ILLINOIS

DISCLAIMER: The views, statistical analysis, findings, and opinions expressed herein are not necessarily those of the Office of Minority Health, the Office of Public Health and Science nor the Department of Health and Human Services. The National Health Law Program, Inc. (NHeLP), under contract #282-00-0026, reviewed and analyzed existing state policies related to collecting racial and ethnic data by managed care organizations and health insurers. The information in this draft report contains the findings of NHeLP and not that of the Office of Minority Health, the OPHS, nor the U. S. Department of Health and Human Services. The study was conducted between October 2000 and May 2001. The policies and/or data per state may have changed since that time. The findings that have been updated in this draft report are the U.S. Census data (updated so that all data is from the 2000 Census) and the Center for Medicare & Medicaid Services (CMS)/HHS Medicaid data (updated from the June 30, 2000 to the December 31, 2002 reports).

ILLINOIS

A. General and Health Demographics

Total Population	12,419,293
Percent Black Population	14.9
Percent American Indian and Alaskan Native Population	0.1
Percent Asian Population	3.4
Percent Native Hawaiian and Other Pacific Islander Population	0.0
Percent Hispanic Population (of any race)	12.3
Percent White Population	67.8
Other (some other race and two or more races)	1.3
Language Use - 1990 census data	
Percent Limited English Proficiency (LEP) Population	4.69 (9.13)
Health Care Delivery Profile	
Percent of Total Non-elderly Population Privately Insured (1997-99)	75.6
Percent of Total Population Enrolled in HMOs	20.30
Medicaid Enrollment (as of June 30, 2000)	1,695,647 (13.65%)
Medicaid Managed Care Enrollment	125,898 (7.42%)
Percent of Total Non-elderly Population Uninsured (1997-99)	15.4

B. Collection and Reporting of Racial and Ethnic Data by Health Insurers and Managed Care Organizations

1. Statutes, Regulations, Policies, and Other Written Guidance

Illinois uses the term "insurer" to refer to insurance companies, health maintenance organizations (HMOs) and limited health service organizations (LSOs).[1] HMOs and LSOs are

[1] HMOs and LSOs are referred to as insurers in relevant insurance statutes. LSOs are similar to HMOs, but only offer "limited health care services" such as dental, vision, pharmaceutical or

labeled as managed care organizations (MCOs). Preferred provider plans (PPPs) are provider arrangements that may be offered by any entity "other than an insurer or HMO, that arranges, contracts with, or administers contracts with a provider whereby beneficiaries are provided an incentive to use the services of such provider."[2] All of these entities are governed by the Insurance Code. This summary will use the term "insurer" to refer to insurance companies, HMOs and LSOs and the term "MCO" when only HMOs and LSOs are affected.

Illinois does not have any statutes or regulations that mandate or prohibit the collection or reporting of racial or ethnic data. However, MCOs licensed by the Department of Public Health must develop quality assessment (QA) programs.[3] This QA program must be designed to identify and evaluate accessibility and quality of care.[4] In addition, the application of an HMO for a Certificate of Authority must provide evidence that the HMO's participating providers reflect the medical needs and characteristics of the service population. Such evidence may include "historical data on the service needs . . ., survey data, or any other data concerning an assessment of the needs and characteristics of the projected HMO population."[5]

Moreover, the Illinois Insurance Department requires that all health insurance policies and any applications related to the policies receive approval from the Department of Insurance (DOI) prior to first use.[6] The collection of racial and ethnic data, specifically, is not grounds for the disapproval of an application.[7]

Also, an application filed with the DOI to operate a PPP must include a description of the standards used to assure that health care services are delivered and accessible to the enrolled population. Standards include, but are not limited to, issues such as the PPP's "efforts to address the needs of beneficiaries with limited English proficiency and illiteracy [and] with diverse cultural and ethnic backgrounds . . .."[8]

2. Discrimination

Illinois has a civil rights statute that prohibits discrimination because of race, color, or national origin with regard to access to public accommodations.[9] However, the Appellate Court of Illinois has held that an insurance company does not constitute a "place of public

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ambulance care. 215 ILCS 130/1002.

[2] 215 ILCS 5/370g(g).

[3] 215 ILCS 134/80(a)

[4] *Id.*

[5] 777 Ill. Admin. Code § 240.40(j).

[6] 215 ILCS 5/355; 215 ILCS 125/4-13 (prior approval of HMO policy forms); 215 ILCS 130/3007 (prior approval of LSO policy forms).

[7] 215 ILCS 5/355.

[8] 50 Ill. Admin. Code at 2051.55(e)(9).

[9] 775 ILCS 5/5-102(A).

accommodation."[10] Therefore, the Illinois Human Rights Act's public accommodations provision does not provide protection against discrimination for those persons who are denied coverage by a health insurance company because of their race or ethnicity.

However, under its Insurance Code, Illinois prohibits "any unfair discrimination between individuals or risks of the same class . . . because of the race, color, . . ., or national origin of [the] applicants."[11] This provision applies to accident and health insurance, as well as motor vehicle and fire insurance.[12]

Finally, each health care entity that files an application with the Department of Insurance to operate a PPP shall include in its application copies of the provider agreements.[13] Each provider agreement must contain a provision that states that the provider will provide health care services without discrimination against any beneficiary on the basis of ethnicity.[14]

3. Confidentiality

In its application for its Certificate of Authority, an HMO must describe and have a policy regarding the "confidentiality, security and release of enrollees' medical records."[15] Moreover, the HMO must protect its members from public disclosure of their confidential medical information. However, the Department of Health has access to this information to perform medical record reviews and effectuate any other regulatory provisions.[16]

In addition, an insurer may not disclose any personal information[17] about a consumer collected or received in conjunction with the insurance transaction unless the disclosure is, among other things: (1) with the express consent of the consumer; (2) a disclosure to an insurer to detect criminal activity or perform administrative functions; (3) a disclosure to a health care provider to verify coverage or to inform the consumer of a medical problem; and (4) in response to an administrative or judicial order, including a search warrant or subpoena.[18]

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[10] *Cut 'n Dried Salon, et al. v. The Dept. of Human Rights, et al.*, 306 Ill. App.3d 142 (1999)(appealing an Illinois Human Rights Commission decision that the denial of an application for insurance coverage was not equivalent to the denial of services of a place of public accommodations).

[11] 215 ILCS 5/424(3).

[12] *Id.*

[13] 50 Ill. Admin. Code § 2051.55(c).

[14] *Id.* at 2051.55(c)(2)(L).

[15] 77 Ill. Admin. Code § 240.50(c)(2).

[16] *Id.* at § 240.100(d).

[17] Personal information means "any information that identifies an individual . . . from which judgments can be made about an individual's character, habits, . . ., health or any other personal characteristics." 215 ILCS 5/1003.

[18] 215 ILCS 5/1014.

C. Collection and Reporting of Racial and Ethnic Data by Other Health Care Entities

1. Department of Public Aid/State Medicaid Agency

a. Statutes, Regulations, Policies and Other Written Materials

There are no state statutes or rules that prohibit or require the collection or reporting of racial, ethnic or primary language data by either the Department of Public Aid (DPA) or the DPA's contracting managed care organizations (MCOs).[19] The DPA does maintain race and ethnicity as characteristics in data records and is able to report utilization information by race and ethnicity.[20]

The application for benefits under the KidCare program (SCHIP) requests the applicant's racial, ethnic and primary language information.[21] It is optional for the applicant to provide this information to the DPA. The application clearly notes that the refusal to provide this information will not prevent the applicant from receiving benefits. If an applicant does choose to provide this information, the following racial categories are to be used: White, Black, Hispanic, American Indian or Alaskan Native, Asian or Pacific Islander, and Other. The language preference choices are limited to English, Spanish or Other.

The Medicaid managed care contract has several provisions that implicate the need for racial, ethnic and primary language data. First, written materials distributed by the MCO must be provided in another language as well as English if five percent (5%) of the potential service area speaks that language.[22] Written materials mean marketing materials, beneficiary handbooks, and any other information or notices distributed to eligible enrollees, prospective beneficiaries, or beneficiaries.[23] In addition, the MCO must ensure that enrollees have access to interpreters.[24]

Second, the contract requires the submission of encounter data and quality assurance information.[25] The quality assurance program required by the contract must be able to "systematically and routinely collect data to review, [which] includes quality oversight and

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[19] The Department of Public Aid clarifies that there are no statutes or rules that prohibit the DPA or its contracting MCOs from collecting and reporting "in the aggregate" racial, ethnic and primary language characteristics of Medicaid recipients. *See* Letter from Nelly Ryan, Bureau of Contract Management, Department of Public Aid, dated January 3, 2001.

[20] *Id.*

[21] KidCare is a health insurance program for Illinois children 18 or younger and pregnant women that was established as part of the State Children's Health Insurance Program initiative.

[22] Illinois Medicaid Managed Care Contract ("Illinois Contract"), § 2.4(b).

[23] *Id.*

[24] 89 Ill. Admin. Code § 142.700(b)(1)(E).

[25] Illinois Contract, § 5.11(a)(1).

monitoring performance and patient results."[26] However, information submitted to the DPA has not been aggregated by member's race, ethnicity or primary language.[27] The contract is silent on the topic of aggregating data by race, ethnicity or primary language.

b. Discrimination

Illinois law states that there must not be any discrimination or denial of medical assistance or social services on account of an applicant's or recipient's race, color or national origin.[28] The contract states that the MCO must abide by all Federal and state laws, including the federal Civil Rights Act of 1964 and the Illinois Human Rights Act.[29] Specifically, it prohibits discrimination because of race, color, national origin, or ancestry in the delivery of services under the Medicaid managed care contract.[30] The KidCare application also includes a notation that the program is "open and accessible without regard to . . . race, . . . [or] national origin."[31]

c. Confidentiality

The Contract includes a provision which requires the contracting MCO to protect all information and data pertaining to providers, beneficiaries, and applicants from unauthorized disclosure. In addition, the DPA is prohibited from disclosing the contents of any records, files, or papers, except for purposes directly connected with the administration of Medicaid.[32] This does not prohibit, however, the exchange of information among the various Illinois administrative agencies, including the DPA, Department of Human Services, and the Department of Revenue.[33]

2. Department of Public Health

a. Statutes, Regulation, Policies, and Other Written Materials

The Department of Public Health (DPH) is one of the largest collectors and reporters of racial and ethnic data in the state. The DPH maintains several databases which track the health status of Illinois residents and seek to measure the extent and impact of various illnesses and disabilities on the state.[34]

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[26] Illinois Contract, Exhibit A.
[27] Ryan Letter.
[28] 305 ILCS 5/11-1.
[29] Illinois Contract, § 9.2(a).
[30] *Id.*
[31] KidCare Application, page 3.
[32] 305 ILCS 5/11-9.
[33] *Id.*
[34] 410 ILCS 520/4(a)(1).

The DPH collects, reports and maintains racial and ethnic information about patients with various diseases and conditions that could have a significant impact on Illinois residents. These include: (1) lead poisoning;[35] (2) cancer;[36] (3) sexually transmitted diseases, including HIV/AIDS;[37] (4) violent injuries;[38] (5) head and spinal cord injuries;[39] and, (6) other trauma injuries.[40] Many of these reporting requirements only apply to hospitals, ambulatory surgical treatment centers, or clinical laboratories, except that all physicians are required to report incidents of lead poisoning and sexually transmitted diseases.

The DPH has taken an active step in ensuring that health care delivery organizations address racial and ethnic disparities in the delivery of health care services. Two DPH publications outline various approaches to delivering culturally and linguistically appropriate health care services.[41] Two of these approaches include the consistent collection of data about minority populations and the maintenance of a database that is able to provide data on race and ethnicity in Illinois.

In addition, the Illinois state legislature and the DPH have taken steps to ensure that health care consumers with limited English proficiency have adequate access to health information and services. The Illinois Language Assistance Services Act requires hospitals and nursing homes to develop policies and procedures that ensure adequate and speedy language-appropriate interpretation services.[42] In addition, the law suggests that health facilities annually review and adopt a policy for providing language assistance services to patients with language or communication barriers.[43] In turn, the health facilities must submit the policy to the Department of Public Health.[44]

b. Discrimination

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[35] 77 Ill. Admin. Code § 845.20(a)(2). Categories for race were: White, Black, Asian American/Pacific Islander, American Indian/Alaskan Native and Other. The regulation also states that Hispanic is not considered a race, but is an ethnicity. Hispanic origin includes all Mexican, Puerto Rican, Cuban, South or Central American, and other Spanish people. Brazilians and Portuguese are not considered of Hispanic origin.

[36] 77 Ill. Admin. Code 840.110(b)(3).

[37] 77 Ill. Admin. Code § 693.30(a)(3)(A)(i); 77 Ill. Adm. Code 693.30(a)(4)(A).

[38] 77 Ill. Admin. Code § 560.120(d)(11).

[39] 77 Ill. Admin. Code § 550.120(c)(11).

[40] 77 Ill. Admin. Code § 515.2050(b)(8).

[41] *Building Cultural and Linguistic Competency: A Tool Kit for Health Care Organizations*, Illinois Department of Public Health, Center for Minority Health Services (1999); *Governor's Leadership Summit on Race & Ethnicity in Public Health: Post Summit Report*, Illinois Department of Public Health, June 11, 1999.

[42] 210 ILCS 87/15.

[43] *Id.*

[44] *Id.*

The Department of Public Health is bound by the requirements of the Illinois Human Rights Act with regard to discrimination on the basis of race, color or national origin and access to public health services. The DPH is a "public accommodation" as defined by statute.[45]

c. Confidentiality

The DPH has several confidentiality provisions incorporated within its reporting requirements. For each of the databases/registries described above, the DPH must ensure that data is maintained in a confidential manner and not unlawfully disclosed. The DPH cannot disclose any health data which makes an individual identifiable.[46] Exceptions to this include: (1) express consent by that individual; (2) disclosure to a governmental entity in Illinois, another state, or to the federal government; and (3) disclosure to an individual or organization for research and statistical purposes, in accordance with specific guidelines.[47]

D. Observations

Illinois does not have any statutes or regulations that mandate or prohibit the collection or reporting of racial or ethnic data.

The state of Illinois has implemented a number of initiatives to address the issues underlying access to health care services by racial and ethnic minorities. First, by developing a teaching tool for cultural and linguistic competency, health care organizations are made aware of the steps needed to deliver culturally sensitive health care services to their beneficiaries and enrollees.

In addition, the Department of Public Health convened a summit on June 11, 1999 to address racial and ethnic health disparities and ways to address them, including improving data collection practices. Finally, the Illinois legislature and the Department of Public Health have created an Advisory Panel on Minority Health.[48] This panel is charged with assisting the DPH by examining various minority health concerns, including access to health care, utilization of quality care, the collection and reporting of data on minority health, and reducing communication barriers for non-English speaking residents.[49]

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[45] 775 ILCS 5/5-101(A)(1). Public accommodation means "a business, accommodation . . . whose goods, services, facilities . . . are extended, offered, . . . otherwise made available to the public."

[46] 77 Ill. Admin. Code § 1005.30(h).

[47] *Id.* In the event that information is released to an individual or organization for research purposes, the patient's name, address, social security number, or any other unique personal data may not be included.

[48] 20 ILCS 2310/2310-210.

[49] *Id.*