

Introduction

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Symposium: The Intersection of Health Care, Education, & the Law

INTRODUCTION

Recent tragedies both within the United States and abroad give us a good reason to pause and reflect on how we are treating each other. As people, we need to examine whether we are recognizing each other as individuals with dreams and rights and dignity. We need to scrutinize our actions or inactions and try to understand that there will always be a better way. This issue of the *Journal of Health Care Law & Policy* is the product of such scrutiny. Within these pages are the thoughts and analysis of some of the best and brightest minds today. Some of the authors are scholars. Others practice in the delivery of services. Still others are parents who navigate the complex system of rules and regulations governing the delivery of services to their children. All of the authors share one common thread; they are people who care about the way we treat children with special needs.

The *Journal* starts off with a few brief words from Susan Leviton. Susan is a Professor of Law at the University of Maryland School of Law. For the past 26 years, she has directed a clinic at the Law School that represents children with special needs and was instrumental in conducting the Children with Special Needs Conference in May, 2001. She is an articulate and tireless advocate for children with special needs and her comments are a wonderful addition to the discussion and analysis in the articles that follow.

The lead article, written by Stuart Rome Lecturer¹, Theresa Glennon, gets the issue off to a start by examining the way the social institutions charged with nurturing children actually divert many African American boys from the paths of successful development. The author uses available statistics to confirm the negative treatment that African American boys encounter in our educational, mental health, and juvenile justice systems. Glennon concludes that African American Boys are more likely to be identified as disabled or delinquent than other children including African American girls, are more likely to be placed in educational, mental health, and juvenile justice programs that exert greater control and deliver fewer services despite identified needs, and that these experiences lead African American boys to stay away from or exit institutional settings.

Glennon's analysis supports the importance of maintaining access to the courts to challenge policies and practices that negatively affect African-American boys and re-evaluates Title VI of the Civil Rights Act to explore its promise as an effective tool to require the social institutions of childhood to effectively educate and aid African American boys. After documenting the dramatic disparities in the treatment of African American boys, the article examines doctrinal developments in the contexts of disability, language, minority and gender discrimination to suggest that a more vigorous approach to Title VI can help protect African American boys from the pervasive discrimination they face in our social institutions. Finally, Glennon outlines more recent legislation that responds to the striking disadvantages black youth experience in our education, mental health and juvenile justice systems and suggests using those provisions to advocate change in institutional practices as well as placing more such requirements into law through legislative advocacy.

Donna Lehr and Jill Green follow with a look at educating children with complex health care needs in public schools. They examine the intersection of health care, education, and the law. Who were these students? Where did they come from? Why were administrators so concerned about their presence in schools? What were the legal and programmatic decisions made regarding these students' educational programs? Their article addresses these questions and the issues and practices that have evolved over the past fifteen years as this

1. His family and friends to celebrate Stuart Rome's life and work as an attorney, community activist, art patron, and humanitarian established the Stuart Rome Lecture. The annual lecture focuses on a scholarly presentation of issues in law, medicine, and ethics.

unique, and growing population of students participate in educational programs in public schools all throughout the country.

They conclude that students with complex health care needs present significant challenges to school personnel when they attend school. To assure that they are educated in an environment that maintains both their health and their rights to a free appropriate public education in least restrictive settings requires comprehensive planning by many individuals including both parents and professionals from within the schools and from the private and public sectors in the community. Careful decisions guided by laws, professional standards, and practical realities will enable students to be educated in a manner that addresses both their unique educational needs and their social and emotional well-being. They also conclude that more research is needed to determine if we are, in fact, assuring that the students are receiving safe care, appropriate educational programs, and that their programs are provided in least restrictive environments in a manner that facilitates their acceptance as a member of the school community.

Teresa LaMaster and John O'Brien identify many of the potholes and obstacles encountered by two parents while traveling through the intersection of law, education, and health care for children with special needs. Their article, while written from their perspective, has nevertheless been influenced by their countless hours of talking with other parents and the common themes that emerged from those discussions. They identify diagnosis, IEP development, language barriers, and evaluation, as four hazards in the intersection of law, education and health care, which create important areas for further study and analysis.

As parents navigating this road, they suggest four sets of particularly urgent questions raised by these concerns. 1. How can the health care and education systems work together so that students who are identified as needing services get a medical diagnosis and access to medical resources as quickly and simply as possible? 2. Given the emotional and political context of the IEP process, to whom should a parent turn for a second opinion on a child's IEP? Who should pay for that second opinion? How can the educational system build parent confidence in IEPs? 3. Can the medical, educational and legal systems develop similar terms of art to talk about similar things? 4. What measures are there to determine the effectiveness of the programs and services to children with disabilities provided by the medical and educational systems?

Next, Leslie Seid Margolis traces the development of the law and policies governing school health services for students with disabilities who receive special education through the public school systems. Beginning with a brief overview of relevant provisions of federal law regarding special education, the article continues with a discussion of the case law through which the parameters of school health services have been defined, culminating with the United States Supreme Court's 1999 decision in *Cedar Rapids Community School District v. Garret F.*² An analysis of the policy and implementation issues raised by the Supreme Court's decision, including the barriers standing in the way of consistent access on the part of students with complex health needs to the health services mandated by federal law follows. The article concludes with several ideas about how practitioners and policymakers might begin to dismantle those barriers.

Gerard Gioia and Peter Isquith then address the contributions of the executive functions on educating children with ADHD. Their argument is structured into four sections advocating for explicit recognition and inclusion of executive dysfunction in the educational programming of students diagnosed with ADHD. First, they define the clinical syndrome of ADHD, including a brief review of its evolutionary history. The definition of the disorder, subtypes of the syndrome, severity of its symptoms, and epidemiology are discussed. They then define the construct of executive function, including its behavioral manifestation, neurological underpinnings, and developmental issues. This area of functioning has gained significantly greater definition and recognition in terms of its impact within a host of developmental and acquired neurological disorders including ADHD.

Next, they explore the relationship between executive dysfunction and ADHD in terms of current theoretical models and recent work conducted by the authors. The traditional triad of symptoms that comprise the diagnosis of ADHD (i.e., inattention, impulsivity, hyperactivity) is not sufficient to fully describe the treatable symptoms. Finally, with the groundwork laid regarding executive function and ADHD, they focus their attention to a model of educational programming including specific strategies and recommendations for addressing various types of executive dysfunction.

In Ellen Callegary's article, she focuses on those implementation problems associated with providing services for children with mental health needs. Additionally, she reviews the legal requirements for spe-

2. 526 U.S. 66 (1999).

cial education and related services in light of the United States Supreme Court's ruling in *Cedar Rapids Community School District v. Garret F.* and the 1997 amendments to the Individuals with Disabilities Education Act (IDEA). Her article consists of four sections, which provide an overview of the IDEA and the legal framework for special education and related services after the *Garret F.* decision and the 1997 amendments to the IDEA, describe the barriers to receipt of services, review problems with the delivery of needed services to children, and finally, posits recommendations for removal of those barriers. She concludes that all special education and related services that a child needs to remain in school and benefit from education must be provided even if those services include such expensive and rare services as an "on site" mental health professional who is available to the child during all school hours or psychiatric care for diagnostic and evaluation purposes.

Ian Hill, Renee Schwalberg, Beth Zimmerman, Wilma Tilson, and Henry Ireys follow next with a discussion of their research on alternative Medicaid managed care models to achieve service integration for children with special health care needs. Their findings focused on the fact that Children with special health care needs often use many different systems of service delivery. These systems include not only the medical care system, but also those providing early intervention, special education, mental health, and a host of other family support services. They acknowledge the need for integrating these systems smoothly together as well as the major challenge that such integration would pose. They examine the capacity of managed care organizations (MCOs) to provide appropriate access to high-quality care for children with special health care needs including concerns around the breadth and adequacy of MCOs' networks, financial incentives that may cause MCOs to limit access to needed but expensive services, MCOs' general lack of awareness of the complex and diverse needs of these children, and inadequate links between MCOs and the multiple health-related, educational, and community-based support systems that families with CSHCN rely on in caring for their children.

In keeping with the *Journal of Health Care Law & Policy's* long standing tradition of publishing excellent student pieces submitted by members of our staff, pieces by Lucy Shum and Anne Nichols Hill follow these seven workshop articles. The article by Ms. Shum addresses barriers to the access of educationally related mental health services for children with serious emotional disturbance. Her article examines who the special education system identifies as SED, what related mental health services the system provides, and how provisions

within the IDEA should facilitate greater access in four sections. She then presents public policy arguments regarding why increasing access to services is critical and that school based mental health services are a part of the answer in Section V.

While not on the topic of children with special needs, Anne Nichols Hill's article closes the journal with her discussion of protecting the rights and interests of human donors of genetic material. She argues that the interests and rights of individual donors of genetic material and the aggregate community of donors need to be protected. In addition, she posits that donors are entitled to a share in the fruits of successful research. These fruits include: access to diagnostic tests and useful treatment, public and legal acknowledgement of their contribution, and the rights to control that preserve the best interest of the other patients similarly situated or the public, and profit. Finally she contends that apportioning the fruits of genetic research is a formidable challenge, but it is imperative that we attempt to address these issues.

It is the goal of the *Journal of health Care Law & policy* to provide an opportunity for professionals from many different disciplines to become informed on pressing health care policy issues and to convey ideas across the barriers of discipline. In keeping with the spirit of our goal, the hopw that this issue stimulates new ideas in the minds of those that read these pages. On behalf of the Law & Health Care Program, I would like to thank the sponsors and participants who supported this conference. I would like to thank the authors for their contributions to this issue. I would also like to thank the Staff and Editorial Board of the *Journal* for their tireless efforts and dedication in producing this first edition of the fifth volume of our *Journal*.

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EDITOR IN CHIEF