Followup of a group of Kauai Pregnancy Study children from birth to 2 years enabled the authors to calculate incidence rates of physical and mental handicaps of prenatal and natal origin and thus to delineate type and duration of care required.

The Community Impact of Handicaps of Prenatal or Natal Origin

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THE IMPACT on a community of children born physically or mentally handicapped is the subject of this paper. It deals with the handicapping conditions of prenatal and natal origin recorded in the first 2 years of life among 1,963 liveborn infants on Kauai, Hawaii, during a 3-year period in the late 1950's. The report is one of a series of papers resulting from the Kauai Pregnancy Study (KPS), a communitywide followup investigation of all pregnancies which occurred on the island during the study years (*1–5*).

In addition to data on the anatomical and clinical types of handicaps, information was also available on the time and circumstances of their first recognition and on the functioning of various professions and agencies in the community in providing diagnostic, treatment, and followup services, special education, and institutional care of the handicapped children. This made it possible to classify the children according to needed care and thus to gain an appreciation of the impact on a community of handicaps of this nature, and to calculate incidence rates in terms of the special services required.

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The study was financed through a grant from the Children's Bureau and the Public Health Service National Institutes of Health Grant No. 7734. Data for the study were collected through the cooperative efforts of the University of California School of Public Health and the Hawaii Department of Health.

The Setting

The island of Kauai lies at the northwest end of the Hawaiian chain, about 100 miles from Honolulu. Although three-fourths of the 30,000 inhabitants were born in Hawaii, the population has a varied ethnic background. The economy centers about the growing and processing of sugar cane and pineapples. There is a cooperative prepayment system of medical care for plantation workers and coverage by insurance plans for most other groups. Virtually all the people have access to medical and hospital care. There are 13 physicians of whom 7 are associated with the plantation health plans. All deliveries take place in the two hospitals serving the island.

Although the population of Hawaii is commonly thought to be atypical of that of the mainland, it closely resembles the mainland white population with respect to the principal health indices; for example, crude death rate, birth rate, infant mortality rate, and life expectancy at birth. Furthermore, the environmental factors that influence health including housing, family income, nutrition, urban-rural differentials, educational status, availability and quality

of medical care, and public health services all compare very favorably with the most progressive mainland communities. Details concerning characteristics of the population and of the socioeconomic situation are contained in earlier papers (*1–5*).

Study Group

The handicapping conditions included are congenital defects, mental retardation, prematurity, birth injuries, cerebral palsy, and convulsive disorders of natal and prenatal origin which were recorded in the first 2 years of life among children from 1,922 single pregnancies and 41 liveborn twins from 21 twin pregnancies with the last menstrual period (LMP) from the 2d lunar month of 1954 through the 11th lunar month of 1956. This group was chosen for the present study because during this period of the Kauai Pregnancy Study all mothers except for 29 were interviewed prenatally, and the children were followed to age 2. Women of Japanese origin constituted the largest ethnic group, 35 percent; the others were Filipino, 23 percent; Hawaiian and part-Hawaiian, 19 percent; Caucasian, 14 percent; and all others including non-Hawaiian mixtures, 9 percent.

Sources of Information

Many records were examined in the process of identifying the handicaps summarized here. KPS case folders contain copies of prenatal, hospital, labor, delivery, and newborn records as well as livebirth and death certificates. Records prepared especially for the study include reports of two interviews with the mother, one during the postpartum period and the other when the infant was around a year old. Other valuable sources were health department records and records of the bureau of crippled children's services, Hawaii Department of Health. The health departments of Hawaii, both State and local, are known for their aggressive service programs for children with handicapping conditions. On the various islands specialists from Honolulu conduct clinics in child development, pediatrics, orthopedics, mental retardation, cerebral palsy, and other fields. For the most part, referrals to these clinics are made by family physicians or by public health nurses as a result of home visits or child health conferences. Children are taken to Honolulu for specific diagnostic procedures, treatment, or care. Records covering these activities were made available on a routine basis to the Kauai Pregnancy Study. In addition to these sources we had records of the special pediatric and psychological examinations conducted under KPS auspices when the children were about 2 years of age.

Pediatric examination. By the time the children were about 2, the families of 185 had moved from Kauai, and 35 had died. Of the 1,714 remaining, virtually all received a special

Table 1. Number of children receiving pediatric and psychological examinations, Kauai Pregnancy Study

Examination status	Pediatric examination	Psychological examination		
		On routine basis (1st period)	On selection basis (2d period)	Total
Total liveborn in time sample	1, 963	855	1, 108	1, 963
Not available for examination [1]	249	95	154	249
Available for examination	1, 714	760	954	1, 714
Not examined	48	27	755	782
Received examination	1, 666	733	199	932
Incomplete IQ score	----------	18	19	37
Examination completed:				
Number	1, 666	715	180	895
Percent	97. 2	94. 1	18. 9	52. 2

[1] 185 moved, 35 died, and 29 mothers were not interviewed during pregnancy which was prerequisite to followup in the study. While records for these are not as complete as for others, some information pertinent to the present study is available for all.

pediatric examination by two pediatricians from Honolulu, both diplomates of the American Board of Pediatrics. Each examined about half of the children. The principal focus of the examination was an assessment of physical status and search for defects, based on a systematic appraisal of all organ systems. Examinations were scheduled as new groups of children attained the appropriate age. The study staff and the public health nurses made strenuous efforts to bring every child to examination so as to avoid possibility of selection. The fact that 97 percent were examined attests to their success (table 1).

Psychological examination. For approximately the first year, children receiving the special pediatric examination were routinely given a psychological evaluation. The 733 examined on a routine basis comprise 96 percent of this cohort. Psychological evaluations were also performed on an additional 199 children, or 20.9 percent, of the 954 reaching the age of examination during the second part of the study. With limited time available from psychologists it was not possible to adhere to our original plan to provide routine psychological examinations for the entire cohort, and the 199 consist mainly of those selected by the pediatricians, those whom they believed might fall below or above the average range of intelligence.

Two psychologists from the University of Hawaii performed about 90 percent of the evaluations, one being responsible for about a half and the other a third. Two others examined the remaining 10 percent. A specially prepared consultation form was completed covering sensory and motor status levels, parent-child relationships, infant behavior patterns, and a general impression of the child's physical and intellectual status. In addition, the Cattell Infant Intelligence Scale (*6*) was completed, resulting in an intelligence quotient (IQ). The median age at psychological examination was 21 months for those routinely examined and 23 months for the selected group.

Cutoff point of followup. To a large extent, the period of followup will determine the type and number of handicaps found. No matter how careful the appraisal, many congenital defects are not recognizable at birth. The handicaps reported in this study were noted during a period of observation which began at birth and, with some exceptions, ended with the special pediatric and psychological examinations given at about 2 years of age. The exceptions concern children with major handicaps who required continuing diagnostic study or care, for whom we have information to approximately school age. During the first 2 years of life, most of the children in the group received some followup by the family physician, and some, at a child health center or by a public health nurse as well as by the KPS staff.

Classification of Handicaps

Handicaps are classified in various ways depending upon the purpose to be served. Most surveys of congenital malformations have been concerned either with determining overall frequency or that of specified anatomic types in connection with the search for etiological factors. General incidence rates are of limited value. Comparability of the findings is usually difficult or impossible because of variations in definition, composition of group studied, source of information, age of fetus, infant, or child at time of diagnosis, and diagnostic procedures. There is an increasing tendency to express rates in terms of total births, but some authors fail to state the gestational age of the fetal deaths included. While an attempt is usually made to distinguish major defects, this also is difficult to interpret. Major defects may include or exclude those incompatible with sustained life, and those listed as minor may include all those not affecting viability or may be much more limited in scope. As the principal focus of this paper is directed to implications of defects in terms of care required, we have classified the congenital and other defects accordingly. However, we also have attempted to organize our data on congenital defects so as to make some kind of meaningful comparison with other incidence figures.

Congenital Defects

For each child the number and description of all reported defects were summarized. Also noted was the age when each condition was first recognized or suspected as reflected in KPS case folders and the source of this informa-

Table 2. All congenital defects of 158 liveborn, including 16 with defects

Congenital defect	All defects	Sex of child		Number of associated defects						
		Male	Female	0	1	2	3	4	5	6
Central nervous system	**63**	**41**	**22**	**32**	**10**	**8**	**9**	**1**	**0**	**3**
Strabismus [1]	28	15	13	21	4	0	2	0	0	1
Optic atrophy	1	1	0	0	0	1	0	0	0	0
Nystagmus	1	1	0	0	0	0	1	0	0	0
Congenital visual defect [1]	1	1	0	0	0	0	1	0	0	0
Ptosis [1]	2	1	1	2	0	0	0	0	0	0
Meningomyelocele, spina bifida	1	0	1	0	0	1	0	0	0	0
Meningocele, spina bifida	1	0	1	0	0	1	0	0	0	0
Meningo-encephalocele	1	1	0	1	0	0	0	0	0	0
Hydrocephalus	1	1	0	1	0	0	0	0	0	0
Facial palsy [2]	1	1	0	0	0	0	0	1	0	0
Microcephaly	3	2	1	0	1	1	1	0	0	0
Cerebral hypoplasia	2	2	0	0	0	0	1	0	0	1
Sturge-Weber syndrome	1	1	0	0	1	0	0	0	0	0
Mental retardation	19	14	5	7	4	4	3	0	0	1
Severe, not tested	3	3	0	0	1	0	1	0	0	1
IQ under 70	16	11	5	7	3	4	2	0	0	0
Cardiovascular system	**12**	**8**	**4**	**8**	**2**	**1**	**1**	**0**	**0**	**0**
Hemangioma of thorax, extensive	1	1	0	1	0	0	0	0	0	0
Heart defects	11	7	4	7	2	1	1	0	0	0
Interventricular septal defect	2	2	0	1	0	0	1	0	0	0
Patent ductus	2	1	1	2	0	0	0	0	0	0
Subendocardial fibroelastosis	1	1	0	0	0	1	0	0	0	0
Acyanotic, type not stated	6	3	3	4	2	0	0	0	0	0
Gastrointestinal system	**22**	**15**	**7**	**14**	**2**	**3**	**2**	**1**	**0**	**0**
Cleft lip and palate	1	0	1	1	0	0	0	0	0	0
Cleft palate	1	0	1	0	0	1	0	0	0	0
Abnormal palate	4	3	1	2	0	1	1	0	0	0
Bifid uvula	2	2	0	1	0	0	1	0	0	0
Malformation of teeth	7	5	2	6	1	0	0	0	0	0
Atresia of gastrointestinal tract [3]	4	3	1	2	1	0	0	1	0	0
Other malformations of system [4]	3	2	1	2	0	1	0	0	0	0
Genitourinary system	**18**	**16**	**2**	**9**	**4**	**2**	**1**	**1**	**0**	**1**
Undescended testicle [1]	8	8	0	5	2	0	0	0	0	1
Hermaphroditism	1	1	0	0	0	0	1	0	0	0
Absence of scrotum	1	1	0	0	0	0	0	1	0	0
Deformity of urethral sphincter	1	0	1	0	0	1	0	0	0	0
Imperforate vagina	1	0	1	0	0	1	0	0	0	0
Hydrocele	6	6	0	4	2	0	0	0	0	0

tion, that is, hospital record, birth certificate, family physician, public health nurse, one of the KPS interviews or examinations, or followup by the bureau of crippled children's services.

In the study tabulations we excluded nevi and skin hemangiomas, such orthopedic conditions as mild metatarsal, genual, tibial, and femoral deviations, and positional talipes. Also omitted were undescended testicle, umbilical hernia, and eye muscle imbalance not persisting to 1 year of age unless they were severe enough to have required repair or unless the child had died before age 1. For the most part, the terminology used by the physician making the diagnosis was used in our tabulations.

Multiple defects were counted separately unless they were part of a recognizable syndrome. However, cleft lip and palate or associated conditions occurring together were counted as one defect, as were identical defects of hands or feet.

We have included among the handicapped children those with IQ scores of less than 70 and three children for whom scores were not obtained but who were judged by the examiner to be severely retarded. The inclusion of low IQ children in whom there is no observable

who died, by sex and number of associated defects, Kauai Pregnancy Study

Congenital defect	All defects	Sex of child		Number of associated defects						
		Male	Female	0	1	2	3	4	5	6
Musculoskeletal system	**50**	**37**	**13**	**27**	**11**	**4**	**4**	**1**	**0**	**3**
Congenital dislocation of hip	1	1	0	0	0	0	0	0	0	1
Deformity of skull	1	1	0	0	0	0	1	0	0	0
Talipes equinovarus, metatarsus varus, and others	8	3	5	4	1	2	1	0	0	0
Polydactylism	3	2	1	1	2	0	0	0	0	0
Inguinal hernia	12	11	1	8	4	0	0	0	0	0
Umbilical hernia [1]	19	13	6	14	3	1	1	0	0	0
Amyotonia congenita	1	1	0	0	0	0	0	0	0	1
Arachnodactyly	2	2	0	0	1	1	0	0	0	0
Other malformations of system [5]	3	3	0	0	0	0	1	1	0	1
Respiratory system	**1**	**0**	**1**	**1**	**0**	**0**	**0**	**0**	**0**	**0**
Diaphragmatic hernia, extensive	1	0	1	1	0	0	0	0	0	0
Skin	**33**	**16**	**17**	**26**	**6**	**0**	**0**	**1**	**0**	**0**
Preauricular skin tab	9	8	1	7	2	0	0	0	0	0
Other skin tabs	17	4	13	16	1	0	0	0	0	0
Syndactylism, minor	3	2	1	1	2	0	0	0	0	0
Pilonidal sinus	1	0	1	0	1	0	0	0	0	0
Pigmented mole, extensive	1	0	1	1	0	0	0	0	0	0
Absence of skin, extensive	1	1	0	0	0	0	0	1	0	0
Congenital sebaceous cyst	1	1	0	1	0	0	0	0	0	0
Miscellaneous, including sense organs	**20**	**11**	**9**	**6**	**3**	**4**	**4**	**3**	**0**	**0**
Blue scleras	2	0	2	2	0	0	0	0	0	0
Myopia	1	0	1	1	0	0	0	0	0	0
Congenital deafness	4	3	1	0	1	0	2	1	0	0
Abnormality of ear canal	3	2	1	0	1	0	0	2	0	0
Deformities of pinna	4	1	3	1	1	1	1	0	0	0
Thyroglossal duct	1	1	0	1	0	0	0	0	0	0
Mongolism	1	1	0	0	0	0	1	0	0	0
Pituitary dwarfism	1	0	1	0	0	1	0	0	0	0
Cretinism	1	1	0	0	0	1	0	0	0	0
Lipoma	1	1	0	0	0	1	0	0	0	0
Congenital diabetes	1	1	0	1	0	0	0	0	0	0
All malformations:										
Number	219	144	75	123	38	22	21	8	0	7
Percent	100	66	34	56	17	10	10	4	----	3

[1] Persisting to 1 year or longer, or repaired.
[2] No birth injury reported.
[3] Biliary, intestinal, and esophageal.
[4] Relaxation of epiglottis and upper tracheal ring, hypertrophic pyloric stenosis, and imperforate anus.
[5] Absence of nose, hypertelorism, underdeveloped mandible.

evidence of perinatal neurological damage or faulty development may be open to some question, but in the light of the prevailing views about the probable role of prenatal and natal factors in mental deficiency, we decided to include those in the lower IQ groups. A study of the influence of sociocultural factors on the IQ scores of the study group is contemplated.

Table 2 shows individual defects in our series grouped under arbitrary anatomical system headings by sex and number of associated defects. A total of 219 defects were recorded for the 158 liveborn with one or more congenital malformations, or 1.4 defects per affected child. The ratio of males to females affected was 1.6 to 1.

Incidence. Of the few studies conducted along somewhat similar lines (*7–9*), that of McIntosh and associates in New York provides the best basis for comparison of incidence because it was also a followup study providing periodic reappraisals of the children. But there were important differences with respect to the size of the study groups, period and methods of

followup, the socioeconomic and ethnic characteristics of the study populations, and, to some extent, the defects included. With all of these limitations in mind, the finding that an overall incidence of children with congenital defects among liveborn surviving the first 28 days of life was of similar order—7.6 percent for the Kauai Pregnancy Study and 7.0 reported by McIntosh—is of little significance.

While no significant ethnic differences were found in overall incidence of congenital defects, there were significant differences with respect to the systems affected, with the Filipino group being highest in cardiovascular defects and the Hawaiians and part-Hawaiians in musculoskeletal defects. The Japanese and Caucasian groups showed significantly lower incidence of skin defects.

Infants of Low Birth Weight

A sizable number of newborns were handicapped at birth by physiological immaturity. In addition to considering birth weight and gestational age, the birth and hospital records were studied in determining which babies to include in the handicapped group. The distribution of the low birth weight and low gestational age babies is shown in the chart. Those treated as prematures including the first week deaths are identified. While 7.4 percent of the single liveborn weighed 5½ pounds or less at birth (quadrants A and B), an additional 2.5 percent were recorded as having gestational ages of less than 37 weeks (quadrant C). Both criteria pertained in 2.6 percent of the single live births. Of all babies considered by the physician at time of delivery to require special prematurity care, nearly two-thirds were of both low birth weight and low gestational age (quadrant B) and the remainder were of low birth weight only (quadrant A).

In this series only 53 percent of the male infants and 42 percent of the female infants weighing 5½ pounds or less at birth were considered to need special newborn care. The fact that the KPS babies were predominately of Japanese and Filipino origin doubtless accounts for somewhat lower birth weights. Of those considered to be not premature and dismissed from the hospital with the mother at 3 or 4 days, none died during the first 2 years of life, a good indication of the physicians' judgment as to their maturity.

The difficulties of obtaining accurate gestational data even in a prospective study such as the Kauai Pregnancy Study are seen in the scatter diagram. None of the babies of recorded gestational age of less than 37 weeks was treated as premature unless the birth weight also was 5½ pounds or less. Ten babies had recorded gestational periods of 34 weeks or less, despite birth weights ranging between 5½ and 8 pounds. It is possible that the mother reported the date of the first missed menses instead of the last normal menses, making an error of 4 weeks. The babies with birth weights of 5 pounds or less and reported gestational age of more than 38 weeks are, for the most part, not premature but the result of faulty intrauterine environment or faulty fetal development.

Ethnic differences in birth weights. As would be expected, there were ethnic differences in the incidence of low birth weights. Twelve percent of Filipino babies weighed 5½ pounds or less at birth compared with 5.5 percent of those of Japanese and Hawaiian origin and 3 percent of the Caucasians. The proportion requiring special care ranged from a high of 75 percent for the minority ethnic group babies (mostly Puerto Rican) through 60 percent for the Caucasians and Hawaiians to slightly more than 40 percent for the Filipinos,

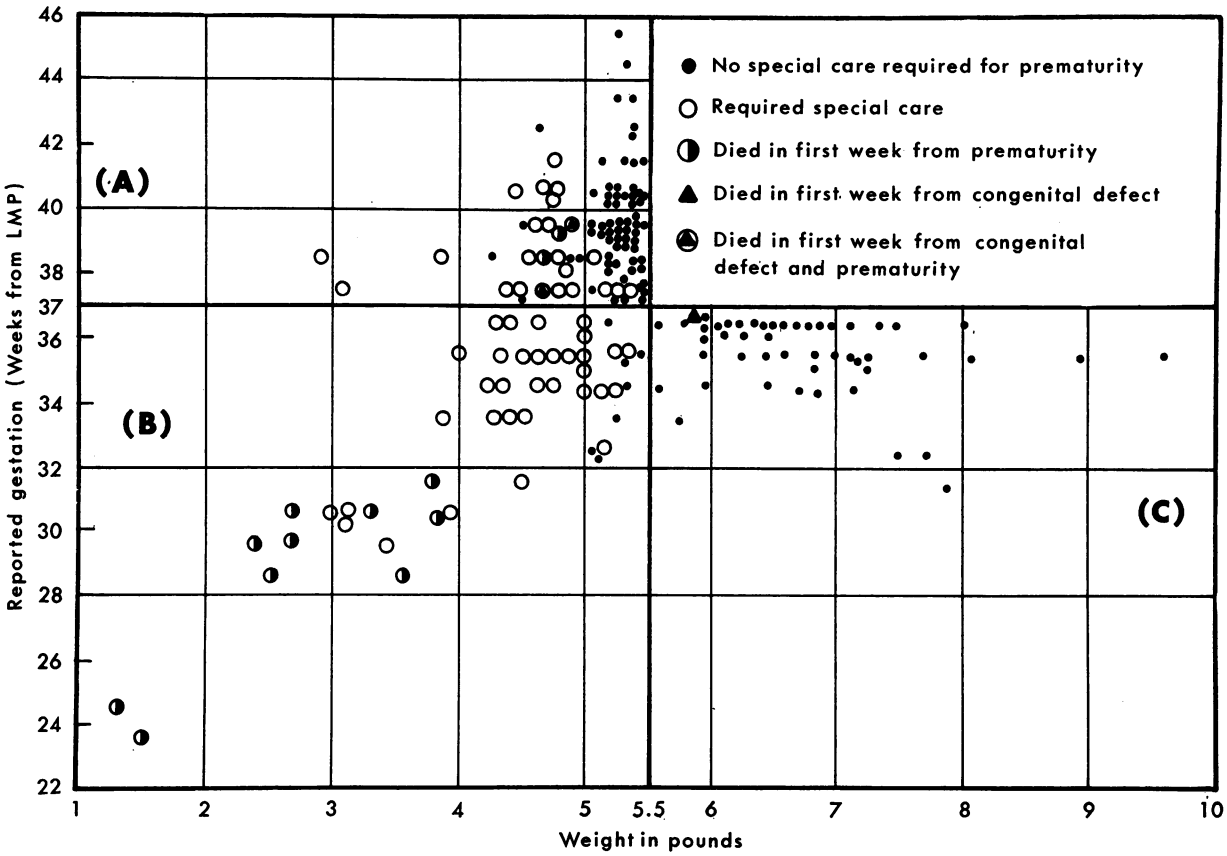
Table 3. Number of children by type of handicap and survival, Kauai Pregnancy Study

Type of handicap	Number of children		
	Total	Surviving 1 week	Surviving 2 years
Total liveborn	1,963	1,940	1,928
All handicaps	303	283	273
Congenital defect, including IQ score under 70	158	150	142
Birth injury [1]	8	7	7
Low birth weight only	137	126	124
No handicap	1,660	1,657	1,655

[1] Includes convulsive disorders and cerebral palsy.

NOTE: See table 7 for estimated incidence rates of handicapping conditions.

Special prematurity care required and first-week deaths for single liveborn weighing 5½ pounds or less or gestation less than 37 weeks, or both, Kauai Pregnancy Study



Japanese, and those of mixed origin. However, none of these differences are significant.

Classification By Type of Care Required

Seldom is information on handicaps at birth collected and presented in such a way as to convey an idea of their social consequences. Those responsible for planning the care of handicapped children have to depend in large part on the results of community surveys, achievement tests, medical examinations in schools, and admissions to special schools and institutions in estimating probable caseloads of various categories of handicapping. Furthermore, there is limited appreciation on the part of the medical profession and the public of the nature and extent to which birth defects contribute to crippling (*10*). Having considerable data on the type and duration of care actually received or planned for children in our series during the 2 years' observation, we undertook to classify them so as to throw light on this aspect.

Handicapping conditions included. Congenital malformations contributed the largest number of conditions requiring care, with immaturity second. In addition a few infants were handicapped by overt birth trauma and neurological deficits which led to cerebral palsy and convulsive disorders diagnosed in early life (table 3). None of the convulsive disorders appeared to be related to postnatal causes. Cases of apparently minor birth trauma—forceps marks, bruises, abrasions, and hematomas of scalp—are excluded from the present study since in none was special care indicated. We have included the children who had IQ test scores under 70 and the three untested who were called severely mentally retarded.

In the classification scheme that follows we have assigned to 1 of 4 classes each of the 283

Table 4. Status at 24 months of 283 children [1] with handicaps of prenatal and

Handicap	Number of children		
	Total	Male	Female
CLASS 1: *Minor handicaps requiring little or no specialized care*			
Birth weight 5½ pounds or less, not requiring special newborn hospital care:			
Low birth weight only apparent handicap	73	33	40
Low birth weight and malformation of teeth	3	1	2
Low birth weight and abnormal palate	1	1	0
Birth weight more than 5½ pounds:			
Abnormal palate; bifid uvula	2	1	1
Relaxation of epiglottis and upper tracheal ring	1	1	0
Malformation of teeth	3	3	0
Undescended testicle	3	3	0
Mild coxa valga	1	1	0
Umbilical hernia	11	7	4
Umbilical hernia, skin tab	1	1	0
Polydactylism; minor syndactylism	3	2	1
Skin tab (1 male died at 29 days) [2]	22	10	12
Blue scleras	2	0	2
Mild deformity of pinnas	1	0	1
Mild convulsive disorder	3	0	3
Total	130	64	66
CLASS 2: *Handicaps amenable to relatively short-term specialized care*			
Birth weight 5½ pounds or less requiring special newborn hospital care:			
Low birth weight only apparent handicap (2 males died at 7 and 10 months)	53	25	28
Low birth weight and umbilical hernia	2	2	0
Low birth weight and skin tab	1	0	1
Low birth weight and congenital sebaceous cyst	1	1	0
Birth weight more than 5½ pounds:			
Strabismus (2 males, 5 lbs., 4 oz.; 5 lbs., 6 oz.) [3]	21	10	11
Strabismus, umbilical hernia	1	0	1
Strabismus, polydactylism	1	1	0
Strabismus, undescended testicle	1	1	0
Ptosis	2	1	1
Myopia	1	0	1
Hypertrophic pyloric stenosis	1	1	0
Hydrocele	4	4	0
Inguinal hernia	8	7	1
Inguinal hernia, undescended testicle	1	1	0
Inguinal hernia; hydrocele (1 died at 2 months)	2	2	0
Inguinal hernia, skin tab	1	1	0
Umbilical hernia, extensive	1	1	0
Metatarsus varus	1	1	0
Mild talipes deformity, minor syndactylism	1	0	1
Pilonidal sinus, skin tab	1	0	1
Thyroglossal duct	1	1	0
Total	106	60	46
CLASS 3: *Handicaps requiring long-term, specialized care and rehabilitation*			
Spina bifida, meningomyelocele, talipes deformity (died at 2 months)	1	0	1
Spina bifida, meningocele, equinovarus	1	0	1
Severe strabismus, congenital nystagmus, bifid uvula, questionable hearing (3 lbs., 2 oz.) [4]	1	1	0
Congenital heart defect (1 male, 5 lbs., 5 oz.) [3] (1 male died at 27 days)	7	4	3

children with 1 or more identifiable handicaps of prenatal or natal origin who survived more than 1 week. Although they have social consequences, we excluded from this classification 23 infants who died in the first week of life because they could not be considered in terms of long-term care. Six of these deaths were ascribed to congenital defects, 14 to prematurity and postnatal asphyxia and atelectasis, and 3 to birth trauma. (Two had a congenital defect not contributing to death.) In children with multiple defects the one requiring the greatest amount of care determined assignment (table 4).

natal origin classified by type of special care required, Kauai Pregnancy Study

Handicap	Number of children		
	Total	Male	Female
Congenital heart defect, umbilical hernia	1	0	1
Congenital heart defect, mild arachnodactyly, mild deformity of pinnas	1	1	0
Atresia of ileum; of jejunum (died at 13 days and 17 days)	2	1	1
Cleft lip and palate, bilateral (5 lbs., 7 oz.) [3]	1	0	1
Imperforate anus, imperforate vagina, deformity of urethral sphincter	1	0	1
Severe talipes equinovarus	1	0	1
Shortened leg, diagnosis pending, talipes equinovarus	1	0	1
Atresia of auditory canal, deformity of pinna	1	0	1
Blue black pigmented mole, extensive	1	0	1
Congenital diabetes (died at 23 months)	1	1	0
Cerebral palsy, permanent speech defect (5 lbs., 0 oz.) [4]	1	1	0
Cerebral palsy, permanent deformity of arm and hand (5 lbs., 4 oz.) [3]	1	1	0
Birth trauma, Erb's palsy	1	0	1
Total	24	10	14
CLASS 4: *Handicaps requiring long-term medical, educational, and custodial care*			
Physical handicaps only:			
1. Congenital deafness, abnormality of pinnas and canals, hypertelorism, facial palsy	1	1	0
2. Sturge-Weber syndrome, strabismus	1	1	0
3. Epilepsy, microcephaly, biliary atresia	1	1	0
4. Cerebral palsy	1	1	0
Physical and mental handicaps:			
5. Severe mental retardation, cerebral hypoplasia, amyotonia congenita, dislocation of hip, strabismus, undeveloped mandible, undescended testicle (died at 20 months)	1	1	0
6. Severe mental retardation, mongolism, abnormal palate, umbilical hernia	1	1	0
7. Severe mental retardation, congenital heart defect	1	1	0
8. IQ 16, congenital deafness, epilepsy	1	0	1
9. IQ 16, cerebral palsy, abnormal palate, lipoma	1	1	0
10. IQ 17, cerebral hypoplasia, congenital deafness, congenital visual defect	1	1	0
11. IQ 20, microcephaly, optic atrophy, cerebral palsy, seizures (3 lbs., 1 oz.) [4]	1	1	0
12. IQ 30, cretinism, umbilical hernia	1	1	0
13. IQ 50, pituitary dwarfism, cleft palate	1	0	1
14. IQ 61, microcephaly, strabismus, deformity of pinnas	1	0	1
IQ score under 70, no physical handicaps:			
15. IQ 47	1	1	0
16. IQ 54	1	1	0
17. IQ 58, mild arachnodactyly	1	1	0
18. IQ 58	1	1	0
19. IQ 64	1	0	1
20. IQ 68, absence of lower incisors	1	1	0
21. IQ 68	1	1	0
22. IQ 68	1	1	0
23. IQ 69	1	0	1
Total	23	18	5

[1] Excludes 20 who died the first week.
[2] Died from infant diarrhea and pneumonia.
[3] Birth weight of child who did not require special newborn hospital care.
[4] Birth weight of child who required special newborn hospital care.

Class 1. In class 1 we have placed the 130 children whose defect or deficit is so minor or of such a nature as to require little or no specialized care and which is not likely to interfere with normal growth and development. Almost one-half of all the children with identified handicaps are in this class.

The 73 infants weighing 5½ pounds or less at birth but for whom no special care was recorded are included in this class. Our reasoning is that in many hospitals a portion of these babies would probably have been regarded as premature and special care provided. This would apply especially to those with birth weights of 5 pounds or less. Although none of those included in this class remained in the

Kauai hospitals after the mother's discharge at 3 or 4 days, the postpartum interviews revealed that often the mothers expressed some concern over the babies' small size. The birth weight of this group ranged between 4¼ and 5½ pounds, the median being 5 pounds, 5 ounces.

Of the other children in this class, the handicaps either resolved spontaneously (umbilical hernia and undescended testicle) or were amenable to minor corrective surgical procedures by the family physician (skin tabs or supernumerary digits, for example). Three children with mild convulsive disorders were placed here because followup indicated that they were handicapped very little, if any, during the period of followup.

Class 2. One hundred six, or somewhat more than one-third of the children with handicaps amenable to relatively short-term specialized care were placed in class 2. It includes the 57 babies whose only apparent problem was low birth weight requiring special care. They remained in hospital after discharge of their mothers, were placed in incubators, and given special nursing care and feeding. The periods of extra hospital care ranged from a few days to 8 weeks, with the median stay being 2½ weeks. The birth weights of these babies were between 3 and 5½ pounds, with a median of 4 pounds, 11 ounces.

An additional 49 children were placed in this class because of congenital defects requiring short-term specialized medical or surgical care of a type generally considered the province of specialists. Strabismus (persisting beyond the first year of life) was the most frequent defect, with hernias next. With specialized care by pediatricians, ophthalmologists, surgeons, and orthopedists, the children in this class would have little or no residual handicap.

Class 3. The 24 children in class 3 constitute 8.5 percent of the total handicapped group. They all suffer from major physical defects requiring long-term, specialized care and rehabilitation. Twenty of these are of congenital origin, with the nine cardiac defects constituting the largest group. Two children with cerebral palsy, one with Erb's palsy, and one with eye muscle paralysis resulting from birth injuries are included. All of these children had extensive skilled diagnostic and treatment services during the 2 years of observation, and in most cases treatment and rehabilitative services will continue for some time. In addition to pediatricians, the specialists serving this group included cardiologists, orthopedists, neurologists, otologists, plastic and general surgeons, and physical and speech therapists. We estimate that more than half of these children, even with the best of care, will be appreciably handicapped as long as they live. The remainder may not be seriously handicapped, but the amount of long-term, specialized care and rehabilitation would in most cases be extensive. There are five low birth-weight babies in this group, of which only two were treated as prematures. One has severe strabismus and nystagmus, weighed 3 pounds, 2 ounces at birth, and probably sustained severe birth injury; the other is one of the cerebral palsied children who weighed 5 pounds. The remaining three are children with congenital heart defect, cleft lip and palate, and the second case of cerebral palsy in the group.

Class 4. The 23 children with handicaps requiring long-term medical, educational, and custodial care were placed in class 4. Four suffered from physical defects only; 10 had combined physical and mental deficiencies; and the remaining 9 had IQ scores under 70 unaccompanied by other significant defects.

Among the four with no evidence of mental retardation, three have multiple congenital defects and one was diagnosed as having cerebral palsy. All of the children with physical handicaps received extensive diagnostic, treatment, and special therapeutic services provided not only by a full range of medical specialists but also by psychologists and educators concerned with special education for the physically handicapped and the mentally retarded.

The nine children with low IQ scores unaccompanied by physical defects are the ones principally identified in the course of the routine mental testing. As pointed out later, we have reason to believe that this number is probably less than half the number that would have been identified if all the children had been tested routinely.

It is of interest that prematurity played a very small role in this most severely handi-

capped group. Only one child weighed 5½ pounds or less at birth—the one with an IQ of 20, microcephaly, optic atrophy, and seizures, who weighed just over 3 pounds.

In estimating the impact on the community of these severe handicaps it is necessary to take into account the amount of auxiliary community services required by the child. Our records reveal an enormous amount of service by public health nurses and social agency personnel working with the children and their families in providing coordinating, liaison, supportive, and followup services.

Residual Handicapping

Nearly half of the children with handicaps needed minimal attention, mostly of a kind that can be given by family physicians. Of the remainder, two-thirds required short-term, specialized care, primarily surgical, except for the prematures who required skilled nursing care under competent medical supervision. Given appropriate care promptly, these children in classes 1 and 2 should have little or no residual handicapping. Most required some extra care, from periodic observation, as in the case of undescended testicle, to skilled surgery for thyroglossal duct. Failure to provide the appropriate care promptly would endanger the lives of some, the prematures for example, or would result in an increase in the number of children with residual handicaps or in more serious handicapping as in the case of strabismus or clubfoot.

The remaining third of those requiring care (classes 3 and 4) suffer handicaps requiring long-term specialized diagnostic and treatment services, special therapy (speech, physical, occupational, and special education in various combinations. Even with the best of care, more than half of those in class 3 and all of the children in class 4 will be permanently handicapped in some degree.

When Handicaps Were Recognized

Because of its importance to casefinding, we looked at the "yield" of various sources of information. Our knowledge of the existence of children with handicaps came from the usual sources—birth records, regular public health department activities, including family physician referrals to the bureau of crippled children's services, Hawaii Department of Health—supplemented by special KPS interviews and examinations.

Birth records. Children with physical defects were divided into two groups, those with defects considered to be generally recognizable in the newborn and those either not recognizable that early or requiring special diagnostic skills and procedures. The classification was that suggested by a study group on congenital malformation statistics (*11*).

The performance of the Kauai physicians was good in their appraisal of the newborns. Of the 10 with defects considered to be recognizable in the newborn on "routine physical examination by reasonably competent general practitioners" 8 were recognized and recorded on the newborns' records (table 5). They included spina bifida with meningocele, cleft lip and palate, imperforate anus and vagina, mongolism, extensive pigmented mole, polydactylism, and syndactylism. However, only the first four defects were recorded on the birth certificate. The two not noted at birth were a case of minor syndactylism and a minor talipes deformity which was recognized by the family physician and referred to the bureau of crippled children's services when the child was 15 months old.

The records of the newborns also yielded 21 defects less frequently recognized before hospital discharge. About half of these were of such a nature as to make early recognition especially desirable from a standpoint of treatment and search for associated defects. They include suspected amyotonia congenita, biliary and jejunal atresias, congenital heart defect, thyroglossal duct, and abnormality of the external ear and canal. Among this group, only five were recorded on the birth certificate. Thus less than one-third of all defects noted at birth appeared on the birth certificates.

Family physicians and crippled children's services. Besides the 29 children with defects reported at birth, the defects of 37 children had been recognized and were being cared for by the family physician or the bureau of crippled children's services before the special KPS examinations. Thirty-three of these children had defects of a type which made early recognition

desirable from the standpoint of initiating treatment, planning for long-term care, or search for associated defects. About half required long-term care. Included were several retarded children with major physical handicaps, Sturge-Weber syndrome, severe strabismus with congenital nystagmus, congenital heart defects, atresia of the ileum, congenital diabetes, and talipes equinovarus. The other half requiring short-term care included pyloric stenosis, ptosis, mild coxa valga, strabismus, and inguinal hernia.

Special KPS records. The KPS home interview when the child was a year old and the special pediatric and psychological examinations at age 2 were provided to make as sure as possible that all recognizable handicaps would come to light during the observation period. It is significant that they yielded 35 additional children with handicaps requiring skilled diagnostic and treatment services, principally cardiac defects and most of the cases of strabismus persisting to age 2. These are conditions more likely to be diagnosed at a special pediatric examination than by the practitioner as he gives general medical care. Additionally, the pediatric examinations yielded several cases of inguinal hernia, hydrocele, myopia, and undescended testicle.

Sources of information on the "mentally retarded." There were 16 children classified as being mentally retarded on the basis of IQ scores under 70 plus 3 who were considered to be "severely mentally retarded" but not tested.

Ten of the group also had severe physical handicaps recognized before the special KPS examinations. However, the mental retardation of two of these children was not revealed until the special examinations.

In an additional nine children the low IQ scores were not accompanied by significant physical defects (table 5). Of these, the family physician apparently spotted only one before the age of 1 year, the remainder first coming to light as a result of special KPS efforts: one at the 12-month interview, four by both pediatrician and psychologist, and three by the psychologist only at the 2-year KPS examinations.

The 19 children identified must represent less than half the probable number with an IQ under 70. Table 6 shows that there is a considerable discrepancy in the proportion of low scores among the group tested routinely by the psy-

Table 5. Source of earliest recognition of physical defects and suspected mental retardation, by detectability, Kauai Pregnancy Study

Source of earliest recognition	Total children	Number with defects generally recognizable in the newborn	Number with defects generally detected later	
			Early recognition especially desirable	Other
Children with physical defects [1]	141	10	79	52
Newborn records (birth certificate)	29(9)	8(4)	11(4)	10(1)
Family physician or bureau of crippled children's services	37	1	33	3
Special study records	75	1	35	39
1-year interview	7	0	7	0
Pediatric examination	67	1	27	39
Psychologist	1	0	1	0
Children with suspected mental retardation and no significant physical defect [2]	9			
Family physician	1			
Special study records	8			
1-year interview	1			
Pediatric and psychological examination	4			
Psychological examination only	3			

[1] Excludes 8 children who died in the first week. Considers the primary physical defect of 10 children also mentally retarded.

[2] IQ score under 70.

NOTE: In children with multiple defects, the reference is to the primary defect.

Table 6. Effect of selection method for psychological examination on percent of children with low IQ scores, Kauai Pregnancy Study

Selection method	Number available for testing [1]	Percent tested	Percent of children with:[2]	
			IQ under 70	IQ 70–79
Mental tests performed routinely	760	96. 4	1. 8	3. 3
Mental tests performed on basis of pediatric selection	954	20. 9	0. 2	1. 0

[1] See table 1.
[2] Difference between percents of children in two groups significant at 1 percent level for each IQ interval.

chologists (1.8 percent) and those tested on the basis of pediatric referral (0.2 percent). As was found in the pediatricians' appraisals studied by Korsch and associates (*12*), the KPS pediatricians tended to overestimate the mental functioning of a sizable number of children in both the under 70 and 70–79 IQ groups. This is in contrast to their consistent performance with regard to physical defects, 7.0 and 7.4 percent in the two examination groups. A better idea of expected incidence of low IQ will be found in table 7, in which the rates are based on findings in the unselected group only.

Followup After Age 2 of Class 4 Children

Followup information on class 4 children, the most severely handicapped, was available and is included in this paper because it adds dimension to the earlier findings, particularly as they relate to the children with low IQ scores (table 8).

Psychologists experienced in testing infants and young children urge caution in the interpretation of test results, particularly in predicting intelligence in the individual child. This is especially true of children without observable handicaps. Within the normal range, test scores are reliable in that they are constant over a short timespan. Marked changes may occur in some children over a long time period, although this is less likely to happen if children have deficits or are retarded (*13, 14*).

Only one child, the last one listed in table 8, appears to be performing adequately in regular school. All of the remainder have had or will probably need some form of special educational service or custodial care because of their mental or physical handicaps.

Although they are not included among the handicapped in the present study, it is also of interest that followup on 29 of the group that scored 70–79 reveals that less than half of them are doing satisfactorily in school. Seven now have scores under 70 or are called retarded by the crippled children's services, with six requiring special educational placement and one custodial care. Another five still had IQ scores of 70–79, and of these only one, a child in the first grade, is doing well in school; the other four are doing poorly, including one who has been recommended for placement in a class for the mentally retarded. The remaining 17 now have scores ranging from 80 to 108, but only 9 are reported to be progressing satisfactorily in school.

Table 7. Estimated incidence of handicapped children recognized by age 2 and type of care required for primary defect, Kauai Pregnancy Study

Type of care	Percent of liveborn
Requiring little or no specialized care	7. 0
Low birth weight not requiring special care [1]	3. 7
Physical defects and disorders [2]	3. 3
Amenable to relatively short-term, specialized care	6. 3
Low birth weight requiring special care [1]	3. 5
Physical defect [2]	2. 8
Requiring long-term, specialized care (medical, educational, custodial)	2. 4
Severe physical handicap without mental retardation [2]	1. 9
Severe physical handicap and mental retardation [2 3]	. 5
Requiring long-term special education and custodial care	1. 3
IQ under 70, no physical handicap [4]	1. 3
Probably requiring special educational services	3. 2
IQ 70–74, no physical handicap [4]	1. 4
IQ 75–79, no physical handicap [4]	1. 8

[1] Rate based on 1,963 liveborn infants.
[2] Rate based on 1,666 children receiving KPS pediatric examinations and 35 who died before examination.
[3] IQ under 70 or diagnosed as severely retarded without test.
[4] Rate based on 715 children receiving a mental test score during routine testing period.

Incidence Rates by Type of Care

Table 7 shows estimated incidence rates of the handicapping conditions requiring specialized care of various types. The rates are based on the number of infants available for study in each of the several categories and the actual care given or planned during the 2 years of followup. It is believed that they represent an accurate picture of the increment of new cases in the area studied. It is unlikely that any appreciable number of observable defects were missed during the period of study considering the number and type of observations, the acuity of the Kauai physicians and nurses, the ready availability of specialists' diagnostic services, and the final KPS pediatric and psychological examinations. Also, most of the children excluded from the calculation of rates for physical defects are unlikely to be selected in terms of handicaps. As shown in table 1, the largest group consisted of children whose parents moved from the island before the special examinations, about half after the child was a year old. The estimates of incidence of retardation are based on the 715 receiving a score when psychological appraisal was a routine part of followup and probably are not affected greatly by the exclusion of the relatively small group for whom the psychologists were unable to obtain an IQ score for a variety of reasons.

With certain precautions, the rates should also be useful in supplementing community surveys as guides in estimating the increments of expected new cases in other communities. Because they are based on relatively small numbers, sampling errors should be borne in mind. Certain adaptations also would need to be made. Where the "true" ratio of late fetal deaths is higher than in Kauai (11.8 per 1,000 liveborn in 1954–56), there would tend to be fewer defective babies among the liveborn. The greatest variation would be expected in the rates for prematurity as birth weights are known to vary with socioeconomic status, medical care, ethnic group, and other factors. In estimating the requirements for special prematurity care it is necessary to use a more refined criterion than the usual birth weight of 5½ pounds or less. The rate of 3.5 percent in our study is based on the number of infants actually given special care. As stated previously, this was about half the babies whose birth weight fell below this figure, but with a predominantly Caucasian group the proportion would no doubt be higher. And, of

Table 8. Results of followup after age 2 of children in class 4, Kauai Pregnancy Study

Identification number and status	Age at followup (years)	IQ score	Age at testing (years)
Physical handicaps only at age 2:			
1. School for deaf	6	------	--------
2. Home custodial care	7	70	5
3. School for mentally retarded	5½	------	--------
4. Muscular dystrophy, regular school	7	------	--------
Physical and mental handicaps at age 2:			
5. Died	1½	------	--------
6. Institution for mentally retarded	6	------	--------
7. Underdeveloped mandible at 2 years; regular school, poor performance	7	------	--------
8. School for mentally retarded	7½	------	--------
9. Died in institution for mentally retarded	4½	------	--------
10. Institution for mentally retarded	5½	------	--------
11. Home custodial care	8	------	--------
12. School for mentally retarded	7½	------	--------
13. School for mentally retarded	7	------	--------
14. Questionable hearing, home custodial care	8	------	--------
IQ score less than 70, no physical handicap at age 2:			
15. Repeating nursery school	7	48	6
16. Regular school, poor performance	7½	64	3
17. School for mentally retarded	7	53	5½
18. Congenital heart defect, to enter school for mentally retarded	7	35	7
19. Questionable hearing; regular school, poor performance	7	67	7
20. Regular school, borderline functioning	7	78	7
21. Regular school, poor performance	7	90	7
22. Regular school, poor performance	8	------	--------
23. Regular school, adequate performance	7½	97	7½

NOTE: Children have same identification numbers as in table 4.

course, the magnitude of first-week deaths will influence the duration of long-term prematurity care. For the Kauai Pregnancy Study, 2.9 percent of the liveborn required prematurity care beyond the first week. Little is known about the extent and sources of variation for congenital malformations and mental retardation, although there is some evidence that social circumstances, ethnic group, and climate may have an influence (*15–17*). In our group there was no significant ethnic difference in the percent of handicapped children requiring care.

The incidence rates for the mentally retarded who also suffered from physical handicaps (mostly faulty development of the central nervous system) are shown separately from the group of children who had no observable physical handicaps (table 7). Their IQ's ranged between 16 and 61. To a great extent, the kind of care required in this group is determined by the nature of the physical defect and begins early in life.

If low IQ scores are not accompanied by other handicaps, the significance of this rating becomes more apparent as the child grows older and is related to demands for academic performance. We have previously cited evidence that most of the group with IQ's under 70 at age 2 (range of 47–69) are in fact educationally handicapped and that a sizable proportion of those who tested between 70–79 were also having difficulties measuring up to expected performance in school. Thus, for the purpose of estimating annual increments of children who will require special educational services, the incidence statistics may be useful in supplementing estimates based on surveys.

Prevalence rates (caseloads) in the various categories will be influenced by several additional factors. Survival rates, specific for the various kinds of handicaps, and the prevailing neonatal, post-neonatal, and childhood mortality rates will influence the length of time the children will require care. In Hawaii, including Kauai, these death rates tend to be lower than in mainland communities. During 1954–56, the years of our pregnancy study, the mortality rate in Kauai for the first year of life was 17.8 per 1,000 live births as compared with 19.7 in Utah, the lowest State rate reported in 1959 for a mainland white population.

While some congenital defects, extreme immaturity, and severe birth injuries are incompatible with life, for other infants the type of care given will influence the length of survival. In our series, 84 percent of all handicapped children were living at age 2 as compared with 99 percent of those without handicaps. As would be expected, the clinically premature and especially those with other handicaps as well had the lowest survival rate, 50 percent.

Also, the rate of accumulated cases will be affected by the duration of required care. This ranges from the relatively short-term intensive care beginning at birth for prematures through a period of a few weeks or months concentrated in later infancy and early childhood for most of the remainder of class 2, to the long-term care required by most of those in classes 3 and 4. In most of the severe physical handicaps, the care begins early in life and continues over many years, while the special services for those with low IQ's are concentrated in the school years.

Handicaps Not Detected in This Study

In addition to the children included in this analysis because of one or more defects or deficits identifiable by the methods used during the 2-year period of observation, it is likely that there are children in whom no defects or deficits were noted during this period, but who will manifest them as they grow older. Also, we can be reasonably sure that some of the "minimally brain damaged" are among the children born to mothers who had complications of late pregnancy, labor, or delivery and that newborns who had respiratory distress or other difficulties may encounter learning and behavior problems as a result of subclinical neurological deficits.

Graham and associates (*18*), Honzik (*19*), and others have devised more refined testing methods which give promise of being very useful in the early identification of these children who represent the lower end of the continuum of perinatal casualties and who may join the ranks of the poor readers, slow learners, and behavior problems in school. A followup study at school age of a group of KPS children to

include those suspect because of their birth histories may throw light on the magnitude of this type of crippling of human capacity and help fill in another gap in our knowledge of the nature and extent of the problem of children who are born physically and mentally handicapped.

Summary and Conclusions

In a 2-year followup study of 1,963 children born on Kauai, Hawaii, those with physical and mental handicaps of natal and prenatal origin were identified and classified principally from the standpoint of their impact on the community. The children with congenital defects, prematurity, mental retardation, and birth injuries were assigned to four groups according to the type and duration of special care required, as well as by anatomical systems and clinical features. The handicaps were those recorded on hospital and physicians' records, birth certificates, records of the local health department, and the bureau of crippled children's services, Hawaii Department of Health, as well as special Kauai Pregnancy Study interviews and pediatric and psychological examinations performed at age 2.

The available data made it possible to calculate incidence rates of all birth handicaps for an entire community. It is believed that these statistics may be useful as guides in estimating the increment of new cases requiring special care in other communities.

Defects and deficits of prenatal and natal origin affected an estimated 17.0 percent of the liveborn in the study group, but almost half of these required little special care beyond that ordinarily given by the family physician. Of the 10 percent of the liveborn requiring special care, almost two-thirds suffered from conditions that were amenable to relatively short-term, skilled medical and nursing care.

The remainder, almost 4 percent of the liveborn, required combinations of diagnostic services, long-term, skilled treatment, special therapy, special education, and custodial care. Even with the best of care, three-fourths of these children will be permanently handicapped to some degree. More than half of these who survive to school age will need some form of special education because of physical or mental handicaps. More than one in five will eventually require some form of custodial or institutional care for the duration of their lives.

The incidence of "severe mental retardation" and children with IQ scores under 70 was 1.8 percent; 3.2 percent had scores under 75, and 5.0 percent were under 80.

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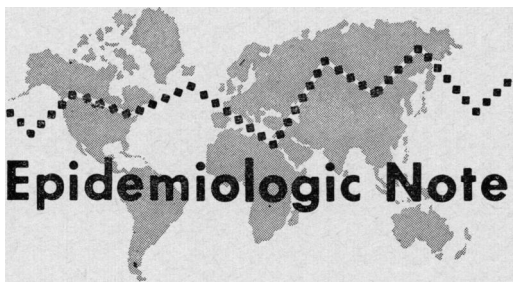

Salmonella derby Gastroenteritis

In March 1963, clusters of laboratory isolations of *Salmonella derby* reported by State health departments alerted the Public Health Service's Communicable Disease Center in Atlanta to an outbreak of *S. derby* gastroenteritis. The reports showed a clustering of such isolates in the New York City area. Five cases of diarrhea in one hospital prompted an investigation by the New York City Health Department with CDC assistance.

Similar clusters of *S. derby* isolations subsequently appearing in New York State, Pennsylvania, New Jersey, and Massachusetts mainly represented cases of *S. derby* gastroenteritis acquired in hospitals. Of 775 *S. derby* isolations reported to CDC from March 1 to July 8, 1963, from 25 States and the District of Columbia, 601 represented hospital-associated cases.

By early April 1963, hospitals, city and State health departments, the CDC, and the Food and Drug Administration had joined the search for a source common to the hospitals with patients harboring *S. derby*. Analysis of case records and interviews at these hospitals ruled out human carriers among physicians, nurses, and other hospital personnel; medications were also eliminated as a source. A careful study of all foods revealed that raw or undercooked eggs had been consumed by more patients than any other single food item or medication within the 48 hours before onset of illness. Patients who developed *S. derby* gastroenteritis were also apparently more likely to consume raw or undercooked eggs than the total hospital population at risk.

With this lead, possible egg sources of 13 of the affected hospitals in three States were investigated. The number of *S. derby* organisms recovered from cracked eggs from farms in one of the geographic areas supplying these hospitals led the Public Health Service to issue this recommendation:

There is sufficient epidemiologic and bacteriological evidence to suggest that everyone should avoid buying and using cracked or unclean eggs. Persons who are ill, especially infants, the elderly, and persons suffering from gastrointestinal disease or malignancies, should not be fed raw or undercooked eggs. An undercooked egg is one in which the white is not firm.