

Health, Education, Advocacy, and Law: An Innovative Approach to Improving Outcomes for Low-Income Children With Intellectual and Developmental Disabilities

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Abstract

Advocates and attorneys working in medical–legal partnerships in the United States have become essential members of a multidisciplinary team that educates healthcare professionals on the rights of individuals with intellectual and developmental disabilities and represents families when appropriate services to which they are legally entitled are denied. This program description presents an innovative program in which advocates and attorneys work closely with healthcare professionals in a pediatric setting to improve implementation of clinical recommendations and outcomes for low-income children with intellectual and developmental disabilities. Since its creation in 2005, Project HEAL (Health, Education, Advocacy, and Law) has provided advocacy and legal services to 1,750 low-income families and children with disabilities facing discrimination and challenges accessing programs and services critical to health, education, and psychosocial functioning. Client satisfaction surveys indicate that families who receive representation are highly satisfied with the outcome of their children’s cases, and healthcare professionals report that their patients and families are better able to access complex service systems with assistance from Project HEAL. The innovative practice of incorporating advocacy and legal services directly into a clinical setting provides better outcomes for children with intellectual and developmental disabilities who might not otherwise have access to critically needed services. Involvement of skilled advocates and attorneys facilitates implementation of the comprehensive clinical recommendations necessary for the well-being of children with disabilities.

Keywords: advocacy, education, health, intellectual disability, law, *World Report*

Introduction

Intellectual and developmental disabilities pose significant challenges for children and families because of the significant need for educational, environmental, and social supports (Boulet, Boyle, & Schieve, 2009). This article demonstrates how advocates and attorneys have been successfully integrated within the clinical team to address psychosocial factors that commonly limit patient functioning. After discussing the evolving conceptualization of disability to include psychosocial correlates of health, the emergence of medical–legal partnerships is addressed. We then discuss the structure and function of our program within the larger medical institution and present quan-

titative and qualitative evidence of the program’s value to clinicians serving children with intellectual and developmental disabilities.

In recent years, research, policy, and legislation have shifted focus from the medical manifestations of disability to the interaction between the medical and social constructs that prevent individuals with disabilities from fully participating in important daily activities, such as employment and education (World Health Organization & World Bank, 2011). Publications central to the dialog on disability, such as the *International Classification of Functioning* (World Health Organization, 2001) and the *World Report on Disability* (World Health Organization & World Bank, 2011), promote a biopsychosocial approach in defining disability, emphasizing the interaction of health condition with social environment and individual factors. Disability is no longer solely defined by a specific health impairment, but rather by a limitation in functioning within a social and environmental context that results from a diagnosed health condition (Leonardi, Bickenbach, Ustun, Kostanjsek, & Chatterji, 2006).

Consideration of the social and environmental barriers experienced by individuals with intellectual and developmental

Received January 29, 2013; accepted May 6, 2014

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disabilities has necessitated a shift in the composition of the clinical team to include individuals experienced with both clinical and advocacy services—an interface between medicine and the law. In the United States, federal legislation, such as Section 504 of the Rehabilitation Act of 1973,¹ the Americans with Disabilities Act (ADA) of 1990,² the Individuals with Disabilities Education Act (IDEA),³ and the ADA Amendments Act of 2008,⁴ was enacted to address and prevent discrimination against individuals with disabilities in the realms of housing, employment, access to public services, and education. Gaps in access to and in the implementation of public programs and services contribute to negative and preventable health outcomes (Betz, Baer, Poulson, Vahanvaty, & Bare, 2004; Cichon, 2004; Smith, Wise, & Wampler, 2002). Under IDEA, eligible children with disabilities are entitled to a free appropriate public education in the least restrictive environment. This means that their educational program should be provided with their nondisabled peers to the maximum extent appropriate. Unfortunately, many eligible children do not receive adequate special education and related services to meet their unique needs and are unnecessarily placed in segregated settings.

When individuals with medical conditions, intellectual disability, and developmental disabilities do not respond to established treatments, social and environmental factors are often an underlying explanation (Shonkoff, Boyce, & McEwen, 2009; Williams, Sternthal, & Wright, 2009). Clinicians are often the first to recognize social and environmental factors related to health outcomes, but they are not adequately equipped to address relevant legal factors because of scheduling demands and a lack of professional training in these domains. Advocates and attorneys have become vital members of the multidisciplinary team, working alongside clinically trained colleagues. Attorneys possess a unique expertise among healthcare teams in addressing the social determinants of health and may work to ensure that law and policy addressing health and safety are enforced (Zuckerman, Sandel, Smith, & Lawton, 2004).

There are a growing number of medical–legal partnerships across the United States, Canada, and Australia that have successfully integrated advocates and attorneys in the healthcare process. The model for medical–legal partnerships, which began with one attorney at Boston Medical Center in 1993 (Zuckerman et al., 2004), has been replicated at 310 hospitals, healthcare

centers, medical schools, and residency programs across the United States. In 2013, nearly 60,000 individuals and families received legal assistance through medical–legal partnerships (National Center for Medical–Legal Partnership, 2014b). Attorneys at medical–legal partnership sites train the healthcare team in how to identify their patients' unmet needs that extend beyond medical care and help families receive the benefits and legal rights to which they are entitled (Conroy, Sandel, & Zuckerman, 2010). Recent research indicates that medical–legal partnerships improve patient health and well-being, advance medical practices, and help to improve social policies and regulations within the United States (Beck et al., 2012; Klein et al., 2011; Pettigrano, Caley, & Bliss, 2011; Weintraub et al., 2010).

Project HEAL

Project HEAL (Health, Education, Advocacy, and Law) is a comprehensive medical–legal partnership within the Maryland Center for Developmental Disabilities at Kennedy Krieger Institute in Baltimore, Maryland. Kennedy Krieger is an internationally recognized institute serving the needs of individuals with intellectual and developmental disabilities through patient care, research, community programs, education, and professional training. Project HEAL is staffed by two attorneys and undergraduate and graduate students. In addition to their law degrees, one attorney has a graduate degree in psychology and clinical experience working with children with disabilities. The other attorney has a master's degree in special education and experience teaching children with disabilities.

Kennedy Krieger Institute provides clinical services to over 20,000 patients each year who may be eligible for advocacy and legal services through the program. Staffing limitations and limited funding sources to maintain or grow the program to its ideal capacity have led Project HEAL to partner with two law firms who accept cases on a pro bono basis as well as assist with the publication of Project HEAL brochures on specific legal topics (e.g., estate planning brochures for families raising children with disabilities). To help support Project HEAL's work, staff have diversified their funding sources by seeking support from local foundations, donors, law firms, Kennedy Krieger clinical departments, and corporate partnership. In the spring of 2013, Project HEAL implemented a sliding scale, fee-for-service model in representation matters and began requesting donations for professional trainings provided to outside agencies.

Project HEAL was inspired, in part, by the first medical–legal partnership founded at Boston Medical Center. Unlike traditional medical–legal partnerships, which serve low-income patients and their families on a host of civil legal matters (e.g., family law, housing, landlord–tenant disputes, estate planning, and public benefits), Project HEAL has exclusively served children with intellectual disability, developmental disabilities, and mental health concerns in matters specifically related to the child's disability (e.g., special education matters and Supplemental Security Income appeals). Project HEAL serves a particularly vulnerable population—families and children with disabilities who live in households earning less than 50% of Maryland's median household income (e.g., a family of four must earn an annual income less than \$52,674 per year).

¹Section 504 of the Rehabilitation Act of 1973 protects individuals from discrimination on the basis of their disability when seeking participation in an organization that receives federal funding, such as the public school system (Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794 (1973)).

²The Americans with Disabilities Act (ADA) of 1990 is a civil rights law that prohibits discrimination against individuals on the basis of disability in public services and employment. Unlike Section 504, the ADA applies to most institutions regardless of whether they receive federal funding or are privately owned (The Americans with Disabilities Act, 42 U.S.C.A. § 12101 (1990)).

³The Individuals with Disabilities Education Act outlines special education policy for individuals with disabilities from birth through adulthood (The Individuals with Disabilities Education Act, 20 U.S.C. § 1400 *et. seq.* (2004)).

⁴The ADA Amendments Act (ADAA) of 2008 was passed in response to judicial decisions that narrowed the definition of disability and as a result reduced access to services. The ADAA expands the definition of disability and further addresses who may receive the protections of the ADA (The ADA Amendments Act, Pub. L. No. 110–325, 122 Stat. 3553 (2008)).

Since the project’s inception in 2005, Project HEAL advocates and attorneys have provided convenient, confidential, and comprehensive advocacy and legal services to thousands of patients through a multi-faceted approach. As exhibited in Figure 1, Project HEAL provides representation (i.e., attorney–client relationship in a civil legal matter); limited representation (i.e., brief advice, education, document review, information and resources, pro bono referrals); case consultations with healthcare professionals, trainees, and educators; professional trainings for healthcare professionals, trainees, and educators; community trainings for healthcare consumers and families; and policy and legislative advocacy. Within the clinical setting, Kennedy Krieger clinicians may refer families and children with civil legal issues directly to Project HEAL for representation, or families may self-refer.

Following an initial referral, Project HEAL advocates or attorneys complete a detailed telephone intake that includes demographic, financial, and diagnostic information, as well as the potential advocacy or legal issue. The attorneys then triage the intakes to determine if a child or family may need full or limited representation. For representation, the child’s parent or legal guardian attends an in-person meeting with an attorney and provides copies of medical and educational records, as well as written consent for release of information. Approximately 20% of all referrals to Project HEAL become representation matters. Attorneys consider the complexity of the legal issue, the capacity of the parent or legal guardian, the geographic location of the case, and the amount of clinical care the child is receiving at Kennedy Krieger Institute in making a decision regarding rep-

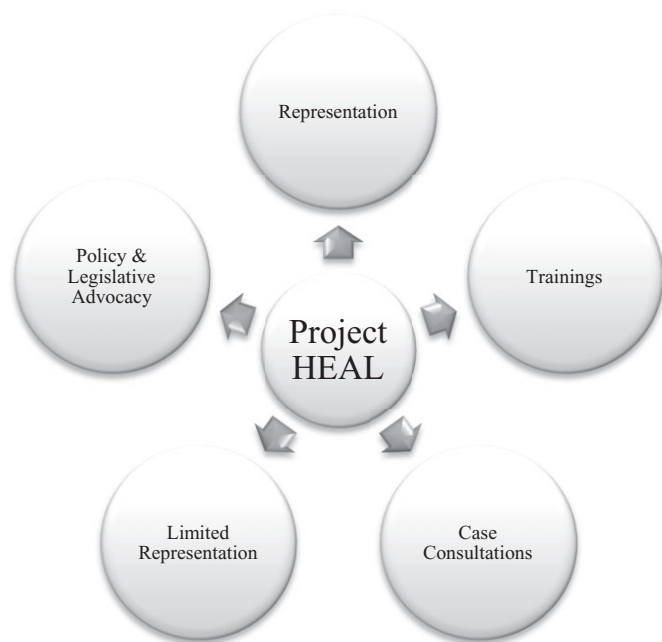


FIGURE 1
Focus of Project HEAL services.

resentation vs. limited representation. As the needs of 80% of the referrals are addressed through limited representation, there is no waiting list for Project HEAL services.

Four hundred twenty-seven patients of Kennedy Krieger and their families have been represented by Project HEAL attorneys between 2005 and 2013. Given that 95% ($n = 405$) of Project HEAL cases are matters related to the child’s educational rights, Figure 2 depicts the primary diagnosis of the children who qualified for special education and related services under IDEA. The federal eligibility criteria of children most commonly referred for Project HEAL services include other health impairments, which include attention-deficit/hyperactivity disorder (25%, $n = 100$) and autism spectrum disorders (24%, $n = 98$). As exhibited in Table 1, the outcomes for those children may involve a change in special education and related services, a more appropriate educational placement, or the implementation of Kennedy Krieger’s clinical recommendations. Other significant outcomes, when school systems failed to provide services to which the children were legally entitled, include more than 570 h of compensatory tutoring and 6 weeks of summer camp programming. At the conclusion of each matter, Project HEAL attorneys disseminate satisfaction surveys to each family. The data indicate that 96% ($n = 89$) of the families who returned surveys are highly satisfied with the services that they receive from Project HEAL. The return rate for satisfaction surveys is low (22%), when sent via postal service with a pre-paid return envelope. Therefore, interns now complete the satisfaction

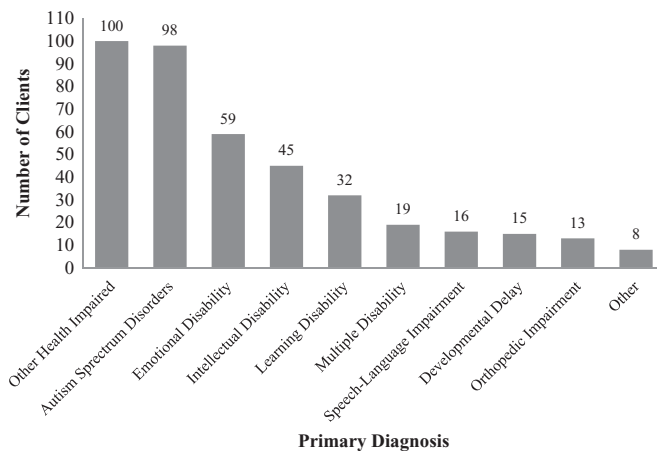


FIGURE 2
Clients referred for special education matters by diagnosis. The bars reflect the number of clients referred for Project HEAL services that met primary diagnosis in each category between 2005 and 2013. Categories are based on criteria listed under the Individuals with Disabilities Education Act (IDEA). Emotional disability and other health impairment represent diagnostic categories. Emotional disability includes emotional and behavioral challenges that interfere with learning and social relationships, and may include pervasive unhappiness, depressed mood, or anxiety. Other health impairment refers to chronic or acute health problems, including attention-deficit/ hyperactivity disorder, which adversely affects a child’s educational performance.

TABLE 1
Client outcomes

Outcome measures in representation matters	Total (<i>n</i> = 405)
Change in special education and related services	145
Added programmatic supports (teachers, classroom, or school)	116
More appropriate educational placement (new classroom, program, or school)	120
Implemented Kennedy Krieger Institute recommendations	91
Changed educational accommodations to meet the child's needs	87
Found eligible for special education-related services	60
Complaint letters filed for procedural violations of the law	35

Note. This table summarizes the client outcomes for the 405 children who received representation in special education matters. Multiple outcomes were achieved for some clients.

surveys via telephone during the conversation about closing a representation matter.

The *World Report on Disability* addresses how individuals with disability experience violations of their human rights (World Health Organization & World Bank, 2011). Project HEAL's legal services address not only access to education but also denials of critical resources. One family assisted through Project HEAL illustrates the role of medical-legal partnerships in advocating for families who have been inappropriately denied access to Supplemental Security Income (i.e., a needs-based program that offers financial benefits to individuals with disabilities, regardless of their age). The child was diagnosed with spina bifida at birth and immediately underwent several surgeries. The child's mother, a single mother of three, lacked the financial resources to care for a child with a complex disability. When the child's mother applied for Supplemental Security Income and submitted the necessary paperwork, she was denied the resource. The child's mother applied two more times after the first denial, and each subsequent application was denied. The child's treating physician at Kennedy Krieger referred the case to Project HEAL. After 18 months of case preparation, a Project HEAL attorney represented the child at a hearing, where the judge awarded the family the monthly benefit as well as back benefits to compensate for the three inappropriate denials.

Service Evaluation

In 2012, Project HEAL staff administered a seven-question online survey to clinicians in an effort to collect impact data. The survey included five Likert scale questions and two open-ended questions that addressed utilization of Project HEAL services. In 1 week, 137 clinicians completed the survey.

Clinicians surveyed included physicians, psychiatrists, psychologists, social workers, and trainees in these fields. Ninety-five percent (*n* = 130) of the clinicians surveyed indicated that families who received Project HEAL representation were more successful at accessing complex service systems. Eighty-nine percent (*n* = 121) of clinicians surveyed indicated that working with Project HEAL greatly impacted their ability to effectively advocate on behalf of their patient.

Project HEAL attorneys frequently present at local, state, and national conferences to increase awareness of the program and service-delivery model, as well as to inspire clinical programs to replicate the program within their own institutions. In addition, Project HEAL serves as a placement for pre-service training and preparation. More than 60 undergraduate and graduate students in the last 5 years have completed a variety of internships, externships, and fellowships for multiple disciplines, including social work, psychology, public health, and law.

Project HEAL's role in improving environmental and social conditions for children with intellectual and developmental disabilities is strengthened through its affiliation with programs committed to research, policy, and care for children with disabilities, including an Intellectual and Developmental Disabilities Research Center, a University Center for Excellence in Developmental Disabilities (UCEDD), and a Leadership Education in Neurodevelopmental and Related Disabilities program. Affiliation with these programs has provided a platform in which Project HEAL staff may provide professional training on a variety of advocacy and legal topics to healthcare professionals and trainees across a variety of disciplines.

Organizationally, because Project HEAL is located within Maryland's UCEDD, an organization actively involved in policy efforts, individual cases referred by Kennedy Krieger healthcare professionals have proven instrumental in positively shaping local and state policies on behalf of all children with intellectual and developmental disabilities in Maryland. Several Project HEAL families, who worked collaboratively with Project HEAL advocates and attorneys, were pivotal in helping to pass legislation that increased parental participation in the special education process. As a result of these efforts, Maryland was the first state to require Individualized Education Program teams to provide data, assessments, and reports to families in advance of a meeting, so that parents and legal guardians are better prepared when they participate in meetings about their child's educational program and placement.

Implications for Program Development

Project HEAL has concluded its first decade of partnering with clinicians to serve families of children with disabilities.

Through access to Project HEAL advocates and attorneys, clinicians and families more effectively navigate the complex systems in which individuals with disabilities live, work, and learn. Between 2005 and 2013, Project HEAL attorneys provided representation and limited representation to 1,750 low-income families and children with disabilities. Project HEAL advocates and attorneys have also provided 1,600 case consultations to healthcare professionals, trainees, and educators, including resources or guidance to clinicians who are helping a family

implement clinical recommendations or access needed services in the community. Project HEAL attorneys have reached an additional 1,650 healthcare professionals, trainees, and educators through 80 professional trainings addressing a variety of civil legal topics affecting children with disabilities, including special education law, public benefits, guardianship and less restrictive alternatives to guardianship, futures and estate planning for individuals with disabilities, and discipline for students with disabilities. The high demand for case consultations and trainings with Project HEAL staff suggests that healthcare professionals, trainees, and educators need specific instruction on social, educational, and occupational legal matters affecting individuals with disabilities to meet the complex needs of their patients.

The National Center for Medical-Legal Partnership emphasizes the need for growth and sustainability of medical-legal partnerships (National Center for Medical-Legal Partnership, 2014c). Given that adults and children with disabilities have ongoing clinical and legal needs, it is important that the focus of this movement includes this vulnerable population and that replication of this model occurs in medical institutions both nationally and internationally. As emphasized in the *World Report on Disability*, the denials of basic rights of individuals with disability are an international experience (World Health Organization & World Bank, 2011), and thus necessitate the implementation of and collaboration between organizations addressing both the medical and legal needs of individuals with disabilities across nations.

In recent years, the National Center for Medical-Legal Partnership has published several tools to assist medical institutions and legal services organizations who hope to replicate the model. There is a textbook on the medical-legal partnership model, titled *Poverty, Health and Law: Readings and Cases for Medical-Legal Partnership* (Tobin Tyler, Lawton, Conroy, Sandel, & Zuckerman, 2011), which covers the theoretical underpinnings of the model and offers strategies for implementation and evaluation. The National Center also developed the *Medical-Legal Partnership Toolkit, Phase 1: Laying the Groundwork* (National Center for Medical-Legal Partnership, 2014a), which helps medical-legal partnerships better coordinate their program activities, assess community needs, and achieve sustainability. The toolkit is free and available online and contains a self-assessment that is designed to align with emerging and aspirational best practices.

The incorporation of advocacy and legal services directly into the pediatric setting provides an innovative and efficient mechanism to improve outcomes for children with intellectual and developmental disabilities, especially those families who might not otherwise have access to legal services. Consultation with advocates and attorneys informs healthcare professionals about the complex social issues and barriers affecting the health and well-being of the families they serve. Healthcare professionals may then integrate this knowledge into their clinical practice and supervision of trainees within the medical-legal partnership site in addition to contributing this experience to their practice at new institutions to which they may move. Attorneys advocating on behalf of patients learn about which psychosocial needs are most critical to the improvement of the child's health through collaboration with the medical teams. Legal advocacy within the clinical setting ensures that comprehensive clinical

recommendations are implemented effectively in the home, school, and community, further contributing to the overall health and well-being of the child.

Acknowledgments

Project HEAL as presented in this paper was supported by grants and financial commitments from Kennedy Krieger Institute, Maryland Center for Developmental Disabilities, Maryland Volunteer Lawyers Service, Equal Justice Works, local foundations, and private donors.

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