

MR/DD Data Brief

April 2000
Vol. 2 • No. 1

Research and Training Center on Community Living • Institute on Community Integration (UAP)

Prevalence of Mental Retardation and/or Developmental Disabilities: Analysis of the 1994/1995 NHIS-D

Introduction

This study uses the National Health Interview Survey's Disability Supplement (NHIS-D) to estimate the prevalence of mental retardation and/or developmental disabilities among the non-institutionalized population of the United States. Prevalence

Estimated number of people in the U.S. with MR and/or DD = 4,132,878

Percent of the U.S. population with MR and/or DD = 1.58%

refers to the proportion of persons in a population who have a particular condition, illness or status. *Mental retardation* is defined by the American Association on Mental Retardation (AAMR) as "significantly subaverage intellectual functioning existing concurrently with related limitations in two or more of the following applicable adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure and work" with such limitations manifested "before age 18" (AAMR, 1992, p.1). A similar definition is posed by the American Psychological

Association (APA) and similar diagnostic practices are outlined by both AAMR and APA for the classification of people as having mental retardation (AAMR, 1992; Jacobson & Mulick, 1996). *Mental retardation* is identified through established professional protocols for determining that the person has a significantly subnormal IQ and concomitant limitation in social and behavioral skills. *Developmental disability* is defined by the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) as a "severe, chronic disability" attributable to "mental" and/or "physical" impairments that are "likely to continue indefinitely;"

About the National Health Interview Survey

In 1994 and 1995, the National Health Interview Survey included a Disability Supplement (NHIS-D) that collected extensive information about disabilities among the individuals sampled as part of the annual census-based household interview surveys. The NHIS focuses on the civilian, noninstitutionalized population in the United States. It describes demographic characteristics, health status, functional limitations, and supports and services used.

This second *MR/DD Data Brief* describes the development of and revisions to the operational definitions of mental retardation and developmental disabilities based on items in the NHIS-D. It also describes the application of those definitions to estimate the prevalence of mental retardation and developmental disabilities in the noninstitutionalized population of the United States. This brief supersedes the first *MR/DD Data Brief* (Vol. 1, No. 1) with slightly revised definitions of mental retardation and developmental disabilities and prevalence estimates that incorporate both 1994 and 1995 data. All analyses, interpretations, and conclusions are those of the authors.



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resulting in substantial functional limitations in three or more “major life activity areas: self-care, receptive or expressive language, learning, self-direction, capacity for independent living and economic self-sufficiency;” are manifested by age 22 and require care, treatment or other services of lifelong or extended duration (PL. 98-527). Unlike mental retardation, classification of developmental disabilities does not benefit from a set of standardized assessment instruments, procedures, and professional training programs to operationalize its basic concepts.

There are many reasons to want accurate estimates of the prevalence of mental retardation and other developmental disabilities. Because definitions of mental retardation and developmental disabilities presume the need for assistance, prevalence estimates help identify the number of people who may be expected to need assistance. When such definitions are used as a condition of eligibility for specific programs, prevalence estimates based on those definitions help in estimating the number of persons who might claim benefits from such programs. When prevalence estimates are combined with service use statistics, they are useful in estimating the number of eligible persons who are not being served. Prevalence estimates for subgroups (e.g., ethnic, age-related or socio-economic groups) assist in identifying the status, needs, and challenges of such groups. Prevalence estimates provide an important statistical context to efforts within a society to plan and provide for groups of interest.

The need for prevalence estimates for policy purposes was addressed by Senator David Durenberger at a 1990 Senate hearing:

At the national level, there is somewhere between 1.7 million and 4.6 million [people with developmental disabilities]. There is no current method to determine the exact figures. This is crazy that we have this kind of wide variance in our estimates. We are going to look for ways to measure who those people are and where they are, so that we can best suit policy to their needs (S. HRG. 101-847, p.3).

The National Health Interview Survey

The National Health Interview Survey (NHIS) is a household survey conducted by the U.S. Bureau of the Census annually since 1957. The NHIS focuses on the civilian, non-institutionalized population in the United States. Each year the NHIS randomly samples approximately 46,000 households with 116,000 members from 201 primary sampling units nationally. In 1994 and 1995, a special two-year Disability Supplement was added to the NHIS to gather nationally representative data on the characteristics, service use, needs, circumstances and experiences of non-institutionalized people with disabilities in the United States.

The NHIS-D was administered in two stages. In an initial visit to each sampled household, the core NHIS interview and the Phase I Disability Supplement was completed for all members in the selected households. During this initial interview, questions were answered by any available adult in the household who was knowledgeable about the health of other household members. In the second phase, interviewers returned to households that included members with disabilities. The Disability Supplement - Phase 2, was conducted several months after the Core and Phase 1 interviews. Interviews were usually face-to-face but sometimes were conducted over the telephone. When possible, the individual with the disability completed the Phase 2 interviews; proxy interviewers were used for approximately 20% of adults and most of the children. The 1994/1995 NHIS and Disability Supplements covered a wide range of topics clustered into the categories described in Table 1.

Defining Mental Retardation and Developmental Disabilities

The NHIS-D permits examination of the implications of various definitions of mental retardation and/or developmental disabilities on prevalence estimates, service eligibility, and other topics requiring large and flexible data sets. To examine the nature and congruence of prevalence estimates for mental retardation and for develop-

Table 1. Major Topical Areas of the National Health Interview Survey on Disabilities

NHIS Core Survey Topics	Disability Supplement Phase I Topics	Disability Follow-Back Survey (NHIS Phase II) Topics
<ul style="list-style-type: none"> • Housing arrangements and household composition. • Demographics (race, ethnicity, family income, education). • Health and medical information (doctor visits, hospital visits, health indicators, conditions). • Abilities and limitations in activities of daily living (ADLs; getting around inside the home, bathing, dressing, eating, and toileting). • Abilities and limitations in instrumental activities of daily living (IADLs; going outside the home, keeping track of money or bills, preparing meals, doing light housework, and using the telephone). • Limitations or specific conditions among household members, service needs and access, and a wide range of related information. 	<ul style="list-style-type: none"> • Disability (sensory, communication and mobility limitations; specific conditions such as Down syndrome and mental retardation; activities of daily living and instrumental activities of daily living; functional limitations; mental health; services and benefits; special health needs of children, early child development; education; relationship to respondent; perceived disability; health care for specific conditions). • Immunizations. • Family resources (access to care, health care coverage, private plan and coverage, income and assets). • Year 2000 objectives (environmental health, tobacco, occupational health and safety, heart disease and stroke, clinical preventative services, family, firearm safety) Acquired Immunity Deficiency Syndrome (AIDS) knowledge and attitudes. 	<ul style="list-style-type: none"> • Work, vocational rehabilitation or school experiences. • Services used (home care services, transportation, work, child care, medical services, assistive devices, educational services, other services, coordination of services). • Assistance with key activities. • Participation in social activities. • Mental health services and needs. • Physical activity limitations. • Personal adjustment skills. • Family structure and relationships. • Impact on the family. • Health insurance. • Housing and long-term care services. • Transportation. • Self-direction.

mental disabilities as defined in the DD Act, investigators from the Research and Training Center on Community Living at the University of Minnesota developed a multi-stage process for operationalizing both mental retardation and developmental disabilities using data elements contained in the 1994/1995 NHIS-D. This process included reviewing the definitions of these constructs used in planning and developing the NHIS-D and its instruments; preparing and revising initial operational definitions using the NHIS-D data elements based on reviews solicited from a panel of national experts in mental retardation and developmental disabilities diagnosis and research; and reviews and revisions of specific codes based on internal validation analyses and internal and external reviews of results. The final definitions are described in the following paragraphs.

Identifying people with mental retardation

People with mental retardation were identified in one or more of the following ways —

- People were identified as having mental retardation if the household respondent answered affirmatively to a question asking whether anyone in the household had mental retardation.
- People were also identified as having mental retardation when mental retardation was indicated as the cause of age-specific general activity limitations. General activity limitations included limitations in play for children ages 5 and younger, limitations in school activities for children ages 5 to 17, limitations in work for adults ages 18 to 69, and overall limitations in activities for persons of all ages.

- People were identified as having mental retardation if mental retardation was identified as the primary cause of limitations in communication, getting along with others, activities of daily living, instrumental activities of daily living, and other functional limitations; or if mental retardation was the ICD code listed as the reason the person had a doctor's visit, a physician consultation regarding communication, or as the reason for receiving occupational therapy.

People were also identified as having mental retardation through a two-step process involving individuals who reported having a condition frequently associated with mental retardation. The first step identified people if the household respondent answered affirmatively to a question asking whether anyone in the household had autism, cerebral palsy, Down syndrome, spina bifida, or hydrocephalus, or who reported having one or more of the conditions listed in Table 2 as the cause of either age-specific general activity limitations in the Core Survey, as the cause of specific activity limitations (e.g., communicating, getting along with others) or as the reason for receiving various services (e.g., occupational or physical therapy) in the Phase 1 Disability Supplement.

Individuals meeting these criteria were identified as having related conditions. In the second step, individuals with a related condition were screened to identify people who also reported having both a learning disability (as reported by the household respondent when

asked if anyone in the household had a learning disability) and a significant functional limitation in learning.

A significant functional learning limitation was ascribed to children ages 1 to 17 years who had problems or delays in understanding things, that is, delays in cognitive or mental development with the problem having been mentioned by a physician or other health care professional. A significant functional learning limitation was also ascribed to individuals ages 5 or older who had serious difficulty learning how to do things that most people their age are able to learn. Individuals who had one or more related conditions who also reported having a learning disability and a significant functional learning limitation were considered to have mental retardation for this analysis. However, children ages 5-17 with related conditions were *not included* in the mental retardation group based on their related condition if their learning difficulty was not serious enough to require special education or to limit or prevent school attendance.

Adults with related conditions were *not included* in the mental retardation group based on their related condition if they completed more than one year of post-secondary education. Furthermore, adults with related conditions were *not included* in the mental retardation group based on their related condition if they had Alzheimer's disease because that condition may have been the cause of their learning limitations.

Overall, 871 people were identified as having mental retardation within the 1994 NHIS-D sample and 740 people were identified as having

Table 2: Related Conditions Screened in Defining Mental Retardation and Developmental Disabilities

• Acromegaly	• Congenital syphilis	• Other brain or CNS conditions or deformities
• Amino acid transport disease	• Copper metabolic disorder	• Other developmental delays
• Autism	• Deformity of the skull	• Reduction deformity of the brain
• Branched chain amino acid disturbance	• Encephalopathy	• Sex chromosome anomaly
• Cerebral palsy	• Epilepsy	• Spina bifida
• Congenital anomaly	• Hydrocephalus	• Thalassemias
• Congenital birth defect	• Klinefelter's syndrome	• Tuberous sclerosis
• Congenital CMV	• Leukodystrophy	• Unknown congenital or birth injury
• Congenital hypothyroidism	• Lipodosis	
	• Noxious substance affecting newborn	

mental retardation within the 1995 NHIS-D sample. Of these people, 116 sample members in 1994 and 106 in 1995 were identified as having mental retardation based solely on having a related condition along with a learning disability and a significant functional learning limitation.

Definition of Developmental Disabilities

According to the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) Amendments of 1996, a developmental disability is a severe, chronic disability of an individual 5 years of age or older that —

- is attributable to a mental or physical impairment or combination of mental and physical impairments;
- is manifested before the individual attains age 22;
- is likely to continue indefinitely;
- results in substantial functional limitations in three or more of the following areas of major life activity: self-care; receptive and expressive language; learning; mobility; self-direction; capacity for independent living; and economic self-sufficiency; and
- reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, supports, or other assistance that are of lifelong or extended duration and are individually planned and coordinated
- except that such a term, when applied to infants and young children, means individuals from birth to age 5, inclusive, who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided (PL 103-120).

A multi-stage process was used to identify individuals with developmental disabilities. The process involved using NHIS-D variables to construct operational definitions for each of the seven areas of functional limitation in the federal developmental disabilities definition: 1) self-care, 2) expressive or receptive language, 3) learning, 4) mobility, 5) self-direction, 6) capacity for independent living, and 7) economic self-sufficiency. The initial operational definitions were

revised following review by a panel of experts in disability research. As conveyed in the DD Act, separate definitional approaches were required for persons 5 years and older and for children from birth to 5 years. In the following summary of the final operational definitions of functional limitations, actual NHIS-D item language is enclosed in quotation marks. In each of the seven areas of major life activity, to meet our criteria, limitations must have been first experienced before age 22 and must have been expected to endure for at least 12 months. This latter expectation was the best available proxy for the DD Act criterion of “is likely to continue indefinitely.” In general, the age limitations noted here reflect the ages of the people who were asked to respond to particular questions on the NHIS-D.

Self-care

- A person 5 years or older “has a lot of difficulty” or “is unable” to dress, eat, bathe, get in and out of bed or chairs, use the toilet, or get around the house.

Expressive or receptive language

- A person 5 years or older “has serious difficulty communicating so the family can understand” or “has serious difficulty understanding others when they talk or ask questions.”
- A person 18 years or older “has serious difficulty” or “cannot use” the telephone.
- A person from 5 to 17 years old “has a problem or delay in speech or language development” mentioned by a doctor and these limitations were serious enough to require special education or to prevent or limit school attendance; or “has significant problems at school communicating with teachers and other students” or “cannot communicate with teachers and other students because of limitations” and these limitations were serious enough to require special education or to prevent or limit school attendance.

Learning

- A person 5 years or older has a diagnosis of mental retardation or autism, and “has serious difficulty learning how to do things most people their age can learn.”

- A person 5 years or older “has serious difficulty learning how to do things most people their age can learn” and the person does not have Alzheimer’s or another senility disorder.
- A person from 5 to 17 years old “has problems or delays in understanding things, that is, delays in cognitive or mental development” that are serious enough to be mentioned by a doctor.
- A person from 5 to 17 years old “has significant problems at school understanding instructional materials” or has been diagnosed as having learning disability and the person has received special education, has had an IEP or has been limited in school attendance.
- An adult ages 18 or older has been diagnosed as having a learning disability significant enough that the person’s overall educational background has included less than 2 years of post-secondary education.

Mobility

- A person 5 years or older “has difficulty” or “is unable” to walk up stairs, walk three city blocks, or transfer to or from a bed or chair.
- A person 5 to 17 years old “has difficulty participating in strenuous activity compared to other children his/her age” (and it is associated with arthritis, rheumatism, disorders of the bone or cartilage, absence or paralysis of an extremity or orthopedic impairment or deformity) or “has significant problems in physical development.”

Self-direction

- A person 5 years or older, because of a physical, mental or emotional problem, “needs to be reminded or have someone close by” for dressing, eating, bathing, toileting, or transferring.
- A person 18 years or older has or needs a “case manager to coordinate personal care, social or medical services” or “has a court appointed guardian” during the last 12 months.
- A person 5 to 17 years old “has significant problems with” or “cannot pay attention in class” or “control behavior in class” due to a limitation and these problems were severe enough that the child has received special education, has had an IEP, or has been limited in school attendance.

Capacity for independent living

- A person 18 years or older “requires help or supervision” or “has a lot of difficulty with” or “is unable” to prepare meals, shop for personal items or medicine, manage his or her money, do light work around the house (such as doing dishes, straightening up, light cleaning or taking out the trash) or do heavy work around the house.

Economic self-sufficiency

- A person 18 years or older “has never been able to work” or “is currently unable to work because of a mental or emotional problem” or “is limited in kind or amount of work” due to a limitation; or “has trouble finding or keeping a job or doing job tasks because of a mental or emotional problem.”
- A person 18 years or older “has participated in” or is “on the waiting list” for a sheltered workshop, transitional work training, supported employment or a day activity center; or “is unable to work” because of a mental or emotional problem.

Determination of Developmental Disability

People 5 years and older were considered to have a developmental disability if they had substantial limitations as defined above in three or more of the seven areas of major life activity that were expected to endure at least 12 months, with limitations in at least one of these areas occurring before age 22.

Based on the definition in the DD Act, children from birth to 71 months old were considered to have a developmental disability if they had a specific congenital or acquired condition that was consistently associated with developmental disabilities among older children and adults in the NHIS sample, or a substantial developmental delay in physical development, chewing, eating or toileting, receptive or expressive communication, understanding instructional materials, cognitive or mental development, participation in strenuous activity, or mobility. Children ages 5 and younger who had only a hearing, vision or speech impairment were not considered to have a developmental disability.

Overall, 1,207 people of all ages in the 1994 sample and 1,118 people in the 1995 sample met the criteria for having a developmental disability. Of those people, 464 in 1994 and 396 in 1995 also met the criteria for having mental retardation. A total of 1,614 sample members in 1994 and 1,462 sample members in 1995 met the criteria for either mental retardation and/or developmental disabilities. An additional 770 people in 1994 and 840 people in 1995 were identified as having cerebral palsy, autism, spina bifida, epilepsy or one of the other related conditions, but did not meet the criteria for either mental retardation or developmental disabilities as defined for these analyses.

Results

Prevalence of mental retardation and/or developmental disabilities

Once we finalized the definitions for mental retardation and developmental disabilities and identified sample members meeting those definitions, we used the population weights provided by the National Center for Health Statistics to estimate the prevalence of those conditions in the general non-institutionalized population of the United States. We used the SUDAAN software crosstabs procedure (accounting for the sampling strategy by using the Taylor Linearization technique) to make population estimates of the prevalence of these conditions overall and in various age categories, and to identify the standard error of estimate (Shah, Barnwell & Bieler, 1997).

Based on our definitions of mental retardation and developmental disabilities we estimate that there are 14.9 people with one or the other or both of those conditions for every 1,000 people in the non-institutionalized population of the United States (See Table 3). Combining the 1994 and 1995 samples using the final population weights divided by two (since we combined two years of data), this suggests that an estimated 3,887,158 non-institutionalized Americans (plus or minus 1.9% or 75,440) have either mental retardation or developmental disabilities or both.

The estimated prevalence of mental retardation and/or developmental disabilities among the non-institutionalized U.S. population varied by age. The prevalence of mental retardation and/or developmental disabilities among non-institu-

tionalized children ages birth to 5 years, is estimated to be 38.4 per thousand. The prevalence of mental retardation and/or developmental disabilities among non-institutionalized children and youth ages 6 to 17 years is estimated to be 31.7 per thousand. Finally, the prevalence of mental retardation and/or developmental disabilities among non-institutionalized adults ages 18 years and older is estimated to be 7.9 people per thousand.

Table 3. Estimated Prevalence of Mental Retardation and Developmental Disabilities in the Non Institutional U.S. Population by Age

Age and Category	Est. N	Prev.	RSE
<i>Neither DD nor MR</i>			
0-5 Years	23,525,867	961.6	0.8%
6-17 Years	44,431,286	968.3	0.6%
18+ Years	188,918,705	992.1	0.3%
Total	256,875,857	985.1	0.2%
<i>DD not MR</i>			
0-5 Years	829,658	33.9	4.2%
6-17 Years	520,894	11.4	5.3%
18+ Years	502,897	2.6	5.5%
Total	1,853,448	7.1	2.8%
<i>MR not DD</i>			
0-5 Years	0	0.0	0.0%
6-17 Years	558,828	12.2	4.9%
18+ Years	386,263	2.0	6.2%
Total	945,091	3.6	3.9%
<i>Both MR and DD</i>			
0-5 Years	109,960	4.5	11.2%
6-17 Years	372,637	8.1	6.3%
18+ Years	606,023	3.2	5.0%
Total	1,088,620	4.2	3.7%
<i>Total MR and/or DD*</i>			
0-5 Years	939,617	38.4	3.9%
6-17 Years	1,452,359	31.7	3.1%
18+ Years	1,495,183	7.9	3.2%
Total	3,887,158	14.9	1.9%

Est. N=Estimated number of people in the U.S. population

Prev=Number of people per 1,000 in the US non-institutionalized population

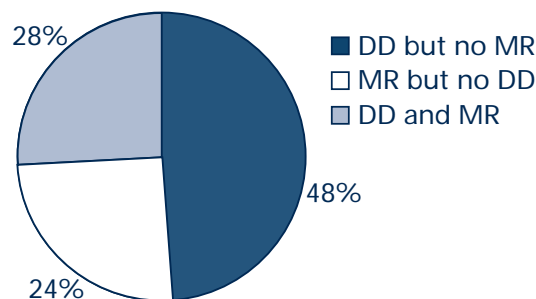
RSE=Relative Standard Error (SE/N*100)

*This category is the sum of the DD and MR, MR not DD and both MR and DD categories.

There is some overlap between people identified with developmental disabilities and those identified with mental retardation, but they are not the same groups (See Figure 1). Across all ages, 28.0% of people meeting the criteria for either mental retardation or developmental disabilities met both sets of criteria; 24.3% met the criteria for mental retardation but not for developmental disabilities; and 47.7% met the criteria for developmental disabilities but not for mental retardation. Because the definition of developmental disabilities varied for persons of different ages, the distribution of population estimates was examined for three age groups (See Figure 2).

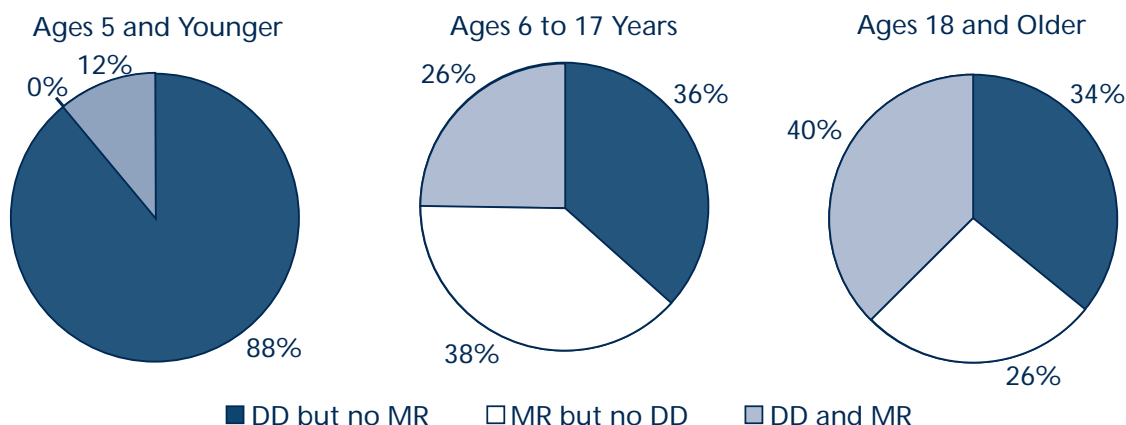
Among non-institutionalized children 5 years and younger, 88.3% met the criteria for having developmental disabilities but not for mental retardation, and 11.7% met both the criteria for having mental retardation and for developmental disabilities. (By definition, children 5 years and younger meeting the criteria for mental retardation also met the criteria for developmental disability.) Among non-institutionalized children 6 to 17 years old, 35.9% met the criteria for developmental disabilities but not for mental retardation, 38.5% met the criteria for mental retardation but not for developmental disabilities, and 25.7% met both criteria. Finally among adults, 33.6% met the criteria for developmental disabilities but not for mental retardation, 25.8% met the criteria for mental retardation but not for developmental disabilities, and 40.5% met both criteria.

Figure 1. Overlap Between Mental Retardation (MR) and Developmental Disabilities (DD) Among Non-institutionalized Persons of All Ages



The NHIS-D sample did not include persons in institutional settings. In 1999, state agencies reported 245,720 individuals with mental retardation and developmental disabilities living in nursing homes, psychiatric facilities or congregate care (institutional) settings of four or more residents (Prouty & Lakin, 1999). Including these persons with the estimated 3,887,158 people with MR/DD in the non-institutionalized U.S. population yields a combined estimated total number of people with mental retardation or developmental disabilities in the United States of 4,132,878 (a prevalence of 15.8 people per 1,000). This estimate does not include people with mental retardation or developmental

Figure 2. Overlap Between Mental Retardation (MR) and Developmental Disabilities (DD) by Age Group



disabilities who are in institutions that do not report their disability status to the state MR/DD agencies (e.g., jails, prisons, rehabilitation facilities, and certain nursing facilities) or in military settings.

Prevalence of selected conditions

The overall prevalence of developmental disabilities in the non-institutionalized population was estimated to be 11.28 per 1,000 people in the United States (See Table 4). The overall prevalence of mental retardation was estimated to be 7.80 people per 1,000. Based on estimates from the *1987 National Medical Expenditures Survey Institutional Population Component* (Lakin, Hill, Chen & Stephans, 1989; Lakin, Prouty, White, Bruininks, & Hill, 1990), an estimated 94.8% of the people with MR/DD in nursing homes, psychiatric facilities or congregate care settings of four or more residents would be expected to have mental retardation. This would yield a combined institutional and non-institutional prevalence for mental retardation of 8.73 people per 1,000.

Table 4. Estimated Prevalence of Selected Conditions in the Non-Institutionalized U.S. Population

Condition	Est. N	Prev.	RSE
Developmental Disabilities	2,942,068	11.28	2.2%
Mental Retardation	2,033,710	7.80	2.7%
Cerebral Palsy	1,049,322	4.02	3.7%
Spina Bifida	161,866	0.62	9.7%
Autism	105,464	0.40	11.4%

Est. N=Estimated number of people with the condition in the U.S. noninstitutionalized population

Prevalence=Number of people per 1,000 in the US non-institutionalized population

RSE=Relative Standard Error (SE/N*100)

While the primary focus of this analysis was to identify the combined prevalence of mental retardation and developmental disabilities, we also estimated the prevalence of three conditions commonly associated with mental retardation and developmental disabilities — cerebral palsy, spina bifida and autism. For each of these three conditions, the NHIS gathered both ICD codes for conditions causing limitations and specifically asked household respondents in Phase 1 whether anyone in the household had the condition. Based on responses to these items, we estimated the self-reported prevalence of cerebral palsy in the non-institutionalized population of the United States as 4.02 people per 1,000, the self-reported prevalence of spina bifida as 0.62 people per 1,000, and the self-reported prevalence of autism as 0.40 people per 1,000.

Discussion

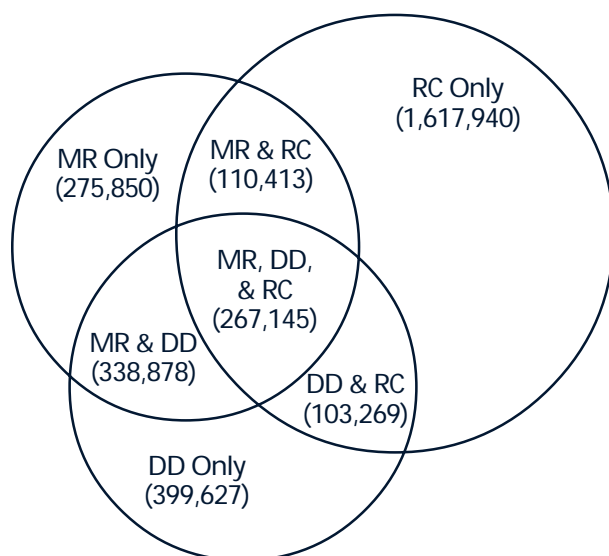
Mental retardation and developmental disabilities are not interchangeable classifications (See Figure 3 for a breakdown by group for adults). Only 28% of the NHIS sample members who met the criteria for either mental retardation or developmental disabilities classifications met the criteria for both. Concordance was lowest among children ages 5 and under (11.7% met both criteria), largely because of the low rate of identification of young children as having mental retardation. Concordance was highest among adults (40.5% met both criteria).

All individuals who met the criteria for mental retardation, but not developmental disabilities, had functional limitations in one or two areas of major life activity, but not the three or more stipulated in the formal definition of developmental disabilities. For children ages 5 to 17 years, the NHIS-D did not provide variables that allowed us to detect functional limitations in work or in independent living. Therefore, in that age group individuals had to have functional limitations in three of five (instead of three of seven) areas. That difference may account for some of the variation between adults and children ages 5 to 17 in the proportion who have both mental retardation and developmental disabilities.

In an official sense, distinctions between mental retardation and developmental disabilities can have important implications in people's lives when they are used as the basis for service eligibility decisions. Where eligibility for services

Figure 3. Intersection of Mental Retardation (MR), Developmental Disabilities (DD) and Related Conditions (RC) for Adults in the NHIS (Population Estimates)

None of the conditions: 187,300,765
 All Mental Retardation: 992,286
 All Developmental Disabilities: 1,108,919
 All Related Conditions: 2,098,767
 Any of the Conditions: 3,113,122



depends on a systematic application of the definitional criteria for mental retardation, mental retardation and related conditions (often specified as including cerebral palsy, autism, spina bifida, and a few other conditions) or developmental disabilities (as defined by the DD Act), different groups of individuals will be deemed eligible.

The degree of overlap between mental retardation and developmental disabilities is much less among persons who are not living in institutional settings than among persons living in institutions specifically designated for persons with mental retardation and developmental disabilities. Most people with mental retardation and/or developmental disabilities living in institutional settings (with four or more residents) designated for persons with mental retardation and/or developmental disabilities have both a functional learning limitation (e.g., a

diagnosis of mental retardation; 94% in the NMES), and perceived functional limitations in capacity for independent living, as well as functional limitations in other areas (e.g., economic self-sufficiency). Therefore, the proportion of people in institutions meeting both mental retardation and developmental disabilities definitions will be substantially greater than the 40% of adults with either mental retardation or developmental disabilities in non-institutional settings.

This analysis has demonstrated the importance of a comprehensive approach to identifying sample members as meeting the criteria for mental retardation, developmental disabilities, and related conditions. The comprehensive approach used in these analyses identified many more sample members with mental retardation and/or developmental disabilities than would have been identified with the single item screens used to identify people with MR or DD in most national data sets (including earlier years of the NHIS). For example, of the sample members who met one or more of the four criteria indicating mental retardation, only 38.4% said yes to the item in the Phase 1 survey in which an interviewer said, "I am going to read a list of medical conditions. Tell me if anyone in the family has any of these conditions . . . Mental retardation."

In all, the people who met our criteria for mental retardation reported more than 100 different ICD codes for the primary cause of one or more functional limitations on the core survey. Similarly, 21.5% (341 cases in 1994, 346 cases in 1995) of the people we identified as having mental retardation or developmental disabilities did not report activity limitations in the activities included in the Core NHIS survey, with children being particularly likely to be "missed" (419 of these who were missed were 0-5 years old, 169 were 6 to 17 years and 99 were 18 years or older). Finally, 28,266 sample members who had one or more activity limitations on the core survey did not meet the criteria for either MR or DD. Clearly, the nature and comprehensiveness of inclusion criteria for establishing the presence of various disabilities are of major significance in prevalence estimates derived from the NHIS.

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MR/DD Data Brief

April 2000, Vol. 2, No. 1

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MR/DD Data Brief is published periodically by the Research and Training Center on Community Living and the Institute on Community Integration (UAP), College of Education and Human Development, University of Minnesota.

Project funding was provided by the National Institute on Disability and Rehabilitation Research (NIDRR), U.S. Department of Education, through a Cooperative Agreement (No. H133A60051) with the Center on Emergent Disability, University of Illinois at Chicago; through a NIDRR Field-Initiated Grant (No. H133G80082) to the Research and Training Center on Community Living at the University of Minnesota; through support of the RISP project provided by the Administration on Developmental Disabilities (Grant No. 90DN0028/03) and through the Rehabilitation Research and Training Center on Aging with Mental Retardation funded by the National Institute on Disability and Rehabilitation Research of the U.S. Department of Education under grant number H133B980046.

Funding for this publication is provided through a NIDRR Cooperative Agreement (No. H133B980047) with the Research and Training Center on Community Living, University of Minnesota. The opinions expressed are those of the authors and do not necessarily reflect the views of the Institute, Center, University, or their funding sources.

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