
Evaluation of the Hospital Discharge Diagnoses Index and the Birth Certificate as Sources of Information on Birth Defects

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Synopsis

The hospital discharge diagnoses index (DI) for newborns and the birth certificate were evaluated as

sources of information about birth defects by comparing them with the same births in the case registry of the California Birth Defects Monitoring Program (CBDMP). The CBDMP is an active surveillance system; the staff visit hospitals to identify children with birth defects diagnosed in the first year of life. The study population comprised 66,481 live births to residents of five counties in the San Francisco Bay area in 1983. Of these infants, 2,543 had at least one birth defect noted on the DI, and 1,623 were in the CBDMP registry; 1,020 with defects noted on the DI were also in the CBDMP registry. For this same population, 399 infants had one or more defects noted on the birth certificate; 304 of these were also in the CBDMP registry.

Reporting of birth defects on the birth certificate was poor for every condition. Reporting on the DI was most reliable for oral clefts and chromosomal defects; for these defects, the DI omitted one-third of the cases but had identified only about 10 percent false-positive (that is, unverified) cases. Major central nervous system malformations were less well reported, with about one-third of them false-positive. For all other birth defects, the DI either omitted more than half of the cases, or more than half of the cases reported were false-positive cases. These findings raise questions about the validity of analytic studies of birth defects if the data are obtained only from the DI or the birth certificate.

ABOUT 3 PERCENT OF ALL LIVEBORN infants have one or more major congenital malformations. The causes of most malformations are not known, but about 10 percent can be ascribed to environmental teratogens, such as radiation, methyl mercury, and the rubella virus. The best known environmental teratogen is thalidomide (1).

Surveillance of malformations is maintained to identify those birth defects that are caused by environmental teratogens and might be prevented, to provide a basis for studies of etiology, and to provide information for planning, provision, and evaluation of services. The systems now used to monitor the incidence of birth defects (2-8) are of three types: some are based on the hospital discharge diagnoses index (DI) for newborns (9, 10); some are based on the birth certificate or on a separate report filed shortly after birth (2, 6, 11, 12), and some are based on a registry (9, 10, 13, 14).

Sources of Data

Hospital discharge diagnoses index. All licensed hospitals maintain a DI which gives the principal diagnosis and additional diagnoses at the time of discharge, coded by the International Classification of Diseases, Ninth Revision, Clinical Modification (ICD) (15). In most cases, the newborn's medical record includes all the congenital anomalies noted before discharge. These anomalies are usually included among the diagnoses in the DI. Because the costs of data acquisition and data reduction are paid by the hospital as the DI is prepared, the added costs for a birth defects monitoring system based on these data are relatively small. DI information is now collected routinely by government agencies in several States as a low-cost tool for the surveillance of those birth defects diagnosed within the first few days after birth (10).

The Birth Defects Monitoring Program (BDMP) of the Centers for Disease Control (CDC) is typical of a DI-based program. CDC's BDMP data come from commercial abstracting services (16). CDC receives tabulations showing the number of cases and the rates for specific congenital defects and groupings of defects for individual hospitals, counties, and higher aggregates. In order to avoid duplicate reports for children who were transferred or discharged and readmitted, CDC's BDMP, like most DI-based systems, only uses reports for the newborn period (defined as birth date to discharge date from birth hospital). In 1983, a typical year, CDC's BDMP included more than 800,000 births, about one-fourth of the nation's total births (17). Although the data are not a random sample, CDC's BDMP can provide incidence data for the United States and geographic subdivisions for those birth defects diagnosed in newborns before their discharge from the hospital of birth (9, 10).

Birth certificate. All States require a birth certificate for all liveborn children, and in most States the certificate asks for information on any birth defects noted in the child (10). Despite many studies showing that birth defects are not well reported on the birth certificate (10, 18-28), it is tempting to use the birth certificate for surveillance of birth defects because there is a certificate for every child. A number of States use the birth certificate for surveillance (10), and at least two recent analytical studies have been based on this source (29, 30). Several countries use a separate report filed shortly after birth for their birth defects data (2, 6, 11, 12), but most States in the United States do not use a separate report (10).

Registries. A registry is a data system that incorporates names or other identifiers in such a way that duplicate reports can be consolidated. Some registries are designed so they may be used for case-control studies, analyses of patient characteristics, or other epidemiologic purposes. A number of States have birth defects registries (10), although they vary in their sources of data and in the completeness and extent of information recorded. The first birth defects registry established in the United States was the Metropolitan Atlanta Congenital Defects Program (MACDP) operated by CDC (9). The largest registry is the California Birth Defects Monitoring Program (CBDMP). Modeled on MACDP, CBDMP compiles and maintains a comprehensive registry of birth defects in California. CBDMP staff visit hospitals to identify children with birth defects, abstract the medical records, and code the data (10, 13).

In the United States, 37 States now have birth defects

monitoring systems; most of them are based on data obtained from the DI, the birth certificate, or a combination of these sources (10). These data are used both for surveillance and for analytic studies. Although DI-based surveillance of birth defects has been evaluated for a European system (31), no study has evaluated monitoring systems in the United States. Because objective evaluation of data sources is needed to provide a basis for valid statistical analyses of congenital anomalies, we evaluated the accuracy and reliability of reporting on the DI and the birth certificate by comparing data from these sources with data obtained through the CBDMP case registry.

Material and Methods

We compared reporting of birth defects from the DI, the birth certificate, and the CBDMP case registry for calendar year 1983, the first full year of operation of the CBDMP case registry. The study population comprised the 66,481 live births to residents of five San Francisco Bay area counties (Alameda, Contra Costa, San Francisco, San Mateo, and Santa Clara) which occurred in 1 of the 42 nonmilitary hospitals with obstetric services in this area. These births constituted 96.1 percent of all live births to residents of the five counties in the year of this study.

In 1983, CBDMP consisted only of the five San Francisco Bay area counties named; it now includes 57 of California's 58 counties. Registry data were obtained using standard CBDMP procedures (32). CBDMP staff collect all data on routine visits to all acute care hospitals having pediatric or obstetric facilities, or both, to offices of the California Children's Services (CCS) (1983-87), and to genetics centers. CBDMP case-finders screen hospital logs, the DI, birth certificates, and death certificates for possible cases of birth defects, review the medical records for the children identified from these sources as potential cases, abstract all pertinent information, and do all coding; DI codes are used only for casefinding.

Birth defects are structural anomalies generally encompassed by ICD codes 740-759 (32). All births and other hospital admissions of infants under 1 year are screened. All defects diagnosed during the first year after birth are included; to ensure completeness of coverage, data collection for births in a given calendar year continues until December of the second succeeding year, or later if this is considered necessary (for 1983 births, until July 1987). If the same child is seen at more than one hospital, reports from each source are maintained as separate computer records; reports are consolidated only when tabulations are made. There is no restriction on the number of diagnoses recorded for

any one child. If warranted, a CBDMP physician calls the child's physician to clarify a diagnosis. All cases in the registry are linked to the California Vital Statistics Live Birth Data File, which establishes residency and date of birth and provides denominator data. An elaborate review system ensures consistency and completeness of abstracting and coding, with multiple redundancy for the key steps.

Perimeters of the CBDMP data follow: (a) only conditions diagnosed or treated in a hospital or by CCS or geneticists are included; (b) only diagnoses written in the medical record are included; (c) only conditions diagnosed before a child is 1 year old are included; (d) specificity of the data is limited to what is written in the record; (e) conditions considered minor, such as metatarsus varus and nevi, which have highly variable clinical definitions, are excluded when they are isolated, but they are included when other congenital anomalies are present. "Minor" conditions are defined in the CBDMP Procedure Manual, and they conform to usual clinical terminology (32).

The DI data for this study were obtained by reviewing the DI printouts from each study hospital for diagnoses suggestive of a birth defect, as defined for CBDMP casefinding procedures (32). For each child with at least one DI diagnosis suggestive of a birth defect, the casefinders recorded the child's age, date of birth, name, medical record number, sex, and the 5-digit ICD code for each diagnosis. Because the date of birth is not recorded in the DI printout, casefinders copied the date of birth from the medical record. Data gathering from the DI continued until December 1984. DI information for newborns was key-entered and linked to records in the CBDMP case registry file and to the California Vital Statistics Live Birth Data File.

Information from birth certificates was obtained from the California Vital Statistics Live Birth Data File for 1983. Only children born in a study hospital to a resident of the five counties studied were retained in the study population. All births with at least one malformation coded on the birth certificate were included in the study.

Data analysis consisted of an examination of concordance of diagnoses for children appearing in any of the three sources, comparing DI data and birth certificate data, respectively, with the data in the CBDMP case registry. Comparisons with the DI were made at the 3-digit, 4-digit, and 5-digit ICD code levels. The California birth certificate reports birth defects using a code with 56 categories; comparisons with the birth certificate were made using the comparable ICD codes. The analysis examined the number of cases from each source, the number of cases in both sets (concordant cases), the malformation rates, the percentage of DI or

birth certificate cases that were not recorded in the CBDMP case registry (which we designated false-positive cases), and the percentage of CBDMP cases that were not recorded in the DI or the birth certificate, which we designated false-negative cases.

Results

Of the 66,481 live births, the DI recorded 2,543 cases (3.83 percent) with at least one ICD diagnosis between 740 and 759 (congenital anomaly); of these, 1,020 were linked to the 1,623 cases in the CBDMP registry with ICD diagnoses between 740 and 759, and 1,523 were not in the registry. Of the same 66,481 live births, 399 (0.60 percent) had one or more congenital malformations noted on the birth certificate; 304 of these births were also in the CBDMP case registry, and 95 were not in the registry.

Several factors affect the information recorded.

1. A child may have several conditions within one broad ICD coding category and a separate diagnosis for each condition. This may result in the number of diagnoses at the 5-digit level or the 4-digit level being greater than the number at the 3-digit level (for example, in tables 1 and 2 the number of cases at the 4-digit level will not usually add up to the number of cases at the 3-digit level).

2. A child may have been examined by more than one physician. If physicians have not agreed on a diagnosis, then each physician's diagnosis may have been coded separately. This, too, may result in more diagnoses at the 5-digit level or the 4-digit level than the number at the 3-digit level. CBDMP tries to remove less precise diagnoses in favor of more precise diagnoses, but this is not always possible.

3. The CBDMP registry diagnosis and the DI diagnosis may differ at the 5-digit level or the 4-digit level but agree at the 3-digit level. This may result in the number of concordant diagnoses being greater at the 3-digit level than at the 4-digit level.

4. The CBDMP registry, the DI, and the birth certificate differ in their treatment of "minor" malformations; specific examples of these differences are mentioned in the following sections.

Concordance of DI and CBDMP rates. The DI and the CBDMP registry were compared at the 3-digit, 4-digit, and 5-digit levels (table 1).

Central nervous system (CNS). About 34 percent of the DI cases were false-positives (cases in which CBDMP review of the medical record showed that no

CNS malformation was present), and more than half of the CBDMP-confirmed cases were not recorded in the DI. The largest single category of CNS anomalies was microcephalus, a diagnosis often not made at birth. However, the DI did not include a number of cases with conditions that would have been obvious at birth, including anencephalus and open spina bifida. Some cases of hydrocephalus reported on the DI were secondary to intraventricular hemorrhage and were miscoded as a birth defect.

Eye. The DI did not include most cases of anophthalmos, buphthalmos, cataract, and other serious eye anomalies (ICD categories 743.4 and 743.5) that may cause blindness. The other conditions included minor defects and, therefore, the DI rates and CBDMP rates were not comparable.

Ear, face, and neck. The DI did not include most of the conditions that impair hearing. More than half the cases of branchial cleft (an important developmental marker) that were in the CBDMP registry were not in the DI, and some cases reported in the DI were not confirmed by CBDMP. Most other defects in this system are minor, so DI rates and CBDMP rates were not comparable.

Heart and circulatory system. The DI diagnoses in this system were often not specific. Most DI diagnoses were ventricular septal defects, patent ductus arteriosus, or unspecified defects (that is, murmurs). Septal defects and patent ductus arteriosus are considered minor defects by CBDMP unless confirmed as a major defect by a diagnostic procedure such as cardiac catheterization or treatment for congestive heart failure; murmur is never considered reportable. The DI did not include most diagnoses of major defects, such as transposition of the great vessels, tetralogy of Fallot, valve anomalies, and hypoplastic left heart.

Respiratory system. The DI did not include or misclassified most cases of choanal atresia and of lung agenesis and dysplasia. Most other conditions recorded were minor and not comparable.

Cleft palate and cleft lip. Although there was some misclassification of these anomalies in the DI, there were few false-positive cases in this group. However, the DI did not include 33 percent of the cases found by CBDMP.

Digestive system. Cases of pyloric stenosis usually were not recorded in the DI, which was expected because the condition usually is manifest after a new-

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born is discharged from the hospital. However, 40 percent to 66 percent of the cases of fistula, atresia, and stenosis (tracheoesophageal, small intestine, and large intestine) were omitted from the DI. There were no false-positive cases of tracheoesophageal fistula, but 25 percent to 54 percent of the cases of intestinal stenosis or atresia that were reported in the DI were false-positive.

Genital organs. The DI did not include most defects of female genitalia and did not include 18 percent of the cases of hypospadias and epispadias. CBDMP considers isolated undescended testicle to be reportable only if it persists beyond the first week, so rates for this condition were not comparable.

Urinary system. The DI did not include 58 percent of the cases noted by CBDMP in this group, and one-third of the cases that were reported in the DI were false-positive cases.

Musculoskeletal. CBDMP considers hip dysplasia a minor defect unless diagnosed by X-ray or treated, and subluxation is always considered a minor defect. When subluxations were excluded from the analysis, the number of false-positive cases in the DI dropped, but the DI did not include half of the hip dysplasia cases found by CBDMP. CBDMP considers metatarsus, pes planus, and similar defects to be minor. When only talipes were included in the foot categories, 28 percent of the DI cases were false-positive, and the DI did not include 56 percent of the cases found by CBDMP. CBDMP considers "polydactyly" to be skin tags and a minor condition unless there is a bone present; the DI rate includes cases of skin tags. Many cases of limb reduction found by CBDMP were cases of phalangeal reduction (stubby fingers and toes); when those cases were excluded, the DI had only 11 percent false-positive cases but did not include 72 percent of the cases identified by CBDMP. Most other categories were also understated in the DI by half or more. Some DI cases of abdominal wall defects were a misclassification of umbilical hernia.

Table 1. Concordance of hospital DI and CBDMP registry diagnoses for congenital anomalies, five San Francisco Bay area counties, 1983

ICD	Malformation Description	Number		Rate ¹		Percent		
		CBDMP	DI	In both	CBDMP	DI	DI, not in CBDMP	CBDMP, not in DI
	Total births	66,481						
	Male	33,913						
	Female	32,568						
740-759	Total cases	1,623	2,543	1,020	24.41	38.25	59.9	37.2
	Male	1,006	1,427	621	29.66	42.08	56.5	38.3
	Female	617	1,116	399	18.94	34.27	64.2	35.3
740-742	Central nervous system	138	87	57	2.08	1.31	34.5	58.7
740	Anencephalus and similar anomalies	14	11	11	0.21	0.17	0.0	21.4
741	Spina bifida	24	12	12	0.36	0.18	0.0	50.0
741.0	With hydrocephalus	15	6	6	0.23	0.09	0.0	60.0
741.9	Without hydrocephalus	11	6	3	0.17	0.09	50.0	72.7
742	Other nervous system	102	64	33	1.53	0.96	48.4	67.6
742.0	Encephalocele	4	4	3	0.06	0.06	25.0	25.0
742.1	Microcephalus	67	23	16	1.01	0.35	30.4	76.1
742.2	Reduction deformity of brain	9	2	2	0.14	0.03	0.0	77.8
742.3	Congenital hydrocephalus	25	27	12	0.38	0.41	55.6	52.0
742.4	Other brain	7	9	0	0.11	0.14	100.0	100.0
742.5	Other spinal cord	1	0	0	0.02	100.0
742.8	Other specified CNS	2	1	0	0.03	0.02	100.0	100.0
742.9	Unspecified CNS	0	2	0	...	0.03	100.0	...
743	Eye	190	29	14	2.86	0.44	51.7	92.6
743.0	Anophthalmos	4	2	2	0.06	0.03	0.0	50.0
743.1	Microphthalmos	15	2	1	0.23	0.03	50.0	93.3
743.2	Buphthalmos	3	1	0	0.05	0.02	100.0	100.0
743.3	Cataract and lens	13	4	3	0.20	0.06	25.0	76.9
743.4	Anterior segment	12	3	2	0.18	0.05	33.3	83.3
743.5	Posterior segment	4	0	0	0.06	100.0
743.6	Eyelids, lacrima, orbit	162	14	6	2.44	0.21	57.1	96.3
743.8	Other specified	5	2	0	0.08	0.03	100.0	100.0
743.9	Unspecified	0	1	0	...	0.02	100.0	...
744	Ear, face, and neck	265	162	47	3.99	2.44	71.0	82.3
744.0	Ear, impairing hearing	10	2	2	0.15	0.03	0.0	80.0
744.1	Accessory auricle	24	115	8	0.36	1.73	93.0	66.7
744.2	Other ear, specified	192	16	15	2.89	0.24	6.3	92.2
744.3	Unspecified ear	8	16	2	0.12	0.24	87.5	75.0
744.4	Branchial cleft	11	8	5	0.17	0.12	37.5	54.5
744.5	Webbing of neck	15	0	0	0.23	100.0
744.8	Other specified face and neck	61	4	3	0.92	0.06	25.0	95.1
744.9	Unspecified face and neck	53	5	1	0.80	0.08	80.0	98.1
745-747	Heart and circulatory system	345	500	144	5.19	7.52	71.2	58.3
745	Bulbus cordis and cardiac septum	237	134	39	3.56	2.02	70.9	83.5
745.0	Common truncus	7	2	2	0.11	0.03	0.0	71.4
745.1	Transposition of great vessels	40	6	2	0.60	0.09	66.7	95.0
745.2	Tetralogy of Fallot	29	7	3	0.44	0.11	57.1	89.7
745.3	Common ventricle	11	0	0	0.17	100.0
745.4	Ventricular septal defect	138	103	21	2.08	1.55	79.6	84.8
745.5	Ostium secundum type atrial septal defect	113	9	6	1.70	0.14	33.3	94.7
745.6	Endocardial cushion	26	6	3	0.39	0.09	50.0	88.5
745.8	Other septal	0	3	0	...	0.05	100.0	...
745.9	Unspecified septal	0	4	0	...	0.06	100.0	...
746	Other heart	145	187	64	2.18	2.81	65.8	55.9
746.0	Pulmonary valve	58	15	2	0.87	0.23	86.7	96.6
746.1	Tricuspid valve	11	1	0	0.17	0.02	100.0	100.0
746.2	Ebstein's anomaly	2	1	1	0.03	0.02	0.0	50.0
746.3	Aortic valve stenosis	4	1	0	0.06	0.02	100.0	100.0
746.4	Aortic valve insufficiency	9	3	1	0.14	0.05	66.7	88.9

Table 1. Concordance of hospital DI and CBDMP registry (continued)

ICD	Malformation Description	Number			Rate ¹		Percent	
		CBDMP	DI	In both	CBDMP	DI	DI, not in CBDMP	CBDMP, not in DI
746.5	Mitral stenosis	5	2	1	0.08	0.03	50.0	80.0
746.6	Mitral insufficiency	3	2	1	0.05	0.03	50.0	66.7
746.7	Hypoplastic left heart	27	5	5	0.41	0.08	0.0	81.5
746.8	Other specified	59	53	16	0.89	0.80	69.8	72.9
746.9	Unspecified	23	111	11	0.35	1.67	90.1	52.2
747	<i>Other circulatory system</i>	200	218	25	3.01	3.28	88.5	87.5
747.0	Patent ductus arteriosus	127	142	11	1.91	2.14	92.3	91.3
747.1	Coarctation of aorta	34	3	2	0.51	0.05	33.3	94.1
747.2	Other aorta	25	2	1	0.38	0.03	50.0	96.0
747.3	Pulmonary artery	18	14	1	0.27	0.21	92.9	94.4
747.4	Great veins	22	3	1	0.33	0.05	66.7	95.5
747.5	Umbilical artery	29	17	3	0.44	0.26	82.4	89.7
747.6	Other peripheral	9	7	1	0.14	0.11	85.7	88.9
747.8	Other specified	5	2	1	0.08	0.03	50.0	80.0
747.9	Unspecified	0	33	0	...	0.50	100.0	...
748	<i>Respiratory system</i>	175	63	22	2.63	0.95	65.1	87.4
748.0	Choanal atresia	14	11	5	0.21	0.17	54.5	64.3
748.1	Other nose	122	11	2	1.84	0.17	81.8	98.4
748.3	Other larynx, trachea, bronchus	13	18	2	0.20	0.27	88.9	84.6
748.4	Cystic lung	2	0	0	0.03	100.0
748.5	Lung agenesis, hypoplasia, dysplasia	27	16	6	0.41	0.24	62.5	77.8
748.6	Other lung	4	8	1	0.06	0.12	87.5	75.0
748.8	Other specified	8	0	0	0.12	100.0
749	<i>Cleft plate and cleft lip</i>	118	83	78	1.77	1.25	6.0	33.9
749.0	Cleft plate	48	24	21	0.72	0.36	12.5	56.3
749.1	Cleft lip	34	23	21	0.51	0.35	8.7	38.2
749.2	Cleft palate with cleft lip	44	36	32	0.66	0.54	11.1	27.3
750-751	<i>Digestive system</i>	402	101	67	6.05	1.52	33.7	83.3
750	<i>Other upper alimentary tract</i>	281	42	31	4.23	0.63	26.2	89.0
750.0	Tongue tie	8	13	5	0.12	0.20	61.5	37.5
750.1	Other tongue	47	4	1	0.71	0.06	75.0	97.9
750.2	Other mouth and pharynx	74	3	3	1.11	0.05	0.0	95.9
750.3	Tracheoesophageal fistula, atresia, stenosis	20	12	12	0.30	0.18	0.0	40.0
750.4	Other esophagus	0	1	0	...	0.02	100.0	...
750.5	Pyloric stenosis	140	3	3	2.11	0.05	0.0	97.9
750.6	Hiatus hernia	0	1	0	...	0.02	100.0	...
750.7	Other stomach	2	1	0	0.03	0.02	100.0	100.0
750.8	Other specified	0	2	0	...	0.03	100.0	...
750.9	Unspecified	3	2	0	0.05	0.03	100.0	100.0
751	<i>Other digestive system</i>	138	59	35	2.08	0.89	40.7	74.6
751.0	Meckel's diverticulum	7	1	0	0.11	0.02	100.0	100.0
751.1	Atresia or stenosis of small intestine	15	11	5	0.23	0.17	54.5	66.7
751.2	Atresia or stenosis of large intestine	34	20	15	0.51	0.30	25.0	55.9
751.3	Hirschsprung's disease	10	2	2	0.15	0.03	0.0	80.0
751.4	Intestinal fixation	23	3	2	0.35	0.05	33.3	91.3
751.5	Other intestine	55	17	2	0.83	0.26	88.2	96.4
751.6	Gallbladder, liver	13	6	0	0.20	0.09	100.0	100.0
751.7	Pancreas	5	0	0	0.08	100.0
751.8	Other specified	1	1	0	0.02	0.02	100.0	100.0
751.9	Unspecified	1	0	0	0.02	100.0
752	<i>Genital organs</i>	328	397	209	4.93	5.97	47.4	36.3
752.0	Ovaries	1	0	0	0.03	100.0
752.1	Fallopian tubes	1	0	0	0.03	100.0
752.2	Doubling of uterus	3	2	1	0.09	0.06	50.0	66.7
752.3	Other uterus	5	1	1	0.15	0.03	0.0	80.0
752.4	Cervix, vagina	32	20	11	0.98	0.61	45.0	65.6
752.5	Undescended testicle	63	176	20	2.86	25.19	88.6	68.3
752.6	Hypospadias and epispadias	198	165	162	5.84	24.87	1.8	18.2
752.7	Indeterminate sex	10	3	2	0.15	0.05	33.3	80.0
752.8	Other specified	64	24	7	0.96	0.36	70.8	89.1

Table 1. Concordance of hospital DI and CBDMP registry (continued)

ICD	Malformation Description	Number			Rate ¹		Percent	
		CBDMP	DI	In both	CBDMP	DI	DI, not in CBDMP	CBDMP, not in DI
752.9	Unspecified.....	3	12	0	0.05	0.18	100.0	100.0
753	<i>Urinary system</i>	97	60	40	1.46	0.90	33.3	58.8
753.0	Renal agenesis.....	20	9	8	0.30	0.14	11.1	60.0
753.1	Cystic kidney.....	21	8	7	0.32	0.12	12.5	66.7
753.2	Ureteral obstruction.....	44	21	15	0.66	0.32	28.6	65.9
753.3	Other kidney, specified.....	12	6	1	0.18	0.09	83.3	91.7
753.4	Other ureter, specified.....	9	0	0	0.14	100.0
753.5	Exstrophy of bladder.....	3	3	3	0.05	0.05	0.0	0.0
753.6	Urethral atresia or stenosis.....	10	3	2	0.15	0.05	33.3	80.0
753.7	Urachus.....	3	1	0	0.05	0.02	100.0	100.0
753.8	Other specified.....	18	4	2	0.27	0.06	50.0	88.9
753.9	Unspecified.....	3	11	0	0.05	0.17	100.0	100.0
754-756	<i>Musculoskeletal</i>	657	676	334	9.88	10.17	50.6	49.2
754	<i>Certain musculoskeletal</i>	370	335	166	5.57	5.04	50.4	55.1
754.0	Skull, face and jaw.....	79	32	10	1.19	0.48	68.8	87.3
754.1	Sternocleidomastoid.....	9	5	2	0.14	0.08	60.0	77.8
754.2	Spine.....	14	1	1	0.21	0.02	0.0	92.9
754.3	Hip dislocation and subluxation.....	109	138	58	1.64	2.08	58.0	46.8
	Hip dislocation ³	97	87	48	1.46	1.31	44.8	50.5
754.4	Genu recurvatum and bowing.....	18	8	3	0.27	0.12	62.5	83.3
754.5	Varus, feet.....	91	65	31	1.37	0.98	52.3	65.9
754.6	Valgus, feet.....	56	30	16	0.84	0.45	46.7	71.4
754.7	Other feet.....	57	51	20	0.86	0.77	60.8	64.9
	Talipes ⁴	164	101	72	2.47	1.52	28.7	56.1
754.8	Other specified.....	69	17	8	1.04	0.26	52.9	88.4
755	<i>Other limb</i>	296	250	112	4.45	3.76	55.2	62.2
755.0	Polydactyly.....	53	110	43	0.80	1.65	60.9	18.9
755.1	Syndactyly.....	62	31	30	0.93	0.47	3.2	51.6
755.2	Reduction, upper limb.....	69	10	9	1.04	0.15	10.0	87.0
755.3	Reduction, lower limb.....	43	12	9	0.65	0.18	25.0	79.1
755.4	Reduction, unspecified limb.....	8	0	0	0.12	100.0
	Reduction, except phalangeal ⁵	54	17	15	0.81	0.26	11.8	72.2
755.5	Other upper limb.....	127	21	12	1.91	0.32	42.9	90.6
755.6	Other lower limb.....	98	85	13	1.47	1.28	84.7	86.7
755.8	Other specified, limb.....	2	1	0	0.03	0.02	100.0	100.0
755.9	Unspecified, limb.....	2	1	0	0.03	0.02	100.0	100.0
756	<i>Other musculoskeletal</i>	218	115	54	3.28	1.73	53.0	75.2
756.0	Skull and face bones.....	138	47	15	2.08	0.71	68.1	89.1
756.1	Spine.....	37	6	3	0.56	0.09	50.0	91.9
756.3	Other rib and sternum.....	38	7	5	0.57	0.11	28.6	86.8
756.4	Chondrodystrophy.....	11	6	5	0.17	0.09	16.7	54.5
756.5	Osteodystrophies.....	10	6	4	0.15	0.09	33.3	60.0
756.6	Diaphragm.....	18	14	10	0.27	0.21	28.6	44.4
756.7	Abdominal wall.....	20	28	7	0.30	0.42	75.0	65.0
756.8	Other specified, muscle.....	7	3	2	0.11	0.05	33.3	71.4
756.9	Other musculoskeletal.....	5	4	1	0.08	0.06	75.0	80.0
757	<i>Integument</i>	225	541	33	3.38	8.14	93.9	85.3
757.0	Hereditary edema of legs.....	2	3	1	0.03	0.05	66.7	50.0
757.2	Dermatoglyphic.....	85	19	3	1.28	0.29	84.2	96.5
757.3	Other specified, skin.....	107	489	12	1.61	7.36	97.5	88.8
757.4	Hair.....	15	3	1	0.23	0.05	66.7	93.3
757.5	Nails.....	34	2	0	0.51	0.03	100.0	100.0
757.6	Breast.....	60	22	13	0.90	0.33	40.9	78.3
757.8	Other specified.....	0	2	0	...	0.03	100.0	...
757.9	Unspecified.....	1	2	0	0.02	0.03	100.0	100.0
758	<i>Chromosomal</i>	93	64	57	1.40	0.96	10.9	38.7
758.0	Down's syndrome.....	57	40	39	0.86	0.60	2.5	31.6
758.1	Patau's syndrome.....	4	2	2	0.06	0.03	0.0	50.0
758.2	Edwards's syndrome.....	8	6	2	0.12	0.09	66.7	75.0
758.3	Autosomal deletion.....	4	0	0	0.06	100.0

Table 1. Concordance of hospital DI and CBDMP registry (continued)

Malformation		Number			Rate ¹		Percent	
ICD	Description	CBDMP	DI	In both	CBDMP	DI	DI, not in CBDMP	CBDMP, not in DI
758.4	Balanced translocation.....	3	2	1	0.05	0.03	50.0	66.7
758.5	Other autosomal.....	12	0	0	0.18	100.0
758.6	Gonadal dysgenesis.....	4	4	2	0.06	0.06	50.0	50.0
758.7	Klinefelter syndrome.....	3	3	2	0.05	0.05	33.3	33.3
758.8	Other sex chromosome.....	0	1	0	...	0.02	100.0	...
758.9	Unspecified chromosome.....	0	6	0	...	0.09	100.0	...
759	<i>Other and unspecified.....</i>	62	52	17	0.93	0.78	67.3	72.6
759.0	Spleen.....	12	8	1	0.18	0.12	87.5	91.7
759.1	Adrenal glands.....	7	3	1	0.11	0.05	66.7	85.7
759.2	Other endocrine glands.....	7	2	2	0.11	0.03	0.0	71.4
759.3	Situs inversus.....	4	1	0	0.06	0.02	100.0	100.0
759.5	Tuberous sclerosis.....	1	0	0	0.02	100.0
759.6	Other hamartomas.....	2	1	0	0.03	0.02	100.0	100.0
759.7	Multiple NOS.....	0	16	0	...	0.24	100.0	...
759.8	Other specified.....	29	17	8	0.44	0.26	52.9	72.4
759.9	Unspecified.....	3	5	0	0.05	0.08	100.0	100.0

¹Rates are per 1,000 live births.

²Sex specific.

³ICD 754.30, 754.31, 754.35.

⁴ICD 754.50, 754.51, 754.60, 754.62, 754.70, 754.71.

⁵ICD 755.20-755.4 except 755.29, 755.39.

NOTE: CBDMP = California Birth Defects Monitoring Program Case Registry; ICD = International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM); DI = hospital discharge diagnoses index for newborn; ... = no cases.

Chromosomal. The DI did not include 31 percent of the cases of Down's syndrome, but only one false-positive case was reported. Other chromosomal conditions were less well reported.

Integument. The DI includes nevi, mongolian spots, and skin tags, whereas CBDMP records the minor defects that accompany major defects but not isolated minor defects. Thus, the DI and the CBDMP rates were not comparable.

Other. The DI misclassified almost all cases of spleen anomalies, endocrine gland anomalies, situs inversus, and tuberous sclerosis. The remaining categories are residual or unspecified.

The DI included many false-positive and false-negative cases at every level of analysis—the 3-digit, 4-digit, or 5-digit ICD codes. The DI assigned many cases to different, and less precise, categories at the 5-digit level than did the CBDMP. Thus, the DI classified many cases of major heart defects as unspecified. When the 4-digit or the 3-digit level of analysis was used, differences in assignment to 5-digit categories were unimportant because categories were merged, but this added minor defects to major defects. Thus, single umbilical artery and murmurs of no clinical importance became merged with major heart conditions at the 3-digit level, and flat feet were merged with talipes at the 4-digit level. The result was that, at every level of analysis, the DI showed marked disagreement with the registry.

Concordance of birth certificate and CBDMP rates.

Analysis was made comparing the birth certificate code and the ICD equivalent (table 2). Rates for anencephalus in the birth certificate and in the CBDMP registry were similar, but 30 percent of the cases recorded in the birth certificate were not confirmed by CBDMP, and 35 percent of the CBDMP-confirmed cases were missed by the birth certificate. Of the hydrocephalus cases, 44 percent reported on the birth certificate were not confirmed by CBDMP, and 87 percent of the cases confirmed by CBDMP were omitted on the birth certificate. The birth certificate did not acknowledge about 90 percent of the major heart conditions and about half of the cases of cleft lip or palate, or both, nor did it record 70 to 94 percent of the cases of fistula, atresia, and stenosis of the trachea, esophagus, and large intestine. Reporting of hypospadias and epispadias on the birth certificate was almost nil. The birth certificate did not record 73 percent of the cases of Down's syndrome confirmed by CBDMP.

Discussion

CBDMP's system of multiple ascertainment and review achieves a high level of ascertainment and accurate diagnoses of birth defects diagnosed in infants younger than 1 year of age (32). CBDMP includes a complete medical chart review of any child who had any condition suggestive of a birth defect noted on the DI, in nursery or obstetrical logs, or on the birth certificate, and CBDMP does all coding. Thus, the CBDMP

Table 2. Concordance of birth certificate and CBDMP registry diagnoses for congenital anomalies, five San Francisco Bay area counties, 1983

BC code ICD		Malformation Description	Number			Rate ¹		Percent	
			CBDMP	BC	In both	CBDMP	BC	BC, not in CBDMP	CBDMP, not in BC
		Total cases.....	1,625	399	304	24.44	6.00	23.8	81.3
01	740	Anencephalus.....	14	13	9	0.21	0.20	30.8	35.7
02	741	Spina bifida.....	24	8	6	0.36	0.12	25.0	75.0
03	742.0	Encephalocele.....	4	7	3	0.06	0.11	57.1	25.0
04	742.1	Microcephalus.....	67	5	1	1.01	0.08	80.0	98.5
05	741.0, 742.3	Hydrocephalus.....	40	9	5	0.60	0.14	44.4	87.5
06	740-742 NEC	Other CNS.....	18	12	0	0.27	0.18	100.0	100.0
07	743.0	Anophthalmos.....	4	4	1	0.06	0.06	75.0	75.0
08	743.3	Cataract.....	13	3	0	0.20	0.05	100.0	100.0
09	743.4	Coloboma ³	0	4	0	...	0.06	100.0	...
10	743 NEC	Other eye.....	178	5	2	2.68	0.08	60.0	98.9
11	744.4	Branchial cleft.....	11	3	0	0.17	0.05	100.0	100.0
12	744 NEC	Other ear, face, neck.....	258	29	21	3.88	0.44	27.6	91.9
13	745.0	Truncus arteriosus.....	7	5	1	0.11	0.08	80.0	85.7
14	745.1	Transposition of great vessels.....	40	9	4	0.60	0.14	55.6	90.0
15	745.2	Tetralogy of Fallot.....	29	2	2	0.44	0.03	0.0	93.1
16	745.4	Ventricular septal defect.....	138	5	2	2.08	0.08	60.0	98.6
17	745.5	Atrial septal defect.....	113	1	0	1.70	0.02	100.0	100.0
18	745.6	Endocardial cushion.....	26	2	1	0.39	0.03	50.0	96.2
19	746.0-746.6	Valve stenosis and insufficiency.....	78	3	3	1.17	0.05	0.0	96.2
20	746.7	Hypoplastic left heart.....	27	3	3	0.41	0.05	0.0	88.9
21	747.0	Patent ductus arteriosus.....	127	4	1	1.91	0.06	75.0	99.2
22	747.1	Coarctation of aorta.....	34	1	1	0.51	0.02	0.0	97.1
23	745-747 NEC	Other heart and circulatory.....	154	20	12	2.32	0.30	40.0	92.2
24	748.0	Choanal atresia.....	14	0	0	0.21	100.0
25	748.5	Lung agenesis, hypoplasia, dysplasia.....	27	7	2	0.41	0.11	71.4	92.6
26	748 NEC	Other respiratory.....	146	11	0	2.20	0.17	100.0	100.0
27	749.0	Cleft palate.....	48	7	5	0.72	0.11	28.6	89.6
28	749.1	Cleft lip.....	34	20	16	0.51	0.30	20.0	52.9
29	749.2	Cleft palate with cleft lip.....	44	23	20	0.66	0.35	13.0	54.5
		Tracheoesophageal fistula, atresia, stenosis.....	20	6	6	0.30	0.09	0.0	70.0
31	751.2	Large intestine atresia, stenosis.....	34	3	2	0.51	0.05	33.3	94.1
32	750-751 NEC	Other digestive.....	364	17	3	5.48	0.26	82.4	99.2
33	752.6	Hypospadias and epispadias.....	198	12	11	5.84	0.35	8.3	94.4
34	752.7	Indeterminate sex.....	10	4	3	0.15	0.06	25.0	70.0
35	753.0	Renal agenesis ³ (bilateral only).....	13	4	4	0.20	0.06	0.0	69.2
36	753.1	Cystic kidney.....	21	3	2	0.32	0.05	33.3	90.5
37	753.2	Ureteral obstruction.....	44	0	0	0.66	100.0
38	753.5	Exstrophy of bladder.....	3	1	1	0.05	0.02	0.0	66.7
39	752-753 NEC	Other genitourinary.....	187	15	5	2.81	0.23	66.7	97.3
40	754.3	Hip dislocation without CNS ³	88	10	7	1.32	0.15	30.0	92.0
41	754.5-754.7	Talipes or clubfoot ³	164	19	15	2.47	0.29	21.1	90.9
42	755.0	Preaxial polydactyly ³	14	16	2	0.21	0.24	87.5	85.7
43	755.2-755.4	Missing extremity.....	96	16	14	1.44	0.24	12.5	85.4
44	756.0	Craniosynostosis ³	6	0	0	0.09	100.0
45	756.4	Chondrodystrophy.....	11	1	1	0.17	0.02	0.0	90.9
46	756.6	Diaphragm.....	18	1	1	0.27	0.02	0.0	94.4
47	756.7	Abdominal wall.....	20	0	0	0.30	100.0
48	754-756 NEC	Other musculoskeletal.....	431	51	27	6.48	0.77	47.1	93.7
49	757	Skin, nails, hair.....	225	5	1	3.38	0.08	80.0	99.6
50	658.8	Amniotic bands ³	13 ²	2	1	0.20	0.03	50.0	92.3
51	758.0	Down syndrome.....	57	16	15	0.86	0.24	6.3	73.7
52	758.1-758.2	Autosomal trisomies.....	12	6	2	0.18	0.09	66.7	83.3
53	758.6-758.7	Sex chromosomes.....	7	1	1	0.11	0.02	0.0	85.7
54	758 NEC	Other chromosomal.....	17	1	0	0.26	0.02	100.0	100.0
55	759 (except 759.7)	Other and unspecified.....	62	35	4	0.93	0.53	88.6	93.5
98	759.7	Multiple nonspecific.....	0	13	0	...	0.20	100.0	...

¹Rates are per 1,000 live births.

²Includes 2 cases with amniotic bands but no diagnoses in ICD 740-759.

³Only part of these ICD categories are included in the birth certificate category.

⁴Sex specific.

NOTE: BC = birth certificate; CBDMP = California Birth Defects Monitoring Program Case Registry; ICD = International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM); ... = no cases.

registry provides a rational standard against which monitoring programs based on the DI or on the birth certificate can be assessed. The results of this study show that neither the DI nor the birth certificate approach the levels of accuracy and completeness needed for routine surveillance of congenital anomalies, or for research on etiology or on demographics of birth defects. Both of these sources failed to acknowledge many defects that are obvious on a casual examination, and both included many false-positive cases among cases that they did report.

The CBDMP registry includes diagnoses made at any time during the first year, whereas the DI and the birth certificate represent only the newborn period. For this reason, neither the DI nor the birth certificate can be expected to be accurate with respect to certain conditions. Many infants with internal defects do not show immediate distress and may be discharged from the hospital as apparently well. However, differences between the three systems were noted in conditions for which the reporting period was not a relevant factor. For example, half of the open spina bifida cases and one-third of the oral cleft cases were not reported on the DI, and reporting on the birth certificate was worse.

Review of the CBDMP case abstracts showed that many anomalies not coded in the DI were found by CBDMP staff at the hospital of birth; the anomalies were noted in the medical record but had not been coded. Some conditions reported by the DI which we counted as false-positive cases were in the medical record but were not confirmed. For example, conditions were reported by the DI that were qualified as only a "possible" defect and were not confirmed by later examination—sometimes an examination done on the same day. Many conditions recorded in the DI were coding errors; that is, a condition was present, but it was not that described by the code. A number of minor conditions were coded in the DI and some were miscoded as major defects; for example, cases of umbilical hernia were misreported on the DI as abdominal wall defect. Also, some hospitals put an arbitrary limit on the number of conditions coded. If priority is given to diagnoses of "liveborn," "preterm," "respiratory distress," and "neonatal jaundice," there would not be room in the DI for many birth defects.

We believe that both the DI rates and the CBDMP registry rates for the five counties studied are representative of birth defect rates that would be found from these sources across the United States for 1983. In support of this opinion, the CBDMP registry rates were in close agreement with those of CDC's MACDP registry (33), and the DI rates were in close agreement with those of CDC's BDMP, which is based on the DI; exceptions were CNS defects and Down's syndrome, in

which CDC's BDMP rates were substantially elevated by the inclusion of stillbirths (17).

However, adoption of diagnosis related groups (DRG) as the basis for payments by many health insurers raises a question regarding whether the 1983 findings can be generalized to the present. DRGs provide an incentive to tailor diagnoses to favor greater remuneration to the institution, which may result in certain defects being overdiagnosed. However, we do not address the question of DRG in this study, beyond noting that DRGs are not likely to improve the reporting of birth defects in the DI and may further impair the DI's accuracy.

Irrespective of the changes that DRGs may introduce, DI rates cannot be accepted at face value. For most major conditions, DI rates are too low, and the diagnoses often are not specific. The DI was more accurate in recording obvious conditions such as anencephalus than in reporting conditions that are not obvious on less than careful observation. It appeared that the DI usually included conditions causing immediate and serious illness or those on a hospital checklist for newborns; otherwise the condition was likely to go unrecorded. This reflects the practice in many hospitals, where medical records coders almost always review the discharge summary, operative reports, and the newborn's examination, but may not review other parts of the medical record.

There are several reasons why the DI is much less reliable than the CBDMP registry, even though both get most of their information from the same source, the medical record:

1. The DI includes poorly described conditions, and some not confirmed by later examination.
2. Procedures for examinations and for recording and coding diagnoses differ among hospitals.
3. Review or verification of the diagnoses or coding is not done at some hospitals, so there is no guard against errors.
4. Chart review is more complete in some hospitals than in others.
5. Some hospitals do not code some conditions for which they do not receive reimbursement.

These are problems that can and should be addressed, but we do not propose solutions here.

The reliability of the birth defects data recorded on the birth certificate was wholly unsatisfactory in every category. The problem is not unique to California; poor reporting of birth defects data on birth certificates has been noted in other States (10, 18, 20-23, 25-29). Problems related to the preparation of the birth certificate include the following:

1. Certificates are often prepared by poorly trained clerks.

2. Information on birth defects is usually provided by the obstetrician, not the pediatrician.

3. Legal requirements for prompt filing make it difficult to add information from examinations made after the child is taken to the nursery or to collate information from more than one physician.

4. There may be no information about infants transferred to another hospital.

Some national surveillance systems avoid these problems by using a second report by the pediatrician that is linked to the birth record (2, 6, 8, 11, 19), and this procedure is being considered by some States (10). Improved reporting is possible when hospitals prepare and edit certificates on computers (34); if the certificate is in a computer record at the county or State level, and that record is accessible to hospitals for adding data, there are then no technical barriers to adding information about later diagnoses, including diagnoses made at other hospitals. Birth certificates with these improvements would still not provide the completeness and detail of a formal registry such as CBDMP, but they may be adequate for fast response to those sentinel conditions that may indicate the presence of a teratogen.

These results show that both the DI and the birth certificate do not report many cases of birth defects (false-negative cases) and report as birth defects many cases that are not verified (false-positive cases). The result is that monitoring systems and analytic studies that are based on the DI or the birth certificate, separately or in combination, do not include many cases that should be included, and include many cases that should not be included. False-positive cases can be removed from the records if case identification is followed by critical review of medical records by persons trained to evaluate these records. However, this would still fail to document as many as 90 percent of the cases of important malformations. The potential for bias in case-control or other analytic studies is obvious, and the validity of studies based solely on DI or birth-certificate data, without individual case review, must be questioned.

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Coinfection with Tuberculosis and HIV-1 in Male Prison Inmates

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Synopsis

An association between past exposure to tuberculosis (TB) and infection with human immunodeficiency virus

type 1 (HIV-1) was investigated using a case-control design among a 6-week sample of 698 male inmates consecutively admitted to the Maryland State prison system. Based on Mantoux testing and measurement of anti-HIV-1, we found a positive but not significant association between HIV-1 and TB infection (odds ratio 2.4, 95 percent confidence interval 0.9-6.3). The power of the study to detect an association of this magnitude was 0.57. Of the entire intake sample, 1.3 percent were found to be coinfecting with TB and HIV-1.

Some misclassification may have been present due to anergy or latent HIV-1 infection. The elevated risk of TB in coinfecting inmates, coupled with the study results, suggest that the inmate screening process on entry to the prison should be modified to improve identification of coinfecting people. Specifically, anergy testing should be added to the admission screening procedure, and appropriate voluntary anonymous HIV-1 antibody testing should be more widely available to inmates.

AFTER DECLINING steadily for three decades, the number of tuberculosis (TB) cases in the United States began to rise in 1986 (1). This increase was pronounced in the New York State prison system, which observed a fivefold increase in the TB incidence among inmates

between 1976 and 1986 (2). These changes have been attributed in part to infection with the human immunodeficiency virus type 1 (HIV-1) (1, 2). A large body of epidemiologic evidence has linked acquired immunodeficiency syndrome (AIDS) and TB through case