proportionate hazard of suicide among Native Americans and Native Alaskans, the cultural causes will need to be addressed by Natives who have regained hope and control of their own lives.

Suicidal behavior, exemplified by the self-inflicted gunshot wound, continues to be a threat to young Alaska Natives. Its prevalence appears to be a function of increasing disruption and alienation, imposed upon a set of behavioral norms that limit one's ability to convey anger and pain.

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A Study of Underreporting of Down's Syndrome on Birth Certificates in an Ohio County, 1970–78

MICHAEL S. BARG, BS
CARL A. HUETHER, PhD

Mr. Barg is a senior medical student in the College of Medicine, Ohio State University, Columbus. Dr. Huether is associate professor, Department of Biological Sciences, University of Cincinnati, Cincinnati, Ohio 45221.

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SYNOPSIS

In a previous statewide assessment in Ohio of the percentage reporting of Down's syndrome (DS) on birth certificates, it was found that 33.9 percent of the cases chromosomally analyzed were so recorded. The objectives of this study were to gain a greater understanding of the basis of this low reporting percentage by concentrating on Hamilton County births only, to compare these percentages among hospitals in the county, and to determine the commonality of

their causes. Since it was anticipated that both a thorough search of hospital records and access to chromosome analysis records would provide essentially complete ascertainment of DS births in the county during 1970–78, the data were also used to test the validity of chromosome analysis as a sampling procedure in estimating the total number of DS births by means of the Lincoln-Peterson capture-recapture method.

The percentage of reporting of DS on the birth certificates by hospital ranged from 0.0 to 57.1, with a mean of 26.0 for the 6 hospitals within the county. Although variation among some hospitals was statistically significant, three of the six hospitals had zero percent reporting. The explanation for these low reporting percentages was fundamentally similar for all hospitals—a communications flow problem, produced by poor timing and use of the wrong sources of available information. The only data typically available to the birth certificate clerk were derived from the labor and delivery sheet, the form with the worst reporting percentage of DS of any in the medical record. On the other hand, by the time of discharge, 92.5 percent of the cases had either been definitely diagnosed as DS and were recorded on the face sheet or were entered as "chromosome analysis pending" in the file.

The use of the chromosome analysis data gave an estimate of total DS births ($\hat{N} = 201 \pm 34$) statistically consistent with the total observed, thereby providing support for this estimation procedure. Annual incidence rates for DS were also calculated for 1970–78, with a total incidence rate for the 9-year period of 1.14 per 1,000 live births.

IN THE UNITED STATES, much of the routinely available information regarding incidence rates for congenital anomalies among newborns is derived from birth certificates. However, it is well known and amply documented that birth malformations are grossly underreported on birth certificates (*1–4*). In a recently completed study (*5*), the investigators estimated the percentage of Down's syndrome (DS) cases reported on birth certificates in Ohio during 1970–79. The names of infants with cytogenetically confirmed DS were obtained from 13 cytogenetic laboratories in the State, and it was found that DS was recorded on the birth certificates of only 33.9 percent of these infants.

To gain an understanding of the basis for this low percentage of reporting, we reviewed the records of hospitals in Hamilton County, which includes Cincinnati. Our primary objectives were to compare the percentages of DS cases reported on birth certificates among hospitals and to determine the basis of the percentages reported by each hospital. We also believed that the detailed review of the records of the hospitals and cytogenetic laboratories necessary to answer these questions would provide nearly complete ascertainment of the number of DS births in the county during 1970–78. Thus, a further objective was to use this number to test the accuracy of chromosome analysis as a sampling procedure for estimating the total number of DS births in the county by the Lincoln-Peterson capture-recapture procedure (*6*), which has been used to estimate total DS births throughout the State (*7*).

Study Methods

Reporting of DS among hospitals. The names of infants with DS who were born in Hamilton County during 1970–78 were obtained from each hospital's medical records department for determining the reporting percentage of DS on birth certificates. In a number of instances the hospital records did not initially list the names of infants who had confirmed DS according to the records of the cytogenetic laboratories, which we had obtained for the second objective of the study. These names were added to the records of the appropriate hospitals. Each birth certificate was then checked for designation of DS or a synonym. This information provided a percentage reporting of DS and a total observed number based on as complete an ascertainment as possible. We believe that these data closely approximated the true DS population.

Data were collected from Cincinnati's two cytogenetic laboratories and the six hospitals in the county having maternity facilities—Bethesda, Christ, Cincinnati General, Good Samaritan, Our Lady of Mercy, and Jewish. By the method used in collecting DS data from the cytogenetic laboratories, all chromosomally analyzed cases reported here were determined to be DS (either 47, trisomy 21, or unbalanced translocations with 46 chromosomes).

All ± values are 95 percent confidence intervals; they were calculated by $\hat{p}\hat{g}/n$ because they are binomially distributed.

To determine the basis for the observed percentage of reporting of DS on birth certificates, the following documents or the equivalent were checked in five hospitals (Jewish Hospital being excluded because its Institutional Review Board was unable to grant approval).

- Labor and delivery sheet, which is filled out by a registered nurse during labor of mother and delivery of infant.
- Newborn nursery diagnosis, which is the pediatrician's assessment of the infant's physical condition after birth and after being admitted to the nursery. Although all hospitals have these units, only Good Samaritan and Our Lady of Mercy kept logbooks on infants' physical conditions. In the other three hospitals, the physicians described the infants in their charts.
- The discharge summary, which includes the physical diagnosis of the infant at the time of discharge from the hospital.
- The face sheet, which is the pediatrician's final summary of the infant's chart information. This document is the source of all numerical descriptive codes of the child's health. These codes are stored in the hospitals' computer systems.

Personnel from each department were interviewed, and the method of collection and flow of diagnostic information on these documents was determined for each hospital.

Estimation and comparison of total DS births. Since we had almost complete ascertainment of the total DS births in Hamilton County during 1970–78 (hereafter referred to as the population), we were able to test the accuracy of the Lincoln-Peterson capture-recapture procedure (*7*) in estimating this number. Chromosome analysis was used as the sampling procedure for the recapture method. In the fundamental form of this method, M individuals in a closed population of unknown size N are marked in some way, and from this population, a sample of n individuals is taken, m of whom are marked. The proportion of marked individuals should be the same in the sample as in the total population so that $m/n = M/N$, which leads to the estimate $N = Mn/m$ for the total population size. When we applied this method to the current project, the "marking" (M) was an infant recorded on the birth certificate as having DS (the first capture), and the recapture sample (n) consisted of infants who were determined to have DS by chromosome analysis in the cytogenetic laboratories. Some of the infants for whom chromosome analysis had been performed were reported to have DS on their birth certificates (m). Therefore, the total number of DS births was estimated as follows.

$$\hat{N}\ (\text{total DS births}) = \frac{M\ (\text{DS on birth certificates}) \times n\ (\text{chromosomally analyzed})}{m\ (\text{chromosomally analyzed and DS on birth certificates})}$$

Since this method of estimation is biased, a modified estimator which is less biased was used (*8*).

$$\hat{N} = [(M + 1)(n + 1)/(m + 1)] - 1 \qquad (1)$$

The following equation, given by Seber (*9*), is an approximate unbiased estimator of the variance of $\hat{N}$.

$$\text{Var}\ (\hat{N}) = \frac{(M+1)(n+1)(M-m)(n-m)}{(m+1)^2(m+2)} \qquad (2)$$

The square root of this value was used to calculate a 95 percent confidence interval for $\hat{N}$.

The only assumption of serious potential concern in using this estimation procedure is that sampling for n must be random with respect to M, that is, each child must have an equal chance of being chromosomally analyzed regardless of whether he or she was designated as DS on the birth certificate. Since the complete ascertainment data are available, these two methods of data collection may be tested for independence by comparing the percentage of reporting of DS through chromosome analysis with the percentage for those not chromosomally analyzed. If there is a positive correlation (rather than the assumed independence) between the probability that an infant is designated as DS on the birth certificate and the probability of being chromosomally analyzed, which seems likely, then $\hat{N}$ is an underestimate of N because m is too large.

Results

Reporting of DS among hospitals. A comparison of the numbers and percentages of DS births reported on the birth certificates for the six hospitals in Hamilton County is shown in table 1. None of the 58 DS infants born in 3 hospitals—Cincinnati General, Our Lady of Mercy, and Jewish—were so designated on their birth certificates; for the other 3 hospitals, the values were 24, 43, and 57 percent reporting. Although the latter two percentages differ significantly from zero reporting ($P < 0.05$), only Christ Hospital differs significantly from Bethesda

Hospital ($\chi_1^2 = 5.2$, $P < 0.05$) among those with a value greater than zero. The total percentage reporting according to this method of presumed complete ascertainment is 26. By summing over hospitals, we were able to compare the percentage reporting annually for the 9-year period. These values ranged from 6 to 38, with a heterogeneity χ^2 test of the data showing no significant variation among years ($\chi_8^2 = 7.7$, $0.5 > P < 0.25$).

We also considered the question of racial bias in the percentage reporting of DS. Of 18 black infants for whom DS was diagnosed, none were reported on the birth certificates, whereas of 155 white infants, 45 were so reported (27.0 ± 7.2 percent). Although the overall percentage is increased somewhat when the DS data for whites only are used, all statistical comparisons remain the same when DS data for blacks are excluded. For both races, the data unequivocally showed that the total number of observed DS births was consistently and significantly greater than the number reported on the birth certificates for each of the 9 years.

To understand these results, we examined each set of specific documents in the medical records of DS infants. The percentage of each of these documents containing the diagnosis of DS is compared by hospital in table 1. These documents were filled out in the following order: labor and delivery sheet, birth certificate (usually signed by the obstetrician at delivery and filled out by the birth certificate clerk later), newborn nursery logbook, discharge summary, and face sheet.

Overall, this sequence of documents showed a definite increase in the percentage of infants with diagnosed DS, although, as might be expected, the percentages for the discharge summary and the face sheet were similar. In instances where the percentage diagnosed was less on the face sheet than on the discharge summary, an error in recording was made by medical records personnel. The discharge records showed that DS entries on the face sheets ranged from 53 percent at Jewish Hospital to 91 percent at Good Samaritan and Cincinnati General.

In several instances, the physicians relied on chromosome analysis as the basis for their definitive diagnosis. Some of the infants had been discharged from the hospital before the positive results of their cytogenetic analysis were available; therefore, the face sheets for these infants did not contain the DS diagnosis. The number pending divided by the total number of chromosomally analyzed cases for each hospital is referred to as "percent chromosome analysis pending" (table 1); this percentage ranged from 10 at Good Samaritan to 23 at Our Lady of Mercy. If the results of the chromosome analysis had been received for these infants before they left the hospital, 160 of the 173 total cases of DS would have been reported on the face sheet. The remaining 13 were obtained from the records of cytogenetics laboratories. Thus, including those marked "chromosome analysis pending," 92.5 percent of the (known) babies having DS were diagnosed as such by the time they left the hospital. There is, of course, the possibility of underascertainment regarding the total DS population. However, since only 13 of 133 chromosomally analyzed cases were not indicated as DS on the medical records, the number missed would seem relatively small.

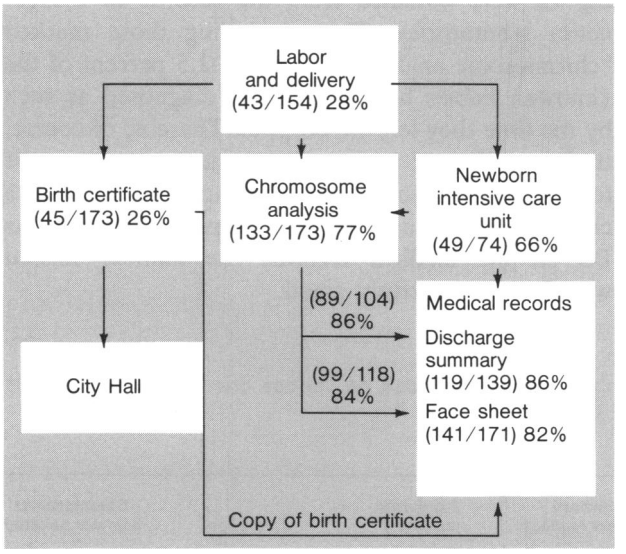
Table 1. Number and percentage of cases of diagnosed Down's syndrome recorded on various documents by hospitals in Hamilton County, Ohio, 1970–78

Hospital	Labor and delivery sheet		Birth certificate		Newborn nursery logbook		Discharge summary		Face sheet		Chromosome analysis pending	
	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent
Bethesda	8/38	21	9/38	24	NA	NA	29/38	76	30/38	79	7/33	21
Christ	11/21	52	12/21	57	NA	NA	17/21	81	16/21	76	3/14	21
Cincinnati General	2/22	9	0/25	0	NA	NA	20/24	83	21/23	91	2/15	13
Good Samaritan	18/55	33	24/56	43	41/56	73	37/38	97	51/56	91	4/42	10
Our Lady of Mercy	4/18	22	0/18	0	8/18	44	16/18	89	15/18	83	3/13	23
Jewish	....	..	0/15	0	....	..	....	..	8/15	53	....	..
Total	43/154	28	45/173	26	49/74	66	119/139	86	141/171	82	19/117	16

NOTE: Variations in numbers of documents seen in Good Samaritan and Our Lady of Mercy hospitals are due to unavailability of some medical records. NA indicates not available.

The typical flow of documents compiled in the records of DS infants is shown in the diagram. The method of information transfer within each hospital had remained relatively stable over the 9 years included in this study, with the exception of increased computerized sophistication within some medical records departments. If fetal distress or a serious abnormality was suspected by the obstetrician upon delivery, the infant was transferred immediately to the newborn intensive care unit (NBICU), if available, or its equivalent. A copy of the labor and delivery sheet was added to the baby's chart upon transfer to the newborn unit. Another copy of this sheet and a blank certificate, usually signed by the obstetrician, were sent directly to the birth certificate clerk. Thus, the prime responsibility for what was actually included on the birth certificate resided with the clerk rather than the obstetrician, although the obstetrician could write in a congenital anomaly when signing the blank document.

Typical flow chart of information on Down's syndrome infants in five hospitals in Hamilton County, Ohio



NOTE: Data for Jewish Hospital are excluded. Only two of the five hospitals kept logbooks in their newborn intensive care units, and fewer discharge summaries were found in the medical records than in the face sheets.

In general, the completed birth certificates were then sent to the Department of Vital Statistics in City Hall 1 day to 3 weeks after delivery. For 89 of 104 cases (85.6 percent), the results of chromosomone analysis were returned before the discharge summary was completed (see diagram). The average time of discharge for these 89 infants was 4 days; it ranged from 0 to 15 days. Of these 89 infants, 72.7 percent were discharged within 1 week after birth, and 91.9 percent were discharged within 2 weeks after birth. The face sheet was filled out 1 or 2 days after the discharge summary was entered in the chart.

The data clearly show that of the (known) DS cases, more than 90 percent in 5 of the 6 hospitals and more than 97 percent in 4 of the 6 hospitals were indicated by the time the infant was discharged; yet, the percentage reporting on the birth certificates ranged from a low of 0 percent to a high of 57 percent. It is important to emphasize that in all hospitals the labor and delivery sheet was the only document with any reference to the infant's health sent to the birth certificate clerk. There was little or no evidence of communication between the clerk and any other department within the hospital; therefore, only the obstetrician's immediate diagnosis (not the pediatrician's) was generally available.

Estimation and comparison of total DS births. Because of the substantial difference in the percentage of DS reporting between white infants (27.0) and black infants (0.0) in the total population, the data for whites were used to test for independence between designation as DS on the birth certificate and being chromosomally analyzed. Of the chromosomally analyzed cases in white infants, 26.7 percent (31 of 116) were designated as DS on the birth certificates, whereas of the cases not chromosomally analyzed, 38.5 percent (15 of 39) were recorded as DS on the birth certificates. A heterogeneity chi-square test shows that these figures are not statistically different ($\chi_1^2 = 1.9$, $0.25 > P > 0.1$); thus, whether chromosome analysis was done was not significantly affected by whether the infant was designated as DS on the birth certificate. Interestingly, the data suggest that a designation of DS on the birth certificate made it less likely that the infant would be chromosomally analyzed. This finding is consistent with the view that when physicians designated DS on the birth certificate, they were so sure of the diagnosis that chromosome analysis was not ordered. It also indicates that N may be an overestimate of $\hat{N}$, since m may now be anticipated to be too small (because fewer infants are both designated DS on the birth certificate and chromosomally analyzed).

Using the chromosome analysis data and the capture-recapture methodology in equation *1*, we

estimated total numbers of DS births in Hamilton County during 1970–78 as follows:

Variable in equation 1	Chromosome analysis: White infants	Chromosome analysis: Nonwhite infants	Chromosome analysis: Total
M (DS on birth certificate)	47	0	47
n (chromosomally analyzed)	116	17	133
m (chromosomally analyzed and DS on birth certificate)	31	0	31
N (estimated population size)	175±29.5	0	201±34.5
Total observed N	155	18	173

NOTE: ± value is 95 percent confidence interval obtained through use of equation 2 to calculate the variance of $\hat{N}$.

For whites only, $\hat{N}$ is 175, or 20 over the actual total 155 observed cases of DS among white infants, but well within the 95 percent confidence interval of ± 30. No separate estimate could be made for nonwhites because none with DS were found on the birth certificates. However, $\hat{N}$ for all races is 201 or 28 over the total observed of 173, again within statistical sampling error of ± 34. These results provide support for the use of chromosome analysis as a "recapture" sampling procedure in estimating total population size, but they also demonstrate the sensitivity of this or any recapture sampling procedure to being independent of designation as DS on the birth certificate. This sensitivity is demonstrated by use of the complete ascertainment percentage reporting to produce m (34.6) instead of the m value obtained through chromosome analysis (31). The new $\hat{N} = 176$ instead of 201 and is clearly closer to the observed N of 173, which is the presumed population parameter.

The values of M, n, and m are too small on a single-year basis to give meaningful estimates of annual DS births. However, if we assume that the observed N represents essentially complete ascertainment, these data may be used to calculate both single-year and total incidence rates for the 9-year period. These rates are given in table 2, with adjustments made for six DS fetuses detected through amniocentesis and known to be electively aborted by Hamilton County residents during 1973–78. The modification is based on a 0.75 probability of each fetus surviving to term. Three-year averages show a decline in incidence rates during the latter half of the decade, which is consistent with both statewide estimates of N and predictions for the State based on demographic changes (7). The overall incidence of 1.14 in Hamilton County is, however, somewhat below the previous statewide estimate of 1.22, which also includes DS fetuses electively aborted through prenatal diagnosis (7). The figure of 1.14 is somewhat above the incidence reported for Utah of 0.93 during 1968–72 (10) and by CDC (11) through the Birth Defects Monitoring Program (1.0 in 1978–79) and in Metropolitan Atlanta (0.96 mean annual incidence 1968–77). These reports do not include DS fetus loss through elective abortion.

Table 2. Total observed number of Down's syndrome (DS) births, number of recorded live births, and DS incidence rates in Hamilton County, Ohio, by year, 1970–78

Year	DS births [1]	Live births	Incidence per 1,000	Three-year average
1970	16	20,418	0.78	
1971	33	18,717	1.76	1.16
1972	16	16,794	0.95	
1973	23.5	16,005	1.47	
1974	12.75	16,219	0.79	1.16
1975	20	16,293	1.23	
1976	20.75	16,234	1.23	
1977	18	17,418	1.03	1.09
1978	17.5	17,893	0.89	
Total	177.5	155,991	1.14	

[1] Includes DS fetuses electively aborted × 0.75 probability fetus would have survived to term.

Discussion

The data for all races show considerable heterogeneity among hospitals in the percentage of DS reporting on the birth certificates (table 1). A comparison of percentages recorded on the labor and delivery sheets among the 5 reporting hospitals also shows significant heterogeneity ($\chi^2_4 = 11.9$, $0.025 > P > 0.01$), but the range is less (9–52 percent versus 0–57 percent). If data for whites only are used in the labor and delivery sheet comparison, the data no longer show significant heterogeneity ($\chi^2_4 = 8.4$, $0.1 > P > 0.05$). Thus, for whites, the difference among hospitals in reporting DS is based more on the differences in the way that the birth certificate clerks handle the data they receive than differences in the way physicians report information on the labor and delivery sheets. It remains clear, however, that even for white infants, the average reporting percentage for the hospitals is low over the 9-year period (31.2 percent on labor and delivery sheets, and 29.0 percent on birth certificates). The statewide percentage report-

ing on the birth certificates for whites during this period was estimated to be 36.5 (*5*). A similar rate of reporting for whites was found in upstate New York by Hook and Chambers (*12*). The birth certificates of 301 white infants born during 1963–74 who were chromosomally analyzed and known to have DS were located. The diagnosis of DS appeared on 37.5 percent of the birth certificates, although this percentage has been revised recently to 33.6 (*13*). In each of these studies, the percentage of reporting for nonwhites was substantially lower than that for whites.

To understand the basis for this underreporting at each hospital, it was necessary to refer to the communication flow charts. The only document available to the birth certificate clerk was the labor and delivery sheet, obviously a poor resource for the clerk to use in completing the section of the birth certificate indicating congenital anomalies (see diagram). The inaccuracy of the labor and delivery sheet clearly accounts for most of the underreporting on birth certificates at all the hospitals in this study.

At least part of the heterogeneity of underreporting among hospitals can be explained by different perceptions of DS among birth certificate clerks. At Cincinnati General, the clerk was unaware that DS is a congenital anomaly. Therefore, she did not record it in the appropriate section of the birth certificate even when it was reported on the labor and delivery sheet. The zero percentage reporting at Our Lady of Mercy Hospital indicated that the obstetricians did not make the diagnosis clear on the labor and delivery sheets. Descriptions referring to no more than some cardinal features of DS or at most "questionable DS" were typical of the obstetricians' comments.

It is doubtful that obstetricians' assessment of newborns' health will ever be a reliable resource for the reporting of DS or other congenital anomalies. Since 90 percent of all DS infants are discharged within 2 weeks of birth, and more than 90 percent of the face sheets showed either a firm diagnosis or chromosome analysis pending, the percentage of reporting could be increased substantially by rechanneling the communication flow to the birth certificate clerk *after* discharge rather than directly from the delivery room. This procedure presumably would not affect greatly the existing time frame of 1 day to 3 weeks for submission of the birth certificate to the local registrar. To avoid other inconsistencies leading to underreporting on the birth certificate, it is also necessary that well-trained clerks, knowledgeable of medical records and exhibiting a good understanding of medical terminology, be involved in the process leading to the reporting of congenital anomalies.

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