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FAMILY-CENTERED APPROACH TO PROVIDING COMPREHENSIVE ASTHMA CARE SERVICES: THE HARLEM FAMILY ASTHMA CENTER

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The relationship between law and public health is...indissoluble. Law and public health may serve each other well or poorly, but they cannot dissociate.
- Wendy E. Parmet[1]

I. INTRODUCTION

There is an ongoing crisis in health care delivery for poor families of color along the Gulf Coast, in New York City, and indeed throughout the United States. Those who suffer from chronic, primary care sensitive conditions such as asthma, hypertension, and diabetes are especially vulnerable to disruptions in the provision of health care in times of upheaval. Further, undiagnosed and untreated health conditions are exacerbated during periods of stress.

As explained by Baker and Koplan: "It takes a system that is competent to handle routine public health situations to handle the emergencies."[2] In this paper, we contend that lawyers are essential in re-imagining, re-inventing, and rebuilding health care systems that advocate for the expressed needs of poor families of color. Because the authors are public health practitioners and health care providers, we emphasize practice-based, interdisciplinary approaches and present as a case study

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[1] LeeBreckenridge et al, *The Role of Law in Improving Public Health*, 23 J. PUB. HEALTH POL'Y 195, 201 (2002).

[2] Edward L. Baker, Jr. & Jeffrey P. Koplan, *Strengthening the Nation's Public Health Infrastructure: Historic Challenge, Unprecedented Opportunity*, 21 HEALTH AFF. (6) 15, 15 (2002).

a program designed to provide family-centered care in Central Harlem, New York, NY, namely, the Harlem Family Asthma Center (HFAC). We believe it is vital to reform US social and health care policies to better enable, implement, and sustain family-centered health care delivery models. To have any hope of being successful, lawyers will need to be integrated team members every step of the way. The long-term goal of this paper, then, is to have the law and justice communities improve upon our ideas and join with those of us in the public health and health care communities in the enduring struggle to provide accessible, humane, and comprehensive health care to poor families of color.

Towards this end, we have organized this paper as follows. First, we discuss what we mean by interdisciplinary practice and the day in, day out involvement of lawyers in our ongoing public health initiatives. Second, we argue for a broader, more inclusive definition of family that takes into account the lived experiences of poor urban residents. Third, we present the HFAC as one model for providing comprehensive asthma care services to poor families, analyze the evaluation data from its first two years of operation, identify its early successes, and suggest progressive solutions for its remaining challenges. Finally, we end this paper by advocating for a role of the courts in redressing current injustices in the delivery of health care and for the continued involvement of lawyers in interdisciplinary initiatives designed to eliminate racial and social disparities in health between the privileged few and the underserved majority in the United States.

II. INTERDISCIPLINARY PRACTICE

Renewed attention is being focused on the value of interdisciplinary approaches in answering societies' big questions and solving the world's big problems.[3] The authors of a recent paper based upon a systematic literature review, interviews, and a field test with interdisciplinary researchers proposed the following definition of interdisciplinary research: "Interdisciplinary research is any study or group of studies undertaken by scholars from two or more distinct scientific disciplines. The research is based upon a conceptual model that links or integrates theoretical frameworks from those disciplines, uses study design and methodology that is not limited to any one field, and requires the use of perspectives and skills of the involved disciplines throughout multiple phases of the research process."[4]

Nieves defines interdisciplinary and multidisciplinary approaches to the research enterprise more eloquently:

"Interdisciplinary and multidisciplinary research involve the study of a given subject from the assembled approaches of multiple disciplines. A multidisciplinary

[3] *See, e.g.*, William A. Darity, *Will the Poor Always Be With Us?*, 61 REV. OF SOC. ECON. 471 (2003); Milennium Development Goals, http://www.un.org/millenniumgoals (last visited Nov. 8, 2007).

[4] Sally W. Aboelela et al., *Defining Interdisciplinary Research: Conclusions from a Critical Review of the Literature*, 42 HEALTH SERV. RES. 329, 341 (2006).

approach seeks to gain new knowledge through the combination of purely disciplinary approaches, much like a patchwork quilt. Interdisciplinary research substantially integrates traditional disciplinary approaches and is often referred to as a kind of seamless woven garment. The advantage of these approaches is the ability to combine the expertise of different disciplines through the exchange of concepts, ideas, and techniques into the development of a comprehensive framework for explanation of a social phenomenon."[5]

While there is no consensus in the public health literature on what interdisciplinary practice entails, public-private partnerships and community-based participatory approaches offer potential models.[6] Likewise, the law literature contains apt examples of interdisciplinary practice wherein lawyers and doctors have partnered to advocate for healthy housing for children and community lawyering has been advanced as an approach for addressing inequalities in access to health care for poor, of color, and immigrant communities.[7]

At the time of the finalization of this paper (February 2008), no less than four lawyers served on the formal editorial team of the *American Journal of Public Health*, namely: Bernard M. Dickens, PhD, LLD, FRSC, department editor for the *Health Policy and Ethics Forum*; Leslie Beitsch, MD, JD, department editor for *Government, Politics, and Law*; Sofia Gruskin, JD, MIA, associate editor for health and human rights; and Stewart J. Landers, JD, MCP, associate editor for lesbian, gay, bisexual, and transgender health. Moreover, in a recent Editor's Choice column, one of us as the editor-in-chief of the *American Journal of Public Health* went so far as to declare, "It takes lawyers to deliver health care."[8] This assessment was based upon first-hand engagement in interdisciplinary projects with lawyers dedicated to, e.g., providing oral health care to seniors in the impoverished communities of Northern Manhattan and the South Bronx, New York, NY and delivering comprehensive asthma care to children in Central Harlem, New York, NY.[9]

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[5] Angel D. Nieves, *"With Them the Pen Must Be Mightier Than the Sword": Writing, Engendering, and Racializing Planning Theory*, 1 J. PLAN. HIST. 215, 216 (2002) (citing PHILIP Q. YANG., ETHNIC STUDIES: ISSUES AND APPROACHES (2000)).

[6] Donald A. Barr, *Ethics in Public Health Research: A Research Protocol to Evaluate the Effectiveness of Public-Private Partnerships as a Means to Improve Health and Welfare Systems Worldwide*, 97 AM J. PUB. HEALTH 19 (2007); Mary E Northridge et al., *What Matters to Communities? Using Community-Based Participatory Research to Ask and Answer Questions Regarding the Environment and Health*, 113 ENVTL. HEALTH PERSP. 34 (2005).

[7] Monisha Cherayil et al., *Lawyers and Doctors Partner for Healthy Housing*, 2005 CLEARINGHOUSE REV. J POV. LAW & POLICY 65; Rose C. Villazor, *Community Lawyering: An Approach to Addressing Inequalities in Access to Health Care for Poor, of Color and Immigrant Communities*, 8 N.Y.U. J. LEGIS. & PUB. POL'Y 35 (2005).

[8] Mary E. Northridge, *It Takes Lawyers to Deliver Health Care*, 95 AM J PUB. HEALTH 376 (2005).

[9] Luisa N. Borrell et al., *Oral Health and Health Care for Older Adults: A Spatial Approach for Addressing Disparities and Planning Services*, 26 SPECIAL CARE IN DENTISTRY 252 (2006); Seth E. Spielman et al., *Interdisciplinary Planning for Healthier Communities: Findings from the Harlem Children's Zone Asthma Initiative*, 72 J. AM. PLAN. ASSOC. 100 (2006).

In preparing this paper for the *Cardozo Journal of Law and Gender*, we heeded the valued advice of Rachel Kalman, one of the editors of this special supplement devoted to the work presented at their February 26-27, 2007 symposium in New York, NY titled, "Poverty and Family Health: Environmental Dangers and Progressive Solutions," and reached out to William J. Dean, Esq., Executive Director of Volunteers of Legal Service (VOLS).[10] As part of the VOLS Children's Project, lawyers work with physicians and social workers at eight New York City hospitals, including Harlem Hospital Center, to improve health outcomes for poor children through the provision of free civil legal services. Project activities include: (1) negotiations with the New York City Housing Authority to expedite repairs on apartments where children with asthma reside and asthma triggering conditions exist; and (2) organization of legal information sessions for health staff on topics such as landlord/tenant issues and immigration.[11] Indeed, the firm of LeBoeuf, Lamb, Greene & MacRae has been invaluable to us at Harlem Hospital Center in addressing complex family needs involving housing, immigration, disability, and child welfare.[12]

III. THE LIVED EXPERIENCE OF FAMILY

The devastation wrought by Hurricane Katrina was so profound and the suffering of its victims so unimaginable, that it created a sense of moral urgency to respond to the preventable deaths of the most vulnerable, delayed action on the part of federal agencies, and egregious gaps in resources available to White and African Americans. In the view of historian Nicholas Lemann, "The United States has an undeniable strain of racial prejudice in its character, but it also has a racial conscience, which periodically comes to the fore. What brings it out is the demonstration of conditions in black America that are intolerable and that are clearly linked to the country's history of departure from its democratic ideals..."[13]

The first point we choose to underscore about this environmental and humanitarian disaster is that the victims of Hurricane Katrina were disproportionately poor, African American, and without health insurance in comparison with the residents of New Orleans and Louisiana overall.[14] Further, many had chronic health conditions and thus relied on the New Orleans public hospital system, which was destroyed in the storm.[15]

The second point we want to emphasize is that even before Hurricane Katrina made landfall on August 29, 2005, Louisiana was one of the poorest states and its

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[10] Volunteers of Legal Service, http://www.volsprobono.org (last visited Nov. 8, 2007).

[11] Interview with William J. Dean, Esq., Executive Director of Volunteers of Legal Service (November 2, 2007).

[12] Northridge, *supra* note 10.

[13] NICHOLAS LEMANN, THE PROMISED LAND: THE GREAT BLACK MIGRATION AND HOW IT CHANGED AMERICA 353 (1992).

[14] Brodie, *supra* note 3.

[15] *Id.*

health statistics were among the worst in the nation.[16] Therefore, the challenge, according to Gillum: "...is not to just rebuild the Gulf Coast as it was, because to do so only continues to promulgate the uneven conditions of its residents. Rather, the focus should be to build a more inclusive and responsive environment that represents a place of opportunity and improves the plight of its diverse residents."[17]

It is our hope that from the shock of Hurricane Katrina, there might arise a social movement that advocates for more accessible, humane, and comprehensive health care to poor families along the Gulf Coast, in New York City, and throughout the United States. According to Treadwell, "In this reimagined recovery scenario, there would be medical and dental care for all of us, despite our resources."[18]

One component of this plan might be to provide comprehensive, family-centered health care, given the co-occurrence among family members of primary care sensitive conditions such as asthma, hypertension, and diabetes. Before we implement such an intervention, however, it is essential to know more about the lived experience of family among residents in diverse communities throughout the United States. For instance, a recent comparison of the sociodemographic and health conditions of men in two predominantly African American neighborhoods in the United States—Overtown, Miami and Central Harlem, New York City—found that fewer than one in five of the men surveyed were legally married (9.3% in Overtown and 18.1% in Central Harlem), while nearly three of five of the men surveyed were fathers (59.7% in Overtown and 62.0% in Central Harlem).[19]

Caring for a family member with a chronic illness disrupts lives, especially among the poor. Recently, caregiving has emerged as a public health concern that will personally affect virtually every individual.[20] In much the same way that "community" was redefined to ensure that community-based health care reached diverse populations, "family" will need to be redefined to ensure that family-centered health care responds to the lived experiences of poor families of color.[21] Our success in holding focus groups with program participants in the Harlem Children's Zone Asthma Initiative to understand more about, e.g., secondhand smoke exposure to African American children has convinced us that involving affected family members in designing comprehensive family-centered health care will better ensure that any instituted programs will meet their complex and urgent

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[16] Donna M. Christensen et al., *From Despair to Hope: Rebuilding the Health Care Infrastructure of New Orleans after the Storm*, 12 HARVARD J. AFR. AM. PUB. POL'Y 17 (2006).

[17] Bria Gillum., *Editor's Note*, 12 HARVARD J. AFR. AM. PUB. POL'Y 7 (2006).

[18] Henrie M. Treadwell, *Reimagining and Recreating Health Care Systems Along the Gulf Coast*, 12 HARVARD J. AFR. AM. PUB. POL'Y 23, 27 (2006).

[19] April M. W. Young et al., *Bringing to Light the Health Needs of African American Men: The Overtown Men's Health Study*, Vol. 4 J. MEN'S HEALTH & GENDER 140 (2007).

[20] Ronda C. Talley & John E. Crews, *Framing the Public Health of Caregiving*, 97 AM J. PUB. HEALTH 224 (2007).

[21] Kathleen M. MacQueen et al., *What is Community? An Evidence-Based Definition for Participatory Public Health*, 91 AM J. PUB. HEALTH 1929 (2001).

needs.[22]

IV. THE HARLEM FAMILY ASTHMA CENTER

Here we present for the first time in the peer-reviewed literature our model of a family-centered approach to providing comprehensive asthma care services in Central Harlem, New York, NY, namely, the Harlem Family Asthma Center (HFAC). This demonstration project was funded in October 2003 through a contract awarded by the New York State Department of Health to the Department of Pediatrics at Harlem Hospital Center under an initiative intended to provide Enhanced Services for Children and Youth. After a year of collaborative team building to offer comprehensive asthma care services (medical, educational, environmental, social, and legal), the clinic began enrolling eligible clients in September 2004.

The HFAC team consists of a: (1) director and allergist (Vincent E. Hutchinson, MD); (2) program coordinator and nurse practitioner (Lucille L. Lebovitz, CPNP); (3) pediatric pulmonologist (Beverley J. Sheares, MD); (4) adult pulmonologist (Gene R. Pesola, MD); (5) social worker (Howard A. Forbes, CSW); (6) evaluator and epidemiologist (Mary E. Northridge, PhD, MPH); (7) biostatistician (Roger D. Vaughan, DrPH, MS); and (8) administrator (Denise Campbell). In addition, Jennifer L. Northridge worked with the HFAC team to conceptualize and design its evaluation forms, build and refine its evaluation database, and analyze and interpret its preliminary evaluation results. Finally, over the next six months, we plan to link clients in need of legal services with lawyers at the firm of LeBoef, Lamb, Greene & MacRae, following the community-based health care delivery model implemented by the Harlem Children's Zone Asthma Initiative, which is also currently under the direction of Dr. Hutchinson.[23]

Children with asthma are identified through the hospital wards and emergency department of Harlem Hospital Center, as well as through referrals from other hospital-based and community-based programs and health care providers. If at least one family member (parent, sibling, grandparent, niece/nephew, etc.) other than the index child has asthma, the family is potentially eligible for enrollment in the HFAC, and a parent/guardian is screened by the program coordinator.

As part of the health care coordination and evaluation for the HFAC, the HFAC team administers the following assessments to each enrolled client/family: (1) demographic questionnaire; (2) past medical history; (3) detailed past and present asthma history; (4) psychosocial assessment; (5) environmental

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[22] Mary E. Northridge et al., *Toward a smoke-free Harlem: engaging families, agencies, and community-based programs*, J HEALTH CARE POOR & UNDERSERVED (in re-review).

[23] Stephen W. Nicholas et al., *Addressing the Childhood Asthma Crisis in Harlem: The Harlem Children's Zone Asthma Initiative*, 95 AM J. PUB. HEALTH 245 (2005); Stephen W. Nicholas et al., *Reducing Childhood Asthma Through Community-Based Service Delivery: New York City, 2001--2004*, 54 MORBITY & MORTALITY WKLY. REP. 11 (2005).

assessment/home inspection; (6) physical assessment; (7) allergy testing/pulmonary function tests; and (8) skills/knowledge assessment. The goal of the evaluation plan is to assess the effectiveness of the HFAC in implementing the planned interventions and improving the following outcomes: (1) reduced hospitalizations for asthma; (2) reduced emergency department visits for asthma; (3) reduced school absences due to asthma; and (4) enhanced family confidence in managing asthma.

TABLE 1: DEMOGRAPHIC CHARACTERISTICS OF CLIENTS ENROLLED IN THE HARLEM FAMILY ASTHMA CENTER AS OF JANUARY 24, 2007, CENTRAL HARLEM, NEW YORK, NY (N = 104)

Demographic Characteristic	Number[24]	Percent
Family Members Enrolled		
Index Child	70	67.3
Family Member of Index Child	34	32.7
Relationship of Family Member to Index Child (n = 36)		
Mother	14	38.9
Sibling	20	55.6
Grandparent	1	2.8
Nephew	1	2.8
Gender		
Male	44	44.0
Female	56	56.0
Age Group (Years)		
0-5	38	36.5
6-10	26	25.0
11-15	21	20.2
16-20	6	5.8
21-30	4	3.8
31-40	4	3.8
41-50	2	1.9
51-60	3	2.9
Latino/Hispanic Ethnicity		
Hispanic	12	16.2
Non-Hispanic	62	83.8
Race		
Black/African American	64	97.0

[24] Totals may differ due to missing values and non-applicable items.

White	2	3.0

As of January 24, 2007, a total of 104 clients were entered into the database and available for analysis, even as enrollment is continuous and ongoing (see Table 1). To date, the overwhelming majority of HFAC clients are African American children, while few (n = 15) adult family members and no fathers have been enrolled.

Nonetheless, for those clients who have completed baseline and follow-up visits at the HFAC, remarkable improvements in their asthma symptoms and management strategies have been documented (see Table 2). As of January 24, 2007, a total of 224 clients visits were recorded at the HFAC, with up to eight visits recorded per client. Due to small numbers of clients with more than four visits (n = 8 clients or less at visits 5, 6, 7, and 8), only the baseline (visit 1) and three follow-up visits (visits 2, 3, and 4) are analyzed here.

From baseline to the third follow-up visit, statistically significant improvements were found for enrolled clients in asthma symptoms reported in the last three months, including school days missed due to asthma, emergency room visits for treatment of asthma, and hospital admissions where the client stayed overnight for asthma ($p \leq 0.05$). Further, over this same time period, statistically significant improvements in reported use of selected asthma management strategies for enrolled clients were documented, including being prescribed a preventative asthma medication, having a spacer device, and having a written copy of her/his asthma plan ($p \leq 0.01$). While indirect, these measures suggest that enrolled family members are gaining confidence in managing asthma. More in-depth, qualitative evaluations are needed to better understand what program components are working well for families, and which require enhancement.

TABLE 2: PERCENTAGE OF ENROLLED CLIENTS WHO REPORTED SELECTED ASTHMA SYMPTOMS AND MANAGEMENT STRATEGIES AT BASELINE AND FOLLOW-UP VISITS, HARLEM FAMILY ASTHMA CENTER, NEW YORK, NY (DATA COLLECTED AS OF JANUARY 24, 2007)

Asthma Symptoms and Selected Management Strategies[25]	**Baseline Visit (n=105)**	**1st Follow-Up Visit (n=55)**	**2nd Follow-Up Visit (n=30)**	**3rd Follow-Up Visit (n=14)**	**p-value**
Asthma symptoms reported in the last 3 months:					
School days missed due to asthma[26]					.0542
0 days	32.4%	51.4%	76.2%	60.0%	
1-9 days	43.2%	31.4%	23.8%	30.0%	
10+ days	24.3%	17.1%	0.0%	10.0%	
Emergency room visits for treatment of asthma[28]					.0245
0 visits	44.4%	55.6%	56.7%	69.2%	
1 visit	17.8%	27.8%	30.0%	23.1%	
2+ visits	37.8%	16.7%	13.3%	7.7%	
Hospital admissions where client stayed overnight due to asthma[27]					.0100
0 admissions	76.5%	96.3%	90.0%	78.6%	
1+ admissions	23.5%	3.7%	10.0%	21.4%	
Reported use of asthma management strategies:					
Client prescribed a preventative asthma medication[29, 28]					.0131

[25] Totals may vary due to missing values and non-applicable items.

[26] The p-values for overall differences are from chi-squared tests on 6 degrees of freedom.

[27] The p-values for overall differences are from chi-squared tests on 3 degrees of freedom.

[28] Preventative asthma medications include: Flovent® (fluticasone propionate), Advair Diskus®

Yes	76.7%	90.9%	93.1%	100.0%	
No	23.3%	9.1%	6.9%	0.0%	
Client has a spacer device such as an Aerochamber, Optichamber, or Inspirease[29]					.0002
Yes	55.9%	75.5%	92.6%	92.9%	
No	44.1%	24.5%	7.4%	7.1%	
Client has a written copy of her/his asthma action plan[29]					<.0001
Yes	37.8%	68.6%	92.6%	100.0%	
No	62.2%	31.4%	7.4%	0.0%	

Based upon the first two years of operation of the HFAC, the project team can point to these early successes: (1) new HFAC space has been secured at the Ron Brown Clinic of Harlem Hospital Center; (2) project staff have begun training primary care physicians to deliver appropriate asthma care; (3) the comprehensive asthma care services provided to enrolled clients have improved their asthma symptoms and increased their use of asthma management strategies; and (4) the administration of the HFAC has instituted an efficient and accountable reporting system. Barriers remaining at present include missed appointments, invalid telephone numbers, and low enrollment of adults, especially men. To address these challenges, our future plans include: (1) creating an HFAC Community Advisory Board; (2) offering family support groups; (3) utilizing integrated pest management services for enrolled families available through the New York City Department of Health and Mental Hygiene; and (4) developing further education and training of primary care physicians around asthma care.

V. CONCLUSION: A WAY FORWARD

One of us (M.E.N.) has previously argued that the harsh intersections of racism and sexism in US society have contorted roles for men of color and damaged their social ties.[29] A corollary of this assertion is that only by reforming historical injustices and reuniting men with their partners, families, and communities will sustained improvements in their health and well-being be

(fluticasone propionate and salmeterol), Pulmicort Respules/ Turbuhaler® (budesonide), Singulair® (montelukast sodium), and Intal® (cromolyn sodium)

[29] Henrie M. Treadwell et al., *Confronting Racism and Sexism to Improve Men's Health*, 1 AM. J. MEN'S HEALTH 81 (2007).

realized.[30] Public policies, including social welfare legislation, have been shaped by discriminatory practices that serve to devalue and stigmatize African American men, but nowhere have racism and sexism been more influential than in the mass migration of generations of African American men and boys into US correctional systems.[31]

It is against this backdrop that we are struggling to provide family-centered health care in Central Harlem, New York, NY. It would be hubris for us as public health practitioners and health care providers to recommend national policies for reforming historical injustices and closing the egregious gaps in health care access between the "haves" and "have nots" in US society.[32] We suspect, however, that readers of this paper in the law and justice communities are in a position to do just that. Working closely with progressive elected officials, it may be possible to advocate effectively towards achieving these health care goals: (1) expand the network of community health centers; (2) integrate family-centered approaches into a range of primary care delivery channels; (3) augment the definition of family with regard to eligibility requirements for programs and policies to reflect the lived experiences of poor families of color; (4) increase reimbursement for primary care services rendered; and (5) enhance the numbers of physicians and other health care professionals of color working in underserved communities throughout the nation.[33]

Stacy believes that on a theoretical level, the conclusion that courts may prompt legislative reform provides a starting point for renewed discussion about the connections between justice, equal opportunity, the Constitution, and the proper role of courts. We end with a quote of his which provides a way forward: "Significant numbers of persons, based on their lack of medical insurance, do not receive cost-justified care that can be expected to prolong or improve their lives. This allocation of health care is fundamentally unjust, and courts can defensibly play the important role of prompting legislative reform of this injustice."[34]

VI. ACKNOWLEDGMENTS

The Harlem Family Asthma Center is funded through contract # C019041, Enhanced Services for Children and Youth, awarded by the New York State

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[30] *Id.*

[31] THEDA SKOCPOL, PROTECTING SOLDIERS AND MOTHERS: THE POLITICAL ORIGINS OF SOCIAL POLICY IN THE UNITED STATES (1992); Henrie M. Treadwell & Joyce H. Nottingham, *Standing in the Gap*, 95 AM J. PUB. HEALTH 1676 (2005).

[32] INSTITUTE OF MEDICINE. UNEQUAL TREATMENT: CONFRONTING RACIAL AND ETHNIC DISPARITIES IN HEALTH CARE (2002).

[33] *Id.*; Juniper Lesnik, *Community Health Centers: Health Care As It Could Be*, 19 J.L. HEALTH 1 (2004).

[34] Tom Stacy, *The Courts, the Constitution, and a Just Distribution of Health Care*, 3-WTR KAN. J.L. & PUB. POL'Y 77, 87 (1993).

Department of Health (Vincent E. Hutchinson, MD, Director). The authors thank John F. Duane, Esq. for his helpful advice in preparing this paper.