# Predicting Needs for Special Education Resources for Mental Retardation from Birth Defects Records

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These data were presented, in part, at the 1990 National Perinatal Association Annual Meeting, New Orleans, LA, November 15-18, 1990.

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A MAJOR OBJECTIVE OF BIRTH DEFECTS surveillance is to provide estimates of the number of affected children in order to plan services, including special education, that they will need (1-3). A large but unspecified number of children with functional handicaps also have birth defects. The purposes of this report are to estimate the contribution of congenital anomalies and multiple congenital anomaly syndromes to the total population of mentally retarded (MR) children in a well-defined geographic area and to compare that estimate to the reported prevalence of MR in the current service delivery system. In addition, these data have implications for newly mandated services such as early intervention.

### **Methods**

This analysis of population-based surveillance data includes (a) independent estimation of the probability of association of MR with each birth defect by a dysmorphologist and a developmental pediatrician, using standard texts, literature reports, and clinical experience; (b) application of Planning of service delivery systems for children with special health care needs would be enhanced by knowledge of numbers of cases anticipated in defined geographic areas.

A method is described for predicting numbers of children who will likely have mental retardation sufficient to require special education services, based on the birth prevalence of birth defects and clinicians' estimates of the likelihood of mental retardation associated with each specific birth defect.

This method is applied to the 1980-82 birth cohort of a 28-county area of south and central Arkansas, and it is compared with special education enrollment data for children ages 6 to 8 in academic year 1988-89. According to this estimate, children with birth defects may account for 32 to 56 percent of the cases of mental retardation among 6- to 8-year-olds reported by the public schools.

these probabilities to cases of birth defects within the study cohort to estimate the number of children having MR; and (c) comparison of the estimate of mental retardation prevalence in the study cohort (born 1980-82) with that reported by the cohort's public school system for the school year 1988-89.

Case ascertainment. The Arkansas Reproductive Health Monitoring System routinely monitors cases of adverse pregnancy outcome in the State. This system is administered by Arkansas Children's Hospital and professionally directed by faculty of the University of Arkansas for Medical Sciences. This study encompasses outcomes of liveborn infants of 28 counties of central and south Arkansas for the 3-year period 1980-82. Cases of birth defects were actively sought in the records of all hospitals and Head Start programs serving the area, including all referral hospitals. The data are population-based, covering 52,490 live births. Problem cases were ascertained through inpatient records and through logbooks kept in nurseries, surgical suites, delivery rooms, and selected pediatric clinics. Medical record review was performed for all infants' cases, and maternal chart review was conducted when an infant with a birth defect was identified in the hospital of birth.

Data abstracted included maternal address and infant's race, sex, hospital of birth, date of birth, hospital source of abstract, specific suboptimal pregnancy outcomes, parental occupations, maternal history (complications, illnesses, drugs, smoking, and alcohol use), and family history (birth defects, consanguinity, epilepsy, deafness, mental retardation, other). Problems were coded according to the British Pediatric Association Classification of Diseases, a modification of the International Classification of Disease, Clinical Modification, Version 9 (ICD-9-CM), as modified by the Centers for Disease Control (CDC), Division of Birth Defects and Developmental Disabilities, to exclude normal variants (4). This methodology has been reported previously (5).

**Probability estimates.** A compilation of the 1,027 ICD-9-CM 6-digit disease codes (including qualifiers such as bilateral, left, and probable) for birth defects was reviewed independently by a developmental pediatrician (C.F.) and a dysmorphologist (C.C.). Based on standard references (6-8) and personal experience, an estimate was made of the frequency of mental retardation within the group of persons assigned a designated code. For most conditions, such as Down syndrome and spina bifida, for example, standard references provided reliable data regarding the prevalence of MR associated with the birth defect or syndrome. In other conditions, such as cleft lip and omphalocele, it was necessary to derive estimates which considered that these defects may be seen in isolation or as one feature of a broader pattern of altered development. In other conditions, such as esophageal fistula and uterine anomalies, no accurate objective data were available, so that the estimate must be considered, of necessity, to be derived from the experience of clinicians, and therefore it is subject to some arbitrariness. The range of 5 to 15 percent was chosen for these conditions without reliable data and for which the probability was thought to be low, but present, in order to reflect the uncertainty of probability estimates.

**Prevalence estimates from birth defects data.** Prevalence estimates for mental retardation were derived by applying our probability estimates to the population-based cohort of infants diagnosed with birth defects and alive at the time of medical record abstraction. Because it is not known

whether multiple problems contribute additively to MR probability, estimates for infants with more than one birth defect were derived in two ways: using the defect with the highest MR probability as the maximum or using the sum of the probabilities as the maximum (not to exceed 1.0). Each infant was therefore assigned a probability of mental retardation of 0.0-1.0. These probabilities were summed across all cases to obtain an estimate of the prevalence of mental retardation among all children with birth defects. The probability ranges and the range of discordant ratings are the bases for estimates of minimum and maximum number of cases anticipated to have mental retardation within this cohort (that is, the lowest rating or rating of 5 percent for 'low' probability forms the minimum).

From the cohort of 52,490 live births, 1,659 infants were identified as having one or more birth defects. Deletion from the data set of those infants who were stillborn, those who were no longer alive at time of hospital abstract, and those who had a birth defect highly associated with early death, yielded a total of 1,506 infants likely to require care and intervention services.

Prevalence estimates from special education data. The number of children designated as mentally retarded (I.Q. less than 70) by public schools serving the 28-county study area was obtained from the Arkansas Department of Education, Division of Special Education, for the school year 1988-89. Children are designated as mentally retarded based on test results from one or more of a list of standard assessment tools, administered by school psychologists or other trained professionals. Data showing the distribution of these children by I.Q. are unavailable. These children (ages 6-8 years) correspond to the study cohort with birth years in the period 1980-82. Prevalence ratios of mental retardation from public schools in the study area were calculated and were compared with national data (9) as a measure of the representativeness of the study population.

# Results

Probabilities assigned to each of the birth defects codes for disorders with concordance in probability estimate are listed in table 1. The two raters agreed on probability assignments for 92.4 percent of the 1,027 codes. Only 44 (2.9 percent) of the cohort of infants with birth defects had a diagnosis within the group of disorders with discordant probability

ICD-9-CM codes <sup>1</sup>	Disorders included	ICD-9-CM codes <sup>1</sup>	Disorders included			
Probability = 0.8-1.0		Probability 0.25-0.49 continued				
740;742.0–.1	Anencephaly; encephalocele; microcephalus	744.214;.80;.88	Microtia, bilateral; macrostomia; other specified face or neck			
742.20;.28;.90	Other specified brain reduction; unspecified brain or spinal cord	748.0;752.00–.01	Choanal atresia; ovarian absence or agenesis or streak			
742.24–.27	or nervous system Agyria; microgyria; holoprosence-	752.70;.865	Hermaphroditism; hypoplastic pe- nis			
742.31–.32;.81	phaly; arrhinencephaly Dandy-Walker Syndrome; hydra- nencephaly; familial dysautono- mia	753.0;.32 754.22;.825	Kidney absence or agenesis or dysgenesis or hypoplasia or fused or lobulation Congenital postural spine curva-			
742.41–.50	Porencephaly; multiple cerebral		ture; shield chest			
743.00104	cysts; other specified brain Anophthalmos; microphthalmos, bilateral	756.04–.05	Craniofacial dysostosis; acroce- phalosyndactyly not otherwise specified			
743.52; 748.185 756.447;.54	Optic disc anomaly; tubular nose Thanatophoric dwarfism; osteo-	756.065;.085	Hemifacial macrosomia; hyperte- lorism			
757.10	petrosis Harlequin fetus	756.38;.40	Other sternum anomaly; asphyxiat ing thoracic dystrophy			
758.0–.528;758.55–.59 758.91–.99	Chromosomal anomalies Chromosomal addition, deletion,	Probability = 0.25-0.49				
759.82;.84;.87	duplication, abnormality not oth- erwise specified Congenital malformation with short	756.43–.445	Achondroplasia or diastrophic dwarf; other specified chondrody-			
139.02,.04,.01	stature or involving limbs or with metabolic disturbances	756.45–.46	strophia Metaphyseal dysostosis; spondy- loepiphyseal dysplasia			
Probability = 0.5-0.75		756.610–.617	Congenital diaphragmatic hernias; hemidiaphragm			
742.21–.23	Corpus callosum, hypothalamus, cerebellar anomaly	756.70 758.69–.81	Exomphalos-omphalocele Turner syndrome (karyotype un-			
742.30	Aqueduct of Sylvius anomaly; un- specified hydrocephaly		specified); Klinefelter; Mosaic XO/XY, XO/XX			
742.51;.88;.99	Atelomyelia; other specified or un- specified nervous system	758.88–.90	Sex chromosome anomaly (other specified or unspecified); Mosaic			
743.10;.38	Microphthalmos; other specified lens anomaly		not otherwise specified			
743.34;.43	Lens coloboma; iris coloboma	Probability = 0.05-0.15				
743.48–.50 745.60–.61	Other anterior eye Single common atrium; ostium pri-	743.21–.31	Enlarged eye or cornea; lens spherical or absent			
745.62–.69	mum defects Common atrioventricular canal;	743.60–.62	Blepharoptosis; estropion; entro- pion			
754 00.750 050 057	endocardial or other cushion de- fect	743.632–.635 743.67;.90	Blepharophimosis; other eyelid Anomaly of orbit or unspecified			
754.20;756.056–.057	Congenital postural scoliosis; acro- cephalosyndactyly, type III or	744.03;.22–.30	eye Inner ear; ears misshapen or mis-			
756.446;757.110	other Metatrophic dwarfism; collodion baby	744.41–.48	placed; eustachian tube absent Preauricular sinus; other branchial			
757.35–.36	Incontinentia pigmenti; xeroderma pigmentosum	745.0–.59;.7–.9	cleft anomaly Bulbus cordis anomaly; cor bilocu-			
758.83; 759.80	Mosaic including XXXXY; congeni- tal malformation affecting face	746.0–.99 747.0–.39	lare; other septal closure Other congenital heart anomaly Circulatory system congenital			
Probability = 0.25-0.49		749.0–.07;.09	anomaly Cleft palate			
741 742.40;.91	Spina bifida Macrocephaly; unspecified spinal cord	749.1–.29 750.10–.11;.13	Cleft lip Aglossia; hypoglossia; tongue dis- located or displaced			
743.102;.32	Microphthalmos, unilateral; cata- ract	750.30–.33 751.11–.41	Esophageal fistula Anomaly of lower alimentary sys-			
743.39–.42;.44	Unspecified anomaly of lens or	751.5359	tem Other intestinal anomaly			
743.53;.63;.636	cornea; absence of iris; other iris Choroid anomaly; other eyelid anomaly	751.53–.59 752.20–.31;752.38–.39 752.41–.42;752.60–.62	Uterine anomalies Vaginal anomaly; hypo or epispa-			
743.81;744.0001	Epibulbar dermoid cyst; ear or au- ricle or auditory canal absence	753.01;.16–.20	dias Unilateral kidney absence or hypo			

#### associated with specific birth defects

ICD-9-CM codes <sup>1</sup>	Disorders included
Probability 0.05-0.15 co	ntinued
	plasia or dysplasia; hydronephro-
	sis; cystic kidney
753.29–.31;.33	Ectopic or accessory or multiple
	kidney; other obstructive renal
750 44 40 00	anomaly
753.41–.48;.60	Accessory or ectopic ureter; other
753.6269	ureter Urethral anomalies
754.21:.578	Congenital postural lordosis; foot
754.21,.5=.78	deformities
754.85-755.60	Deformity of hand or digits or limb
734.83-733.88	or shoulder
755.665667	Hip dysplasia
755.685-756.03	Other limb anomaly; craniosyn-
	ostosis
756.07;.0809	Localized skull defects; unspeci-
	fied skull or face bone anomaly
756.1136	Anomaly of vertebrae or sacrum or
	spine or ribs or sternum
756.39;.48–.506	Thoracic cage anomaly (unspeci-
	fied); other chondrodystrophy;
	osteogenesis imperfecta; fragilitas
	ossium
756.520;.530	Chondroectodermal dysplasia; in-
	fantile cortical hyperostosis
756.5657;758.5859	Osteopoikilosis; multiple epiphy-
	seal dysplasia; other osteodystro-
756.71072	phies
/30./10/2	Gastroschisis; prune belly syndrome
756.8081	Polands syndrome; other absent
750.0001	or hypoplastic muscle
756.8486	Amyotrophia; Ehlers-Danlos; con-
100.04 .00	genital torticollis
757.11530	Congenital ichthyoses; abnormal
	palmar creases; other skin anom-
	aly
757.37–.50	Cutis laxa hyperelastica; skin ab-
	sent; hair anomaly; absent nails
757.58;.68	Hypoplasia fingernails or toes;
	other gonadal dysgenesis
759.00–.19	Anomaly of spleen or adrenal
	gland
759.23–.49	Endocrine gland (other); situs in-
750.00 00	versus; conjoined twin
759.6069	Hamartomas
759.89–.99	Probable other specified anomaly;
	embryopathia; congenital anoma- lies not otherwise classified
	HES HOL OTHERWISE CLASSIFIED

<sup>1</sup> British Pediatric Association modification of ICD-9-CM, as modified by the Division of Birth Defects and Developmental Disabilities, Center for Environmental Health and Injury Control, Centers for Disease Control, Atlanta, GA.

ratings, reflecting rater discordance primarily for rare birth defects. Table 2 displays the distribution of the study population as to the probability of mental retardation; a small effect of rater discordance can be seen within each probability range.

Table 3 depicts the range of MR probability estimates derived from various combinations of probability ratings and paradigms for handling multiple birth defects. Estimates for numbers of children with MR were computed in two ways. First, the probabilities were computed using a probability of 0.05 for infrequent conditions, with a range based on separate estimates for conditions with rater discordance. Second, the probabilities were recomputed taking the extreme minimum and maximum probabilities for each condition across the two raters. The latter estimates are referred to as the 'overall minimum estimate' and the 'overall maximum estimate' in table 3.

Data on school enrollment and children defined as mentally retarded participating in special education in school districts in the study area are given in table 4. The number of children roughly drawn from this birth cohort that were ages 6-8 and were classified as mentally retarded by the Special Education Division of the Arkansas Department of Education for the school year 1988-89 was 747. As shown in the table, the MR prevalence estimate from cases of birth defects accounts for 32 to 56 percent of the MR prevalence in the public schools.

## Discussion

It is known that birth defects contribute significantly to fetal loss (10,11), low birth weight (12), infant mortality (13,14), and child mortality (15,16). In addition, it has been suggested that the number of newborn minor physical anomalies correlates with the child's developmental score at age 5 years (17) and with short attention span, peer aggression, and impulsivity at age 3 (18). To our knowledge this is the first report that has used data from the surveillance of birth defects to predict the prevalence of mental retardation within a defined population. Since many States have established birth defects registries, analyses of data such as those we have reported may prove to be an attractive method of finding and tracking children in need of educational services. Our findings suggest that a State birth defects monitoring system will identify many children who may benefit from early intervention.

Determination of the relative contribution of prenatal, perinatal, and postnatal factors in the etiology of neurodevelopmental abnormalities has been difficult to assign with accuracy. In this study, as in most others, the causes of mental retardation have been inferred from population data. Many conditions, such as Down syndrome, are assumed with a high degree of accuracy to be causative of the mental retardation, whereas other conditions, particularly single defects of presumed

Table 2. Effect of inter-rater differences regarding probability
estimates of mental retardation upon the number and distribu-
tion of cases of birth defects in 28 Arkansas counties

Estimated probability of	Mini	mum	Maximum		
mental retardation	Number	Percent	Number	Percent	
0.00	222	14.7	206	13.7	
0.05–0.15	979	65.0	967	64.2	
0.16–0.33	108	7.2	115	7.6	
0.34-0.49	0	0.0	10	0.7	
0.50–0.79	67	4.4	76	5.0	
0.80–1.00	130	8.6	132	8.8	
	1,506	100.0	1,506	100.0	

Table 3. Number of children with mental retardation (MR) predicted from a review of cases of birth defects in 28 Arkansas counties

	Number of children				
Estimate type	Single highest MR probability per case	Sum of all MF probabilities per case			
Probability for infrequent con-		· · · · · · · · · · · · · · · · · · ·			
ditions = 0.05 Probability for infrequent con-	<sup>1</sup> 247–254	<sup>1</sup> 267–274			
ditions = 0.15	345-350	396-401			
Overall minimum estimate <sup>2</sup>	243	263			
Overall maximum estimate <sup>3</sup>	354	405			

1 Range due to rater discordance

<sup>2</sup> Probability for infrequent conditions set at 0.05 and minimum rating of discordant pairs. <sup>3</sup> Probability for infrequent conditions set at 0.15 and maximum rating of

<sup>3</sup> Probability for infrequent conditions set at 0.15 and maximum rating of discordant pairs.

multifactorial etiology such as cleft lip and palate, are almost certainly not causal, but rather temporal in their relationship. Previous studies have attempted to distinguish between severe and mild mental retardation in assigning risks attributed to birth defects. While prenatal factors have been found to account for about 50 percent of cases of severe mental retardation, they account for no more than 25 percent of cases of mild mental retardation (19). In this report, no distinction is made between mild and severe mental retardation. The relationship of a particular anomaly to mental retardation is, in most cases, not known with accuracy, so that an assignment of risk involves a consideration of the range of conditions which might be associated with that particular anomaly.

Rater discordance had little effect on the number of children from the study cohort predicted to have mental retardation; it affected less than 3 percent. As illustrated in table 2, only 14 percent of the children with one or more birth defects were estimated to have no association with MR; 8-9 percent were estimated to have very high likelihood of association with MR. Children having birth defects with a low probability estimate comprised 65 percent of the study cohort. As data on the likelihood of an association with MR for these birth defects are generally lacking, the assigned 5-15 percent probability range strongly affects the predicted MR case number; table 3 demonstrates this effect. This table also illustrates the effect of two approaches to consideration of children with multiple birth defects. The maximum estimate of the proportion that were MR related increased from 47 to 56 percent of birth defects cases when multiple problems were considered to be additive, again reflecting the strong influence of defects that had high prevalence, but a low probability of being MR related.

The case rate of birth defects for the 28-county Arkansas area during 1980-82 was 31 per 1,000 live births. This rate can be compared with that for metropolitan Atlanta, 3.4 percent, ascertained by the Metropolitan Atlanta Birth Defects Monitoring Program (CDC) for 1980-85 (personal communication from Larry D. Edmonds, CDC, February 13, 1987), and to that for much of the State of California, 2.7 percent (20), ascertained by the California Birth Defects Monitoring Program for the years 1983-86. These programs have case ascertainment methods similar to those employed in this Arkansas study. The case rate of birth defects does not include minor anomalies unlikely to be ascertained in hospitals or in Head Start Programs. Because these anomalies are not commonly associated with MR, they are thought to have little effect on the predicted prevalence of MR.

In- or out-migration of children with birth defects or developmental disabilities could have occurred during the interval from birth to school age. Although families with young children are known to be highly mobile, we are unaware of any reports that document a higher mobility for families with children who have special health care needs. Within the State of Arkansas, services for persons with birth defects are most available within the 28county study area. Although in- or out-migration undoubtedly does occur, it is more likely that families with affected children would migrate into the study area. Therefore, any bias due to net migration increases the denominators in our computations, and it is unlikely to affect the findings of our study in any significant manner.

The prevalence of MR in public schools for this cohort of 6- to 8-year-olds was 14.5 per 1,000 compared with 7.85 per 1,000 for the nation in 1988-89. Patrick and Reschly (21) reported a wide range of MR prevalence from State school systems;

higher prevalence is generally found in southern States and is most closely related to parental median educational level. Studies reviewed by McLaren and Bryson (19) estimated the prevalence of MR to be 6-8 per 1,000 population and to be highly dependent on ascertainment method, sex, and age. The prevalence of MR in childhood may also be associated with rurality and levels of socioeconomic status in the community. The prevalence of school-recognized MR increases strongly with age until the teen years (9,22), but MR associated with cases of birth defects is likely to be diagnosed early and does not increase appreciably with age. The proportion of children in public school with MR predicted by prevalence estimates derived from birth defects data is therefore anticipated to be somewhat high, due to late diagnosis of MR within the school system (that is, the denominator increases with age).

# Conclusion

The data presented in this study suggest that children with malformations and their sequelae represent a significant proportion of the population with neurodevelopmental handicaps. Recognition of this association is helpful in predicting the number of persons who might have preventable causes of disability, in anticipating the special educational needs of affected children, and in planning for provision of special services within a given population. It is possible that early recognition of the association of MR with specific birth defects, along with early aggressive therapeutic treatment, may ameliorate to some extent this birth defect sequela. For conditions that are relatively common and contribute significantly to the overall prevalence of MR, such as cleft lip or cleft palate or both, we recommend that a multidisciplinary approach to assessment and longitudinal care, including developmental evaluation and referral, be part of the health care supervision of affected children.

Objectives for the Healthy People 2000 goals include broader multidisciplinary evaluation for persons with cleft lip or cleft palate or both (23). A similar approach could be instituted for children with congenital heart defects, neural tube defects, and other selected malformations. Children with MR not attributable to birth defects should be further studied to identify possible associated risk factors. Although infants with birth defects later constitute a significant proportion of the population with mental retardation in schools, early inter-

Table 4.	Pu	blic	schoo	data	a for	198	88–89	on	enre	ollme	nt a	and
number	of	child	iren	with	menta	al	retard	atio	n (i	MR)	in	28
			1	Arkans	sas co	oun	ties					

Category	Number or range
Group	
Children ages 6-8 with MR (IQ less than 70) .	747
Children ages 6-8 enrolled in school	51,689
Estimate type	
Proportion of MR predicted from birth defects data:	
Using the single highest MR probability	0.32-0.47
Using the sum of all MR probabilities	0.35-0.56

SOURCE: Special education and school enrollment data obtained from the Division of Special Education, Arkansas Department of Education.

vention activities based solely on this source to find children will fail to identify the majority of children later determined to have a developmental disability.

As many States have already established birth defects registries, this may be an attractive child find method. The potential use of data in a birth defects registry for planning of developmental services has been suggested (1-3). These data may be especially beneficial in providing estimates of the demand for early intervention services under Public Law 99-457, Part H of the Individuals with Disabilities Education Act (24), and the appropriateness of perinatal risk factors as biological and environmental markers of risk for developmental delay (25, 26).

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