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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).

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A. General and Health Demographics

Total Population	2,926,324
Percent Black Population	2.1
Percent American Indian and Alaskan Native Population	0.3
Percent Asian Population	1.2
Percent Native Hawaiian and Other Pacific Islander Population	0.0
Percent Hispanic Population (of any race)	2.8
Percent White Population	92.6
Other (some other race and two or more races)	1.0
Language Use - 1990 census data	
Percent Limited English Proficiency (LEP) Population	1.29 (2.49)
Health Care Delivery Profile	
Percent of Total Non-elderly Population Privately Insured (1997-99)	81.3
Percent of Total Population Enrolled in HMOs	12.57
Medicaid Enrollment (as of June 30, 2000)	265,042 (9.06%)
Medicaid Managed Care Enrollment	236,075 (89.07%)
Percent of Total Non-elderly Population Uninsured (1997-99)	11.3

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

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

Iowa uses the term "insurer" to encompass health insurance companies and health maintenance organizations (HMOs). This state summary will use the term "insurer" to refer to

¹ Iowa Code § 514A.1.

these entities, unless there is a distinction made within the statutes or regulations regarding the issue being discussed.

The Iowa Department of Commerce, Insurance Division (DOC) supervises all insurance business transacted in the state, including HMOs. Iowa does not have any statutes, regulations, or policies that mandate or prohibit the collection or reporting of racial and ethnic data.²

Iowa does require that all health insurance policies or any application related to the policies be filed with the DOC and receive departmental approval prior to its use.³

2. Discrimination

Iowa's civil rights statute prohibits a person from denying another individual "the full and equal use" of the services and facilities in any place of public accommodation. The statute, however, does not specifically include insurance companies within the definition of public accommodation, and there is no case law which has addressed this matter.

Under Iowa's unfair competition provisions, an insurer may not discriminate between "individuals of the same class involving essentially the same hazards" in premiums, rates or fees charged for any health insurance policy.⁶ However, the statute does not provide any particular prohibition against discriminating on the basis of race or national origin.⁷

3. Confidentiality

² Presently, the Iowa Department of Commerce, Insurance Division does not "see a need to regulate the collection and reporting of racial, ethnic, and primary language data, since insurers are not requesting this type of information from current or potential insureds." Letter dated December 1, 2000 from James Thornton, Attorney, Insurance Division.

³ Iowa Code § 514A.13. The Department of Commerce has indicated that if insurers began requesting racial and ethnic information, it would want to have assurances that such information would not be used in underwriting the insurance policy. Letter dated December 1, 2000 from James Thornton, Attorney, Insurance Division.

⁴ Iowa Code § 216.7(1)(a).

⁵ Iowa Code § 216.2(12).

⁶ Iowa Code § 507B.4(7)(b).

⁷ Interestingly, Iowa prohibits an insurer who issues *casualty insurance* policies (*i.e.* fire insurance, surety and guaranty bonds) from having risk classifications based upon the race or national origin of the insured. *See* Iowa Code § 515F.4(3).

As a state agency, the DOC maintains certain records as public records, including rate and policy form filings by insurers.⁸ However, records deemed confidential Iowa's public records law, such as medical records, are not available for public inspection.⁹

In addition, an HMO may not disclose any information communicated to a provider without the express consent of the person who is the subject of such information. ¹⁰ Nor may an HMO release its membership list of enrollees, "except to the extent necessary to conduct research or analyses regarding cost or quality issues." ¹¹

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

- 1. Department of Human Services (DHS)
 - a. Statutes, Regulations, Policies and Other Written Materials

DHS administers Iowa's Medicaid program and the Healthy and Well Kids in Iowa (HAWK-I) program, Iowa's SCHIP. There are no statutes or rules that prohibit or require the collection or reporting of racial, ethnic or primary language data by DHS regarding Medicaid applicants or recipients. However, the DHS Policy Manual indicates, within its "System Coding Instructions", that racial and ethnic data are collected. The code entitled "Ethnic Code" offers the following racial categories: (1) White, not of Hispanic origin; (2) Black, not of Hispanic origin; (3) American Indian or Alaskan native; (4) Asian or Pacific Islander; (5) Hispanic; and (6) Indochinese. The data field does not provide a category entitled "Other". The code is a category entitled "Other".

The Iowa Medicaid Managed Care Contract provides that "enrollee handbooks . . . shall be made available in languages other than English, if in [Iowa's] determination a significant number of enrollees are conversant only in those other languages." ¹⁴

In addition, Iowa's Managed Substance Abuse Care Plan Contract requires contractors to "ensure access to treatment services for all cultural [and] ethnic . . . groups, to include but not limited to: African American, Native American, Hispanic, . . . [and] Asian. . . ."¹⁵

⁸ 191 IAC 1.3.

⁹ Iowa Code § 22.7.

¹⁰ Iowa Code § 514B.30.

¹¹ *Id*.

¹² Letter from Dennis Janssen, Manager, Managed Care & Clinical Services Unit, Division of Medical Services, DHS dated November 30, 2000.

¹³ *Id*.

¹⁴ Iowa Contract, § 4.16.

¹⁵ Iowa Substance Abuse Contract, p. 30-17.

The HAWK-I program requires its contracting health plans to provide "all plan literature and brochures in English and any other language when enrollment in the plan by enrollees who speak the same non-English language equals or exceeds 10 percent of all enrollees in the plan." ¹⁶

b. Discrimination

Providers "with 15 or more employees shall be in compliance with Title VI of the 1964 Civil Rights Act." In addition, the DHS Policy Manual provides that "[d]epartment staff and vendors supplying goods or services to clients for which direct payment is made by the [DHS] may not discriminate on the basis of race, color [or] national origin. .." Finally, DHS will terminate a contract with an HMO if it is found that the HMO discriminated against persons eligible to be covered under the contract on the basis of race or national origin. ¹⁹

c. Confidentiality

All medical records maintained by a HAWK-I health plan must be kept confidential.²⁰ However, written consent is not required for the transmission of medical records to other health care providers who are providing services to enrollees under a subcontract with the health plan.²¹

In addition, HMOs providing services within the Iowa Medical Managed Care program must "maintain the confidentiality of medical record information." Medical records of an enrolled Medicaid recipient can only be released with the written consent of the enrollee, unless the medical record is being transmitted to a health care provider who is providing services to the enrollee under a subcontract.²³

2. Department of Public Health

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

The Department of Public Health (DPH) collects and requires health care providers to report racial and ethnic information for various medical conditions, diseases or registries. These

¹⁶ 441 IAC 86.15(514I).

¹⁷ 441 IAC 152.2(234)(5).

¹⁸ Letter from Dennis Janssen.

¹⁹ 441 IAC 88.2(249A).

²⁰ 441 IAC 86.15(514I).

²¹ *Id.* One exception to the written consent provision is that consent is required for the transmission of medical records relating to substance abuse, HIV or mental health treatment.

²² 441 IAC 88.9(249A).

²³ *Id*.

are abortion,²⁴ HIV/AIDS,²⁵ and sexually transmitted diseases (STDs).²⁶ The DPH also collects racial and ethnic data with regard to births,²⁷ but prohibits the collection of race data with regard to marriages.²⁸

b. Discrimination

Under Iowa's civil rights provisions, a person has a right to fully enjoy any place of public accommodation without being discriminated against because of his race or national origin.²⁹ The Department of Health is a "place of public accommodation" as statutorily defined and thus may not deny health care services to a person because of his race, color, or national origin.³⁰

c. Confidentiality

Public health regulations state that the DPH records are open for public inspection and copying under Iowa's Fair Information Practices law.³¹ However, the following records may be withheld from public inspection to the extent necessary to prevent identification of individuals: (1) records which identify a person with a contagious or infectious disease; and (2) records which identify a person with an STD.³² Certified copies of vital records including births, deaths, adoptions, and marriages may be issued to a person with a direct and tangible interest.³³

HIV screening records are strictly confidential. A person may "not be compelled to disclose the identity of any person upon whom an HIV-related test is performed . . . in a manner which permits identification of the [person]." However, information must be available for release to (1) the test subject; (2) a health care provider providing care to the subject; or (3) a person allowed access by a court order. 35

²⁴ Iowa Code § 144.29A(1)(d). See also http://www.idph.state.ia.us/dir off/itoprept00.pdf.

²⁵ Iowa Code § 141A.6(6)(e).

²⁶ Iowa Code § 139A.31

²⁷ Iowa Code § 144.14(2). The state collects race information for a child of unknown parentage when taken into custody.

²⁸ Iowa Code § 144.36(3).

²⁹ Iowa Code § 216.7(1)(a).

³⁰ Iowa Code § 216.2. Public accommodation "includes each state and local government unit . . . that offers services, facilities, benefits, grants or goods to the public . . ."

³¹ 641 IAC 175.13.

³² *Id*.

³³ 641 IAC 96.7. Persons with a "direct and tangible interest" are the registrant, registrant's family or legal representative and persons conducting family research upon demonstrating a direct lineal connection.

³⁴ Iowa Code § 141A.9.

³⁵ *Id*.

The following records must be kept confidential: (1) cancer screening records; (2) chlamydia screening records; (3) sterilization records; and (4) patient records in the AZT drug reimbursement program.³⁶

D. Observations

Like many states, Iowa requires prior approval for all insurance policy forms and applications. An Iowa state official indicated that if insurers began to collect racial and ethnic data, they would want to receive assurance that the information would not be used in a harmful manner.

Interestingly, unlike most other states, Iowa prohibits the collection of racial data with regard to marriages.

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³⁶ *Id*.