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The Reporting of Race and Ethnicity in the National Notifiable Diseases Surveillance System

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Synopsis

The authors used 1987 data from the Epidemiologic Surveillance Project (ESP) of the Centers for Disease Control to examine the completeness of race-ethnicity reporting in the National Notifiable Diseases Surveillance System. And, to the extent possible, they used ESP to assess racial and ethnic disparities in the occurrence of selected notifiable infectious diseases. For the 30 reporting areas (29 States and the District of Columbia) that provided data to ESP for all of calendar year 1987, approximately 60 percent of case reports were accompanied by specified race-ethnicity for affected persons. This percentage varied widely by disease and State.

In general, non-Hispanic whites had morbidity rates (cases per 100,000 population per year) that were among the lowest compared with rates for other groups, and Native Americans commonly had rates that were among the highest. The ranking of morbidity rates among blacks, Hispanics, and Asians and Pacific Islanders varied by disease,

although the last group had strikingly higher rates for malaria and tuberculosis. The age distribution of persons with cases was often lower among minority groups than among non-Hispanic whites, but the authors were unable to calculate age-specific or age-adjusted rates. Potential biases that limit interpretation of the findings are reviewed.

Efforts to eliminate racial-ethnic disparities in the occurrence of infectious diseases would be aided by effective surveillance data. For the ESP to meet its potential in this regard, however, substantial improvements in the reporting of race-ethnicity for notifiable diseases are needed.

MAJOR DISPARITIES exist in the health of persons in different race and ethnic groups in the United States (*1*). To set priorities for intervention, a Task Force on Black and Minority Health, organized by the Department of Health and Human Services, developed a list of priority diseases and conditions: cancer, cardiovascular and cerebrovascular diseases, chemical dependency, diabetes, injuries, and infant mortality and low birth weight (*1*). These were selected primarily because of their contribution to disparities in mortality between white and other Americans (*2*). Had an index based on morbidity been employed, infectious diseases probably would have been included. The social, environmental, and economic disadvantages associated with minority status are also associated with an increased risk of infectious diseases (*3,4*), and efforts to eliminate health disparities between white and minority Americans should not overlook infectious diseases.

A public problem in tracking efforts to improve the health of minorities is the limitation of current information resources, and the Office of Minority Health of the Department of Health and Human Services is seeking to identify and improve minority health information resources (*2*). We therefore sought to determine whether the National Notifiable Diseases Surveillance System (NNDSS) of the Centers for Disease Control (CDC), which provides information on more than 40 infectious diseases, could be used to monitor the occurrence of infectious diseases of public health importance among members of different race and ethnic groups.

Background

Since 1961, State health departments have reported weekly to CDC case counts for notifiable diseases, which are determined collaboratively by the Council of State and Territorial Epidemiologists and CDC (*5,6*). CDC publishes provisional data from State reports in the Morbidity and Mortality Weekly Report and final data in the annual "Summary of Notifiable Diseases." Before 1985, the data reported to the notifiable diseases system were limited to case counts. In 1985, six States started participating in the Epidemiologic Surveillance Project (ESP), a computer-based network for disease reporting that provides basic demographic information, including race-ethnicity, for persons reported as having a notifiable disease (*7,8*). Currently, nearly 40 States, New York City, and the District of Columbia are ESP participants (for simplicity, we will use the term "States" for all reporting areas).

In addition to the NNDSS, parallel surveillance systems for selected diseases are operated by other CDC programs. These systems may collect more detailed information on risk factors or events associated with disease and have different timeframes or scopes for data collection. For the acquired immunodeficiency syndrome (AIDS), States report detailed case information to CDC exclusively through another system, and thus our analysis excludes AIDS data.

Methods

We have limited our analysis to the 30 States that joined the system before January 1, 1987 (see box). We included all provisional reports for the 1987 calendar year, including any corrections that were received by February 1988.

The following categories are recommended for reporting race-ethnicity through ESP: white non-Hispanic, black non-Hispanic, Hispanic, Native American (includes American Indians, Eskimos, Aleuts), Asian and Pacific Islander, and unspecified (for brevity, the first two groups will be referred to as "white" and "black"). However, the completeness of race-ethnicity information varies widely by disease and State. We therefore limited our calculation of morbidity rates to States and diseases for which 90 percent or more of case reports had specified race-ethnicity.

We calculated morbidity rates (reported cases per 100,000 population per year) using the 1980 census (*9*). Because many respondents in the 1980 census

inappropriately identified their race as "other" (for example, some white Hispanics reported their race as other), the Bureau of the Census "corrected" the classification of race for many persons (*10*). We obtained these "race-corrected" data from a computerized data base maintained by the Lawrence Berkeley Laboratory of the University of California (*11*). Because the corrected census data are not available by race, ethnicity, and State for intercensus years, we were unable to use more recent population estimates for calculation of morbidity rates. Likewise, further population breakdowns by these variables and age are not available, and we were unable to calculate age-specific or age-adjusted rates.

We calculated 95 percent confidence intervals for morbidity rates using an exact method (*12*). When fewer than 10 cases were reported for a specific race-ethnic group, we did not calculate rates.

Results

Overall, 60 percent of case reports for 1987 from 30 States included the race-ethnicity of persons with cases; however, this proportion varied widely by disease (table 1). In comparison, reporting of other demographic variables is nearly complete; approximately 95 percent of case reports specify age and 99 percent specify gender.

Because the reporting of race-ethnicity was incomplete, calculation of morbidity rates by race-ethnicity for various diseases was limited to relatively few States (table 2).

In general, the morbidity rate for whites was lower than that for blacks. Exceptions were for campylobacteriosis, hepatitis A, and hepatitis non-A, non-B, for which rates for whites were higher than those for blacks and where the 95 percent confidence limits were not overlapping (table 2).

For those diseases for which we calculated rates for Native Americans, this group commonly had rates that were among the highest, with rates for hepatitis A among Native Americans nearly 11 times the rate among whites (table 2). Approximately half of hepatitis A cases among Native Americans were reported from Alaska, and approximately one-third from Washington. Rates for Native Americans in these States were 235 and 157 cases per 100,000 per year, respectively—higher than the overall Native American rate of 105 in the 11 States included in hepatitis A calculations.

There was no consistent pattern for the ranking of morbidity rates among Hispanics or Asians and Pacific Islanders compared with the other race-ethnic groups. For malaria and tuberculosis, the rate among Asians and Pacific Islanders was markedly higher than the rate among the other groups (table 2).

For several diseases, we examined the age distribution for reported cases, and in general, affected minority group members were younger than whites. For example, 2.7 percent of tuberculosis cases among whites occurred in persons less than 10 years of age compared with 6.4 percent for blacks, 8.2 percent for Hispanics, 12.0 percent for Asians and Pacific Islanders, and 11.8 percent for Native Americans. For aseptic meningitis, 34.5 percent of cases among whites were in persons less than 5 years of age compared with 45.9 percent for blacks. For meningococcal infections, the age distributions were similar for whites and blacks. For salmonellosis, 17.0 percent of cases in whites were in persons less than 1 year of age, compared with 35.2 percent for blacks and 30.2 percent for Hispanics. For shigellosis, white and Hispanic age distributions were similar, with 34.3 percent and 36.4 percent of reported cases, respectively, occurring among persons less than 1 year of age compared with 52.4 percent of the cases among blacks.

Notifiable Disease Reporting Areas That Joined the Epidemiologic Surveillance Project Before January 1, 1987

Alabama	Mississippi
Alaska	Montana
Arkansas	New Hampshire
Colorado	New Mexico
Connecticut	North Carolina
District of Columbia	North Dakota
Florida	Ohio
Georgia	Oregon
Indiana	Pennsylvania
Kentucky	South Carolina
Louisiana	Texas
Maine	Vermont
Massachusetts	Washington
Michigan	West Virginia
Minnesota	Wisconsin

Discussion

There are two main findings in the data. First, the reporting of race-ethnicity for notifiable infectious diseases is incomplete, varying widely by State and disease. Second, to the extent that race-ethnic-specific rates can be determined, minority group members commonly suffer higher infectious disease morbidity than whites—a burden that appears to fall heavily on minority children.

In addition to the lack of completeness, there are

Table 1. Race and ethnicity of persons with reported cases of notifiable diseases, 29 States, by disease, 1987

Disease	Number of cases	Race-ethnic group (percent)					
		White	Black	Hispanic	Asians-Pacific Islander	Native American	Unspecified
Amebiasis	693	32.8	7.4	5.8	12.4	0.9	40.8
Anthrax	1	0.0	0.0	0.0	0.0	0.0	100.0
Aseptic meningitis	5,733	54.2	11.5	2.5	0.3	0.5	30.9
Botulism	22	59.1	0.0	13.6	0.0	0.0	27.3
Brucellosis	74	31.1	1.4	48.6	0.0	0.0	18.9
Campylobacteriosis	14,239	40.8	3.1	2.0	0.3	0.4	53.4
Cholera	7	57.1	14.3	14.3	0.0	0.0	14.3
Diphtheria	1	100.0	0.0	0.0	0.0	0.0	0.0
Encephalitis	795	58.6	5.8	2.3	0.3	0.4	32.7
Encephalitis (postinfectious)	53	73.6	15.1	1.9	0.0	0.0	9.4
Gonorrhea [1]	12,732	20.3	57.1	0.2	0.4	8.2	13.8
Hepatitis A	10,576	60.0	4.0	8.6	0.5	3.9	22.9
Hepatitis B	12,678	42.3	17.5	4.4	1.9	1.0	32.8
Hepatitis non-A, non-B	1,383	60.6	7.4	4.7	0.5	1.3	25.5
Hepatitis unspecified	1,287	44.7	10.2	17.5	0.3	0.9	26.4
Legionellosis	562	53.2	7.5	0.7	0.7	1.1	36.8
Leprosy	41	14.6	2.4	17.1	14.6	0.0	51.2
Leptospirosis	15	40.0	13.3	6.7	0.0	0.0	40.0
Malaria	311	28.0	17.7	5.1	17.0	1.0	31.2
Measles (imported) [2]	315	35.6	0.0	1.9	0.0	0.3	62.2
Measles (indigenous) [2]	1,346	39.5	4.1	7.4	0.1	0.9	48.1
Meningococcal infections	1,362	52.2	11.2	2.1	0.5	0.7	33.3
Mumps	6,642	30.1	8.5	1.3	0.1	0.1	59.9
Pertussis	1,290	34.9	7.1	2.4	0.2	0.8	54.7
Plague	9	66.7	0.0	0.0	0.0	22.2	11.1
Poliomyelitis	3	33.3	0.0	0.0	0.0	0.0	66.7
Psittacosis	58	44.8	3.4	1.7	0.0	1.7	48.3
Reye syndrome	26	53.8	11.5	0.0	0.0	3.8	30.8
Rocky Mountain spotted fever	281	48.0	11.0	0.0	0.4	0.7	39.9
Rubella	41	48.8	0.0	7.3	9.8	0.0	34.1
Salmonellosis	23,639	33.1	9.4	3.4	0.6	0.6	52.9
Shigellosis	8,735	26.5	18.3	11.9	0.4	2.3	40.5
Syphilis [3]	71	36.6	57.7	0.0	0.0	1.4	4.2
Tetanus	20	60.0	15.0	5.0	0.0	0.0	20.0
Toxic shock syndrome	161	69.6	1.9	3.1	0.6	0.6	24.2
Trichinosis	10	20.0	0.0	0.0	0.0	40.0	40.0
Tuberculosis [4]	1,803	35.3	37.1	4.3	4.5	4.8	13.9
Tularemia	80	63.8	7.5	1.3	0.0	1.3	26.3
Typhoid fever	138	22.5	6.5	18.8	8.0	0.0	44.2
Typhus, murine	23	47.8	0.0	52.2	0.0	0.0	0.0
Varicella [5]	2,188	0.5	2.1	0.2	0.0	0.1	97.1
Total	109,444	37.3	15.5	4.2	0.8	2.0	40.2

[1] Case reports from 5 States. [2] Case reports from 28 States. [3] Case reports from 5 States. [4] Case reports from 10 States. [5] Case reports from 6 States.

multiple reasons for urging caution in interpreting the race-ethnic-specific data:

- Morbidity rates are based on data from relatively few States, which may not be representative of the United States, particularly for specific race or ethnic groups.
- States use different procedures for reporting notifiable diseases (*13*), and these variations may affect race-ethnic comparisons, particularly if members of certain race-ethnic groups are more likely to reside in specific States.
- The quality and completeness of disease reporting may vary by race or ethnic group, reflecting differences in access to medical care, use of private or public care providers, and completeness of disease reporting by different providers. For example, in an investigation of shigellosis reporting in Washington, reporting was more complete at a university hospital than a private hospital that served different patient populations (*14*).
- Methods for classification of race-ethnicity may differ between notifiable disease reports and the census. States may vary in their use of race-ethnicity coding categories, and changes in the population since 1980 may bias the calculation of

Table 2. Morbidity rates [1] (cases per 100,000 population) for selected notifiable diseases and States, 1987

Disease	States	Race-ethnicity	Number of cases	Rate	95 Percent confidence limits
Amebiasis	AK, AL, FL, LA, ND	White, non-Hispanic	53	0.38	0.28, 0.49
		Black, non-Hispanic	18	0.51	0.31, 0.82
		Hispanic	3	...	.....
		Asian, Pacific Islander	11	11.14	5.86, 20.60
		Native American	0	...	... ...
		Unspecified	4	...	... ...
		Total	89	0.47	0.38, 0.58
Aseptic meningitis	AL, DC, FL, GA, MS, ND	White, non-Hispanic	912	5.47	5.12, 5.84
		Black, non-Hispanic	223	4.39	3.84, 5.02
		Hispanic	20	2.00	1.26, 3.15
		Asian, Pacific Islander	5	...	... ...
		Native American	1	...	... ...
		Unspecified	47	...	... ...
		Total	1,208	5.27	4.98, 5.58
Campylobacteriosis	AL, DC, FL, ND	White, non-Hispanic	1,540	13.82	13.14, 14.53
		Black, non-Hispanic	178	6.47	5.57, 7.51
		Hispanic	20	2.19	1.37, 3.45
		Asian, Pacific Islander	3	...	... ...
		Native American	1	...	... ...
		Unspecified	78	...	... ...
		Total	1,820	12.19	11.64, 12.77
Gonorrhea	AK, ND	White, non-Hispanic	680	72.98	67.65, 78.73
		Black, non-Hispanic	173	1,082.87	930.83, 1,258.89
		Hispanic	25	186.44	123.31, 279.54
		Asian, Pacific Islander	24	241.79	158.50, 365.56
		Native American	999	1,196.53	1,124.41, 1.273.18
		Unspecified	53	...	... ...
		Total	1,954	185.29	177.21, 193.73
Hepatitis A	AK, AL, AR, DC, FL, KY, MN, MS, ND, TX, WA	White, non-Hispanic	4,231	11.97	11.61, 12.33
		Black, non-Hispanic	321	5.25	4.69, 5.86
		Hispanic	736	17.82	16.56, 19.17
		Asian, Pacific Islander	34	9.48	6.67, 13.41
		Native American	284	105.46	93.72, 118.65
		Unspecified	327	...	... ...
		Total	5,933	12.83	12.51, 13.16
Hepatitis B	AL, DC, FL, GA, MN, MS, ND, WA	White, non-Hispanic	2,608	10.72	10.31, 11.14
		Black, non-Hispanic	1,064	20.33	19.13, 21.60
		Hispanic	122	10.60	8.84, 12.70
		Asian, Pacific Islander	83	34.93	27.99, 43.53
		Native American	52	32.47	24.49, 42.93
		Unspecified	265	...	... ...
		Total	4,194	13.48	13.07, 13.89
Hepatitis, non-A, non-B	AL, DC, FL, GA, KY, LA, MN, MS, ND, NH, WA, WI, WV	White, non-Hispanic	517	1.37	1.26, 1.49
		Black, non-Hispanic	66	0.95	0.74, 1.21
		Hispanic	14	1.03	0.59, 1.78
		Asian, Pacific Islander	2	...	... ...
		Native American	8	...	... ...
		Unspecified	23	...	... ...
		Total	630	1.35	1.25, 1.46
Legionellosis	AK, AL, DC, FL, GA, KY, MT, NH, WA, WV	White, non-Hispanic	96	0.38	0.31, 0.46
		Black, non-Hispanic	12	0.26	0.14, 0.46
		Hispanic	0	...	... ...
		Asian, Pacific Islander	2	...	... ...
		Native American	2	...	... ...
		Unspecified	3	...	... ...
		Total	115	0.36	0.30, 0.44

Table 2. Morbidity rates [1] (cases per 100,000 population) for selected notifiable diseases and States, 1987, continued

Disease	States	Race-ethnicity	Number of cases	Rate	95 Percent confidence limits
Malaria	AR, DC, FL, GA, KY, MN, MS, ND, TX, WA, WI, WV	White, non-Hispanic	63	0.15	0.12, 0.19
		Black, non-Hispanic	46	0.68	0.50, 0.91
		Hispanic	14	0.33	0.19, 0.57
		Asian, Pacific Islander	46	11.81	8.74, 15.89
		Native American	1	...	... ...
		Unspecified	4	...	... ...
		Total	174	0.32	0.28, 0.38
Measles, indigenous	AK, AL, DC, GA, KY, LA, MN, MS, ND, NH, WA, WI, WV	White, non-Hispanic	137	0.53	0.44, 0.63
		Black, non-Hispanic	23	0.40	0.26, 0.62
		Hispanic	27	2.24	1.51, 3.31
		Asian, Pacific Islander	1	...	... ...
		Native American	0	...	... ...
		Unspecified	2	...	... ...
		Total	190	0.57	0.49, 0.66
Meningococcal infections	AL, AR, DC, FL, GA, KY, MN, MS, ND	White, non-Hispanic	288	1.12	0.99, 1.25
		Black, non-Hispanic	77	1.34	1.06, 1.68
		Hispanic	5	...	... ...
		Asian, Pacific Islander	3	...	... ...
		Native American	3	...	... ...
		Unspecified	9	...	... ...
		Total	385	1.17	1.06, 1.29
Pertussis	AK, KY, MS, ND, SC, TX	White, non-Hispanic	68	0.39	0.31, .50
		Black, non-Hispanic	17	0.45	0.27, 0.74
		Hispanic	22	0.71	0.46, 1.10
		Asian, Pacific Islander	0	...	... ...
		Native American	4	...	... ...
		Unspecified	2	...	... ...
		Total	113	0.46	0.38, 0.56
Rocky Mountain spotted fever	AL, AR, FL, GA, IN, KY, MI, MS, OR, TX, WI	White, non-Hispanic	104	0.21	0.17, 0.25
		Black, non-Hispanic	13	0.15	0.08, 0.26
		Hispanic	0	...	... ...
		Asian, Pacific Islander	1	...	... ...
		Native American	0	...	... ...
		Unspecified	2	...	... ...
		Total	120	0.19	0.16, 0.23
Salmonellosis	DC, FL, ND	White, non-Hispanic	2,326	28.07	26.95, 29.24
		Black, non-Hispanic	703	39.77	36.91, 42.85
		Hispanic	64	7.27	5.65, 9.35
		Asian, Pacific Islander	17	26.37	15.87, 43.19
		Native American	8	...	... ...
		Unspecified	118	...	... ...
		Total	3,236	29.32	28.32, 30.35
Shigellosis	DC, FL, ND	White, non-Hispanic	494	5.96	5.45, 6.52
		Black, non-Hispanic	455	25.74	23.45, 28.24
		Hispanic	49	5.57	4.16, 7.43
		Asian, Pacific Islander	4	...	... ...
		Native American	12	29.90	16.20, 53.84
		Unspecified	31	...	... ...
		Total	1,045	9.47	8.91, 10.06
Syphilis	AK, ND, NH, WI	White, non-Hispanic	26	0.42	0.28, 0.62
		Black, non-Hispanic	41	20.39	14.82, 27.95
		Hispanic	0	...	... ...
		Asian, Pacific Islander	0	...	... ...
		Native American	1	...	... ...
		Unspecified	2	...	... ...
		Total	70	1.05	0.82, 1.33

Table 2. Morbidity rates [1] (cases per 100,000 population) for selected notifiable diseases and States, 1987, continued

Disease	States	Race-ethnicity	Number of cases	Rate	95 Percent confidence limits
Tuberculosis	AK, CO, KY, ME, MS, ND, NM	White, non-Hispanic	622	6.16	5.69,6.66
		Black, non-Hispanic	280	21.94	19.48,24.71
		Hispanic	61	6.87	5.30,8.89
		Asian, Pacific Islander	52	77.38	58.37,102.29
		Native American	76	34.67	27.50,43.65
		Unspecified	8	...	... ...
		Total	1,099	8.76	8.25,9.29
Typhoid fever	AR, DC, FL, ME, TX, WV	White, non-Hispanic	15	0.07	0.04,0.12
		Black, non-Hispanic	9	...	... ...
		Hispanic	21	0.54	0.34,0.84
		Asian, Pacific Islander	3	...	... ...
		Native American	0	...	... ...
		Unspecified	2	...	... ...
		Total	50	0.17	0.13,0.22

[1] Reported cases per 100,000 population limited to States for which 90 percent or more of case reports had specified race (see text). Rates were not calculated when fewer than 10 cases were reported.

NOTE: State abbreviations are those used by the U.S. Postal Service.

morbidity rates for 1987, particularly if some groups have grown more rapidly than others because of immigration or higher fertility (*15,16*).

• For most diseases, these data do not distinguish between cases of illness acquired inside or outside a State or the United States. Thus, morbidity rates may not reflect the risk of acquiring disease in the reporting area, making the interpretation of the high rates of malaria and tuberculosis among Asians and Pacific Islanders difficult.

• We were unable to calculate age-specific rates for the race-ethnic categories of interest. In addition, reporting completeness may vary by age. For example, the jaundice characteristic of hepatitis A in adults is usually not found in infants and young children. Thus, cases in young children are less likely to be diagnosed and reported, and high age-specific rates among infants and children may not be recognized unless associated adult cases are reported and investigated.

Despite these limitations, the findings are generally consistent with previous reports for these and other infectious diseases. For example, for AIDS—a disease with high rates of reporting (*17*)—the rate of adult cases among non-Hispanic blacks and Hispanics is more than three times the white rate, and the gap is greater for AIDS among children (*18*). In 1985, national data for tuberculosis (collected through a parallel system) revealed that the rate among persons of minority races was more than fivefold the rate for whites (*19*), including particularly high rates among Asians and Pacific Islanders (*20*).

In a study of syphilis in the United States from 1967 to 1979, sex-specific rates among persons of minority races were higher than rates for whites, regardless of whether care was received from public or private sources (*21*). Also, data from the 1978 National Health and Nutrition Examination Survey revealed a 4.7-fold lifetime risk of syphilis infection among blacks compared with whites, after controlling for other risk markers (*22*). In 1979, age-adjusted rates of gonorrhea were roughly 10 times higher among persons of black and other minority races compared with rates for whites (*23*). More recently, an increase in syphilis cases has been observed in the United States, and in two of three geographic areas where the largest numerical increase in cases occurred (New York City and California), the percentage increase among blacks was markedly higher than the increase among whites or other race groups (*24*). An increase in cases of congenital syphilis has also been noted in 1983–85, and a disproportionately high number of cases have been reported among blacks and Hispanics (*25*).

For many of the diseases examined in this report, rates were highest among Native Americans. The problem of infectious diseases among Native Americans is well recognized and has been targeted by the Indian Health Service for special surveillance and intervention efforts (*26,27*). In addition, for major categories of infectious diseases, national vital statistics reveal higher mortality rates due to infectious diseases among persons of minority races compared with whites (*28*), and infectious diseases contribute to racial disparities in both infant and childhood mortality (*29,30*).

Reducing disparities in health among different

groups of Americans has been emphasized as an important national health objective (*1*). Effective disease surveillance can support efforts to achieve minority health goals, and the NNDSS has the potential for serving this process. Because the data in this system are based on reports from State health departments, achieving this potential will place an increased burden on State reporters. State support for this surveillance is more likely if States adopt minority health objectives.

Equally important, the desirability of collecting additional information through the notifiable disease system must be balanced with the need to maintain timely reporting for infectious diseases of public health importance. The race-ethnic categories used in the ESP are broad and encompass diverse subgroups that may vary widely in health status: Native Americans include members of different tribes and Alaskan Natives; Asians and Pacific Islanders include persons of Chinese, Japanese, Filipino, and Southeast Asian ancestry; Hispanics include persons of Mexican, Central American, South American, Puerto Rican, and Cuban heritage.

At present, collection of more detailed information on ethnicity or national origin may not be feasible, given the need to improve reporting for the basic race and ethnicity groups. By highlighting the problem of infectious disease disparities in broad terms, however, data from this system may provide an impetus for more focused projects that should consider the determinants of health disparities, such as living conditions, health-related behaviors, and access to preventive and therapeutic services.

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Providing Access to Home Care for Disabled Children: Minnesota's Medicaid Model Waiver Program

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Synopsis

Home care programs for severely disabled, usually technology-dependent, children got a boost in 1981 when the Federal Government gave States permission to use Medicaid to fund home care under the Medicaid model home- and community-based waiver (2176). The model waiver program was unique because it eliminated the bias toward hospitalization by waiving parental income and assets when determining eligibility for children cared for at home and by allowing Medicaid to cover needed home care services.

In 1985 Minnesota received Federal approval for the model waiver, and the results are detailed in this report. Although the waiver could provide funding for up to 50 children, after 2 years only 24 children had received approval. Stringent and complex eligibility criteria acted as barriers to accessing the model waiver. In addition, the interaction between the waiver and the State's health care system contributed to inconsistencies in eligibility. This interaction demonstrates the difficulty of administering publicly funded programs in the current health care environment.

Recommendations are made for adjusting criteria for eligibility in the waiver program. Unresolved problems facing technology-dependent children on home care programs are discussed.

In the early 1980s, home care for high-risk, severely disabled children began to receive widespread attention as an option to long-term hospitalization. Home care was reported as less costly than hospitalization (*1-7*) and was believed to be more effective in promoting a child's mental, emotional, and physical health, although the effect on the child remains unsubstantiated (*8*).

By 1986, Minnesota and 13 other States offered funding for home care to disabled children through Medicaid home- and community-based model waivers (*8*). This program was unique because it removed parental income and assets as an eligibility consideration, thus permitting States to offer special services to a specified population normally not covered by Medicaid. It was expected that these allowances would make home care more attainable for seriously disabled children.

When Minnesota sought approval for its waiver, the population specified for service was defined as chronically disabled children (*9*). However, the specified population could have been defined more narrowly as technology-dependent. All but one child receiving waiver funding were technology-dependent. Technology-dependent children are defined as those who require the use of medical technology to compensate for the loss of a normal vital body function, and who require substantial daily skilled nursing care to avert death or further disability (*8*). Meeting the needs of technology-dependent children poses a challenge to public policy because, while their numbers are small