
ADVOCACY IN HEALTH PROCEEDINGS IN NEW YORK STATE

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Individuals and communities navigating the healthcare system without an advocate often experience devastating outcomes and become burdened with unnecessary costs. These negative outcomes undermine the very utility of our healthcare system. The creation of a legal right to counsel for individuals with critical health related claims would meet an important and unmet need in our health and legal systems by empowering patients, improving the quality of health for many, and preventing unnecessary costs to the health care system.

A dedicated group of healthcare advocates, lawyers, public policy analysts, and other concerned individuals gathered together at Touro Law Center to strategize around creating a civil right to counsel in New York State. At this conference, entitled An Obvious Truth: Creating an Action Blueprint for a Civil Right to Counsel in New York State, participants split into panel sessions to discuss the various issue areas in which such a right could attach. One such panel discussed how establishing a right to counsel in health related proceedings could improve patients' healthcare experiences and produce greater benefits to the health care system as a whole. This reflection emerges from that discussion as an exploration of the issues and questions raised therein.

The creation of a legal right to counsel for individuals with critical health related claims would meet a crucial and overlooked need in society. Not only would creation of such a right potentially

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improve healthcare for individuals, it would also improve the functionality of the health care system as a whole.

This Article explores strategic considerations and challenges involved with establishing a right to representation in health-related adjudications. First, it asks, in what type of proceedings are health related decisions being made, and in which of those proceedings would a civil right to counsel be beneficial? Second, what are the potential benefits and savings to anticipate from establishing this right? Third, what are the risks or stakes involved for individuals in these proceedings who do not have access to counsel? And fourth, what barriers or limitations would prevent people from obtaining access to counsel even if the right were established?

As advocates address practical concerns about financing and implementing a right to counsel in health proceedings, they also must identify the core values that mandate the creation of this right. This includes values for human dignity, the human right to health, and fundamental fairness and accountability in the systems upon which we rely for our safety and security.

It is the panel's hope that this reflection will launch a larger, sustained conversation among healthcare advocates, patients, and access to counsel advocates about how to meet this important need. By working together to articulate a vision for civil legal and public health systems that work effectively and equitably for all people, regardless of their income or background, health and right to counsel advocates can achieve the progress necessary to create a civil right to counsel in health proceedings.

TABLE OF CONTENTS

INTRODUCTION	440
I. WHAT MAKES ADVOCACY IN HEALTH PROCEEDINGS DIFFERENT FROM OTHER CIVIL CLAIMS?	442
II. TYPES OF PROCEEDINGS WHERE HEALTH RELATED RIGHTS ARE ADJUDICATED.....	444
A. Mental Health Matters.....	445

2009]	<i>ADVOCACY IN HEALTH PROCEEDINGS</i>	439
	B. Public Benefits	447
	C. Medical Treatment in Prisons	448
	D. Community Health Claims.....	450
III.	IDENTIFYING THE BENEFITS OF A RIGHT TO COUNSEL	451
	A. Cost Savings.....	452
	B. Systemic Benefits.....	456
	C. Identifying the Risks of Not Providing a Right to Counsel.....	458
	1. <i>Limits on Individuals</i>	459
	2. <i>Complexity of Claims/Competency of Individual</i>	460
	D. Barriers to Accessing the Right to Counsel, Insufficiencies of the Right	461
IV.	CREATING AN ADVOCACY FRAMEWORK FOR HEALTH PROCEEDINGS IN NEW YORK	462
V.	CONCLUSION.....	464

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INTRODUCTION

Various sources of international law recognize a person's right to the highest attainable level of health as an inalienable human right.¹ The right to health, according to the American Bar Association, involves "access to appropriate health care for treatment of significant health problems whether that [treatment] is financed by government . . . or as an employee benefit, through private insurance, or otherwise."² Yet, many individuals with important health-related civil claims are not adequately equipped to advocate on their own behalf, either because their medical condition renders them unable to represent themselves effectively or because their claims are too complex to handle on their own without sufficient familiarity with the

¹ See, e.g., Universal Declaration of Human Rights, G.A. Res. 217A, at 71, U.N. GAOR, 3d Sess., 1st plen. mtg., U.N. Doc A/810, Art. 25.1 (Dec. 12, 1948), available at <http://www.un.org/Overview/rights.html> ("Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services. . . ."); International Covenant on Economic, Social and Cultural Rights, G.A. Res. 2200A (XXI), 21 U.N. GAOR Supp. (No. 16) at 49, U.N. Doc. A/6316 (Dec. 16, 1966), 993 U.N.T.S., Art. 12.1 (Jan. 3, 1976), available at http://www.unhchr.ch/html/menu3/b/a_ceschr.htm (recognizing "the right of everyone to the enjoyment of the highest attainable standard of physical and mental health"); International Convention on the Elimination of All Forms of Racial Discrimination, G.A. Res. 2106 (XX), Annex, 20 U.N. GAOR Supp. (No. 14) at 47, U.N. Doc. A/6014 (Dec. 21, 1965), 660 U.N.T.S. 195, Art. 5 (e) (iv), (Jan. 4, 1969), available at http://www.unhchr.ch/html/menu3/b/d_icerd.htm; Convention on the Elimination of All Forms of Discrimination against Women, G.A. Res. 34/180, 34 U.N. GAOR Supp. (No. 46) at 193, U.N. Doc. A/34/46, Arts. 11.1 (f), 12, (Sept. 3, 1981), available at <http://www1.umn.edu/humanrts/instrree/elcedaw.htm>; Convention on the Rights of the Child, G.A. Res. 44/25, annex, 44 U.N. GAOR Supp. (No. 49) at 167, U.N. Doc. A/44/49, Art. 24 (Sept. 2 1990), available at <http://www.unhchr.ch/html/menu3/b/k2crc.htm>.

² See Am. Bar Ass'n House of Delegates, *Task Force on Access to Civil Justice*, 112A (Aug. 7, 2006), available at <http://www.abanet.org/legalservices/sclaid/downloads/06A112A.pdf>.

system. Individuals and communities navigating the healthcare system without an advocate often experience devastating outcomes and become burdened with unnecessary costs. Something must be done to remedy this problem that undermines the very utility of our healthcare system.

The American Bar Association's 2006 resolution in favor of a civil right to counsel, or Civil Gideon, finds that health is a basic human need for which a right to counsel should attach when individuals find themselves involved in critical legal matters pertaining thereto.³ This Article will explore the strategic considerations, challenges, and limitations of establishing a right to representation in adjudications involving healthcare. It surveys the types of claims in which a right to counsel could attach, discusses the benefits of establishing this right, and offers preliminary reflections about viable strategies for achieving it. It is the panel's hope that this reflection will launch a larger, more sustained conversation among healthcare advocates and patients, and provide access to counsel advocates about how to meet this important need.

Panel participants began the discussion with a brainstorming exercise that illustrated the vast landscape of instances in which a right to representation would be beneficial for individuals with important health claims. After discussing the strategic advantages of pushing for a right to counsel in specific health claims versus advancing the case for a broader entitlement in health proceedings generally, panelists decided that both issue-specific and more general right to

³ *Id.*

counsel efforts should be pursued. The panel next surveyed the types of arguments most likely to be effective in advancing this right. For instance, panel participants discussed various arguments based on economic efficacy, equity, fairness, systemic improvements, and their likelihoods of success. Finally, the panel considered the practical limitations of establishing a legal right to counsel in important healthcare claims. What work would remain for the healthcare community and for those fighting for greater access to representation in important civil claims, even if this right were established?

To guide the discussion, the panel set forth five topical considerations about the work and strategy necessary to establish a right to counsel for individuals with important health related claims. First, at what sorts of proceedings are health related decisions being made, and in which of those proceedings would a civil right to counsel be beneficial? Second, what are the potential benefits and savings to anticipate from establishing this right? Third, what are the risks or stakes involved for individuals in these proceedings who do not have access to counsel? Fourth, what barriers would prevent people from obtaining access to counsel, even if such a legal right were established? And what are other limitations to providing a right to counsel in the area of health? The panel discussion culminated in an outline of the strategic questions that must be addressed as advocates work to establish a right to counsel in health proceedings. Panelists also began articulating and framing the core values guiding this right to counsel movement.

I. WHAT MAKES ADVOCACY IN HEALTH PROCEEDINGS

DIFFERENT FROM OTHER CIVIL CLAIMS?

Establishing a right to counsel in health claims involves a more complex vision of the role of representation than other areas of Civil Gideon advocacy. For instance, Civil Gideon advocacy in the housing or child custody contexts generally involve clear roles for counsel and forums for adjudicating claims;⁴ but health related proceedings could potentially involve a range of claims, remedies sought, and roles for the attorney.⁵ Health claims could involve government administrative proceedings, public hearings, civil court, private proceedings conducted by a health insurer, etc. Additionally, the role of the lawyer changes depending on the type of claim—from a prosecutorial role against a corporate actor creating public health hazards, to an adversarial role against a government entity over government provided health coverage, to a traditional litigator’s role in civil court.

Moreover, health claims arise in an environment in which non-lawyers can, in certain instances, make better, more effective advocates for patients because of their expertise and familiarity with processes within the healthcare system. Panelists discussed this in the context of medical treatment decisions, where institutional actors such as skilled nurses or social workers can work within the system and on behalf of the patient to ensure that a patient’s rights are protected. This includes protecting patients’ rights to be informed of

⁴ Andrew Scherer, *Why People Who Face Losing Their Homes in Legal Proceedings Must Have a Right to Counsel*, 3 CARDOZO PUB. L. POL’Y & ETHICS J. 699, 730 (2006).

⁵ See generally Transcript of Health Break-Out Session, An Obvious Truth: Creating an Action Blueprint for a Civil Right to Counsel in New York State [hereinafter Health Break-Out Session].

risks, alternatives, and benefits of treatment, and the right to adequate language services. Thus, advocates for a right to counsel in health claims must also determine how non-lawyer advocates should factor into their efforts.

II. TYPES OF PROCEEDINGS WHERE HEALTH RELATED RIGHTS ARE ADJUDICATED

Currently, the only health related proceedings for which New York State law provides a statutory right to counsel are those pertaining to involuntary commitment proceedings.⁶ This leaves a broad range of health related claims in which individuals have no right to legal representation. As a non-exhaustive list, the panel identified over a dozen such claims which people could be forced to adjudicate without a lawyer, including: unfair hearings; matters pertaining to a person's Medicare, Medicaid, Veterans Administration benefits, and disability benefits; mental health decisions such as voluntary commitment and involuntary medical treatment; end-of-life decision making; private health insurance treatment and medication decisions; nursing home care; hospital discharge proceedings; medical treatment in prisons; public health matters; community-based health claims; and more.⁷

Among the dozen or so matters identified by panel participants, four classes of claims appeared to generate the greatest interest from the group. These were claims pertaining to a patient's mental health needs, public benefit matters, community health claims, and

⁶ N.Y. MENTAL HYG. LAW § 81.10 (McKinney 2008).

⁷ See generally Health Break-Out Session, *supra* note 5.

claims pertaining to medical treatment in prisons. A common thread among these various matters is that they all involve inadequately resourced or underrepresented population groups.⁸ Because the injustices produced by a lack of access to adequate representation are perhaps most egregious in cases involving vulnerable populations, this may be a particularly helpful starting point for discussing when in the adjudicative process a right to counsel should attach, how to go about advocating for the establishment of this right, and other important considerations.

A. Mental Health Matters

Panelists discussed the benefits of creating a right to counsel for mentally ill or potentially mentally ill individuals involved in matters that could determine their institutionalization, medical treatment, or other important health decisions. Namely, such a right would provide necessary protection to members of this highly vulnerable population as they take on crucial matters that could affect their agency, health, and physical security.⁹ They also discussed the limitations of the current entitlement to a right to representation in involuntary commitment proceedings with specific attention to the fact that it is only a limited statutory right that some panelists assert is inade-

⁸ Paul Von Zielbauer, *As Health Care in Jails Goes Private, 10 Days Can Be a Death Sentence*, N.Y. TIMES, Feb. 27, 2005, at 1.

⁹ Lisa Brodoff, Susan McClellan & Elizabeth Anderson, *The ADA: One Avenue to Appointed Counsel Before a Full Civil Gideon*, 2 SEATTLE J. FOR SOC. JUST. 609, 623 (2004) (“Using the ADA to get representation for these clients as a reasonable accommodation could be the difference between hunger and adequate nutrition, illness and health care, or homelessness and shelter.”).

quately enforced as it stands.¹⁰

Providing a right to counsel to individuals in mental health proceedings would protect a population group that is particularly vulnerable to irreparable harm. Mental Hygiene Legal Services provides representation to individuals facing involuntary confinement as a limited statutory right.¹¹ But individuals with other mental health claims do not enjoy this entitlement. If they cannot afford a lawyer, these individuals may be forced to navigate two complex systems—the American legal system and the healthcare system—pro se, while also managing mental health issues that may hinder their capacity to advocate for themselves effectively. The consequences—lack of adequate mental health services or inappropriate health services—could be devastating.

Although patients facing involuntary confinement in New York State are entitled to access to counsel, several serious limitations create barriers to the realization of this right. The right only extends to individuals who face institutionalization in a state facility.¹² Unpredictable funding schemes for mental hygiene legal services

¹⁰ N.Y. MENTAL HYG. LAW § 81.10.

¹¹ See N.Y. MENTAL HYG. LAW § 9 (McKinney 2008).

¹² N.Y. MENTAL HYG. LAW §§ 47.01, 47.03. The former section provides that Mental Hygiene Legal Services “shall provide legal assistance to patients or residents of a facility . . . or any other place . . . required to have an operating certificate” Compare N.Y. MENTAL HYG. LAW § 1.03, with Mental Hygiene Legal Services—History and Purpose. Section 1023.1(d) provides further definitions stating “[p]atient shall mean a person residing in a facility for the mentally disabled which is licensed or operated by the Department of Mental Hygiene or the Department of Correctional Services, or a person residing in any other place for whom the service has been appointed counsel or court evaluator pursuant to Mental Hygiene Law article 81.” See also N.Y. MENTAL HYG. LAW §§ 81.01, 81.10; Ughetto v. Acrish, 518 N.Y.S.2d 398, 406 (App. Div. 2d Dep’t 1987) (holding an “involuntarily committed mental patient . . . has the right to have an attorney observe [psychiatric] examination” in preparation for a hearing).

have made it unclear how this right to representation can be adequately and predictably enforced.¹³ Additionally, many people who would qualify for such services lack access—geographic, linguistic, or otherwise—to information about obtaining it. And because legal service attorneys have heavy caseloads along with limited resources and time, this gives rise to serious concerns about the quality of representation available to individuals who do manage to obtain it.¹⁴

B. Public Benefits

Claims pertaining to health related public benefits such as Medicare, Medicaid, Child Health Plus, disability benefits, veterans' health benefits, and other programs involve important health decisions that could give rise to the need for representation. The types of claims involved are almost limitless and may range from adjudicating an agency's failure to provide proper explanation of benefits, to medical malpractice claims against physicians that accept patients under one of these programs, to claims over whether these programs must cover a particular procedure or medication, etc. But what invokes the need to provide access to counsel for these individuals is not solely the nature of the claim involved, but also the fact they

¹³ See N.Y. JUD. LAW § 35(5) (McKinney 2008) (providing “[a]ll expenses for compensation and reimbursement under this section shall be a state charge to be paid out of funds appropriated to the administrative office for the courts for that purpose”); see also Gary Muldoon, *Court-appointed Law Guardians Face Issues Involving Liability, Conflicts and Disqualification*, 76 N.Y. ST. B.J. 30, 31-32 (Jul./Aug. 2004) (“A private attorney who acts as law guardian may be paid by New York State at the rate fixed by statute, now \$75 per hour.”).

¹⁴ Office of Mental Health—2000 N.Y. State Chartbook of Mental Health Information, http://www.omh.state.ny.us/omhweb/chartbook/PDF_files/series_d/D1.PDF (last visited Oct. 25, 2008). See O'Connor, *infra* note 15 at 366 (wherein a mental health case “fell through the cracks” due to insufficient staffing and large caseloads, among other things).

likely lack financial and other resources necessary to pay for representation on their own and this public benefit is likely their only access to treatment.¹⁵ Panelists noted that with the veteran population continuing to grow, and thus veterans' benefits claims increasing, right to counsel advocates should devote substantial attention to pushing for a right to representation in health claims related to public benefits.¹⁶

C. Medical Treatment in Prisons

Panelists also raised concerns about providing access to representation to prison inmates with important health claims. New York State has a duty to provide reasonable and adequate medical care to the inmates of its prisons.¹⁷ Yet inmates are generally vulnerable to

¹⁵ See, e.g., Erin O'Connor, Comment, *Is Kendra's Law a Keeper? How Kendra's Law Erodes Fundamental Rights of the Mentally Ill*, 11 J.L. & POL'Y 313 (2002) (discussing involuntary outpatient treatment, Kendra's Law, and the right to counsel for mentally ill individuals).

¹⁶ See Jonathan Creekmore Koltz, *Unstacking the Deck: In Defense of the Veterans Benefits, Healthcare, and Information Technology Act of 2006*, 17 FED. CIRCUIT B.J. 79 (2007). Until recently, section 5904 of title 38 to the United States Code prevented veterans from obtaining paid counsel before the Board of Veterans' Appeals made its final decision on a case. *Id.* at 80. This all but forced veterans to appear *pro se* to preliminarily argue on their own behalf. See also 38 U.S.C.A. § 5904 (West 2008) (which provides "[t]he Secretary may prescribe in regulations reasonable restrictions on the amount of fees that an agent or attorney may charge A fee that does not exceed 20 percent . . . shall be presumed to be reasonable"). See BD. OF VETERANS' APPEALS, HOW DO I APPEAL? (2002), available at <http://www.va.gov/vbs/bva/010202A.pdf>, for an instruction booklet designed for veterans looking to appeal unsatisfactory decisions.

¹⁷ *Kagan v. State*, 646 N.Y.S.2d 336 (App. Div. 2d Dep't 1996).

[A]n inmate, who "must rely on prison authorities to treat [the inmate's] medical needs," "has a fundamental right to 'reasonable' and 'adequate' medical care." Further, it is the State's duty to render medical care "without undue delay" and, therefore, whenever "delays in diagnosis and/or treatment [are] a proximate or aggravating cause of [a] claimed injury," the state may be liable.

Id. at 339. (alteration in original) (internal citations omitted). See also *Rivers v. State*, 552 N.Y.S.2d 189, 189 (App. Div. 3d Dep't 1990) (stating that "[i]t is fundamental law that the State has a duty to provide reasonable and adequate medical care to the inmates of its pris-

suffering serious harms due to a lack of access to adequate medical services in prisons.¹⁸ Prisons often lack the resources necessary to provide adequate care, and prisoners as a population group do not generate the sympathy and concern necessary to produce a public outcry to correct this inadequacy. On their own, prisoners are virtually powerless to advocate for better quality of care at prison hospitals. But with the help of legal advocates who can pressure prisons and state departments to meet this critical need, prisoners can get the basic health services that every human being deserves.¹⁹

Panelists provided compelling yet disturbing anecdotes to illustrate the gravity of this need for a right to counsel for prisoners with important health claims. One panelist reflected upon a case involving a large New York State correctional facility in which the sole doctor serving the prison was not actually admitted to practice medicine in New York State.²⁰ Another panelist discussed a case involving untrained prison guards who performed medical care triage on the prisoners, inevitably causing severe injuries due to failure to treat patients with critical health needs.²¹

Unacceptable inadequacies in the medical care prison inmates

ons”).

¹⁸ See, e.g., *Kagan*, 646 N.Y.S.2d at 10-17 (listing “incidents of ministerial neglect”); John Caher, *State Liable for Malpractice Due to Failure to Timely Diagnose Prisoner’s Cancer*, 230 N.Y.L.J. 1 (2003). See also Michele Westhoff, *An Examination of Prisoners’ Constitutional Right to Healthcare: Theory and Practice*, 20 HEALTH LAW. 1, 9 (2008).

¹⁹ Prisoners’ Legal Services of New York (“PLSNY”) has been successful in litigating to protect inmate’s rights throughout the state on a variety of issues including AIDS and health care. For a synopsis of some of the major PLSNY cases, see Prisoners’ Legal Services of New York—Selected Successful Litigation, <http://www.plsny.org/litigation.htm> (last visited Oct. 25, 2008) (discussing mental healthcare in prisons).

²⁰ See Health Break-Out Session, *supra* note 5, at 13.

²¹ See *id.*

receive will continue to go unnoticed if it is only the prisoners themselves fighting for better treatment. Effective legal counsel for these individuals, however, could produce tremendous improvements to the way the system works.

D. Community Health Claims

Lawyers, community-based organizations, and activists often collaborate to address important public health issues pertaining to communities. For instance, residents of a building contaminated with lead paint, or residents of a neighborhood receiving contaminated water, or having been exposed to polluted air, may organize against this public health threat. Although there are statutes that create a cause of action for these individuals (for instance, a public nuisance statute), no statutes create an analogous right to representation.²² Access to representation would enable a community, regardless of its financial resources, to advocate for its members' rights to live in a safe and healthy environment where adequate healthcare is accessible. Some communities, especially low-income communities and communities of color, lack the resources necessary to pay for high quality health care.²³ Providing groups from these communities with the valuable

²² See, e.g., N.Y. PUB. HEALTH LAW §§ 1370-1375 (McKinney 2008) (Article 13 includes regulations for the control of Lead Poisoning.); N.Y. PUB. HEALTH LAW § 1102 (McKinney 2008) (Article 11, title I protects consumers from contamination of potable water.); NY ENVTL. CONSERV. LAW §§19-0101-19-1105 (McKinney 2008) (Article 19 is the "Air Pollution Control Act").

²³ N.Y. STATE DEP'T OF HEALTH, N.Y. STATE MINORITY HEALTH SURVEILLANCE REPORT 78 (2007), available at http://www.health.state.ny.us/statistics/community/minority/docs/surveillance_report_2007.pdf

Cost was a factor in preventing doctor visits for 24.0% of Hispanic New Yorkers. This was significantly higher than the rates for Black non-

resource of access to counsel can make a remarkable difference in their claims for better access to care or against public health threats. Access issues such as geographic barriers, transportation difficulties, language barriers, and even experiences of racism against patients are examples of important community-based health claims in which access to representation would render tremendous benefit to communities and their local healthcare facilities.

Successful strategizing to create a right to counsel in health proceedings must recognize the array of claimants and claims that are involved. Some claims will involve the health of individual patients, others will involve the health interests of entire communities, and still others may affect the public at large.²⁴ Right to counsel advocates must continue to cultivate a sophisticated appreciation of the complexity of claims involved. This will help ensure that proposed legislation and other solutions are appropriate to meet the needs of the expected beneficiaries.

III. IDENTIFYING THE BENEFITS OF A RIGHT TO COUNSEL

Widespread public resolve as well as the confidence and sup-

Hispanic and Asian non-Hispanic New Yorkers (14.6% and 13.5%, respectively). Among White non-Hispanic New Yorkers, the percentage not seeing a doctor due to cost was significantly lower (8.2%) than all race/ethnicity groups.

Id.

²⁴ See, e.g., Natalie White, *Toxic Mold Case in California Settles for \$22 Million*, DAILY RECORD, Jan. 13, 2006; Erin Ailworth, *Chelsea Development Settles Pollution Claim*, BOSTON GLOBE, Sept. 12, 2008, at C.3; Kathleen Burge, *Landlords Settle Lead Paint Case*, BOSTON GLOBE, Sept. 21, 2008, at 6; see also Charles Russell, *Environmental Equity: Undoing Environmental Wrongs to Low Income and Minority Neighborhoods*, 5 J. AFFORDABLE HOUS. & CMTY. DEV. L. 147 (1996) (“The problems have ranged from overpopulated, unhealthy tenement houses, to the siting of incinerators in low income, minority neighborhoods. . . . [T]he focus of much of the environmental equity movement has been on ‘environmental racism . . . ’”).

port of legislators and other key decision makers are integral to establishing a right to counsel in health proceedings. To garner support, advocates must effectively and persuasively communicate the benefits this right will produce for individuals, communities, and the healthcare system as a whole. Health care advocates and advocates for a right to counsel must devote significant energy to conveying the core values and objectives that guide the Civil Gideon movement for health claims. Two main benefits of a right to counsel are: *savings*, both economic and value-based, and *systemic improvements* to the operation of the healthcare system.

A. Cost Savings

Right to counsel advocates should focus on assessing and communicating how the existence of a right to counsel can potentially reduce healthcare costs in New York State. First, this requires advocates to consider the burden New York State will incur by providing, implementing, and maintaining a right to counsel in health matters.²⁵ Second, advocates must examine the current costs and inefficiencies created by a lack of representation.²⁶ Finally, advocates must evaluate how the costs of establishing and implementing a right to counsel in New York State compare with the expenses created by a failure to provide adequate representation to those who need it most.²⁷ There is scant data on these fiscal issues and further attention to this matter from the advocacy community is necessary. This is a

²⁵ Health Break-Out Session, *supra* note 5, at 6.

²⁶ *Id.* at 28-29.

²⁷ *Id.* at 45-48.

critical area in which dedicated advocacy work could be particularly helpful in advancing statewide right to counsel efforts.

Consideration should be given to determining how to measure and describe costs and savings. Strategically speaking, it is important to recognize the different ways of evaluating costs and savings—not only the various economic factors that contribute to this assessment, but also the value-based savings that deserve attention. For instance, it could theoretically be argued that death is economically advantageous in cases where the alternative is that a person will live life with a prolonged illness that is costly to treat.²⁸ Therefore, it is important to include a quantification of indirect economic benefits, as well as value-based benefits, since these can outweigh purported economic advantages. An ill person may, for example, participate in the economy as a consumer, encourage family members to continue generating income (as opposed to potential interruptions in income-earning due to the family member's death), or even remain employed as he or she manages the illness. Therefore, the economic benefits of the early death of a seriously ill person may be outweighed by the economic benefits of providing that person with the tools—including ac-

²⁸ *Id.* at 43-44; see James J. Mongan et al., *Options for Slowing the Growth of Health Care Costs*, 354 NEW ENG. J. MED. 1509 (2008).

The aging of the population and increasing numbers of patients with chronic illnesses contribute to the problem, but the increasing numbers of effective therapies for these populations are major factors in cost trends. . . . The improved care of patients with chronic conditions . . . is a promising focus for cost reduction, because about 70% of health care costs are generated by 10% of patients, most of whom have one or more chronic diseases.

Id.; cf. Ezekiel Emanuel & Linda L. Emanuel, *The Economics Of Dying—The Illusion of Cost Savings at the End of Life*, 330 NEW ENG. J. MED. 540 (1994) (“Medicare payment for the last year of life of a beneficiary who died was \$13,316, as compared with \$1,924 for all Medicare beneficiaries (a ratio of 6.9:1).”).

cess to legal representation—to advocate for rights that would extend his or her life.

This hypothetical demonstrates that the cost/benefit discussion is flexible and allows room for consideration of a range of factors, including indirect costs and benefits and value-based costs and benefits. For every calculable cost associated with direct representation, advocates must identify the hidden costs associated with not providing that representation. This includes erosion of accountability in the health care system, especially where individual claims represent persistent systemic problems impacting wider population groups.

For every cost, advocates must also identify the economic benefits a right to counsel could produce, even giving attention to benefits that flow to other areas of public life. For example, one panelist noted that access to representation to secure adequate medical care for children could produce savings in spending on public education. In the Rochester City School District, asthma is the leading cause of absences for school age children.²⁹ Other studies show that children who miss more than ten percent of their school days are more likely to fail the grade and have to repeat it.³⁰ In this case, researchers could compare the cost of providing legal counsel to help push for reforms to ensure that more children receive quality, afford-

²⁹ Health Break-Out Session, *supra* note 5, at 48; see Heather Hare, UNIV. OF ROCHESTER MED. CTR., *Children with Asthma More Likely to Have Behavior Difficulties*, Feb. 6, 2006, <http://www.urmc.Rochester.edu/pr/news/story.cfm?id=1017>.

³⁰ See Rachel Spaethe, *Survey of School Truancy Intervention and Prevention Strategies*, 9 KAN. J.L. & PUB. POL'Y 689, 696 (2000) (“[S]chools can ‘mandate course failure, suspension, or transfer to special programs after a certain number of unexcused absences.’ The problem with this approach is that research indicates that retaining a student ‘one grade increases a student’s chances of dropping out by forty to fifty percent; those retained two grades have a ninety percent greater chance of dropping out.’”).

able primary care to treat their asthma, with the annual cost of each child's public education (panelists estimated this at \$13,000 for children without disabilities, and about \$18,000 for children with disabilities).³¹ Such data would provide advocates with a strong case for creating systems to ensure that everyone receives quality care and cost the public less money than the more aggressive spending involved with treating improperly managed medical conditions and a students' additional time spent in the public education system.

For every cost of providing representation, advocates must also identify the value-based benefits that truly guide this movement. For example, the New York Governor's 2008 budget recommended that Medicaid pay for health education for asthma and diabetes, as a matter of good practice.³² This acknowledges that certain costs are beneficial to the public and therefore, should be paid for by the public. This is important not only for advancing the notion that the public benefits when it pays for certain services, but also for highlighting a values-based approach to contemplating the importance of this service. It remains critical that advocates appeal to this human-centered perspective as a guiding principle, even while making cost-benefit

³¹ Health Break-Out Session, *supra* note 5, at 48; N.Y. STATE EDUC. DEP'T, THE NEW YORK STATE SCHOOL REPORT CARD FISCAL ACCOUNTABILITY SUPPLEMENT FOR NYC CHANCELLOR'S OFFICE (2008), *available at* <http://www.emsc.nysed.gov/irts/reportcard/2007/supplement/300000010000.pdf> (noting the average cost per child per year for general education is \$9,168 and \$22,354 for special education).

³² Press Release, New York State Governor's Office, Governor Paterson Announces \$5 Million Investment in Nursing Education to Address Nursing Shortage in New York State (Apr. 8, 2008), http://www.ny.gov/governor/press/press_0408083.html ("For the first time, Medicaid will cover the services of certified diabetes and asthma educators, many of whom are nurses. Providing patients with education will help them manage their chronic diseases more effectively, keeping them healthier and preventing hospitalizations or loss of work time.").

arguments for establishing a right to counsel.

While economic arguments are both rhetorically useful in countering the arguments of opponents and practical in crafting and promoting legislative solutions, the incalculable, immeasurable benefits, such as improved quality of life for patients, human dignity, and equal access to effective health care services, should remain paramount to the debate. Ultimately, returning to these underlying values fueling the movement will help illuminate the goals and objectives that would be better achieved through provision of a civil right to counsel. To the extent that providing a right to counsel advances the achievement of these goals, this should be articulated in a way that persuades others that the costs of implementation are well worth the benefits of achieving the goals.

B. Systemic Benefits

Lawyers working on behalf of their clients can help make the system more accountable to the law and to its intended beneficiaries. One panelist likened the use of her advocacy skills and familiarity with the governing laws to holding up a mirror to the system, allowing healthcare advocates to see more clearly how the system is functioning and where reform is necessary.³³ In this way, access to an attorney who is knowledgeable about the healthcare system, its limitations, and its key players can be of great benefit to the individual as well as to the healthcare system as a whole. Lawyers help their individual clients and, perhaps more importantly, also perform a sort

³³ Health Break-Out Session, *supra* note 5, at 29.

of systemic cleansing or tweaking, helping the larger system work better for patients in general.

Large programs with large sources of funding sometimes produce bureaucratic and institutional pressures that prevent the system from working properly. Individuals working from within that system may be unable to control the inefficiencies, bureaucratic barriers, or pressures at play.³⁴ An unaffiliated lawyer, however, trained to identify patterns, practices, or improperly applied policies, may be better equipped to bring attention to these misapplications in order to catalyze necessary improvements to the system.

For instance, access to counsel could produce significant systemic improvements to how hospitals spend state funds, which could in turn enhance the quality of services such as charity care programs. In 2006, there was state legislation entitled Manny's Law.³⁵ It is the patient financial assistance law, which requires all hospitals to promulgate and post charity care policies on access for the uninsured.³⁶ Panelists said there is a critical need for thorough analysis of how these funds flow to patients, in light of suspicions that these resources are being misspent and absorbed in the bureaucratic machinery.³⁷

³⁴ Lisa C. Ikemoto, *Racial Disparities In Health Care and Cultural Competency*, 48 ST. LOUIS U. L.J. 75, 124 (2003).

³⁵ N.Y. PUB. HEALTH LAW § 2807-k (McKinney 2008).

³⁶ See Fred Mogul, *Manny's Law, Designed to Help Uninsured, Gets Update*, WNYC.COM, June 29, 2007, <http://www.wnyc.org/news/articles/81385> (explaining that Manny's law requires hospitals to supply uninsured patients with discounted medical service and noting this may increase hospitals charitable care); see also CONSERVAPEDIA, *Manny's Law*, http://www.conservapedia.com/Manny%27s_Law (last visited Oct. 25, 2008) (stating that "Manny's Law . . . conditions state funding to hospitals on their termination of overcharging the uninsured . . .").

³⁷ According to panelist Judy Wessler, there is \$847 million at the state level in what is called "the charity care pool." Shelter Break-Out Session, *supra* note 5, at 26. But, these funds do not attach to any patient getting a piece of care. There is an effort right now to try

Because lawyers provide the pressure necessary to create more transparent processes and deter misuse of funds, either via negotiations, litigation, or other measures, giving healthcare advocates the right to a lawyer would help them fight to restore and preserve accountability to hospital funding systems. Panelists noted the success of Mental Hygiene Legal Services in this regard,³⁸ primarily because the lawyers work closely with patient treatment providers, and have become an informal part of the quality control system for mental health services.

C. Identifying the Risks of Not Providing a Right to Counsel

Given the substantive right at stake in health related civil proceedings—the right to health and adequate health services—it is patently inequitable to deny people access to competent legal counsel in their adjudications. Panelists discussed an array of concerns about the risks involved in not providing a right to counsel in important health claims, but these can be separated into two main categories: (1) the risks posed by personal individual limitations; and (2) the

to make it a more accountable system, where the money actually follows the patients. Press Release, N.Y. State Exec. Chamber—Eliot Spitzer, An Agenda to Fundamentally Reform New York's Health Care System (Jan. 26, 2007), *available at* http://www.ny.gov/governor/keydocs/0126071_speech.html. In 2007, Governor Spitzer gave a speech which addressed the current problem with healthcare in New York. He stated the problem with healthcare is the system, noting that the system currently lacks accountability and there is a need to “remove the bureaucratic hurdles . . . and guard against fraud” His agenda to fix the system requires “shift[ing] money away from the institution-centered health care system of our past, towards a more effective patient-centered system for our future.” *Id.*

³⁸ N.Y. COUNTY LAWYERS' ASS'N, REPORT ON FIDUCIARY ISSUES: RECOMMENDATIONS FROM A GUARDIANSHIP PERSPECTIVE (2000), *available at* http://www.nycla.org/siteFiles/Publications/Publications1189_0.pdf (discussing the excellent benefits that Mental Hygiene Legal Services provide).

risks posed by the complexity of a particular health claim. Both sets of concerns lead to the conclusion that a right to counsel in health claims should attach when a person faces personal limitations based on health or capacity, or when the health claim at hand involves complex legal matters and requires a deeper familiarity with the healthcare system than can be expected of the average person.

1. *Limits on Individuals*

Perhaps more demonstrably in health related cases than in other kinds of adjudications, the issue at the heart of an individual's claim could also be that which compromises an individual's ability to effectively advocate on his or her own behalf. Practically speaking, it takes tremendous energy and strength to gather important facts, draft a letter, file a complaint, or to initiate a legal claim related to one's health, while also managing an illness. Panelists concluded it is impractical to expect a patient who is a layperson unaccustomed to doing these sorts of tasks to do it at the worst possible time, when he or she is feeling ill and weak.³⁹ The aggrieved person who is sick, disabled, indigent, or facing death may face insurmountable limits and burdens that prevent the person from being able to be his or her own best advocate. The risk involved in sending this person into adjudication without effective counsel could be the loss of his or her claim, or exacerbation of his or her health condition.

³⁹ Health Break-Out Session, *supra* note 5, at 32.

2. *Complexity of Claims/Competency of Individual*

The American legal system, which is based on state and federal constitutional rights, common law, and a combination of federal and state statutes, local ordinances, and procedural rules, is complex to say the least. The rules involved in health related claims are often maddeningly complex, even for skilled advocates who are trained in such areas. The rules are often sub-regulatory or found in sources such as insurance and health-care provider manuals, not in published regulations.⁴⁰ Because health claims are particularly complicated, it is substantively inequitable to deny access to counsel to a person who cannot afford a lawyer and has important health related rights at stake.

Right to counsel advocates must stress the patent unfairness of requiring people to advance a health claim alone, when the complexity of their claim or the status of their health poses a hindrance to their ability to represent themselves. They must also stress the importance of implementing an equitable solution: to provide access to counsel for those individuals.

⁴⁰ *Id.* at 33; see also Diana Douglas, *Attorneys Caught In The Web Of Medicare/Medicaid Fraud: An Overview of an Attorney's Ethical Duties and Criminal Liability in the Wake of United States v. Anderson*, 21 J. LEGAL MED. 395, 426 (2000) (explaining that rules and regulations are so complex "attorneys must continue to research fraud and abuse statutes and case law, and keep abreast of the ethical standards of the profession"). See, e.g., *Visiting Nurse Ass'n Gregoria Auffant, Inc. v. Thompson*, 447 F.3d 68, 77 (1st Cir. 2006) (holding that compliance with the Medicaid manual, although only interpretive rules, must be complied with for provider to receive reimbursement).

**D. Barriers to Accessing the Right to Counsel,
Insufficiencies of the Right**

Health care advocates and right to counsel advocates must recognize potential barriers preventing individuals from taking advantage of the right to counsel, even if it were established by law. For instance, individuals in geographically or socially isolated communities may not experience the outreach and communication necessary to access this right, and thus may slip through the cracks of a flawed health care system without even knowing that help was available. Linguistic barriers, prevalent in immigrant communities, may also pose a hindrance for some patients. A movement to establish a right to counsel in health care claims must contemplate such factors that prevent patients from accessing this right and develop implementation plans targeting the elimination of such barriers.⁴¹ This could involve establishing advocates whose sole purpose is to conduct the necessary outreach to ensure these communities know about and are able to obtain services, or instituting reporting requirements for hospitals or legal aid groups serving these communities.

The legal community must also recognize and explore instances in which the services of an attorney could be adequately, or

⁴¹ Language barriers have proven to be a hindrance in obtaining rights outside of health care and should be taken into account when improving the healthcare system. See Marry Ann Dutton et al., *Characteristics of Help-Seeking Behaviors, Resources and Service Needs of Battered Immigrant Latinas: Legal and Policy Implications*, 7 GEO. J. ON POVERTY L. & POL'Y 245, 285 (2000) (A study addressing how to reach out to battered Latina women suffering abuse, found that "English speaking difficulties were a barrier to receiving services." The study further noted "[t]o reach non-English speaking immigrants, community education campaigns must be designed in Spanish and other languages spoken in local immigrant communities."); see also Wallace J. Mlyniec, In re *Gault at 40: The Right to Counsel in Juvenile Court-A Promise Unfulfilled*, 44 No. 3 CRIM. L. BULL. 5 (2008) (stating that in the juvenile realm "language barriers . . . weaken the right to counsel").

even more sufficiently, replaced by a different type of advocate, such as a medical professional, public health specialist, or community advocacy group. In doing so, advocates for a right to counsel can continue to refine their agenda and demands as well as clarify what services will be necessary to ensure that individuals navigating the healthcare system are not forced to risk losing their right to basic health.

IV. CREATING AN ADVOCACY FRAMEWORK FOR HEALTH PROCEEDINGS IN NEW YORK

Advocates must work together to create a framework that develops the various arguments for a right to counsel presented through legislative and litigation-based strategies. Which argument or set of arguments should be used is a question that will likely remain up for debate. However, the successes and failures of the access to counsel movement in other areas are informative for advocates grappling with that question. Panelists emphasized the importance of using past successes as both a model for advocacy strategies and as an argument in and of itself for expanding the right to counsel to the area of health claims.

In order to create an effective framework for right to counsel advocacy, advocates should consider which types of claims, if any, require immediate attention or more highly coordinated efforts. For instance, should advocates talk about prioritizing claims based on potential success, or should they engage in ranking claims by which need for representation is perceived as the most dire? Panelists discussed the fact that some health-related proceedings involve claim-

ants who have almost exhausted all remedies—indigent individuals in serious risk of losing healthcare coverage altogether if their claim is not resolved properly.⁴² Medicaid hearings are illustrative. Perhaps individuals with the most severe need for health care coverage, and the fewest resources for obtaining it, should have first access to counsel to help them secure coverage. Or, strategically speaking, is this a matter of identifying right to counsel campaigns that are most likely to yield success, in an effort to build by increment a body of health claims in which a right to counsel attaches?

New York State has recognized the right to counsel in two of the five main Civil Gideon areas—child custody and housing proceedings.⁴³ These past successes in the right to counsel movement can serve as evidence of the public’s will to establish this right, and the government’s recognition of the importance of access to counsel for indigent individuals with important civil claims. In this way, these past advances serve as arguments, in and of themselves, for expanding access to counsel to the health claims context. Advocates should focus on crafting hard-hitting arguments that New York State must expand the current landscape of access to counsel entitlements to include civil claims related to health.

Advocates must emphasize the benefits—both to the health-care system and to individuals given access to counsel—that provision of this right to representation would produce. Some of these have been discussed above—improved health outcomes and the in-

⁴² Health Break-Out Session, *supra* note 5, at 40.

⁴³ Andrew Scherer, *The Importance of Collaborating To Secure A Civil Right To Counsel*, N.Y. STATE JUDICIAL INST. (2004), available at <http://www.courts.state.ny.us/ip/partnersinjustice/Right-to-Counsel-Collaboration.pdf>.

tangible benefit this creates, added accountability in the health care system which makes the system function more smoothly, indirect cost savings in other social areas that are impacted by public health, etc.

It is critical that this advocacy framework involve consistent reference to the notion that healthcare is a fundamental right, recognized by international human rights laws, which the government is obligated to provide to its people. Rather than rely on private entities motivated largely by profits to provide adequate health services out of sheer moral obligation, the government must provide services that empower individuals to demand quality healthcare. Appealing to this core value that health is a fundamental right and therefore that governmental entities should ensure that every person, regardless of income, has access to that right, is integral to building public support for a right to counsel in health proceedings.

V. CONCLUSION

Rather than identifying solutions, much of the health panel discussion involved outlining the larger prevailing questions that should guide activists and organizers involved in the movement for a right to counsel in health proceedings. In what sorts of proceedings are we seeking a right to counsel for health related claims? How can we identify and frame a discussion about the potential benefits and savings this right will produce? How can we effectively communicate the risks involved by *not* providing a right to counsel? And what barriers would prevent people from obtaining access to counsel, even if such a legal right were established? In addition, advocates must

engage in deliberate strategizing, taking into account the lessons learned from other Civil Gideon movements, and noting the distinctions that make this particular effort unique from other right to counsel campaigns.

Panelists concluded the discussion with optimism, taking heart from the progress of efforts to establish a right to counsel in other areas involving basic human needs, such as those pertaining to housing, child custody, public benefits, and special/vulnerable populations. Many of the rights and entitlements existing in those areas did not exist years ago, but only came into being through the dedicated work of innovative and creative advocates.

Advocates must continue to identify, explore, and debate the strategic and organizational questions that will guide their groundwork to establish a right to counsel in important health claims. By working together to articulate a vision for civil, legal, and public health systems that work effectively and equitably for all people, regardless of their income or background, health advocates and right to counsel advocates can achieve the progress necessary to create a civil right to counsel in health proceedings.