

# Developmental Disabilities

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## PUBLIC HEALTH IMPORTANCE

Developmental disabilities are a group of heterogeneous conditions that are attributable to mental and/or physical impairments, manifested before the person attains the age of 22 years, and likely to continue indefinitely. Persons with developmental disabilities require specialized services and have substantial functional limitations in at least three of the following areas: self-care, receptive or expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency (1). Examples of developmental disabilities include mental retardation, neuromuscular disorders such as cerebral palsy, blindness and deafness, learning disabilities, epilepsy, and autism. As a group, these conditions may have similar etiologies because they often coexist.

Although precise prevalence rates for developmental disabilities in the United States are not available, an estimated 8%–16% of school-age children have difficulties that justify specialized educational services (1). These conditions are costly to the individual, affected families, and the country as a whole. In 1984, federal, state, and local governments spent about \$16.5 billion for mental retardation and developmental disabilities services (2).

Surveillance of developmental disabilities is challenging, in general, and more so in the United States than in some European countries. Conducting surveillance is difficult because of a number of factors. The case definitions for developmental disabilities often rely on clinical examinations and clinical judgment rather than on results from laboratory reports or pathology findings. No standard national or state-specific case definitions or terminologies have been established for developmental disabilities, although

recent attempts to address this problem have been made (3). Also, because these conditions evolve over time and are related to the maturation of the nervous system, a child may be several years old before a definitive diagnosis of a developmental disability can be made. Despite these limitations that are inherent to the surveillance of developmental disabilities, ongoing mental retardation registries have been maintained in Great Britain since the 1940s (4).

Although various studies of developmental disabilities have been conducted in the United States, few meet the explicit criteria for surveillance, as defined by the CDC (5). In the absence of large, population-based centralized registries of individuals receiving services for developmental disabilities, as in Europe, an efficient developmental disabilities surveillance system in this country should attempt to identify cases from sources that see the most children with these conditions. Because we do not have a uniform system of health care in the United States, to obtain information on all preschool children with developmental disabilities it is necessary to access records from multiple community agencies. A recent mandate for preschool services through state departments of education may eventually help to overcome this problem, although not all children with developmental disabilities are served by public school systems (6). Identifying school-age children with developmental disabilities from school records alone yields more complete ascertainment of cases than any other single source because of the more than 15-year requirement that all school-age children with specific physical, emotional,

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or cognitive impairments be identified and that educational services be provided (7).

U.S. surveys of children with developmental disabilities have usually yielded prevalence rates that are similar to those from other countries. For example, in population-based studies of school-age children in the United States and other countries researchers have reported that the prevalence for cerebral palsy is around 1.5–2.5 per 1,000 children. However, rates as high as 5.0–5.8 per 1,000 children have also been reported from other studies conducted in the United States (8). These differences in rates are likely to be related to differences in case definitions, methods of ascertainment, characteristics of the populations studied such as age and sociodemographic factors, and the periods studied. For additional information about related topics and surveillance activities, see the Prevalence of Birth Defects chapter.

## HISTORY OF DATA COLLECTION

Surveillance of developmental disabilities at CDC is a relatively recent activity. In 1992, we began our major effort in developmental disabilities surveillance, the Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP).

Before the inception of the MADDSP, CDC and the Georgia Department of Human Resources conducted the Metropolitan Atlanta Developmental Disabilities Study (MADDS), a population-based study of five developmental disabilities (mental retardation, cerebral palsy, hearing impairment, vision impairment, and epilepsy) in 10-year-old children living in five metropolitan Atlanta counties between 1985 and 1987 (9). MADDS was funded from 1984 to 1990 by the Agency for Toxic Substances and Disease Registry through a cooperative agreement involving CDC and the Georgia Department of Human Resources.

Because the MADDS was the first population-based study of multiple disabilities among U.S. school-age children, a major focus of the study was to develop methods for the surveillance of children with developmental disabilities. Many education, health, and social service agencies in the Atlanta area were used as sources to ascer-

tain cases for the study (9).

After the first year of MADDS surveillance, we calculated the prevalence rates of epilepsy and compared it with previously reported rates in the literature. Our rates were much lower than we had expected. We suspected that children with isolated epilepsy (i.e., without other disabilities) would be less likely than children with multiple disabilities to attend special education programs or require special services. We therefore added the 22 laboratories in Atlanta that regularly perform electroencephalograms as additional sources for identifying epilepsy cases. As a result, our estimated prevalence rate of epilepsy nearly doubled, increasing from 3.3 to 6.5 per 1,000 10-year-old children.

MADDSP was unique in that we used individual school records to identify children with disabilities. By using these records, we were able to identify about 95% of the children with either mental retardation, cerebral palsy, vision impairment, or hearing impairment (Table 1).

## CDC SURVEILLANCE ACTIVITIES

### Metropolitan Atlanta Developmental Disabilities Surveillance Program

Surveillance of developmental disabilities at CDC is the responsibility of the National Center for Environmental Health. This center conducts the MADDSP, which is an active, population-based surveillance system for mental retardation, cerebral palsy, vision impairment, and hearing impairment among children aged 3–10 years whose parents are residents of the Atlanta metropolitan area.

MADDSP has two main purposes:

- To provide regular and systematic monitoring of prevalence rates of selected developmental disabilities according to various demographic, maternal, and child characteristics.
- To provide a framework and database for conducting studies of children with the selected conditions.

**TABLE 1. Percentage of 10-year-old children identified as having selected developmental disabilities by three types of sources — Metropolitan Atlanta Developmental Disabilities Study, 1985–1987**

Source	Mental retardation	Cerebral palsy	Hearing impairment	Vision impairment
Public schools and other Georgia Department of Education programs	97.8	85.0	97.0	93.5
Georgia Department of Human Resources, various programs	1.8	6.3	3.0	4.9
Selected hospitals	0.4	8.7	0.0	1.6

## CASE DEFINITIONS

Under the MADDSP case definition, children must meet the following three criteria:

- They must be 3–10 years of age at any time during the calendar year of ascertainment.
- They must have one or more of the four conditions of interest.
- Their parents or legal guardians must reside in the surveillance area at some time during the calendar year of ascertainment.

The age range of 3–10 years was chosen because the lower bound corresponds with the beginning of the age span covered by Part B of the Education for All Handicapped Children Act (7), which mandates that public school systems provide services to children with special needs (public school systems being a major source of case ascertainment for our surveillance system), and because the vast majority of children served under that act enter the special education system by the age of 10 years (10).

The MADDSP defines the four developmental disabilities as follows:

- Mental retardation. Either 1) an intelligence quotient (IQ) of 70 or less on the most recent psychometric test performed by a psychometrist; or 2) a written statement by

a psychometrist that a child's intellectual functioning falls within the mentally handicapped range.

- Cerebral palsy. Either 1) a diagnosis made by a qualified health professional and so noted on a medical record; or 2) physical findings in a medical record that are consistent with the condition. For the purposes of the MADDSP, cerebral palsy is defined as a group of nonprogressive disorders afflicting young children in which abnormalities of the brain cause paralysis, involuntary movement, or incoordination. The definition excludes motor disorders caused by spinal cord abnormalities.
- Vision impairment. A measured visual acuity of 20/70 or worse in the better eye with correction. In the absence of a measured visual acuity, a child is considered to meet the case definition if the medical record includes 1) a functional description, by an eye specialist, of visual acuity of 20/70 or worse (e.g., light perception only) or 2) a statement by an eye specialist that the child has low vision or blindness.
- Hearing impairment. A measured bilateral pure tone hearing loss averaging 40 decibels or worse, unaided, in the better ear at frequencies of 500, 1,000, and 2,000 hertz. In the absence of a measured bilateral hearing loss, a child is considered to meet

the case definition if the medical record includes a description, by a licensed and/or certified audiologist or qualified physician, of a hearing level of 40 decibels or worse in the better ear.

## POPULATION CHARACTERISTICS

The surveillance area for the MADDSP is the five-county Atlanta metropolitan area (Clayton, Cobb, DeKalb, Fulton, and Gwinnett counties) that includes the city of Atlanta. In 1990, the area had a population of about 2.2 million, which included about 250,000 children aged 3–10 years. Slightly >30,000 births a year are recorded in the area. A special feature of the area is the existence of an active birth defects surveillance program operated by CDC—the Metropolitan Atlanta Congenital Defects Program. (See the Prevalence of Birth Defects chapter.) Consequently, we can link children identified in the MADDSP to the birth defects registry to obtain additional medical data.

## ASCERTAINMENT PROCEDURES

Cases are ascertained by reviewing existing educational, medical, and social service records at selected sources within the surveillance area. The ascertainment methodology of the MADDSP relies, in large part, on the experience of its predecessor, the MADDs. As was pointed out earlier, in the MADDs it was found that information needed to identify and describe most children with the four conditions of interest is available from the special education departments of local public school systems (Table 1).

The first step in identifying children with any of the chosen conditions is to acquire electronic data files from these selected primary sources:

- The nine public school systems serving the five-county area.
- Other Georgia Department of Education programs for children with developmental disabilities (e.g., the psychoeducational centers in the five-county area, state schools for the blind or deaf).

- Georgia Department of Human Resources programs for children with mental retardation and other special health-care needs (e.g., county mental retardation service centers, state hospitals and residential care facilities, Children's Medical Services).
- The large public hospital (and selected associated clinics) offering specialized infant and pediatric care in Atlanta and the two major private pediatric care hospitals (and selected associated clinics) in the surveillance area.

## DATA COLLECTED

In addition to identifying information and a standard array of demographic data on each case, the MADDSP collects the most recent and earliest evaluation data relevant to the specific type of developmental disability. For example, for a child with mental retardation, scores on tests of cognitive and adaptive functioning are recorded. The hearing level in each ear and the type of hearing loss are noted for children classified as hearing impaired. The best corrected vision (in each eye) or general description of visual acuity (e.g., light perception only) is recorded for children with vision impairment. For children with cerebral palsy, a medical diagnosis and/or functional description of the child's disability is recorded as well as a level of functioning determined by ambulation ability and the use of assistive devices. For all children identified, we record the presence of selected other medical conditions (e.g., major birth defects, autism, epilepsy) and information on etiology. For children identified through the public schools, we record information on all special education services the children receive through the public schools, the primary program for which they are eligible to receive special education services, the delivery model, and the servicing school.

## DATA MANAGEMENT

Detailed data at each primary source are entered on laptop computers by MADDSP staff and are edited on-line at the point of entry

to reduce the amount of batch editing done at CDC. Batch edit programs are run monthly to eliminate duplicate records for the same child and to check for errors not identified at the point of entry. Children born in Georgia are linked to Georgia birth certificates so that demographic and medical data from the birth certificates can be added to the case records. For children born outside Georgia, requests are made in writing to the appropriate state or city vital records office for copies of the birth certificates. The data are stored in a series of files on the CDC mainframe. Various types of analytical files are created, with personal identifiers removed.

## REPORTING OF FINDINGS

Rates produced from the MADDSP may be of two types:

- **Point prevalence rates** of a specific developmental disability for a given age use the estimated number of children of that age living in the five-county area (from census data) as the denominator. Such rates permit the use of all case children, regardless of where they were born.
- **Birth cohort prevalence rates** of a specific condition use the number of live births in a given year in the five-county area (minus infant deaths) as the denominator and the number of case children aged 3–10 years who were born in that year in the surveillance area. Case children born outside the surveillance area are excluded from these rates.

Either of these two types of rates can be computed for children of a specific age, sex, or race to examine variations in the occurrence of the conditions. Further, we are able to examine the prevalence rate for multiple disabilities, for example, for the joint occurrence of mental retardation and cerebral palsy. Mental retardation can be analyzed according to four standard severity levels: mild (IQ, 50–70), moderate (IQ, 35–49), severe (IQ, 20–34), and profound (IQ, <20).

The first surveillance report from the MADDSP will be released in 1994. Subsequent reports will be released yearly.

## Disability Prevention Programs

In addition to the intramural MADDSP, CDC supports developmental disabilities surveillance activities extramurally in 28 states through its Disability Prevention Program (11). The approaches used for developmental disabilities surveillance in those states range from a multitiered, active case-finding system in Rhode Island to a passive, data linkage system in Florida. Technical information about these state-based developmental disabilities surveillance programs are available from CDC (see the Additional Resources section of this chapter).

## GENERAL FINDINGS

Because the MADDSP is a new surveillance system, data are not yet available. However, data collection in the MADDSP, the prototype for MADDSP, ended in 1990, and some results have recently been published. In the MADDSP, developmental disabilities were identified among 1,608 case children aged 10 years who resided in metropolitan Atlanta in 1985–1987. The prevalence rates for the five conditions studied in the MADDSP were within the ranges described from previous population-based studies (Table 2) (8,9,12).

The overall surveillance methods and overall prevalence rates for each disability have been described elsewhere (9), and detailed data on children with vision impairment have been published, allowing an examination of variations in the prevalence, by race and by sex (13). Demographic differences in prevalence rates permit identification of subgroups that may be at an unusual risk for the conditions of interest. Sixty-one 10-year-old children in metropolitan Atlanta were identified as having vision impairment (defined as legal blindness). The prevalence of legal blindness was higher among whites than among blacks and was higher

among boys than among girls. Of the four race-sex groups, black boys were found to have the highest prevalence of legal blindness, whereas black girls were found to have the lowest prevalence of legal blindness (Table 3). This low prevalence among black girls is noteworthy and warrants further investigation.

Plans are under way to publish data on other MADDSP topics such as the sociodemographic characterization of children with mental retardation and children with cerebral palsy; biomedical conditions in children with mental retardation as well as children with cerebral palsy; the prevalence and methods used to identify children with epilepsy; the association between mothers' reported alcohol use during pregnancy and mental retardation; and links between maternal occupational exposures and mental retardation.

### INTERPRETATION ISSUES

Because the MADDSP covers a well-defined population, its output is representative of that population. Moreover, the program has some inherent flexibility in that other developmental disabilities, such as autism and cystic fibrosis, could be added to its coverage with minimal effort. The MADDSP is relatively noninvasive in that only existing records are reviewed. No attempts are made to contact children, their families, or individual physicians, psychologists, or other health-care professionals to gather data. Further, the agencies and institutions that are the primary data sources for the MADDSP appear to accept and support the program.

**TABLE 2. Prevalence\* of five developmental disabilities among 10-year-old children in selected study areas**

Disability	Prevalence	
	MADDSP <sup>†</sup> (1985–1987)	Estimates previous studies
Mental retardation	12.0	3.1–43.6 <sup>§</sup>
Epilepsy	6.1	3.6–6.7 <sup>¶</sup>
Cerebral palsy	2.3	2.0–3.0 <sup>**</sup>
Hearing impairment	1.1	0.8–2.0 <sup>§</sup>
Visual impairment	0.7	0.3–0.6 <sup>§</sup>

\* Per 1,000 children.  
<sup>†</sup> Based on an estimated 89,534 children aged 10 years residing in the area, 1985–1987 (9).  
<sup>§</sup> See Yeargin-Allsopp et al. (9).  
<sup>¶</sup> See Hauser and Hesdorffer (12).  
<sup>\*\*</sup> See Paneth and Kiely (8) and Yeargin-Allsopp et al. (9).

Regarding coverage and representativeness, the MADDSP may have some limitations. Racially and ethnically, the MADDSP covers large numbers of black and white Americans, but Hispanics, Asians, and Native Americans probably are underrepresented. Even for black and white Americans, certain factors peculiar to residents of the Atlanta area may limit the generalizability of some MADDSP findings to other geographic areas (e.g., rural areas, other urban areas with different ethnic mixes, and areas with a very different socioeconomic makeup).

When interpreting findings from the MADDSP, we also must consider limitations in the surveillance methodology. Perhaps the most important point to keep in mind is that, for the sake

**TABLE 3. Prevalence\* of legal blindness among 10-year-old children by race and sex — Metropolitan Atlanta Developmental Disabilities Study, 1985–1987**

Sex	White		Black		Total	
	N	Rate	N	Rate	N	Rate
Male	25	8.6	15	8.8	40	8.7
Female	18	6.7	3	1.8	21	4.9
Total	43	7.7	18	5.4	61	6.8

\* Per 10,000 children.

of simplicity, the MADDSP uses only selected sources in the Atlanta area to identify case children. In general, the children identified at those sources receive medical, educational, or social services related to their conditions. Thus, only children in need of special services are ascertained by the MADDSP. Children with very mild forms of these conditions—presumably those who do not need special services—may not be included. Nevertheless, we believe that the MADDSP includes almost all children with moderate-to-severe forms of the four conditions of interest. One exception may be a child with a severe disability who is not served through any of the mechanisms we use as primary sources or who is in a residential program outside Georgia (for example, a child with severe mental retardation who has been placed in a residential facility outside Georgia without any contact with local agencies). On the other hand, any child included in the MADDSP almost surely has the condition, at least as we have defined the conditions for surveillance purposes (i.e., predictive value positive is virtually 100%).

Because the MADDSP is relatively new, it will most likely need time to mature into a surveillance system of known dimensions and scope. CDC analysts are engaged in an ongoing examination of the data to test the system's coverage of children at different ages for each of the selected conditions under surveillance. As new resources become available, special studies may be initiated to check the completeness of the system for a particular condition and to document characteristics of missing cases.

## EXAMPLES OF USING DATA

Because the United States has no other ongoing population-based surveillance systems for multiple developmental disabilities, the MADDSP is expected to serve as an important resource for current data on developmental disabilities affecting U.S. children.

Potential uses of MADDSP data include 1) detecting the introduction of new and potent etiologic agents into the population, 2) correlating disability rates for smaller geographic areas with

environmental exposure data to identify the presence of possible environmental exposures of concern, 3) identifying subgroups that have a higher-than-expected risk for developmental disabilities, 4) documenting the effects of new prevention activities, and 5) identifying overall services needs of the community and possibly projecting future needs.

## FUTURE ISSUES

### Year 2000 Objective for Serious Mental Retardation

The year 2000 national health objectives call for a reduction in the prevalence of serious mental retardation (IQ <50) in school-age children to no more than two cases per 1,000 children (14). The baseline rate—2.7 cases per 1,000 children aged 10 years in 1985–1987—was derived from data collected in MADDSP. Using data collected in the MADDSP, we can track our progress toward meeting this objective during the 1990s.

### Public Laws Affecting Services for Children With Special Needs

The MADDSP's efficiency in identifying children with developmental disabilities is greatly influenced by federal laws under which the vast majority of these children are identified at a single source (6,7). As the scope of such legislation changes, our ability to ascertain children with developmental disabilities could be facilitated or hindered. Recent legislation requires states to serve certain groups of children from birth to the age of 3 years (6,15). As this law is enacted locally, we may see increases in our counts of children above the age of 3 years, mainly because of a greater awareness and attention to those younger children who are at a high risk of developmental problems. These developments might enable us to extend our coverage to children under the age of 3 years. We also need to be aware of new trends in special education placement (e.g., mainstreaming) that may affect our case ascertainment method.

## Data Needs

In the future, we will have numerous opportunities for enhancing our surveillance of developmental disabilities.

- Other developmental conditions such as autism need to be included in the system.
- We need to improve ascertainment of children with milder forms of cerebral palsy who do not require special services. Such an effort might necessitate canvassing additional sources in the area.
- We need to retrieve and review hospital birth records for children with developmental disabilities, thereby acquiring detailed data on medical risk factors.
- We must conduct clinical examinations and laboratory studies of selected children to gain more data on biomedical factors associated with their disabilities.
- We need to assess cognitive and adaptive functioning of groups of children to estimate the sensitivity of the MADDSP procedures for identifying children with mild mental retardation.

## ADDITIONAL RESOURCES

For technical information about state-based developmental disabilities surveillance programs supported by CDC, contact Joseph G. Hollowell, M.D., Chief, Developmental Disabilities Branch, National Center for Environmental Health, Centers for Disease Control and Prevention, Mailstop F-15, 4770 Buford Highway, NE, Atlanta, GA 30341-3724, (404)488-7360.

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