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I. INTRODUCTION

Funding agent. Insurer. Researcher. Motivator. Educator. Monitor. Regulator. Advisor. Each of these terms describes the various roles of government in health care delivery. With the tragic events of September 11 when New York City and Washington, D.C. were the targets of terrorist attacks, many people have raised questions about the status of public health and safety issues in the United States. They look to the government to assure them that threats to their well-being are under control. In discussing the country's preparedness, a few of the television commentators have raised the fact that the public health system does far more than prepare the nation for defense against biological attacks, and that it is high time it received more attention.

The federal public health system began with the establishment of a Marine Hospital for seafarers in 1798, and it was Abraham Lincoln who set the stage for the Food and Drug Administration that monitors the purity of foods and the safety of medicines.[1] The federal government opened a one-room laboratory on Staten Island for research on disease in 1887, created the first Communicable Disease Center in 1946, licensed the polio vaccine in 1955, and made comprehensive health care available to millions through Medicare and Medicaid in 1965.[2] It has been almost 40 years since the release of the first Surgeon General's Report on Smoking and Health and about 20 years since legisla-

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1. Department of Health and Human Services: Historical Highlights, http://www.hhs.gov/about/hhshist.html (last visited May 20, 2002).

2. *Id.*

tion on organ transplants was signed into law.[3] Mandatory nutrition labeling, free immunizations to all children in low-income families, and support for communities to help people with AIDS have all occurred in the 1990s.[4] While certainly not an exhaustive list, they illustrate the breadth of government involvement in health care.

Another prominent role of government is being a partner: the federal, state and local governments work together and with thousands of health care organizations and providers in the United States and around the globe to carry out the missions of the public health system. One of those partners is the Illinois Department of Human Services.

II. Illinois Department of Human Services

The public health system has two primary missions: (a) to ensure the health of all citizens; and (b) in order to fulfill the first role, to make services available to groups who appear to be at increased risk of poor health, such as those with limited incomes, minority groups or persons with behavioral risk factors. These roles are based on the application of the science of epidemiology and the principle of social justice. Public health work was first assigned as a permanent function of Illinois state government in 1877 with the organization of the State Board of Health.[5]

The State Board of Health was created to regulate medical practitioners and to promote sanitation and hygienic activities to control and prevent disease.[6] The Board received an initial appropriation of $5,000. At its 50th anniversary as an official agency, then-Governor Len Small stated that the Department of Public Health ("DPH") was "participating in a movement so pregnant with possibilities for individual and public benefit" that it should "stimulate pride and confidence in the character of our government."[7] The responsibilities of DPH continued to grow rapidly in various areas consistent with the dual mission of the public health system and continues to be a major leader in public health issues today. However, a little over a century after

3. *Id.*
4. *Id.*
5. Public Health in Illinois: *A Timeline of the Illinois Department of Public Health*, *at* http://www.idph.state.il.us/about/timeline.htm (last visited May 20, 2002).
6. *Id.*
7. *Id.*

its inception, in 1997, nineteen programs from DPH were merged into the newly created Department of Human Services.[8]

Research has shown that risk factors are the same for a multitude of health problems. The most effective approach for addressing these persistent and complex issues is through a comprehensive and integrated delivery system. The Department of Human Services (DHS) was designed to develop just such a system for Illinois families. In addition to programs from DPH, all of the services from the Departments of Mental Health and Developmental Disabilities (DMHDD), Alcoholism and Substance Abuse, and Rehabilitation Services and selected activities from Public Aid and Children and Family Services were combined into DHS. In assuming DMHDD responsibilities, DHS became a direct provider of health care and other services for persons in the State's psychiatric hospitals and State Operated Developmental Centers.

A. Direct Provider of Services: Mental Health

In 1999, the first ever Surgeon General Report on Mental Health was issued, declaring that "there is no health without mental health."[9] With advances in psychotropic drugs and therapeutic techniques, more people today receive treatment in less-restrictive community settings. Still, DHS operates 10 psychiatric hospitals serving adults with severe mental illness who need publicly-funded inpatient treatment.[10] Some hospitals also treat children and adolescents.[11] All State hospitals are accredited by the Joint Commission on the Accreditation of Health Care Organizations.[12]

State hospital admissions and census have both declined during the 1990s.[13] The daily census of the psychiatric hospitals is estimated at between 1,800 and 1,900 patients.[14] The majority of State hospital admissions are voluntary. About one-third are patients committed by a civil court for involuntary hospitaliza-

8. *Id.*
9. U.S. Department of Health and Human Services, *Mental Health: A Report of the Surgeon General*, *available at* http://www.surgeongeneral.gov/library/mentalhealth/index.html (last visited May 20, 2002).
10. Illinois Department of Human Services Fact Sheets: *Mental Health and Developmental Disabilities*, *at* http://www.state.il.us/agency/dhs/mhddfsnp.html (last visited May 20, 2002) [hereinafter *Mental Health Fact Sheets*].
11. *Id.*
12. *Id.*
13. *Id.*
14. *Id.*

tion because a judge deems the person currently dangerous to self or others or that the person is unable to care for himself or herself because of mental illness.[15] After admission, a professional team develops an individual treatment plan that may include medicines, counseling and therapy, and rehabilitation. About one-half of State hospital patients are treated and discharged within 35 days; those committed by a civil court stay no longer than 180 days.[16] Seventy percent of people admitted for the first time do not need to return to a State hospital within five years, if ever.[17]

	Fiscal Year 1990	Fiscal Year 1999[18]
State Hospital Admissions	19,296	9,603
Children & Adolescents	1,030	344
Persons Admitted 3 Times in a Year	937	371

DHS also provides forensic mental health services when the court finds a criminal defendant to be unfit to stand trial or not guilty by reason of insanity (NGRI) and orders hospital treatment.[19] Unlike the trend in general State hospital admissions, the forensic population continues to grow. Today, almost 40 percent of the budgeted beds in State psychiatric hospitals are forensic.[20] Treatment strategies for forensic patients follow the same protocols as regular patients with ongoing court involvement. Because of this criminal court involvement, forensic patients typically stay longer than civil patients.[21]

DHS is required under the Sexually Violent Persons Commitment Act to accept custody and provide treatment to sexually violent persons who have served their prison sentences but are deemed by the court to constitute a significant threat to the community if released.[22] The United States Supreme Court has held that the purpose of the detention is to facilitate additional treatment and is not to be punitive.[23] Following detention to the

15. *Id.*
16. Mental Health Fact Sheets, *supra* note 10.
17. *Id.*
18. *Id.*
19. *Id.*
20. *Id.*
21. *Id.*
22. 725 ILL. COMP. STAT. ANN. 207/40 (West 2001).
23. *See* Allen v. Illinois, 478 U.S. 364, 373 (1986) (construing an earlier version of this law entitled the *Illinois Sexually Dangerous Persons Act* (formerly codified at Ill.Rev.Stat., ch. 38, ¶¶ 105- 1.01 *et seq.* (1985)).

Treatment and Detention Facility (TDF), a clinical review is conducted to determine the level of risk the person poses to others. As with the forensic population, the census at the TDF, currently 173, has grown steadily since January 1, 1998, when DHS began the program.[24]

B. Direct Provider of Services: State Operated Developmental Centers

A developmental disability is a severe, chronic condition that is first manifested in childhood (prior to age 18), is likely to continue indefinitely, results in substantial functional limitation in areas of major life activity and reflects a need for care, treatment or services of extended duration. Developmental disabilities include mental retardation, cerebral palsy, epilepsy, autism and other conditions resulting in impairments similar to those caused by mental retardation.

DHS manages the operations of nine State-operated developmental centers (SODCs) and two developmental service programs at State centers which are operated in conjunction with a State psychiatric hospital.[25] SODCs serve persons whose developmental disabilities are complicated by severe medical fragility or behavioral needs.[26] They provide residential habilitation services, an inter-disciplinary approach to meeting resident needs that are designed to maximize their independence and improve their quality of life.[27] Although the trend is changing, some of these individuals remain in an SODC many years.[28] Although not licensed, all SODCs are certified as meeting federal standards to participate in the Medicaid program by DPH.

The population of these centers has declined steadily since 1990 as new community alternatives have been developed.[29]

	Fiscal Year 1990	Fiscal Year 1999
Residents in SODCs	4,326	3,302

24. Ill. Dep't. of Human Services Office of Community Health and Prevention, Treatment Detention Facility Census Figures (internal census report)(on file with author).

25. Mental Health Fact Sheets, *supra* note 10.

26. Office of Developmental Disabilities *at* http://www.state.il.us/agency/dhs/ddnp.html.

27. *Id.*

28. *See* Mental Health Fact Sheets, *supra* note 10.

29. *Id.*

C. *Issues in Providing Direct Services for Persons with Mental Illness or Developmental Disabilities*

DHS faces many of the challenges of the private sector in the delivery of direct care services, particularly with respect to its workforce. Employees at State facilities include medical doctors, psychiatrists, pharmacists, dentists, nurses, technicians, aides, dieticians, and those who provide direct care for residents. Although some progress has been made in the last year, staff at the management level of the State facilities need to be more diversified. DHS is also experiencing difficulty in the recruitment and retention of direct care workers, even though they are government employees and tend to have higher salaries and fringe benefit packages than their counterparts in the community system. Overtime and staff shortages in some units are increasing problems, due to staff injury as well as turnover. There are about 3,000 injuries per year in the facilities, with about 1,000 due to assault or altercations with residents. To address this problem, the Department has initiated a massive statewide worker safety initiative over the past two years. Finding staff who are bilingual to work directly with residents is also an issue.

The majority of State facilities have been in existence for decades. Unlike the private sector, building improvements and renovations at the DHS hospitals and SODCs must compete with other State capital projects for funding priority. The costs of maintaining the staffing and other operations to ensure resident safety and high-quality care takes a disproportionate share of the budgets for mental health and developmental disabilities, causing some tension with the community providers.

A recent Supreme Court decision emphasized the importance of a participant's choice to live in the most integrated setting possible, taking into account the needs of other patients and state resources.[30] As a result of *Olmstead*, some advocate groups believe no one should remain in an SODC. In contrast,

30. Olmstead v. L.C. *ex rel.* Zimring, 527 U.S. 581 (1999); *see also* Illinois Department of Human Services, *Olmstead Decision, at* http://www.state.il.us/agency/dhs/olmweb.html (last visited May 20, 2002). In a 6-3 decision, Justice Ginsburg, writing for the Court held that unjustified isolation of the mentally ill constitutes discrimination based on a disability. *Id.* at 597. The Court, however, conditioned this holding by recognizing that states "are required to provide community-based treatment for persons with mental disabilities when the State's treatment professionals determine that such placement is appropriate, the affected persons do not oppose such treatment, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities." *Id.* at 607.

there remain other very vocal groups that believe it is appropriate for state government to care for these vulnerable citizens and vigorously oppose efforts to move large numbers of residents from an institution into the community. These passionate points of view make it more difficult to integrate the services of the community with the State facilities into a comprehensive community system of care. Fortunately, DHS and its partners have enjoyed great success in sharing a common vision of comprehensive service delivery in other areas of health care delivery.

D. Service Integration: DHS and Other State Government Agencies

A quality health care delivery system is of little value to those who don't know about it, have difficulty maneuvering within it, or can't access it. One of the primary reasons DHS was created was to overcome these and similar problems in the health and human service system. Service integration and coordination is a priority among State government agencies, across and within each division of DHS, and with community organizations. A good illustration of service integration and coordination of health care services between government agencies is the relationship between DHS and the Department of Public Health (DPH).

DHS and DPH have established a strong partnership to support programs that address specific public-wide health concerns. For example, DHS is working closely with DPH and 75 local health departments to promote the use of the American Cancer Society's *Make Yours a Fresh Start Family* curriculum with pregnant and post-partum women who are smoking. In another collaboration, DHS, DPH and the University of Illinois Division of Specialized Care to Children administer the *Newborn Hearing Screening Program* to identify newborns with suspected hearing loss prior to hospital discharge. Hospitals refer these infants to DPH and notify the parents and child's physician of the test results and give them guidance for follow-up testing. As appropriate, families are referred to the DHS-administered Early Intervention Program designed to enhance the growth and development of infants and toddlers who have developmental disabilities and delays. The two departments are also working jointly on a new, data-driven campaign with the Department of Public Aid (DPA), *Every Child By Two*, to ensure that every

child eligible for the Special Supplemental Nutrition Program for Women Infants and Children (WIC) is fully immunized by two years of age. To accomplish this goal, linkages between DHS's Cornerstone Information System and the DPA's Medicaid Management System were recently enhanced to import immunization records of Medicaid eligible children. This data match added 30,000 children and 1.5 million immunization records to the Cornerstone data base, data that will be extremely useful for follow-up purposes by the local health departments who immunize many of these children for free.[31]

As the Medicare agency for Illinois, DPA has a significant role to play in the health care delivery system. DHS plays a critical support role by taking applications for the federal insurance programs as well as the State-sponsored KidCare initiative at its 131 local offices around the State. In addition to assistance with medical insurance, eligible persons in need can access a variety of health care services through the local offices.

E. Service Integration Across DHS Divisions

DHS local offices are not just "welfare" offices anymore. Increasingly, they are the hub of essential services within a broader community network that supports families as they move from dependency to self-sufficiency. Research shows that families at risk typically have multiple inter-related needs that when addressed together, achieve better outcomes. A major initiative of the Department is the *co-location of staff* representing programs from all of its divisions in the local offices to facilitate comprehensive, family-oriented service delivery. It is no longer unusual to find welfare caseworkers sharing office space with a domestic violence professional, a mental health counselor, a teen parent educator and a substance abuse provider. Local office staff also engage and partner with others to build stronger, more connected communities that improve outcomes for all families. For example, DHS policy strongly encourages collaborative relationships between its local offices and local health departments to increase referrals to important prevention and intervention health care services. Coordination of the various divisions and offices within DHS has also resulted in multi-disciplinary programming such as the domestic violence/substance

31. State of Illinois Maternal and Child Health Services Block Grant Application and Annual Report *available at* http://www.state.il.us/dpa/html/maternal_child_health.htm (last visited May 20, 2002).

abuse, juvenile justice/mental health, and child care/health development initiatives.

Studies have shown that between one-fourth and one-half of men who abuse their partners have substance abuse problems.[32] Research also shows that women who abuse alcohol and other drugs are more likely to be victims of domestic violence.[33] The Illinois Family Violence Coordinating Council established a Domestic Violence-Substance Abuse Interdisciplinary Task Force to explore mutual interests, strengthen practice and policy, and promote collaboration within communities. One result of its work is *Safety and Sobriety: Best Practices for Domestic Violence and Substance Abuse Services,* a best practices manual for community use in assisting victims of domestic violence and substance abuse.[34] DHS, through its Office of Alcoholism and Substance Abuse and Bureau of Domestic Violence, annually co-sponsors a Safety, Sobriety and Justice Conference to bring substance abuse prevention and treatment professionals, domestic violence workers and advocates, social workers, and representatives of the criminal justice system including judges, law enforcement, attorneys and probation officers together for networking and professional development. The benefits of supporting community collaborations to address co-occurring problems were also the incentive behind the juvenile justice/mental health program.

Recognizing that many of the minors who become involved in the juvenile justice system have mental health issues, in June of 2000 staff in the Office of Mental Health and the Division of Community Health and Prevention (CHP) worked together to develop a *Mental Health/Juvenile Justice* (MH/JJ) pilot program. MH/JJ features teaming a community agency clinician with juveniles with mental illnesses upon their release from detention centers. The community agency clinicians assess the minors' needs for services, identify funding to pay for services, and work with the courts to monitor their progress. The pilots were so successful that funding was added to the DHS budget last year to take the program statewide. Coordination across DHS divisions is not only used to improve interventions, but also as a prevention strategy.

32. Illinois Department of Human Services, *Best Practices for Domestic Violence and Substance Abuse Services, available at* http://www.state.il.us/agency/dhs/bpracticesnp.html (last visited May 20, 2002).

33. *Id.*

34. *Id.*

The *Illinois Coalition for Health System Development in Child Care* seeks to link child care facilities and health and other service providers. CHP and the Office of Child Care are collaborating to support a "Child Care Nurse Consultant" for each of Illinois' 24 Child Care Resource and Referral Network Agencies. These nurse consultants work to improve access to health services by children and families and improve the health status of children, families and child care providers. CHP staff have also demonstrated their commitment to integrating programs and services within the division itself.

F. Service Integration within DHS Divisions: WIC and Family Case Management

The integration of programs within DHS divisions has also proven beneficial to the families served. From its beginning, DHS assumed primary responsibility for many maternal and child health programs that are designed to make services available to groups who appear to be at increased risk of poor health. These programs are housed in the Division of Community Health and Prevention.[35] *Family Case Management* (FCM) is one of the foundations of its family health efforts.[36] FCM is a statewide program that provides comprehensive service coordination to pregnant women, infants, and high-risk children.[37] Family assessments are conducted and care plans developed on a wide range of needs including heath care, mental health, social health, education, vocation, child care, transportation, psychosocial, nutrition, environment, development and other services.[38] Most FCM providers are authorized to complete Medicaid Presumptive Eligibility applications for pregnant women and to assist families in completing KidCare applications for their children.[39] Contacts with clients include home and office visits at a frequency necessary to meet the clients' needs. Last year, 114 FCM agencies were funded by DHS, including local health departments, community-based organizations and federally qualified health centers.[40] The program served 333,700

35. Division of Community Health and Prevention *available at* http://www.state.il.us/agency/dhs/chpnp.html (last visited May 20, 2002).

36. Family Case Management *available at* http://www.state.il.us/agency/dhs/OFH/fcmofhnp.html (last visited May 20, 2002).

37. *Id.*

38. *See id.*

39. *Id.*

40. *Id.*

individuals in fiscal year 1999.[41] DHS is particularly proud of the impressive results that have been achieved in integrating FCM and WIC. .

The mission of the WIC Program is to improve the health status of women, infants and children; to reduce the incidence of infant mortality, premature births and low birth weight; and, to aid in the development of children.[42] The program serves income-eligible pregnant, breast-feeding and postpartum women, infants and children up to 5 years of age who have a medical or nutritional risk.[43] The program serves approximately 466,000 individuals in Illinois and provides health screening, nutrition education and counseling, supplemental foods, and information about health services.

An important role of DHS in health care delivery is that of evaluating the effectiveness of programs. The Birth Outcomes Study released in July of 2000 compared the experiences of Medicaid-eligible women who participated in either WIC or FCM to those of Medicaid-eligible women who were not enrolled in either program.[44] The women in the study who participated in a DHS program had low incomes and were at risk of a poor pregnancy outcome.[45] They also had characteristics that are often associated with pre-term birth or infant death: 63 percent were single, 25 percent were teens, 33 percent were African-American and 30 percent were Hispanic.[46] The study showed that women enrolled in one of the programs had a 50 percent lower infant mortality rate, a 62 percent lower premature birth rate, and were 33 percent less likely to have a low birth weight child than those who did not participate in either program.[47] On average, if a woman participates in WIC or FCM, the cost of services for an infant in his or her first year of life drops by 50 percent.[48] The average Medicaid expenditure during the first year of life for infants born to women participat-

41. Ill. Dep't of Human Services Office of Community Health & Prevention, Family Case Management Census (internal census figures)(on file with author).

42. Special Supplemental Nutrition Program for Women, Infants and Children (WIC), *available at* http://www.state.il.us/agency/dhs/wicnp.html (last visited May 20, 2002).

43. *Id.*

44. ILLINOIS DEPARTMENT OF HUMAN SERVICES REPORT, BIRTH OUTCOMES STUDY (2000).

45. *Id.*

46. *Id.*

47. *Id.*

48. *Id.*

ing in either program totaled $5,035.[49] The cost for infants born to women who did not participate in either program was $10,675.[50] Updated results for 2001 are equally impressive.[51] Nevertheless, the gap between Caucasian and African-American women in the rates of premature births and infant mortality has remain unchanged in the last four years. While DHS and its partners have enjoyed many successes, issues such as poverty, school failure, child abuse, and others affect low-income, minority status individuals disproportionately, causing the continuation of unacceptable disparities in health status, well-being and self-sufficiency.

G. Disparity Issues in Birth Outcomes

A critical issue facing the public health care system is disparity in health care access and outcomes. A recent study showed four statistically significant changes in infant mortality rates by race, location and length of life between 1998 and 1999: 1) the neonatal mortality rate among African-American infants in Chicago increased; 2) the increase in the neonatal mortality rate among African-American infants caused the neonatal mortality rate among all non-white infants in Chicago to worsen; 3) the increase also caused the neonatal mortality rate among all infants in Chicago to worsen; and, 4) the post-neonatal mortality rate significantly improved for the general population in Chicago.[52]

Looking at historical trends was not particularly helpful in providing an explanation. The number of births to African American women in Chicago steadily decreased during the 1990s. With the exception of 1993, the number of neonatal deaths in the 1990s among African American infants in Chicago has steadily decreased from 1990 to 1998 by 53.9 percent.[53] Among the risk factors for low birth weight and infant mortality are age and marital status of the mothers.[54] In 1999, the proportion of infants born to African American teen mothers decreased overall. Among infants born to adolescents, the proportion of infants born to older teen mothers increased. The

49. *Id.*
50. *Id.*.
51. ILLINOIS DEPARTMENT OF HUMAN SERVICES REPORT, BIRTH OUTCOMES STUDY: FOLLOW-UP (2001).
52. *Id.*
53. *Id.*
54. *Id.*

proportion of infants born to single mothers also decreased. Other risk factors such as the beginning of prenatal care, the number of prenatal care visits, the length of pregnancy, weight gain, and the interval between pregnancies did show unfavorable changes among African American mothers. In looking at them individually, none of those changes was large enough to explain why the neonatal mortality rate had jumped so significantly. While the combination of unfavorable factors might give some understanding of "what happened", there is no absolute explanation from the data.[55]

Because of the success of WIC/FCM in affecting birth outcomes, a goal of DHS is to afford every Medicaid-eligible pregnant woman the opportunity to participate in these programs. DHS has the capacity to absorb the estimated 5,000 Medicaid-enrolled women and children in Chicago who are not participating in WIC without additional resources. As one strategy to boost enrollments, all staff in the local offices in Chicago were challenged to make it one of their top priorities to reach out to eligible women and refer them for services. The beauty of a comprehensive department like DHS is that when one area identifies a problem, all can work together to solve it. DHS has also enjoyed great success in working with partners in the community to help solve challenging issues in the delivery of health care and human services.

H. Collaboration with the Community

The Department's collaboration with the community to deliver health care takes many forms. With both federal and General Revenue dollars, DHS funds literally hundreds of organizations to provide health care and related services to families in need. Among the providers that receive financial support from DHS are: hospitals; community mental health centers; health departments; school-based health clinics; Healthy Start Family Centers; family planning providers; food banks; homeless shelters; substance abuse treatment facilities; counselors; physical, occupational and speech therapists; domestic violence shelters; and, community and faith-based organizations. Out of an annual budget of approximately $5 billion, $1.6 billion is passed through to the community in grants to support programs that serve clients and customers of the Department. These funds are

55. *Id.*

used to improve access to health care; develop health education materials; provide and maintain systems for the collection of vital statistics; pilot, replicate and evaluate programs; pay administrative costs; and, provide direct and support services. In addition to money, DHS staff are often called upon to participate in staff development activities.

DHS works cooperatively with the provider community in its efforts to continually educate and upgrade the skills of their employees. For example, DHS is committed to the viability of the Illinois Institute for Maternal and Child Health Leadership to develop program knowledge and leadership skills among health care professionals in the core public health functions of assessment, policy development and assurance. During the first six months of the Institute, participants work in teams to address a maternal and child health issue proposed by one of the members and in the last six months, work independently to address a problem in their respective agencies. While not as formal, DHS also regularly sponsors or co-sponsors numerous conferences, workshops and roundtable meetings. These sessions are designed to promote information sharing among staff working on common or complimentary programs and to provide the latest updates from research and evaluations on health and human services issues to front-line workers. The continuing education and professional development of public health care workers is a critical foundation of the delivery system infrastructure and one DHS takes very seriously. DHS also uses these forums to distribute and explain recent developments in law and policy.

Although some providers complain that government policies are nonsensical and burdensome and change too frequently, many DHS policies are actually crafted with substantial involvement from those affected by them and the public at large. For example, community meetings are currently being held around the State to discuss the pending re-authorization of the legislation governing Temporary Assistance for Needy Families (TANF), a program that provides funding for cash assistance and other activities to support family self-sufficiency. At these meetings, DHS staff assigned to the respective community where the meeting is held walk the audience through a variety of statistics that demonstrate "where we've been" and "where the caseload is today." Statewide figures and regional/community data are provided. Key DHS welfare-to-work policies such as Work Pays and child care are also described and discussed.

Time is set aside on the agenda to focus attention on those families who have continuously received TANF since 1997 and thus are approaching their 5-year limit on receiving cash assistance. The majority of these cases are in Chicago. Many of them have significant health care barriers. Following the plenary session, the audience breaks into small groups to respond to a series of questions about priorities to emphasize during the federal reauthorization debate and suggested changes or additions to current State policies. Attendance at the seven community meetings that have already occurred has been excellent, with significant representation from the health care community. Illinois is one of the few states that has spent all of its TANF money in the past four years and has taken advantage of the flexibility in the federal law to re-direct funds that previously paid for cash assistance into child care, transportation, prevention and other health and family support programs. This is not a unique process. Within the last year and a half, community meetings have been held to ensure public participation in the strategic plan for the developmental disabilities system and to set the future direction for the DHS Office of Rehabilitation Services.

In addition to hosting formal community meetings, DHS holds focus groups, including some with program participants, to get feedback on its priorities and policies. Many of our federal plans and grant applications require that public hearings be conducted to obtain comments prior to their submission. The State of Illinois also has a formal rulemaking process overseen by the Illinois General Assembly that requires several public review periods. Strategic plans and polices are frequently posted on the Department's web site with instructions on how the public may submit its reactions to DHS. A number of advisory councils and committees established in law provide ongoing input into program requirements as well. These same councils and committees are routinely consulted on the development of Illinois reactions to proposed federal legislation or administrative directives, too.

Like most states, Illinois maintains an office in Washington, D.C. to monitor federal law and policy developments. Staff in that office routinely consult with the Department on issues being studied in Congress or by the Administration that affect the operations of its programs. DHS staff frequently participate in national associations and on task forces with other states that

take an active role in crafting or commenting upon legislation, regulations and administrative guidance. Typically, these staff consult with their colleagues at the local level in the development of their contributions to these efforts. Thus laws and policy are rarely created in a vacuum at either the federal or state level. Occasionally, DHS is asked by segments of the provider community to participate with them on local policy development to carry out strategic objectives. For example, it can be argued that services for pregnant women, infants and young children in Chicago are not delivered through a "service delivery system" at all. Services are delivered by no less than 100 provider agencies at over 125 locations across the City, and are supported by close to $130 million in funding. DHS and the Chicago Department of Public Health are seeking to improve maternal and child health status by creating a coordinated system from these disparate programs under the strong leadership of the local health department. This fragmentation hampers everyone's efforts to provide quality health care, as vividly portrayed in Laurie Abraham's study of one poor African-American family from North Lawndale.

I. Mama Might Be Better Off Dead

In 1993, the University of Chicago Press published a book about the failure of health care in urban America.[56] Laurie Kaye Abraham documented, from May 1989 to April 1990, the lives of four generations of an African-American family who live in one of Chicago's poorest neighborhoods. Each generation had its challenges: some in managing their own health conditions; others in navigating the system of care that was supposed to assist them. Trying to keep the family together was a young woman named Jackie. As evidenced by the following brief passage, that was no easy task:

> Her husband's kidneys failed before he was thirty; her alcoholic father had a stroke because of uncontrolled blood pressure at forty-eight; her Aunt Nancy, who helped her grandmother raise her, died from kidney failure complicated by cirrhosis when she was forty-three. Diabetes took her grandmother's leg, and blinded her great-aunt Eldora, who lives down the block.[57]

56. LAURIE KAYE ABRAHAM, MAMA MIGHT BE BETTER OFF DEAD (1993).
57. *Id.* at 17.

The family's challenges somewhat resemble a Gordian Knot in the way their problems enmeshed with each other. Thus it is difficult to look at their situation in simple cause and effect terms. For example, Jackie's grandmother, Cora Jackson, was not put on insulin when first diagnosed with diabetes.[58] Her primary tools for taking care of herself were diet, oral medication and regular medical checkups.[59] None of those things occurred. Whether the importance of adhering to the diabetic diet was never conveyed by health professionals or was never understood by Mrs. Jackson is not clear. It was known, however, that the difference between the diabetic diet and the way she was used to eating was substantial. Even after her diagnosis, Mrs. Jackson ate only the food that the family could afford and that could be easily accessed in the neighborhood; prepared the way it had always been fixed.[60] What effect additional health education and increased resources would have had in changing the family's eating behavior is unknown.

Mrs. Jackson also was inconsistent in taking her medications. Because her medication was not covered by Medicare, Jackie would often skip doses to make them last longer. She did not tell the doctors or nurses how she was forced to handle her grandmother's medication. Jackie rarely told them anything that she thought they might disapprove. When Mrs. Jackson's blood sugar levels became increasingly high, the physician who occasionally cared for her encouraged her to replace it with insulin.[61] She refused because she didn't want to give herself shots.[62] The physician did not push it. This was not unusual for him; unbeknownst to Jackie or her grandmother their doctor had failed a peer review by DPA's Medical Quality Review Committee and was on "continuous monitoring status" because of serious quality-of-care concerns.[63] Jackie didn't force the issue either. She was very uncomfortable asking the woman who raised her to do anything she didn't want to do, feeling ungrateful and disrespectful.

As Mrs. Jackson's condition worsened, she wound up in the emergency room where she typically saw a different doctor or resident each time. Without an ongoing relationship with a doc-

58. *Id.* at 62.
59. *Id.*
60. *Id.* at 139, 148.
61. *Id.* at 71.
62. *Id.*
63. *Id.* at 72.

tor, and because her medical file was often not available for review, her immediate problems could not be viewed in the context of her medical history.[64] She finally was admitted to the hospital and an amputation of her right leg was performed due to continual gangrene infection.[65] During her hospital stay, she participated only intermittently in physical therapy due to blood pressure and bleeding problems.[66] As a result, she never successfully learned to help get herself out of bed or to move herself around in her wheelchair. The amputation and loss of freedom resulted in a deepening depression that largely went untreated.[67] Two doctors were caring for Mrs. Jackson at this point and both scheduled follow-up visits with her upon discharge. Because of Medicaid spend-down provisions, Jackie could not afford to take her to see both physicians, so she alternated them. When her grandmother didn't seem any better after several follow-ups, Jackie quit taking her to either of the doctors. Mrs. Jackson began to refuse to eat, and her depression and inactivity intensified.

In the absence of consistent medical care and full disclosure of how her situation was being managed at home, Mrs. Jackson again was in and out of the hospital and emergency room with a host of old and new problems. She declined so quickly that during the period of the study, her second leg was amputated as well.[68] Shortly thereafter, doctors inserted a feeding tube to pump nutrients and insulin into her system.[69] Still, endocrinologists struggled to control her fluctuating blood sugar. To compound her problems, she got pneumonia, her kidneys began to fail, she began to retain fluid in her lungs, and she was subjected to transfusions to combat chronic anemia.[70] When she finally stabilized, she was moved to a nursing home. Jackie felt a mixture of guilt and relief. Within six weeks, characterized by further withdrawal and continued medical failing, Mrs. Jackson's heart stopped.[71] Yet a medical team injected Mrs. Jackson with five doses of cardiac stimulants, administered electric shock six times, and pushed a tube through her nose and down her wind-

64. *Id.* at 65.
65. *Id.* at 70.
66. *Id.* at 79.
67. *Id.* at 81.
68. *Id.* at 213.
69. *Id.*
70. *Id.* at 233.
71. *Id.* at 236.

pipe in an effort to force air into her lungs. After one-half hour, they stopped their efforts at resuscitation.[72]

Clearly a major barrier to the family was poverty. On more than one occasion, there wasn't enough money for Jackie to do all the things that needed to be done for her grandmother, at the time and in the manner they ideally should have been done. Mrs. Jackson only received her green card on the day of the month that her medical bills and receipts proved she'd met her spend-down of $394, over half of her social security check. During the period of her grandmother's illness, she was also struggling to help her father in the aftermath of his stroke and her husband with his dialysis. Her husband's frequent drug use reduced the money Jackie had available to support the family by hundreds of dollars a month. She also had three children she was attempting to raise. Jackie had to make choices with every dime she spent; some of those choices had unknown consequences. What would her situation have been like if, during the years of the study, she had the $120,000 Medicare spent for hospital care in the last six months of her grandmother's life?

The book does describe some of the services Jackie and her family likely were eligible to receive to help them cope with their escalating medical problems. Shortly after the first portion of her grandmother's right foot was amputated, Jackie was informed that she was eligible for homemaker services.[73] She canceled the service after two weeks because she couldn't afford the $110 co-pay out of her grandmother's $619 social security.[74] In a limited number of situations, Medicare will pay for home health assistance. Jackie refused this service because she did not understand that it would not cost her anything.[75] The agency may not have been clear on this point with her because it was just coming out of a period when it had sharply curtailed home visits in response to Medicare denials. Other services for which the family was eligible could not be accessed because there either were no providers in the neighborhood who would accept the government's low reimbursement rates or the few who did had no openings.

While *Mama Might Be Better Off Dead* provides numerous other examples of the failure of the health care system for this

72. *Id.*
73. *Id.* at 159.
74. *Id.* at 156.
75. *Id.* at 159.

North Lawndale family, it clearly shows the complicated relationship among health care financing, health care access, quality of care, continuity of care, the influences of culture and environment, and the behavior risk factors and life-style choices that result in poor health outcomes.

Conclusion

In the aftermath of the terrorist attacks, Americans are acutely conscious of the role government plays in ensuring their health and safety. This role includes a variety of tasks, including the establishment of laws, policies and regulations to ensure the health of all citizens. It also has a service delivery role to remove barriers, improve access and ensure the quality of care provided to persons at increased risk.

Since its creation, DHS has played a key role in the State of Illinois in delivering on the promise of the public health care system. There are some disagreements regarding the role of government in direct care, however few would argue that other roles are necessary. Strong relationships have been formed with other State government agencies to fulfill common missions in prevention and access to public health insurance. Significant progress has been made in streamlining and integrating services to address complex health issues through a multi-disciplinary, research-based approach across and within programs administered by the Department. Processes are in place to ensure wide participation of interested parties in the development of state laws, policies and regulations regarding health and human service delivery. Similar procedures are used to inform and influence federal law and policy as well. Virtually all of the successes in improving health care access and delivery to persons at risk or in need of services have been the result of collaborations between DHS and its many community partners. While its role as a source of funding is important, DHS makes other contributions in the areas of staff and systems development that are also critical. Models are available that demonstrate disparities in health status and outcomes can be overcome. The various organizations that comprise the public health system must continue to work cooperatively together to implement them.