabilities in programs operated or licensed by the Office for People With Developmental Disabilities (OPWDD).¹⁴ The series highlighted Jonathan Carey, a 13-year-old child with autism and a repeated victim of abuse and neglect.¹⁵ Jonathan was slowly crushed to

death in the back seat of a state-operated van by an employee of the OPWDD.¹⁶ The state employee who crushed Jonathan was later convicted of negligent homicide; the state also settled with the family civil suit for \$5 million.¹⁷ The *Times*' report exposed the care of Jonathan prior to his death and reported that he sustained numerous unexplained injuries including a black eye and a broken nose in less than 18 months at the state institution.¹⁸

The *Times*' investigation revealed that the tragic death of Jonathan Carey was not an isolated incident and published a series of articles exposing systemic concern with the state's system of care.¹⁹ In 2009, OPWDD alone received 13,000 allegations of abuse in state-operated and licensed facilities but less than 5 percent were referred to law enforcement.²⁰ Furthermore, only 30 out of the 233 workers involved in these allegations were successfully terminated from employment, and in 25 percent of the cases the employee was transferred to another home serving individuals with disabilities.²¹ In 2010, OPWDD only reported roughly 47 percent of the allegations of physical abuse to law enforcement, and 25 percent of sexual abuse of individuals with developmental disabilities at group homes and institutions in New York State were never reported to law enforcement authorities.²² The *Times* articles prompted state and federal reviews of New York's current system and its failure to protect individuals with disabilities from abuse and neglect.

The State Examines Its Care of Individuals with Disabilities

As an example of how history often repeats itself, New York State's response to the public outcry of abuse and neglect resembled the prior action it took over 30 years prior—leaders examined the concerns through public comment/hearings, and the state engaged in legislative reform of the system.

Governor Andrew M. Cuomo called the state's response to abuse and neglect allegations alarming and vowed to reform the state agencies that provide residential care to individuals with disabilities, the elderly, and children.²³ A new position, Special Advisor to the Governor for Vulnerable Persons, was created and Clarence Sundram was appointed to this position in March 2011 to "assist Governor Cuomo in strengthening the state's system of protection and safety for vulnerable New Yorkers in residential care setting."²⁴ Mr. Sundram was responsible for broadly evaluating the state's system and providing recommendations concerning the state's programs related to developmental disabilities, mental health, alcohol and substance abuse, children, and the elderly.²⁵

In April 2012, Mr. Sundram released a report, "The Measure of a Society: Protection of Vulnerable Persons in Residential Facilities Against Abuse & Neglect," to address problems of abuse and neglect of vulnerable people in residential programs operated or supported by

agencies of the state of New York.²⁶ The report exposed "gaps and inconsistencies" within the six state agencies that serve vulnerable New Yorkers, including formidable barriers to reporting abuse and neglect by direct support staff and residents; poor articulation of "zero tolerance" policies; ineffective investigations of abuse and neglect; unsuccessful disciplinary actions against employees who abuse and neglect; and variations in the rate of reporting between different types of residential programs.²⁷

The report attempts to answer questions about why the system of reporting and investigating incidents of abuse and neglect is not protecting the vulnerable in New York.²⁸ An examination of the legal framework of the state agencies that serve vulnerable persons shows that each of the state agencies differ significantly in reporting, investigating, and defining abuse and neglect.²⁹ For example, Office of Mental Health (OMH) defines abuse as "any of the following acts by an *employee*: improper medication administration, physical abuse, psychological abuse, sexual abuse."³⁰ The Office of Alcohol and Substance Abuse Services (OASAS) defines abuse as "maltreatment of a person that would endanger the physical or emotional well-being of such person through the action or inaction on the part of *anyone*."³¹ An examination of these two definitions shows that OMH focuses on employee-only conduct while OASAS includes investigations by anyone coming into contact with a person within its care.

Further discrepancies can be found in the type of conduct that will constitute abuse. For example, OPWDD has the broadest definition of physical abuse which includes "physical contact which is not necessary for the safety of the person and/or *causes discomfort* to the person ... [or] the handling of a person with more force than is reasonably necessary."³² In contrast, the Department of Health (DOH) defines physical abuse as "inappropriate physical contact which *harms or is likely to harm* the patient."³³ These two regulations both define physical abuse as hitting, pinching, kicking, and shoving, but differ in determining what other conduct may be considered physical abuse—OPWDD uses the "causes discomfort" standard and DOH uses the "harms or is likely to harm" standard.

Furthermore, each state agency has different standards for who investigates the reported abuse and neglect, the training requirements for these investigators; the standard of proof used in the investigation; the requirements for reporting possible crimes to law enforcement; and the requirement to report to external oversight entities.³⁴

These inconsistencies between state agency definitions and reporting requirements are especially problematic to providers who operate programs that are licensed or certified by more than one state agency. Mr. Sundram's report found 112 agencies that were issued operating certificates to provide residential/inpatient care by multiple state agencies.³⁵ The children and adolescents residential programs are often licensed or certified by more than

one state agency.³⁶ In fact “[a]t least 14 agencies serving children have multiple certified programs located on the same campus, often just yards apart from each other, thus exacerbating problems for staff who must adhere to varying standards as residents mingle during campus activities and programs.”³⁷

The report identifies several other concerns with the existing system including: the lack of consistent requirement to maintain a registry of prior abusers, no mandate to conduct trend analysis of incidents of abuse and neglect, and no universal requirement to report to external parties with oversight/investigatory powers.³⁸ Mr. Sundram’s report recommends comprehensive reform to the way New York State investigates, documents, and responds to incidents of abuse and neglect within New York State’s system of care. This reform includes: (1) adopting a common set of definitions for abuse and neglect so that no matter which system serves an individual there is a universal definition; (2) implementing one statewide, centralized, 24-hour staffed hotline for reporting abuse and neglect of vulnerable persons; (3) establishing an entity with the authority to investigate and prosecute all offenders who abuse and neglect vulnerable individuals within the state’s system of care; (4) instituting common standards for investigations and requiring the use of trained investigators; (5) creating standards that differentiate between treatment of serious and repeated acts of abuse and neglect and lesser offenses and incidents that are caused or contributed to by workplace conditions; (6) creating one interagency Statewide Central Register for all abuse and neglect of vulnerable persons so that offenders do not shuffle from one system to another; and (7) giving responsibility of oversight and monitoring of all state-licensed or operated programs to one entity.³⁹ To accomplish this reform the report calls for the enactment of legislation to protect vulnerable children and adults.⁴⁰

The New York Assembly also responded to public scrutiny of the system and held public hearings⁴¹ in June 2011 aimed at “carefully examining the quality of care and safety measures in homes for individuals with developmental disabilities.”⁴² The hearings exposed the same problems with the state’s system of investigating abuse and neglect: lack of reporting to law enforcement, lack of transparency, retention of workers who commit physical and sexual abuse, and the state’s inadequate oversight structure.⁴³ These hearings also revealed that each state agency had a different threshold for categorizing conduct as abuse or neglect, and different procedures for reporting, investigating, and confirming the existence of abuse or neglect.⁴⁴

Federal Auditors Expose Problems in New York’s Protection and Advocacy System

In July of 2011, New York’s federally funded Protection and Advocacy (P&A) system also received scrutiny when it underwent a review from the U.S. Department of

Health & Human Services, Administration on Developmental Disabilities (ADD). The federal P&A system was created to provide federal oversight of each state’s systems of care for persons with disabilities.⁴⁵ Under federal law, each state’s governor designates a single state or non-profit agency to serve as the state’s P&A.⁴⁶ The designated P&A must administer each of the seven P&A programs.⁴⁷

ADD conducted on-site review of New York’s designated P&A agency CQC-APD. ADD is responsible for ensuring that a state’s P&A agency is meeting the federal programs requirements of improving the lives of people with disabilities and their families. ADD was particularly “interested in knowing the extent to which the Agency [CQC-APD] has the authority and independence to carry the function of the P&A.”⁴⁸

CQC-APD administers the P&A program by contracting with nine not-for-profit law offices and two law schools.⁴⁹ In December 2011, ADD issued notice to CQC that it was out of compliance with several requirements of the federal P&A program, including a lack of independence from other state agencies that provide treatment and services to individuals with developmental disabilities. The federal audit found that,

gubernatorial appointment of Chair and Commissioners [of state agencies including CQC-APD] and the influence of the political structure (due to staff reporting lines) call into question the independence of [CQC-APD]. The reporting structure does not support the NY P&A’s independence and objectivity that is also responsible for directing [other state] agencies providing treatment and service to individuals with developmental disabilities, including the Director of the Office of People with Developmental Disabilities.⁵⁰

ADD required CQC-APD to respond with a corrective action plan to ensure that New York’s P&A was taking proper steps to comply with federal program requirements.⁵¹

CQC-APD conducted an internal review of its system and responded by holding three public hearings to obtain comment from current or former clients of the P&A system, advocates, stakeholders, and other individuals interested in the P&A system.⁵² The public hearings addressed whether New York should operate its P&A system through a not-for-profit or maintain its current structure through CQC-APD.⁵³ In April 2012, following this public comment period, CQC-APD issued a report to Governor Cuomo recommending that the agency turn over the federally funded and mandated P&A function to an independent not-for-profit agency to be chosen by the Governor.⁵⁴ CQC-APD found that most other states designated not-for-profit agencies as the P&A operator for the state and “the most common reason has been to ensure the independence and autonomy of the P&A.”⁵⁵ It

also concludes that because CQC-APD is a state agency, controlled by the governor, it “cannot bring litigation or engage in independent legislative advocacy, two core activities of the federal P&A system.”⁵⁶ To improve New York’s P&A system, CQC-APD recommended that the Governor designate a nonprofit organization to serve as the P&A agency in New York.⁵⁷

New York State Redefines the System

On May 7, 2012, after receiving the reports from Mr. Bearden, Chair of CQC-APD, and Mr. Sundram, Special Advisor to the Governor on Vulnerable Persons, Governor Cuomo announced reforms to the state’s system of protecting vulnerable New Yorkers. The Governor unveiled legislation to create a Justice Center for the Protection of People with Special Needs which would direct how the State protects New Yorkers in State operated, certified, or licensed facilities and programs.⁵⁸ “The Justice Center would have a Special Prosecutor and Inspector General... who will investigate reports of abuse and neglect and prosecute allegations that rise to the level of criminal offenses.”⁵⁹ The Justice Center would also operate a 24/7 hotline, a statewide database that will track all reports of abuse and neglect, and a statewide register of workers who have committed serious acts of abuse who will be prohibited from ever working with people with disabilities or special needs.⁶⁰ The legislation mirrored many of the suggestions from Mr. Sundram’s report “The Measure of a Society: Protection of Vulnerable Persons in Residential Facilities Against Abuse & Neglect.”

The legislation was introduced in the New York State Senate (Senate Bill 07400) on May 8, 2012 and passed the Senate on May 16, 2012.⁶¹ However, the legislation stalled in the New York State Assembly. On June 17, 2012, four days before the end of the legislative session, Governor Cuomo, Senate Majority Leader Dean Skelos, and Assembly Speaker Sheldon Silver announced an agreement on legislation to reform New York State’s system of oversight.⁶² The legislation was voted on and unanimously passed both houses of the Legislature.⁶³

The agreed-upon legislation was similar to the original measure proposed by the Governor in that it creates a Justice Center for the Protection of People with Special Needs which will have a Special Prosecutor and Inspector General to investigate reports of abuse and neglect and prosecute allegations that rise to the level of criminal offenses.⁶⁴ The revised legislation included additional provisions not in the Governor’s proposal, such as a new Advisory Council, composed of at least 15 members, to provide guidance to the Justice Center in the development of programs, policies and regulations.⁶⁵ Members of the group will include individuals with experience in the care of persons with disabilities and individuals or family members of individuals who participated in state mental health programs.⁶⁶ The legislation also requires the Gov-

ernor to appoint a not-for-profit agency to serve as New York’s federal Protection and Advocacy agency, removing this function from the state.⁶⁷

The Justice Center will be primarily responsible for tracking, investigating, and pursuing serious abuse and neglect complaints for operated, certified, or licensed entities within the six state agencies: Department of Health (DOH), OMH, OPWDD, Office of Children and Family Services (OCFS), OASAS, and the State Education Department (SED).⁶⁸ The legislation also creates a 24/7 hotline to receive complaints of abuse and neglect to investigate and/or refer to law enforcement; develops a register of workers who have committed serious or repeated acts of abuse; represents the state in all public employee disciplinary cases or those where the state is seeking termination; develops common standards for investigations and requires the use of trained investigators; consolidates background checking, including review of criminal history for any employee, volunteer, or consultant at any facility or provider agency operated, licensed or certified by OMH, OPWDD, and OCFS.⁶⁹ The legislation also eliminates CQC-APD and transfers all the powers and authority of CQC-APD, other than the federal Protection and Advocacy function, to the newly created Justice Center. The federally funded Protection and Advocacy program will be designated to an independent not-for-profit agency in New York State.⁷⁰

New Yorkers Wait for Reform

Over the last year, New York’s system of care for individuals with disabilities has been heavily criticized for its inability to protect the individuals it serves. The state responded, as it did 30 years ago, with the creation of a new state agency to provide oversight of the care to individuals with disabilities. Over the next year, proponents and critics will be watching to see the impact of this legislation and whether the new system, both public and not-for-profit, will be more effective at addressing the abuse and neglect of citizens within New York State’s care.

Endnotes

1. *Developmental Disabilities Act Extension and Rights of Mentally Retarded*, 1973: Hearing on S. 427 and S. 458 Before the Subcomm. on the Handicapped of the S. Comm. on Labor & Public Welfare, 93d Cong. 562 (1973) [hereinafter *Developmental Disabilities Act 1973 Hearing*].
2. S. REP. NO. 94-160, at 29 (1975).
3. S. REP. NO. 93-1169, at 33 (1973).
4. *Developmental Disabilities Act 1973 Hearing*, *supra* note 1 (statement of Geraldo Rivera).
5. In 1973, Congress described these public institutions as
hopeless places dedicated to custodial care of lifelong residents. All too often these institutions are far removed from urban areas and represent an effort of society to forget its obligations to their residents... these circumstances tend to generate environments in which residents can be neglected and even abused,

and which unfortunately often lead to deterioration of the residents' physical and mental condition.

S. REP. NO. 93-1169, at 29–30.

6. N.Y. STATE COMM'N ON QUALITY OF CARE FOR THE MENTALLY DISABLED, IMPROVING LIVES, PROTECTING RIGHTS: KEEPING THE DREAM ALIVE i (2002–2003), <http://cqc.ny.gov/uploads/Publications/ar0203.pdf> [hereinafter *Improving Lives*].
7. *Id.*
8. *See id.*
9. *Id.*
10. These rights were later extended to individuals with other disabilities, including mental illness, with the passage of the federal Protection and Advocacy for Individuals with Mental Illness Act of 1986. 42 U.S.C. § 10801.
11. Pub. L. No. 94-103, § 201; 89 Stat. 426 (codified as 42 U.S.C. § 15009). The Supreme Court later ruled that there was no individual right of action against states for failure to comply with the Bill of Rights provisions of this Act. *Pennhurst State Sch. & Hosp. v. Halderman*, 451 U.S. 1 (1981).
12. Pub. L. No. 94-103, § 203, 89 Stat. 426, 504 (codified as 42 U.S.C. § 15043).
13. *Improving Lives*, *supra* note 6, at 1.
14. Danny Hakim, *At State-Run Homes, Abuse and Impunity*, N.Y. TIMES, Mar. 13, 2011, at A1 [hereinafter *At State-Run Homes*].
15. Danny Hakim, *A Disabled Boy's Death, and a System in Disarray*, N.Y. TIMES, June 6, 2011, at A1 [hereinafter *A Disabled Boy's Death*].
16. *Id.*
17. Danny Hakim, *\$5 Million Payment to End Suits Over Death of 13-Year-Old Boy in State Care*, N.Y. TIMES, Sept. 22, 2011, at A25.
18. *A Disabled Boy's Death*, *supra* note 15..
19. *See At State-Run Homes*, *supra* note 14; Russ Buettner, *For Disabled Man Left in Van, Cause of Death is Unclear*, N.Y. TIMES, Aug. 4, 2011, at A22; Danny Hakim, *For Disabled Care Complaints, Vow of Anonymity Was False*, N.Y. TIMES, Nov. 12, 2011, at A1; Danny Hakim & Russ Buettner, *In State Care, 1200 Deaths and Few Answers*, N.Y. TIMES, Nov. 6, 2011, at A1; Danny Hakim, *In Treating Disabled, Potent Drugs and Few Rules*, N.Y. TIMES, Dec. 23, 2011, A1; Russ Buettner, *An Operator of Group Homes Keeps State Aid Despite Faults*, N.Y. TIMES, Dec. 28, 2011, A1.
20. *At State-Run Homes*, *supra* note 14.
21. *Id.*
22. Danny Hakim, *Progress Claimed in Reporting Abuse at Group Homes*, N.Y. TIMES, June 14, 2011, at A17 [hereinafter *Progress Claimed in Reporting*].
23. Danny Hakim, *Cuomo Vows Reform at Residential Care Agencies*, N.Y. TIMES, Oct. 12, 2011.
24. *The Governor's Special Advisor on Vulnerable Persons: A Message from Clarence J. Sundram*, N.Y. State Governor, <<http://www.governor.ny.gov/advisorvulnerablepersons>> (last visited Oct. 16, 2012).
25. *Id.*
26. Clarence J. Sundram, *The Measure of a Society: Protection of Vulnerable Persons in Residential Facilities Against Abuse & Neglect* (2012), <<http://www.governor.ny.gov/assets/documents/justice4specialneeds.pdf>>.
27. *Id.* at 6.
28. *See generally id.*
29. *Id.* at 22–28.
30. 14 N.Y. Comp. Codes R. & Regs. § 524.4 (N.Y.C.R.R.) (emphasis added).
31. 14 N.Y.C.R.R. § 836.4 (emphasis added).
32. 14 N.Y.R.C.C. § 624.4 (emphasis added).
33. 10 N.Y.R.C.C. § 81.1 (emphasis added).
34. Sundram, *supra* note 26, at 22–29.
35. *Id.* at 31.
36. *Id.*
37. *Id.*
38. *Id.* at 27–30.
39. *Id.* at 65–78.
40. *Id.* at 66.
41. Public Hearings were held by Assembly Committee on Mental Health, Mental Retardation and Developmental Disabilities (Chaired by Assemblyman Felix Ortiz); the Committee on Codes (Chaired by Assemblyman Joseph Lentol); and the Committee on Oversight, Analysis and Investigation (Chaired by Assemblyman Jonathan Bing).
42. Press Release, New York State Assembly, News Release, Assembly Speaker Sheldon Silver (May 27, 2011) (on file with author); Letter from Sheldon Silver, Speaker N.Y. State Assembly, to Felix Ortiz, Chair Comm. on Mental Health, Mental Retardation & Developmental Disabilities, Joseph Lentol, Chair Comm. on Codes, & Jonathan Bing, Chair Comm. on Oversight, Analysis and Investigation (Mar. 25, 2011), <<http://assembly.state.ny.us/Press/20110525a/letter.pdf>>.
43. *Progress Claimed in Reporting*, *supra* note 22.
44. *Id.*
45. Roger Bearden, Report on the Administration of the Protection and Advocacy and Client Assistance Program (2012) (on file with author).
46. Protection and Advocacy for Persons with Developmental Disabilities, 42 U.S.C. § 15041 et seq., 45 C.F.R. § 1386.1 et seq.; Protection and Advocacy for Individuals with Mental Illness, 42 U.S.C. § 10801 et seq., 42 C.F.R. § 51.1 et seq.; Protection and Advocacy for Individual Rights, 29 U.S.C. § 794e, 34 C.F.R. § 381.1 et seq.; Protection and Advocacy for Assistive Technology, 29 U.S.C. § 3004; Protection and Advocacy Beneficiaries of Social Security, 42 U.S.C. § 1320b-21; Protection and Advocacy for Individuals with Traumatic Brain Injury, 42 U.S.C. § 300d-53; Protection and Advocacy for Voting Accessibility, 42 U.S.C. § 15461. The federal government has also established the Client Assistance Program (CAP) to assist individuals with disabilities in accessing vocational rehabilitation services. Client Assistance Program, 29 U.S.C. § 732, 34 C.F.R. § 370.1 et seq.
47. The P&A program consists of seven programs: Protection and Advocacy for Persons with Developmental Disabilities; Protection and Advocacy for Individuals with Mental Illness; Protection and Advocacy for Individual Rights; Protection and Advocacy for Assistive Technology; Protection and Advocacy for Beneficiaries of Social Security; Protection and Advocacy for Individuals with Traumatic Brain Injury; and Protection and Advocacy for Voting Accessibility. *Id.* at 1.
48. Letter from Sharon B. Lewis, Comm'r Admin. of Developmental Disabilities, to Roger Bearden, Chair Comm'n on Quality of Care and Advocacy for Persons with Disabilities (Dec. 13, 2011) (on file with author) [hereinafter Letter from Sharon B. Lewis].
49. New York Lawyers for the Public Interest; Legal Services of Central New York; Disability Advocates, Inc.; Neighborhood Legal Services, Inc.; Nassau/Suffolk Law Services; Legal Services of the Hudson Valley; Albany Law School; Legal Aid Society of Northeastern New York; Western New York Advocacy for the Developmentally Disabled; Long Island Advocacy Center; and Touro College of Law. CQC-APD administers the Client Assistance Program through its contracts with Western NY Independent Living; Regional Center for Independent Living; Westchester Independent Living Center; Capital District Center for

Independence; Long Island Advocacy Center; Resource Center for Independent Living; Catskill Center for Independence; and Center for the Independence of the Disabled NY. Bearden, *supra* note 45, at 3-4.

50. Letter from Sharon B. Lewis, *supra* note 48.

51. *Id.*

52. Press Release, N.Y. State Comm'n on Quality of Care and Advocacy for Persons with Disabilities, Notice of Public Forums (Jan. 10, 2012) (on file with author).

53. *Id.*

54. Bearden, *supra* note 45, at 10.

55. *Id.* at 8.

56. *Id.* at i.

57. *Id.* at 10.

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59. *Id.*

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61. S.07400, 2012 N.Y. Leg Sess.

62. Press Release, Andrew M. Cuomo, Governor Cuomo and Legislative Leaders Announce Agreement on Legislation to Protect People with Special Needs and Disabilities (June 17, 2012) (on file with author).

63. A.10721, 2012 N.Y. Leg Sess.; S.07749, 2012 N.Y. Leg Sess. The bill was signed by the Governor on December 17, 2012. 2012 N.Y. Laws Ch. 501.

64. A.10721, N.Y. Leg Sess.; S.07749, N.Y. Leg Sess.

65. A.10721, N.Y. Leg Sess.; S.07749, N.Y. Leg Sess.

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67. A.10721, N.Y. Leg Sess.; S.07749, N.Y. Leg Sess.

68. A.10721, N.Y. Leg Sess.; S.07749, N.Y. Leg Sess.

69. A.10721, N.Y. Leg Sess.; S.07749, N.Y. Leg Sess.

70. Roger Bearden, Commission on Quality of Care and Advocacy for Persons with Disabilities Solicitation of Interest (2012), <<http://cqcsol.ny.gov/uploads/SOI/CQCSOI.pdf>>.

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The Achieving a Better Life Experience (ABLE) Act of 2011:¹ Good Intentions, Questionable Results

By Edward V. Wilcenski and Tara Anne Pleat

On November 15, 2011, the second iteration of the ABLE Act was introduced as bill H.R. 3423 in the House of Representatives.² As of the writing of this article, the ABLE Act has been in Committee and no major actions have been taken. The supporters of this Act describe it as a low-cost tool for families to save for future disability related expenses in a similar manner to that which is available to families for future educational expenditures through College Savings Plans. In the authors' opinion, while well intentioned, the ABLE Act falls short of its mark.



Special Needs Trusts are essentially discretionary spendthrift trusts, which by design allow a Trustee to make distributions of any type for the benefit of a disabled beneficiary. However, this general grant of discretion is circumscribed by instructions to the effect that it should not be exercised in a fashion, which would have an adverse impact on a beneficiary's eligibility for publicly funded benefits.⁵ If drafted properly, the principal and undistributed income held by the Trustees of such trusts will be disregarded when determining eligibility for most means-tested programs. Distributions from a Special Needs Trust will impact benefit eligibility differently depending on the program. For example, using a Special Needs Trust to buy groceries (food) for an SSI recipient will generally result in a decrease in the recipient's SSI payment.⁶



I. Introduction

Planning for clients who have children and other family members with special needs can be challenging. In many cases, these clients have the same tax and estate planning objectives as any family, but the unique needs of the family member with the disability forces planners to consider issues outside their traditional areas of familiarity: wills and trusts, taxation, investments and fiduciary management. With the special needs family, the focus is often on issues such as guardianship, maintaining public benefits, and future access to community-based support services, issues with which most tax and estate planning professionals have limited experience. Should the ABLE Act become law, it will add yet another option for planners and family members alike.

ABLE Act accounts are often framed as an estate planning alternative to traditional Special Needs Trusts. As such, a brief summary of the law and rules governing Special Needs Trusts is in order.

II. The Special (Supplemental)³ Needs Trust

The Special Needs Trust is the most commonly used estate planning tool for individuals who require fiduciary management and oversight (usually because of a cognitive disability) and who participate in one or more "means tested" government benefit programs. The two main government benefit programs which support individuals with disabilities in the community are the Supplemental Security Income (SSI) and Medicaid programs, both of which have income and resource limitations which will limit the amount of property the participant can own (outright or through a custodian, conservator or guardian).⁴

While all Special Needs Trusts will meet this general criterion, there are actually two discrete subsets of Special Needs Trusts: "First Party" Special Needs Trusts and "Third Party" Special Needs Trusts. The line of demarcation between the two is drawn to identify the source of the property used to fund the trust, and not necessarily the name of the settlor or beneficiary of the trust, a fact which in many cases can lead to confusion among those who may be unfamiliar with these planning documents.

Special Needs Trusts, which are designed to hold the property of someone other than the person with the disability, are most commonly referred to as "Third Party" Special Needs Trusts, and will be referenced as such throughout this article. With a Third Party Special Needs Trust, funds remaining in the trust upon the death of the lifetime beneficiary may go directly to the remainder beneficiaries selected by the creator of the trust.

With a First Party Special Needs Trust, the state Medicaid program must be repaid upon the death of the lifetime beneficiary before anything can be distributed to the remainder beneficiaries (or, if the First Party Special Needs Trust is managed as a "pooled trust" by a not-for-profit organization, funds may be retained by the trust to be used by the organization for other, related purposes).

Intuitively, this distinction between the two types of Special Needs Trusts makes sense. A third party (a parent, grandparent, etc.) can do with his or her property

whatever he or she may want, including disinheriting a child with a disability altogether. To the extent the third party would like to create a trust which explicitly limits the availability of trust funds so that the beneficiary can continue to receive benefits from the Medicaid program or otherwise, the third party should have the right to do so. The Third Party Special Needs Trust is the variation most commonly seen by planners working with the parents of an individual with a disability

If an individual with a disability already owns assets which would otherwise need to be exhausted before government benefits were available, then there must be some accommodation in the rules of the benefit program itself before those assets can be disregarded in determining ongoing benefit program eligibility. These assets could come from many different sources: a lawsuit recovery, an unexpected inheritance, or accumulated savings by someone injured later in life. The First Party Special Needs Trust is in many ways a creature of the federal Medicaid statute (through statutory provisions which were later incorporated into the Supplemental Security Income program).⁷ Congress allowed individuals with disabilities to put their own assets into a First Party Special Needs Trust in order to maintain Medicaid and Supplemental Security Income program eligibility, but at a price: upon the beneficiary's death, property remaining in the First Party Special Needs Trust is subject to a "payback" to the state's Medicaid program for all medical assistance provided to the beneficiary during his or her life.

The ABLE Act is widely hailed as an alternative to the use of Supplemental Needs Trusts. The authors believe that the benefits of using these accounts are being greatly exaggerated by its proponents, and that the financial risks have gone largely unpublicized.

III. Mirroring the Qualified Tuition Programs

The ABLE Act would result in an amendment to Section 529 of the Internal Revenue Code ("the Code"), which is the section of the Code which governs the establishment, funding, and use of Qualified Tuition Programs (referred to throughout the balance of this article as "529 accounts").⁸ There are several tax-related benefits that apply to 529 accounts, which would similarly apply to ABLE Act accounts.

First, in the context of estate and gift taxes, a contribution to a 529 account is treated as a gift to the named beneficiary of the account, which qualifies for the federal gift tax annual exclusion.⁹ In 2012, an individual could contribute \$13,000 to a 529 account without having to file a federal gift tax return. For families who intend to use 529 accounts in connection with estate tax planning, a contribution between \$13,000 and \$65,000 can be made in a single year, and the donor can elect to treat the contribution as being made over a five calendar-year period for gift tax purposes.¹⁰ This allows an individual to utilize as

much as \$65,000 in annual exclusions to shelter a larger contribution. Funds in the 529 account (and the future growth of the 529 account) are removed from the donor's estate more quickly than if he or she made contributions each year.

From an income tax standpoint, while contributions to a 529 account are not deductible for federal income tax purposes, the investments within the account are permitted to grow on an income tax deferred basis, and so long as the withdrawals are for qualified higher education expenses, withdrawals or distributions from the plan are income tax free.¹¹

The ABLE Act would add a new provision to Section 529 whereby state "ABLE programs" and "ABLE accounts" would be treated in the same manner as qualified tuition programs. Additionally, "qualified disability expenses" would be treated in the same manner as qualified higher education expenses.

The proposed legislation defines a Qualified ABLE Program as "a program established and maintained by a State or agency or instrumentality thereof under which a person may make contributions to an ABLE account which is established for the purpose of meeting qualified disability expenses of the designated beneficiary of the account...."¹²

IV. Qualified Disability Expenses

Much like the Section 529 definition of qualified higher education expenses, the ABLE Act defines "qualified disability expenses" as "any expenses which are made for the benefit of the individual with the disability who is a designated beneficiary."¹³

The legislation goes on to itemize specific categories of expenses, namely, education, housing, transportation, employment support, health prevention and wellness, financial and legal expenses, and assistive technology expenses. The Secretary of the Treasury is required to issue regulations within six months of passage to further define these qualified disability expenses.

V. Who Is Eligible for an ABLE Act Account?

A 529 educational savings plan can be established for any individual with a social security number who is expected to incur educational expenses at some point in the future. ABLE accounts can only be established and maintained for someone who is determined to be an "individual with a disability," a determination which must be made and/or certified on an annual basis.¹⁴

The ABLE Act provides that an individual of any age is considered an individual with a disability in a given year if the individual is blind or "has a medically determinable physical or mental impairment, which results in marked and severe functional limitations, and which can be expected to result in death or which has lasted or can

be expected to last for a continuous period of not less than 12 months.”¹⁵ The ABLÉ Act goes on to provide that an individual shall not be treated as an individual with a disability unless the individual is (1) receiving or is qualified to receive Supplemental Security Income; (2) receiving Social Security Disability benefits; or (3) files a disability certification with the Secretary of the Treasury each year.¹⁶ In other words, if a person has not been determined eligible for Supplemental Security Income or Social Security Disability benefits, then each year the individual with the disability or that individual’s parent or guardian must provide a certification of disability, supported by the written diagnosis of a physician, in order to use the ABLÉ Act account.¹⁷ The ABLÉ Act language does not make clear whether a confirming diagnosis must be obtained each year.

At first blush, this disability definition may seem reasonable and easy to meet. However, while many individuals with disabilities receive Supplemental Security Income or Social Security Disability income benefits and would thus easily qualify for participation in an ABLÉ account, some are concerned that the ABLÉ Act definition will exclude many individuals whose disabilities are more difficult to identify and define. For example, there is a fairly significant movement to modify how autism spectrum disorders are diagnosed and categorized.¹⁸ Many advocates believe that this redefinition will make it harder for individuals on the spectrum to meet the definition of “disabled” for the purposes of the Supplemental Security Income and Social Security Disability programs, notwithstanding the fact that their disability leaves them unable to work. These individuals would be forced to have their disability confirmed by a physician on an annual basis, something which a physician may be reluctant to do. The same concern exists for many individuals with mental illness, acquired head injuries, learning disabilities or other “high functioning” individuals with disabilities. In addition, given the risk of being caught by the “Medicaid Tax” (explained below), many individuals with disabilities and their families may be reluctant to use the ABLÉ accounts after being fully informed of this risk.

VI. The Hidden “Medicaid Tax”

What the authors find most frustrating about the commentary and dialogue surrounding ABLÉ accounts is the fact that its proponents seem to leave out what is perhaps the most costly and potentially damaging result of using the ABLÉ account as an alternative to the traditional Third Party Supplemental Needs Trust. Specifically, the ABLÉ Act contains a provision entitled “Transfer to State,” which reads as follows:

Subject to any outstanding payments due for qualified disability expenses, in the case that a designated beneficiary dies or ceases to be an individual with a disability, all amounts remaining in the quali-

fied ABLÉ account, not in excess of the amount equal to the total medical assistance paid for the designated beneficiary after the establishment of the account... [must be repaid to the State Medicaid program].¹⁹

In other words, when a beneficiary of an ABLÉ account dies, the Medicaid program must be repaid from funds in the account for all Medicaid benefits paid out on that beneficiary’s behalf during his or her life. This is in stark contrast to what happens upon the beneficiary’s death when a traditional Third Party Trust is used to hold family assets for a family member with a disability. With the Special Needs Trust, funds remaining after the beneficiary’s death will go wherever the parents (or other person establishing the trust) chooses—to other family members, to charity, etc. By choosing an ABLÉ account over a traditional Third Party Supplemental Needs Trust, families are subjecting their assets to a voluntary “Medicaid Tax” that they would not otherwise have to pay.

Perhaps more alarming is the fact that this “Medicaid Tax” may be demanded by the state Medicaid program during the life of the beneficiary with the disability, as the proposed legislation states that the claim can be made if he or she “ceases to become an individual with a disability.” Since the determination of whether or not a person is an “individual with a disability” is made on an annual basis, the ABLÉ account could be subject to claim by a state Medicaid program much earlier than the date of death, such as in the case of the termination of Supplemental Security Income benefits due to an individual’s securing employment or when a physician refuses to recertify a beneficiary’s disability in a particular year.

Explanation of this “Medicaid Tax” is suspiciously absent from much of the promotional materials being circulated by various national disability organizations, which support the ABLÉ legislation. Whatever the motive for failing to publicize this confiscatory feature of the ABLÉ Act legislation, the authors believe that this omission represents a disservice to the disability community and presents a substantial financial risk of which families should be aware.

VII. Plan Limits and Impact on Means Tested Government Benefit Programs

Section 529(b)(6) of the Internal Revenue Code requires state 529 programs to set maximum contribution limits so that 529 plans do not become overfunded.²⁰ The same contribution limits will apply to ABLÉ accounts, and those limits will likely vary from state to state. In New York State that limit is currently \$375,000.²¹

Section 4 of the ABLÉ Act provides that ABLÉ accounts should be disregarded as resources available to the individual with the disability for the purposes of maintaining access to means-tested government benefit

programs during any period in which the beneficiary is considered an individual with a disability.

There is one significant exception to this provision. If the individual with a disability is a Supplemental Security Income recipient, distributions from an ABLE account for housing-related expenses will not be disregarded, and will be considered “in kind support and maintenance” to the SSI beneficiary, a characterization which will have the effect of reducing the Supplemental Security Income benefit.²² In addition, for Supplemental Security Income beneficiaries, only the first \$100,000 of an ABLE account is disregarded in determining financial eligibility. As such, if an ABLE account exceeds \$100,000, the monthly SSI benefit will be suspended and reinstated once the account dips below \$100,000. Should the SSI beneficiary reside in a state where eligibility for Supplemental Security Income means automatic enrollment in the State Medicaid program, as is the case in New York State, the Act goes on to say that the suspension of Supplemental Security Income benefits due to a highly funded ABLE account is to have no impact on that beneficiary’s eligibility for Medicaid.²³ Nonetheless, the potential loss of monthly Supplemental Security Income benefits (which in 2012 can be up to \$1,133 per month for individuals with disabilities who reside in group residences) will substantially diminish the appeal of using ABLE accounts for many families.

VIII. So What Is Good About the ABLE Act?

As explained above, the authors do not believe that the ABLE account represents a viable estate planning alternative to a traditional Third Party Special Needs Trust, as it subjects families to an unnecessary “Medicaid Tax.” For high net worth clients who are of sufficient means to pay privately for services for their family members with a disability, Supplemental Security Income and Medicaid coverage may not be an issue, so the “Medicaid Tax” may not be a concern. But for the overwhelming majority of families, Medicaid coverage is and will continue to be a critically important benefit, and as such, the “Medicaid Tax” feature of the ABLE account makes it a poor substitute for Third Party Special Needs Trust.

However, the authors believe that there is one particular subset of individuals with disabilities who may indeed benefit from the use of the ABLE account as an alternative planning option: mentally competent but physically disabled individuals who have assets which exceed the SSI resource threshold of \$2,000, but who do not expect to accumulate assets in excess of \$100,000. Under current law, the only viable option for protecting assets without disrupting coverage is the First Party Supplemental Needs Trust described above, which allows a Trustee to manage such funds during life, but subjects the funds to repayment to the Medicaid program at death (or, in the case of a pooled trust, allows the not for profit organization to retain the funds at death). These individuals could establish ABLE accounts on their own, and could manage distributions from the accounts without the need for a Trustee.

Funds in the accounts would grow on a tax-deferred basis, and distributions from the accounts would have the tax and government benefit program features described above. The ABLE accounts would allow these individuals to retain custody and control of their own property, thereby promoting independence without sacrificing critically important services and support from government benefit programs. As with the First Party Special Needs Trust, repayment to Medicaid would typically occur at death.

It is important to remind readers that even for this relatively small subset of individuals, the “Medicaid Tax” provision of the ABLE Act would still pose the risk that they would have to repay Medicaid while they are still living, as in the case where there is a determination that an ABLE account beneficiary’s Supplemental Security Income or Social Security Disability income is discontinued, or where a physician refuses to certify continuing disability. But if the individual is willing to assume this risk in exchange for retaining control of his or her funds, the ABLE Account does provide a viable alternative.

IX. Conclusion

The ABLE Act has garnered a lot of support from members from Congress and from disability organizations around the country, and many believe that it has the momentum to pass in its current form. Should it pass, the authors would encourage advocates and professionals to help educate families about both the benefits and the risks of using these accounts so that they can make an *informed* decision about incorporating these accounts into a more comprehensive Special Needs Estate Plan.

Endnotes

1. H.R. 3423, 112th Cong. (2011).
2. H.R. 1205, 111th Cong. (2009).
3. The terms “Special Needs Trust” and “Supplemental Needs Trust” have come to be used interchangeably, and while there is some basis for using different terms, for the sake of simplicity this article will continue to refer to both as “Special Needs Trusts,” and distinguish between the two by using the terms “First Party” (referring to the self-settled payback trust) and “Third Party” (referring to the more traditional estate planning-type trusts). For a comprehensive and well-written treatise on the topic, see THOMAS BEGLEY & ANGELA CANNELOS, *THE SPECIAL NEEDS TRUST HANDBOOK* (Aspen Publishers 2012).
4. While both the SSI and the Medicaid program are federal programs, there can be significant variations in the *application* of the program rules across state and regional lines. With government benefits, there is no substitute for inquiry into local practice. We also remind readers that while these two programs represent the most frequently encountered means tested programs, there are others (such as the Section 8 program and the Veteran’s Improved Pension), which have their own rules and limitations; those should be considered as well.
5. New York provides model language for drafters of these instruments in its Estates Powers and Trusts Law. See N.Y. Estates, Powers & Trusts Law § 7-1.12 (EPTL). While use of the model language is not required, it does establish the presumption that the creator of the trust sought to supplement, and not supplant, government benefits.

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6. See SI 00835.001 *Introduction to Living Arrangements and In-Kind Support and Maintenance*, SOCIALSECURITY.GOV, <<https://secure.ssa.gov/apps10/poms.nsf/lnx/0500835001!opendocument>> (last visited Aug. 6, 2012).
7. See 42 U.S.C. §§ 1396p(d)(4)(A), (C); 42 U.S.C. § 1382b(c)(1)(C)(ii) (III).
8. I.R.C. § 529.
9. See I.R.C. § 2503(b).
10. I.R.C. § 529(c)(2)(B).
11. See I.R.C. § 529(c)(3)(A)(i).
12. H.R. 3423, 112th Cong. § 3(a)(2) (2011).
13. H.R. 3423, 112th Cong. § (3)(a)(3).
14. H.R. 3423, 112th Cong. § 3(a)(1)(C).
15. *Id.*
16. *Id.*
17. See H.R. 3423, 112th Cong. § 3(a)(1)(C)(iii). The disability certification is defined as a certification to the satisfaction of the Secretary of the Treasury that the beneficiary is in fact a beneficiary with a disability, and must contain a copy of the beneficiary's diagnosis, signed by a physician. One can reasonably expect that this process will be defined in greater detail in the Treasury Regulations, which will be issued if the legislation passes.
18. See Benedict Carey, *New Autism Rule Will Trim Many, A Study Suggests*, N.Y. TIMES, Jan. 20, 2012, at A1.
19. H.R. 3423, 112th Cong. § 3(a)(4).
20. I.R.C. § 529(b)(6).
21. *Frequently asked Questions*, NY'S 529 COLLEGE SAVINGS PLAN, <<https://uii.nysaves.s.upromise.com/content/faqs.html#11>> (last visited Aug. 6, 2012).
22. H.R. 3423, 112th Cong. § 4(a). Generally, whenever a third party pays for housing or food related expenses, those payments are considered "in kind support and maintenance (ISM)," a form of unearned income, to the SSI recipient and results in a reduction in the monthly SSI benefit. See SI 00835.001 *Introduction to Living Arrangements and In-Kind Support and Maintenance*, SOCIALSECURITY.GOV, <<https://secure.ssa.gov/apps10/poms.nsf/lnx/0500835001!opendocument>> (last visited Aug. 6, 2012).
23. See H.R. 3423, 112th Cong. §4(b)(2).

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Ensuring Effective Communication with Deaf and Hard of Hearing Individuals

By Michael Mulé

Every state or local government entity or program that receives federal financial assistance must ensure that communication with deaf and hard of hearing individuals and their companions is as effective as communication with anyone else.¹ Over 500,000 people in New York have some form of hearing difficulty and every day they engage with government entities and programs.²

This article will explain the general difference between deaf and hard of hearing individuals, the effective communication requirements of government entities, the types of interpreters that must be used, the undue burden defense that may be available to government entities, the legal consequences when government entities do not comply with these requirements, and the steps that government entities can take to ensure that communication with deaf and hard of hearing individuals is effective.



Who Is Deaf, Who Is Hard of Hearing?

Before discussing effective communication, it is important to understand the general distinctions between individuals who are deaf and those who are hard of hearing. There are many gradations of hearing loss and some people become deaf or hard of hearing at different points in their lives. A deaf person is someone who may not be able to recognize spoken words, even with the assistance of specialty hearing devices, and who may primarily communicate using a form of sign language instead of spoken words. Someone who is hard of hearing may be able to recognize spoken words with the assistance of hearing aids or other hearing devices but may not communicate by using a form of sign language.³

It is also important to note that “most deaf [and hard of hearing] people find the term ‘hearing impaired’ to be offensive [as it] suggests that they are defective in some respect.”⁴ Similarly, while disability rights laws may define someone who is deaf or hard of hearing as having a disability, that individual may not. They may not consider their lack of hearing as a disability but may identify as being Deaf with a capital “D” and having a connection to a distinct linguistic and cultural group, similar to how someone from Spain may identify as being Spanish.⁵ Even if the deaf or hard of hearing individual may not regard himself or herself as having a disability, he or she may meet the legal definition of disability and be protected by federal and state disability rights laws.

Disability Rights Law and Deaf and Hard of Hearing Individuals

Title II of the Americans with Disabilities Act and Section 504 of the Rehabilitation Act of 1973 prohibit discrimination on the basis of disability by a public entity or government programs and activities that receive federal financial assistance.⁶ Under Title II, a public entity is defined in Title II as “any department, agency, special purpose district, or other instrumentality of a State or States or local government.”⁷ Public entities include all programs, services, and activities of a state or local government as well as its agencies and instrumentalities, without exception.⁸ Section 504 prohibits disability discrimination by government entities operating programs or activities that receive federal financial assistance and provides similar protections as Title II.⁹

The ADA and Section 504 define a qualified individual with a disability as someone who “has a physical or mental impairment [that] substantially limits one or more of... [the] major life activities...has a record of such an impairment...or...is regarded as having such an impairment.”¹⁰ Many deaf and hard of hearing individuals are protected by Title II and Section 504 because the statutory definition of major life activities includes hearing, reading, and communicating.¹¹ Government entities also must provide reasonable accommodations, remove communication barriers, and provide auxiliary aids and services for a qualified individual with a disability, unless doing so would fundamentally alter the nature of the service or activity or impose an undue burden.¹²

Public entities must “make reasonable modifications in policies, practices, or procedures” when necessary to avoid discrimination on the basis of disability.¹³ “[W]hether a particular modification is ‘reasonable’ [or not] involves a fact-specific, case-by-case inquiry that considers, among other factors, the effectiveness of the modification in light of the nature of the disability in question and the cost” to the public entity.¹⁴ In cases involving deaf and hard of hearing individuals, federal courts have focused on specific instances during the interaction between the individual and the government entity.¹⁵

Effective Communication Requirements of Government Entities

Effective communication exists when there is sufficient communication to provide a deaf or hard of hearing individual with the same level of government services received by individuals who are not deaf or hard of hearing.¹⁶ Government entities ensure effective communica-

tion with deaf and hard of hearing individuals, companions, and members of the public by providing necessary auxiliary aids and services.¹⁷ Title II regulations define a companion as “a family member, friend, or associate of an individual seeking access to a service, program, or activity of a public entity, who, along with that individual, is an appropriate person with whom the public entity should communicate.”¹⁸

Title II and Section 504 regulations describe how government entities can ensure effective communication with deaf and hard of hearing individuals by providing auxiliary aids and services.¹⁹ Both statutes prohibit a government entity from charging a deaf or hard of hearing individual for the cost of any auxiliary aid or service.²⁰ The Title II regulations provide an extensive list of auxiliary aids and services that includes, among many others, qualified interpreters on-site or through video remote interpreting (VRI) services; telephone handset amplifiers; assistive listening devices; telephones compatible with hearing aids; “open and closed captioning, including real-time captioning; voice, text, and video-based telecommunications products and systems, including text telephones (TTYs), video-phones, and captioned telephones”; “or other effective methods of making aurally delivered information available to individuals who are deaf or hard of hearing.”²¹

The type of auxiliary aid or service that ensure[s] effective communication will vary [depending on] the method of communication used by the [deaf or hard of hearing] individual; the nature, length, and complexity of the communication involved; and the context in which the communication is taking place.²²

Nevertheless, “[t]he auxiliary aid requirement is a flexible one, and [government entities] can choose among various alternatives as long as *the result is effective communication*.”²³ In determining which type of auxiliary aid and service is necessary, Title II and Section 504 require a government entity to give “primary consideration to the request[]” made by the deaf or hard of hearing individual.²⁴ The government entity must honor the choice of auxiliary aid or service unless “it can demonstrate another effective means of communications exists or that the use of the means chosen would not be required.”²⁵ The auxiliary aid or service that ensures effective communication for a particular interaction may be an interpreter.

Interpreters for Deaf and Hard of Hearing Individuals

Many deaf and hard of hearing individuals, but not all, communicate using a form of sign language and may require a qualified sign interpreter to ensure effective communication. A qualified interpreter is someone who is able “to interpret effectively, accurately, and impartially, both receptively and expressively, using any necessary

specialized vocabulary.”²⁶ Qualified interpreters include sign language interpreters, oral transliterators, and cued language transliterators. The definition of a qualified interpreter focuses on “the actual ability of the interpreter in a particular interpreting context to facilitate effective communication between the public entity and the individual with disabilities.”²⁷

A government entity cannot require a deaf or hard of hearing individual to bring or provide a qualified interpreter.²⁸ The government entity cannot rely on an adult accompanying a deaf or hard of hearing individual to serve as an interpreter unless it is an emergency situation or the interpreter is specifically requested, the adult agrees to provide the service, and it is appropriate under the circumstances.²⁹ Minor children also cannot be used as interpreters for deaf and hard of hearing individuals except in exigent circumstances.³⁰ While qualified interpreters and other auxiliary aids and services must be provided, there may be times when doing so could impose an undue burden on a government entity.

The Undue Burden Defense

Title II “incorporates the regulations applicable to federally conducted activities under Section 504 with respect to program accessibility” which requires that the government entity demonstrate that access cannot be accomplished without imposing an undue financial or administrative burden after considering all available resources.³¹ The undue hardship inquiry requires not simply an assessment of the cost of the accommodation or auxiliary aid or service in relation to the government entity’s overall budget, but a case-by-case analysis weighing factors that include:

- (1) [t]he overall size of the [government entity] with respect to number of employees, number and type of facilities, and size of budget;
- (2) [t]he type of the [government entity’s] operation, including the composition and structure of the [government entity’s] workforce; and
- (3) [t]he nature and cost of the accommodation [or auxiliary aid or service] needed.³²

While the undue burden test focuses primarily on the financial resources of the entity involved, it has much less application to a government entity which “can raise taxes in order to finance any accommodations that it must make.”³³ Congress intended the undue burden standard of Title II to be significantly higher than the “readily achievable” standard of Title III, and that the program access requirements of Title II “should enable individuals with disabilities to participate in and benefit from the services, program, or activities of public entities in all but the most unusual cases.”³⁴ The only categorical limit on the obligation to provide reasonable accommodations or

modifications appears to be in cases of truly extraordinary cost.³⁵

If the auxiliary aid or services requested by a deaf or hard of hearing individual cause either an undue burden or the fundamental alteration of services or programs, the government entity must issue a written statement of its reasons for denying the request.³⁶ This determination must be made by a high level official who has “budgetary authority and responsibility for making spending decisions.”³⁷ If an action required by Title II or Section 504 would result in such a burden or alteration, the government entity must take any other action that will ensure that, to the maximum extent possible, individuals with disabilities will receive the benefits or services provided by the entity.³⁸ When a government entity does not provide effective communication and cannot demonstrate that the requested auxiliary aid or service imposes an undue burden, it may be in violation of Title II or Section 504 requirements.

Legal Consequences When Effective Communication Is Denied

A government entity that denies a deaf or hard of hearing individual effective communication can be subject to a federal lawsuit or a federal investigation. The enforcement of Title II is based on the Rehabilitation Act of 1973, which incorporates the enforcement provisions of Title VI of the Civil Rights Act of 1964.³⁹ The Title II enforcement regulations contemplate an administrative process that includes (1) a complaint of discrimination by an individual to an agency with jurisdiction over the subject matter;⁴⁰ (2) an attempt at informal resolution;⁴¹ (3) a formal letter of compliance or noncompliance;⁴² and (4) potentially a referral by the federal agency to the Attorney General for enforcement.⁴³

Any individual who believes he or she has been subject to disability discrimination can file an administrative complaint with the Department of Justice (DOJ) or the federal agency that provided the funding to the government entity or he or she can file a lawsuit at any time whether or not the agency finds a violation.⁴⁴ Title II regulations also require government entities with more than 50 employees to designate an employee who will investigate complaints and adopt and publish grievance and complaint procedures.⁴⁵

Several New York government entities have been subject to effective communication investigations by federal agencies. The Title II and Section 504 investigations in the chart were based on administrative complaints that alleged deaf and hard of hearing individuals were not provided effective communication or were denied access to auxiliary aids and services.

Federal Investigations of New York Government Entities

- **Law Enforcement**—In November 1995, DOJ and the Rochester Police Department entered into a Settlement Agreement, after it was alleged that the communication between the deaf complainant and the Police Department “was not effective because interpreting services were not provided.” [http://go.usa.gov/dZN \(.txt\)](http://go.usa.gov/dZN (.txt)).
- **State Court**—In September 1996, DOJ and the Town of Lloyd entered into a Settlement Agreement, after it was alleged that in a proceeding involving a deaf witness, the “the Court did not secure the services of a qualified oral interpreter(s).” [http://go.usa.gov/dZR \(.txt\)](http://go.usa.gov/dZR (.txt)).
- **Town Services**—In December 1997, DOJ and the Town of Phelps entered into a Settlement Agreement, after it was alleged that the town did not provide auxiliary aids and services and did not give primary consideration to the auxiliary aids and services requested by deaf and hard of hearing individuals. <http://go.usa.gov/dZn>.
- **Probation Department**—In November 1998, DOJ and the Albany County Probation Department entered into a Settlement Agreement, after it was alleged that the Probation Department failed to provide the complainant “with a sign language interpreter when necessary to ensure that communications with him were as effective as communications with hearing persons.” <http://go.usa.gov/dZU>.
- **City and County Public Benefits Agency**—In October 1999, the U.S. Department of Health and Human Service, Office of Civil Rights (HHS/OCR) issued a Letter of Finding which determined that the public assistance offices in New York City and Nassau and Suffolk Counties denied deaf and hard of hearing individuals “the means by which to effectively communicate with office staff and, thus, an equal opportunity to participate in and benefit from the services and programs...” <http://bit.ly/mUk637>.
- **County Human Service Agency**—In February 2008, HHS/OCR and the Sullivan County Department of Family Services entered into a Resolution Agreement, after the complainant alleged that “staff discriminated against her on the basis of disability (deaf or hard-of-hearing), by failing to provide her with a qualified sign language interpreter, in violation of the ADA and Section 504.” <http://go.usa.gov/dZE>.
- **Law Enforcement**—In November 2009, DOJ and the New York City Police Department entered into a Settlement Agreement, after it was alleged that “employees, including police officers, did not effectively communicate with people with hearing impairments in violation of Title II of the ADA.” <http://go.usa.gov/dZm>.

How to Ensure Effective Communication

There are several steps a government entity can take to identify and provide auxiliary aids and services and ensure effective communication with deaf and hard of hearing individuals. At the outset, government entities should identify local and state resources that can provide auxiliary aids and services and train staff on Title II and Section 504 effective communication requirements. These resources can include statewide interpreter contracts,⁴⁶ independent living centers,⁴⁷ centers for assistive technology,⁴⁸ and ADA Technical Assistance Centers.⁴⁹

A government entity should have effective communication policies and procedures in place and train staff on how to identify the communication needs of a deaf or hard of hearing individual and how to access and provide the necessary auxiliary aids and services. One way to identify communication needs is to use a communication assessment form.⁵⁰ The communication assessment form allows the deaf or hard of hearing individual to identify their preferred method of communication. Staff should also be trained on how to access and use auxiliary aids and services, including how to work with a sign language interpreter in person⁵¹ or through video or remote interpreting devices.⁵²

Government entities are required to provide deaf and hard of hearing individuals notice of available auxiliary aids and services.⁵³ The notices should be posted in public locations⁵⁴ and use universal symbols. Some examples of universal symbols that can be used to provide notice are included below.⁵⁵ Universal symbols and a Teletype (TTY) number should also be included on print materials and on websites to identify that auxiliary aids and services are available.

Aside from the effective communication policies and procedures included in the settlements and resolution agreements above, DOJ has created a toolkit that explains the Title II effective communication requirements and includes a checklist for government entities.⁵⁶ Other DOJ resources that can be used to develop policies and procedure includes a guide for law enforcement that explains how to communicate with deaf and hard of hearing individuals,⁵⁷ a video,⁵⁸ and a model policy for law enforcement on communicating with deaf and hard of hearing individuals.⁵⁹ These resources can be used to create staff training.

Conclusion

When government entities take steps to comply with effective communication requirements, they can prevent

litigation and federal investigation and ensure that deaf and hard of hearing individuals have equal access to programs, services, and opportunities.

Endnotes

- 45 C.F.R. § 84.52(d)(1); 28 C.F.R. § 35.160(a)(1); see, e.g., *Rothschild v. Grottenthaler*, 907 F.2d 286, 293 (2d Cir.1990); *Clarkson v. Coughlin*, 898 F. Supp. 1019, 1035–38 (S.D.N.Y. 1995).
- U.S. Census Bureau, American Community Survey, 2008-2010 American Community Survey 3-Year Estimates, B18102: Sex by Age by Hearing Difficulty, <<http://go.usa.gov/pcD>>.
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American Sign
Language (ASL)
Interpreter



TTY/TDD
(text/telephone)



Assistive listening device
(sound amplifier)



- title II regulation. In enacting title II, Congress required that the Department adopt regulations that tracked the communications provisions of 28 C.F.R. Part 39 (the regulation implementing section 504 of the Rehabilitation Act of 1973). This regulation required 'effective communication with members of the public.' 28 C.F.R. S 39.160 (a).").
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Injured on the Job: The Fear of Future Expenses

By Thomas G. Benjamin

I. Introduction

Imagine waking up one morning, going through your normal routine, heading off to work, and thinking about what exciting things you were going to do after work. Except this day, those thoughts suddenly change to “how am I going to get through this, am I going to be able to work again, and how am I going to pay these medical bills?” All these questions and thoughts might be the result of getting seriously injured at work from a robbery, an explosion, a defective piece of equipment, a slip and fall, or even by a co-worker. No matter what the cause, for a period of time in our history serious injuries were prevalent in the workplace with the injured employee having limited assistance in dealing with the injury or the expenses incurred as a result. The injured employee was never really protected until labor laws like the workers’ compensation law were created and enacted across the country.



II. Triangle Shirtwaist Factory Fire

On March 25, 1911 the conditions of the workplace in which workers were subject to, the hours individuals worked, and the pay these workers received came to the attention of the public and the nation as a whole. It was late afternoon on a Saturday, almost quitting time, for the workers at the Triangle Shirtwaist Factory located in New York City when a fire developed on the eighth floor of the ten-story factory.¹ The fire quickly spread across that floor and the two upper floors due to non-existent sprinkler systems, inadequate and deteriorated fire-fighting equipment, and floors and aisles strewn with scrap linens and other combustible materials.² Hundreds of women and child workers became trapped due to doors being chained shut to prevent stealing, floors and aisles too narrow for multiple people, debris scattered around the floors and aisles, and the single elevator inadequate from being overcrowded with each use.³ Those who were able to make it out a window onto a fire escape found themselves trapped again on rusted old pieces of metal, most of which collapsed due to deteriorated metal and the number of people trying to escape on them.⁴ For those who did not make it to a stairwell, down the elevator, or out the fire escape, the trapped workers, in a last ditch effort to try and save themselves, jumped out of the windows hoping to survive the landing.⁵ Once the fire was finally extinguished and a count was taken of all the victims in the various places, one hundred and forty-six (146) women and children lost their lives.⁶ This tragedy was

at the time the worst workplace accident in New York’s and the nation’s history, causing shock and anger among the population.⁷ Fueled by this outrage and a push by the voters the New York State legislature created the Factory Investigating Commission⁸ (hereinafter “Commission”). With the creation of this Commission, change—the outcome of most tragedies that have such an impact on the population—was about to happen.⁹

When it was created the Commission was charged with investigating the “issues related to the health and safety of workers, the condition of the buildings in which they worked, and existing and additional necessary laws and ordinances.”¹⁰ In carrying out this charge the Commission conducted fifty-nine (59) public hearings and took testimony from four hundred seventy-two (472) witnesses, compiling over seven thousand (7,000) pages of testimony from employers, workers, union officials, and experts.¹¹ With all the time it was taking to compile all of this information, and in light of all the Commission was accomplishing, it was authorized to continue its research and investigation an additional two years.¹² When everything was said and done, the Commission drafted twenty-six (26) different bills between 1911 and 1914, seventeen (17) of which were sent to the legislature for approval and thirteen (13) of which were approved and became law.¹³ After determining that the government had a duty to preserve the health and safety of the workers, the Commission focused all of its bills and recommendations on this duty. As part of the government’s duty and through extensive negotiations between businesses and unions, the Workers’ Compensation Law in New York State was developed.¹⁴

III. The NYS Workers’ Compensation Law

The Workers’ Compensation Law is broken down into two main sections or areas of protection: workers’ compensation for the general employee and for civil defense volunteers, and disability benefits. Since workplace injuries are still widespread and occur relatively frequently, with 3,063,400 injuries occurring nationwide in 2010 of which 4,690 resulted in the individual’s death, the focus of this review will be on the workers’ compensation benefits afforded to employees injured in the general workplace.¹⁵ As workers’ compensation benefits and laws vary from state to state, this review will specifically look at those benefits under New York law.

A. Protections to the Employers and Employees

Ever since individuals began working they were faced with potential injuries and death, and not until 1914, when New York State passed its Workers’ Compensation Law, were these individuals truly protected. Prior to its

enactment, an individual who was injured in the workplace had only one recourse to try and obtain payments for medical bills, lost wages, and the lost income due to an inability to work in the future due to a permanent disability—sue his or her employer. Unfortunately, with the defenses available to the employer at common law—assumption of risk, the fellow-servant doctrine, and contributory negligence—most of these suits were won by the employer or dragged out over an extended period of time, giving the employee or his or her dependents little to no relief.¹⁶ In fact, the owners of the Triangle Shirtwaist Factory, after being acquitted of manslaughter charges, were sued by surviving family members and after three years of litigation each family received only \$75 in compensation.¹⁷ With the Workers' Compensation Law, employees and their dependents no longer needed to fear drawn-out lawsuits or the possibility of little to no relief for their injury, although this peace of mind did not come without a price.

As part of the agreement, employees gave up their right to sue their employer when their employer properly obtained workers' compensation insurance to protect their employees.¹⁸ Although this may seem like a one-sided benefit to the employer, it was actually a benefit to both the employer and the employee. The employer no longer feared the possibility of being sued, and the employee no longer faced long delays before receiving compensation. Now, when an employee gets injured, instead of having to show how the injury has impaired his or her earning capacity he or she simply needs to show what his or her exact injury was, how much he or she was being compensated to determine what benefits he or she will receive, and that an employee-employer relationship existed.¹⁹ Under the Workers' Compensation Law, a fixed schedule has been created to determine what compensation the employee will receive for his or her injury,²⁰ and without evidence to the contrary, the injury is presumed to be compensable.²¹ With each of these changes and the precise layout of the Workers' Compensation Law, the long and drawn-out litigation process was virtually eliminated.

Even in cases where the employer violated the law and failed to obtain workers' compensation insurance for its employees, there were still benefits to both the employer and the employee. Nonetheless, in cases where the employer violated the law, the benefits were more to the employees than the employers, as the law was not going to reward those employers who violated it. In these situations, the injured employee has an option where he or she can seek standard workers' compensation benefits as if the employer was properly insured or may directly sue the employer.²² If the employee decides to pursue the standard benefits as though the employer was properly insured, the employee would be covered by and paid from the "Uninsured Employer's Fund" ("Fund") which will step in and cover the claim as though the employer was properly insured.²³ Even though the Fund would

cover the claim brought by the employee, the employer is not relieved from liability as if the employer had obtained proper coverage. Under the Workers' Compensation Law the employer that is uninsured is directly liable for the claim and must reimburse the Fund for the expenses and costs incurred by the claim.²⁴

For those injured employees who would prefer to forgo a guaranteed fixed outcome and would rather throw the dice in the courtroom, they had the alternative option of bringing a suit against the uninsured employer.²⁵ Despite the risk involved, the likelihood of the injured employee winning the suit is substantially greater than it previously was. Under the Workers' Compensation Law, an employer that fails to secure the proper insurance and faces a lawsuit from an injured employee cannot use as a defense the basic defenses available to it at common law. In fact, the Workers' Compensation Law states that "in such an action it shall not be necessary to plead or prove freedom from contributory negligence nor may the defendant plead as a defense that the injury was caused by the negligence of a fellow servant nor that the employee assumed the risk of his or her employment, nor that the injury was due to the contributory negligence of the employee."²⁶

B. Enforcing Compliance

In an effort to help ensure that employers obtained the required workers' compensation coverage, the legislature has taken several steps to ensure compliance. The first and most common method to ensure compliance is to penalize those employers who fail to obtain the required workers' compensation coverage. Under the Workers' Compensation Law, when an employer has an employee subject to the Workers' Compensation Law and fails to obtain the workers' compensation coverage, the employer is subject to a fine of \$2,000 for every ten (10) days the employer goes without coverage.²⁷ With the possibility of being assessed a penalty of \$72,000 per year for failing to obtain workers' compensation coverage, employers are less likely to play "Russian Roulette" and obtain the required coverage. In the past, some employers would avoid getting a workers' compensation policy which, depending on the type of employee, type of business, and past history of the employer, would cost on average less than one thousand dollars (\$1,000) per year.²⁸ Prior to 2007, the only ways employers were caught without coverage was if they properly paid employees on the books, an employee suffered an accident, or someone reported the employer. So if employers ensured a safe workplace to avoid an employee getting injured and convinced the employee to get paid under the table, that employer would often go unnoticed for not having the proper coverage.

In 2007 the tables were turned and the Workers' Compensation Board was given a substantial boost in its enforcement capabilities. With the legislative changes that took effect in 2007, Workers' Compensation Investigators

now have the ability to enter an employer's place of business unannounced and inquire about its coverage. If an employer is unable to show that it had workers' compensation coverage and the investigator witnesses individuals who would be considered employees under the Workers' Compensation Law, the investigator can immediately shut the business down and issue a stop work order. The premise behind this was that the employees' health and safety was in jeopardy and until the employer obtained proper coverage it could not open, and the employees' health and safety was not protected.

In addition to now having the ability to shut an employer down, the investigators were also given the ability to subpoena the employer's records. The purpose behind this ability was to ensure employers were properly reporting employees and maintaining records on these employees. By ensuring that the employer was maintaining records for its employees, the employer could no longer pay individuals "under the table," thereby enabling state agencies to better monitor compliance with the various laws. If the employee did suffer an injury, his or her weekly wage was documented, thereby helping the claims process move along. If the employer did not maintain adequate records for the individuals it had working for it, the employer was subject to a penalty of \$1,000 for every ten days that the employee worked and no records were maintained.

IV. Conclusion

Ever since the Triangle Shirtwaist Factory fire, the protections and benefits given to employees have increased drastically. We've witnessed an evolution from a time when employees had little to no protections and needed to fight for every cent they got, to a time when employee benefits are basically guaranteed by statute, and the employer is mandated to obtain the proper insurance. Even in those cases when an employer does not obtain the proper insurance, those uncovered employees who get injured are protected by the Uninsured Employer's Fund or given a substantial advantage in bringing a lawsuit against the uninsured employer. In either case, when an employee gets injured today, the covered employee and the uncovered employee are given the ability to easily collect compensation for his or her injury and have his or her medical bills paid. From the most basic to the gravest injury, employees are now protected and can continue on with their lives without worrying about where their next paycheck may come from and how their medical bills will be covered.

With the continued legislative advancements in penalties and enforcement methods, along with increased employer awareness and education, the number of uninsured employers will continue to decline and hopefully one day there will be no uncovered employee, leaving all employees free from having to face the fear and uncertainty of his or her future after being injured.

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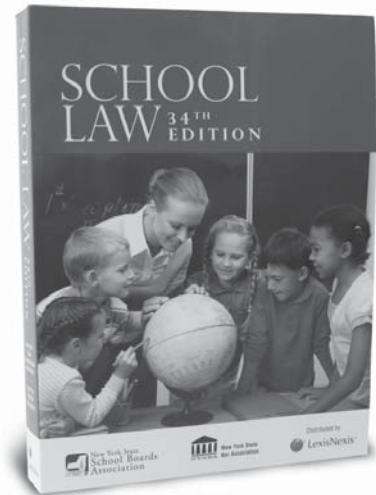
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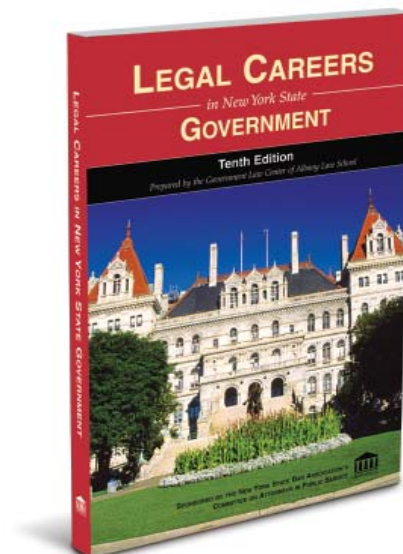
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