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Characteristics of and Service Use by Persons with MR/DD Living in Their Own Homes or With Family Members: NHIS-D Analysis

Introduction

The disability supplements to the National Health Interview Survey (NHIS) provide a unique opportunity to learn about the status and characteristics of people with mental retardation and/or developmental disabilities (MR/DD). Most of the information available in the research literature about individuals with MR/DD comes from studies of those who received various services. A review of all articles published in the *American Journal on Mental Retardation* between 1980 and 1989 found that only 18.4% of those articles pertained to people living with their families or in their own homes; the others focused on people in residential, school, work or other service settings (Ittenbach, Larson & Swindell, 1992). Among the studies that included people living with their families or in their own homes, most concerned services received by those individuals. Few studies of persons with MR/DD are population-based household surveys in which inclusion of an individual with MR/DD was based on random selection of the household in which that individual lived. As a result, there is little information about the characteristics, needs, and service use patterns of non-institutionalized people with MR/DD. This *MR/DD Data Brief* provides a general summary of such information based on data gathered

Estimated number of people in the U.S. with MR and/or DD living in non-institutional settings = 3,887,158

Percent of the U.S. population = 1.49%

About the NHIS

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, describing demographic characteristics, health status, functional limitations, and supports and services used.

We identified 3,076 individuals in the combined 1994/1995 NHIS-D sample as having mental retardation and/or developmental disabilities (MR/DD), estimating that 3,887,158 (plus or minus 1.9%) non-institutionalized Americans meet the criteria for one or both of these categories, a prevalence rate of 1.49%. This issue of *MR/DD Data Brief* uses the NHIS-D to describe people with MR/DD living in the community in terms of basic demographic characteristics, functional and other limitations, residential services history, medical services received, social activities, transportation used, and waiting list status, and compares people with and without MR/DD in regard to health status and service, functional limitations, major activity status, and school status.

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in the 1994 and 1995 Disability Supplements to the National Health Interview Survey.

Methodology

In 1994 and 1995, a special two-year supplement was appended to the National Health Interview Survey to gather nationally representative information on non-institutionalized persons with disabilities who were identified as part of the annual NHIS sample of approximately 108,000 persons in 48,000 households. This special Disability Supplement (NHIS-D) gathered more specific information than the NHIS "core" survey on diagnostic, functional, social, and behavioral characteristics; service needs and use; and general circumstances and experiences of sample members with disabilities. The NHIS-D was conducted in two phases. The first phase was completed at the time of the initial NHIS household survey with reference to all household members. The regular NHIS core and Phase I supplemental data were used to identify persons with disabilities to be included in Phase II follow-back interviews which occurred several months after the initial household visit. Separate Phase II interviews were developed for children and adults. Phase II interviews included detailed questions about in-home and out-of-home social and health services; housing and family structure; and physical, emotional and social functioning of sample members.

One of the important strengths of the NHIS-D is its two-year time span that allows more reliable sampling of low incidence disabilities such as mental retardation and developmental disabilities. To use this strength, we combined the 1994 and 1995 samples using the final population weights divided by two before computing the estimates reported here. Estimates of characteristics of non-institutionalized people without MR/DD based on the NHIS samples are provided for the sake of comparison.

Chi-square analyses were conducted using the SUDAAN statistical package, which allowed us to account for both the weighting of data and the complex sampling design used in the NHIS-D. Where population estimates are provided, the standard error of estimate was calculated using SUDAAN. Standard errors are presented as relative standard error (RSE). The RSE was computed by dividing the standard error of estimate by the population estimate and multiplying the result by 100. Since the NHIS-D is a survey administered to a sample of people from the population rather than to every person in the U.S., we can only estimate the true number in the population with a particular characteristic. Adding and subtracting the standard error in relation to the population estimate indicates the range of values in which the true population value can be expected to fall 68 times out of 100. Ninety-five times out of one hundred the true population value for a characteristic will be within the range identified as plus or minus twice the standard error. As the RSE increases, the precision of the estimate decreases and our confidence about the estimate decreases. By convention, a RSE exceeding 30% indicates a population estimate that is considered unreliable (Adams & Marano, 1995). For the analyses reported in this brief, this occurred only twice when fewer than 20 sample members reported having a particular characteristic.

For this brief, the category MR/DD includes all persons identified from the NHIS-D who had mental retardation (as defined categorically), developmental disabilities (as defined functionally) or both. The definitions and process used to identify these individuals is fully described in the previous *MR/DD Data Brief* (Larson, Lakin, Anderson, Kwak, Lee, & Anderson, 2000). For analyses based on the core or Phase I disability supplement, we compared the characteristics of persons with MR/DD and other survey participants. For analyses based on the Phase II adult follow-back survey, only responses from adults with MR/DD who completed the Phase II follow-back were used. The population estimates in this paper are based on weights associated with the survey from which the questions were asked. For the Phase II questions, differences in sample sizes were accounted for in the weighting process so that our estimates are for the total number of people in the entire U.S. population regardless of which survey the data came from.

Demographic Characteristics

Family characteristics and living arrangements of people with MR/DD are presented in Table 1. The vast majority of persons with MR/DD in the United States who do not live in institutional settings live with relatives (84.7% plus or minus 2.6%), usually with one or both parents (as opposed to 41.0% in the general population).

While nearly half of the people in the general population live with a spouse (46.6%), only 6.7% of people with MR/DD live with a spouse. An overwhelming majority of non-institutionalized adults with MR/DD have never been married (73.3%). Adults without MR/DD were four times as likely to be currently married than were people with MR/DD (60.1% vs. 14.0%). However, the formerly-married rates (divorced, separated, widowed) were similar between the people with MR/DD and people without MR/DD (12.6% and 15.5% respectively). Most people with MR/DD who are younger than 25 and who have never married live with both parents (61.3%). Among individuals without MR/DD the percentage is 69.5%. Nearly one-third (31.2%) of persons with MR/DD who are younger than 25 years and who have never married live with just their mothers (compared to 19.8% for people without MR/DD). Both groups lived with their father only at about the same rate (2.0% and 2.1%). Relatively few people in either group live with other relatives (4.3% and 3.0% respectively), or with a non-relative (1.2% and 5.6% respectively).

The Phase II Disability survey contained additional information about the family status for individuals with disabilities who were surveyed (see Table 2). Based on responses to Phase II, an estimated 219,357 individuals with MR/DD had a child who lived with them (an estimated 14.4% of all adults with MR/DD). About twice that number, 430,257 adults with MR/DD, reported they had a child who was living (28.0% of all adults with MR/DD in non-institutional settings).

Health Status

Table 3 presents estimates of the general health status of people with and without MR/DD in the non-institutionalized U.S. population. People with MR/DD reported being in poorer health than did people without MR/DD. Only 42% of people with MR/DD (or their proxies) reported that their health was very good or excellent, while 67% without MR/DD reported having very good or excellent health. Nearly one-quarter (24.5%) of people with MR/DD reported that their health was fair or poor (compared to 9.8% for people without MR/DD). There were no differences in the proportion who use Medicare. However, people with MR/DD (45.6%) were more than five times as likely to use Medicaid as people without MR/DD (8.8%). An estimated 223,813 Americans with MR/DD are dually eligible for both Medicaid and Medicare (6.6% of

Table 1: Family Characteristics of the U.S. Non-Institutionalized Population

Family Characteristics	People with MR/DD			People w/o MR/DD	X^2
	Est. Pop.	RSE	%	%	
Living Arrangement (All ages)					
With relative	3,291,167	2.6%	84.7%	41.0%	1457.97**
With spouse	261,560	8.0%	6.7%	46.6%	
Alone	271,973	7.7%	7.0%	10.5%	
With non-relative	62,457	18.5%	1.6%	1.8%	
Marital Status (Age 14 and older)					
Never married	1,409,834	3.9%	73.3%	24.3%	632.4**
Married	270,007	8.0%	14.1%	60.1%	
Formerly married	243,122	8.0%	12.6%	15.5%	
Never Married, Under 25 Lives With:					
Both parents	1,638,729	3.4%	61.3%	69.5%	169.2**
Mother	832,617	4.8%	31.2%	19.8%	
Father	53,833	16.9%	2.0%	2.1%	
Other relative	115,374	13.2%	4.3%	3.0%	
Other	32,157	22.2%	1.2%	5.6%	

* $p < .05$, ** $p < .01$

Table 2: Parenthood Among Adults with MR/DD (Phase 2)

	Est. Pop.	RSE	%
Child in household	219,357	11.1%	14.4%
Has a living child	430,279	7.9%	28.0%

those with MR/DD). Persons with MR/DD were also much more likely to report using psychotropic medications (10.5% vs. 2.4%) than those without MR/DD.

Table 4 presents estimates of the mental health status and service use of persons with MR/DD based on the Phase 2 Disability Supplement. Overall, an estimated 246,444 (+/- 11.9%) of adults with MR/DD used an outpatient mental health service during the previous year. An estimated 4.3% of adults with MR/DD used inpatient mental health services in the last year. Just over 2% of adults with MR/DD reported using services for alcohol or drug abuse in the previous year.

Functional Limitations

The Developmental Disabilities Assistance and Bill of Rights Act of 1997 (DD Act) definitions of *functional limitations* were used as the basis for our definition of *developmental disabilities*. The NHIS contains variables we used to identify limitations in four areas for people of all ages (i.e., learning, language, mobility and personal care). For self-direction, limitation could be identified in the NHIS for people ages 5 years and older. In the areas of economic self-sufficiency and independent living, the NHIS variables permitted only examination of the limitations among adults ages 18 years and older. Table 5 presents the percentages of people with and without MR/DD with substantial functional limitations in the areas defined in the DD Act for whom there was an expected duration of at least 12 months and whose limitations first appeared during the developmental period. People who acquired limitations in these areas after the developmental period or whose limitation was not expected to continue indefinitely are not identified as having a functional limitation in these tables.

The most common areas of substantial functional limitations for people with MR/DD are economic self-sufficiency (88% of adults with MR/DD), learning (73% of all people with MR/DD), and self-direction (61% of people with MR/DD ages 6 years and older). Just under half (46%) of adults with MR/DD had a substantial functional limitation in independent living. Just over one third (38%) of people with MR/DD had

Table 3: Health Status and Services for the U.S. Non-Institutionalized Population

Characteristic	People with MR/DD			People w/o MR/DD	χ^2
	Est. Pop.	RSE	%	%	
Reported Health Status					
Excellent	810,760	4.6%	21.2%	38.0%	502.52**
Very good	797,143	4.8%	20.8%	29.2%	
Good	1,283,506	3.5%	33.5%	23.1%	
Fair	588,580	5.2%	15.4%	7.1%	
Poor	349,548	7.0%	9.1%	2.7%	
Participation in Government Health Programs					
On Medicaid	1,550,987	3.9%	45.6%	8.8%	563.82**
On Medicare	479,245	6.7%	14.0%	12.8%	3.17
Both Medicare and Medicaid	223,813	9.8%	6.6%	1.0%	76.94**
Mental Health (For Adults)					
Uses psychotropic medication	406,231	6.8%	10.5%	2.4%	138.04**

*$p < .05$, ** $p < .01$

Table 4: Mental Health Service Use by Adults with MR/DD (Phase II)

Service	%	Est. Pop.	RSE
Used outpatient mental health service in past year	16.3%	246,444	11.9%
Used inpatient mental health service in past year	4.3%	65,521	19.7%
Services for alcohol/drug abuse	2.2%	32,878	24.9%

substantial functional limitations in language. The least common functional limitations for people with MR/DD were limitations in mobility (present in 10% of people with MR/DD) and personal care (10%). People without MR/DD in the non-institutionalized U.S. population reported very few limitations in these areas, with 1.8% or fewer of people without MR/DD experiencing any of these limitations.

The presence of functional limitations in various areas among persons with MR/DD differed by age. Because of differences in how the NHIS assessed functional limitations, and because of differences in how the DD Act defined developmental disabilities for children ages 5 and younger, that age group has been eliminated from analysis of age related differences in functional limitations. As Table 6 shows, children ages 6 to 17 years differed from adults in all of the areas of functional limitations that were measured for that age group. Children and youth were more likely to have a functional learning limitation, a limitation in self-direction or a language limitation than were adults. Some of these differences are related to differences in the questions available in the NHIS-D to assess functional limitations for children and adults. Most striking among these item differences is in self-direction. Both children ages 6 and older and adults were considered to have a substantial functional limitation in self-direction if because of a physical, mental or emotional problem they “needed to be reminded or have someone close by” for dressing, bathing, toileting or getting in and out of bed. For adults, a substantial functional limitation in self-direction was also identified by having a case manager or a court appointed guardian. For children, the supplemental criterion was whether the child received special education because of significant problems in paying attention or in controlling their behavior in school. While the additional criteria both measure age-specific functional limitations, they are dissimilar.

Three areas of functional limitation were different for younger adults (ages 18 to 39 years) than for older adults (ages 40 and older). Older adults with MR/DD were more likely to have a limitation in self-direction (53%) than younger adults (48%), but were less likely to have func-

Table 5: Specific Functional Limitations for People in the US Non-Institutionalized Population

Functional Limitation	People with MR/DD			People w/o MR/DD
	Est. Pop.	RSE	%	
Economic self-sufficiency (18+ years)	1,313,891	3.9%	88.0%	1.7%
Learning	2,838,834	2.8%	73.0%	1.8%
Self-direction (6 + years)	1,761,735	3.5%	61.0%	1.0%
Independent living (18+ years)	679,711	5.2%	45.5%	0.2%
Language	1,490,597	3.6%	38.3%	0.2%
Mobility	395,210	6.4%	10.2%	0.1%
Personal care	367,875	6.4%	9.5%	0.01%

Note: For economic self-sufficiency and independent living only people 18 and older are included in the analysis; for self-direction only people 6 and older are included. Limitations (or the condition causing the limitation in the case of economic self-sufficiency and independent living) must have occurred before age 22 and must have been expected to endure for at least one year.

Table 6: Specific Functional Limitations of People with MR/DD by Age in the U.S. Non-Institutionalized Population

Limitations	6-17 years	18-39 years	40+ years	χ^2
Economic	—	88.6%	87.0%	0.69
Learning	99.2%	87.9%	87.3%	121.42***
Self-direction	70.1%	48.1%	52.6%	77.56**
Independent living	—	49.1%	39.6%	8.72**
Language	64.3%	33.4%	24.5%	213.51**
Personal care	10.0%	13.6%	13.4%	4.95**
Mobility	14.4%	10.8%	10.5%	5.76**

$^{**}p < .01$, $^{***}p < .001$

tional limitations in independent living (40% and 49% respectively) or in language (25% and 33%). These differences were present even though the exact same items and criteria were used to measure functional limitations in the two adult age groups. One possible explanation for the differences is that since the NHIS only includes people who are not in institutions, a greater proportion of people with MR/DD who are 40 years old or older and who have functional limitations in independent living may not have been in the NHIS sample because they were living in congregate care settings. This possibility is supported by the data available about people with MR/DD who live in state-operated institutions for people with MR/DD. Among adults with MR/DD living in state-operated institutions, 60% are 40 years old or older (Prouty & Lakin, 1999). Furthermore, 86% of adults ages 40 or older with MR/DD living in state institutions have severe or profound mental retardation compared with 81% of individuals 22 to 39 years old. Increasing pressures by states to limit new admissions to institutions and other congregate care settings (effectively limiting access to such services by younger individuals with MR/DD) could also be reflected in these age-related differences in functional limitations. Conversely, these differences could suggest that as individuals with MR/DD age, they acquire skills and therefore no longer have a substantial functional limitation in certain areas.

Specific Areas of Needed Assistance

Table 7 summarizes specific areas of assistance needed by adults with MR/DD from the Phase 2 survey. Of adults with MR/DD, 66% received some kind of assistance with activities of daily living (i.e., eating, dressing, using the bathroom, bathing, getting in and out of bed) or instrumental activities of daily living (i.e., cooking, shop-

Table 7: Limitations of Adults with MR/DD in the U.S. Non-Institutionalized Population

Limitation	%	Est. Pop.	RSE
Receives help with ADL/IADLs*	65.7%	1,023,687	5.7%
Never left alone for 2+ hours	29.1%	528,784	6.7%
Needs ongoing supervision for safety reasons	25.1%	392,539	9.7%
Received services from a non-profit agency at some time	16.2%	251,807	10.9%
Has a guardian	16.5%	220,122	8.9%
Has difficulty leaving the house	14.0%	216,048	9.2%

* ADL – Activities of Daily Living (bathing, dressing, eating, using a toilet, getting in and out of bed)
IADL – Instrumental Activities of Daily Living (shopping, managing money, cooking, working around the house, using the telephone)

Table 8: Major Activity Status for Adults in the U.S. Non-Institutionalized Population

Activity	Adults with MR/DD			Adults w/o MR/DD	X^2
	Est. Pop.	RSE	%		
Employed	391,595	7.1%	26.2%	65.6%	362.83**
Looking for work	66,973	14.8%	4.5%	2.7%	
Not looking	1,036,613	4.3%	69.3%	31.7%	
Primary Activity					
Working	303,912	7.8%	20.5%	62.8%	423.19**
Keeping house	214,480	8.7%	14.4%	16.8%	
Going to school	173,248	10.8%	11.7%	6.4%	
Something else	793,317	4.9%	53.4%	14.0%	
Employment Programs - Phase 1					
Day activity center	178,204	10.4%	12.1%	0.2%	91.17**
Shelter workshop	136,538	12.4%	9.2%	0.04%	64.90**
Supported employment	53,517	17.4%	3.6%	0.03%	32.42**
Transitional work training	53,134	16.8%	3.6%	0.09%	33.85**

* $p < .05$, ** $p < .01$

ping, managing money, using the telephone, doing housework). A substantial minority required ongoing supervision for safety reasons (25%) and/or could not be left alone for more than two hours at a time (29%). Among non-institutionalized adults with MR/DD, 16% had received services from a non-profit agency at some time in their lives, and 16% currently had a legal guardian. Some adults with MR/DD had difficultly leaving the house at all (14%).

Participation in Major Life Activities

The NHIS provided detailed information about the extent to which sample members participated in the major life activities typical for people of a given age. Table 8 summarizes information about work status and supports received by adults. Only 26% of adults with MR/DD were employed at the time of the survey compared with 66% of adults without MR/DD. The number looking for work (unemployed) was twice as high for people with MR/DD than for other adults (4.5% vs. 2.7%). Almost 70% of adults with MR/DD were not working and were not looking for work. Adults (18 years and older) with MR/DD were almost twice as likely to be going to school as adults without MR/DD (11.7% vs. 6.4%). This discrepancy may be due, at least in part, to the provision of free public special education services through age 22 for individuals with MR/DD, but may also reflect perceptions that non-vocational day centers for adults with MR/DD are “schools.” Among adults with MR/DD, 12.1% received services from a day activity center, 9.2% worked in a sheltered workshop, 3.6% received supported employment assistance, and 3.5% had received employment training. The use of these services among adults without MR/DD was less than 0.3%. Since the NHIS does not include the 245,720 people with MR/DD who are estimated to be living in nursing homes, psychiatric facilities or congregate care settings of four or more residents, most of whom receive employment or other day program services, these population estimates should be considered an underestimate.

Health-Related School Limitations for Children

The school status of children ages 5 to 17 years is summarized in Table 9. The majority of children with MR/DD report receiving special classes or attending a special school because of an impairment or a health problem (63.5%) compared with 1.5% of children without MR/DD. Nearly 8% of

Table 9: Health Related School Limitations (Ages 5-17) in the U.S. Non-Institutionalized Population

School Status	People with MR/DD			People w/o MR/DD	x^2
	Est. Pop.	RSE	%		
Attends a special school or special classes because of any impairment or health problem	1,070,066	4.1%	63.5%	1.5%	
Needs a special school or special classes because of any impairment or health problem	115,571	11.9%	6.9%	0.3%	
Unable to attend school because of an impairment or health problem	97,305	12.5%	5.8%	0.5%	708.75**
Limited school attendance because of health	32,195	20.9%	1.9%	0.9%	
Other school limitation	56,071	16.1%	3.3%	2.2%	
Not limited	312,683	7.4%	18.6%	94.7%	

* $p < .05$, ** $p < .01$

children with MR/DD had either limited attendance at school or were reported to be unable to attend school at all due to a health limitation or impairment compared with 1.5% of children without MR/DD. An estimated 6.9% of the children with MR/DD were reported to need special classes or a special school because of health limitations or impairments, but were not receiving these services. Less than one-fifth (18.6%) of children with MR/DD reported having no limitations associated with attending school, as compared to 94.7% of all children without MR/DD. The numbers reported on Table 9 for children receiving special education (both for children with and children without MR/DD) are lower than would be expected based on child count statistics published by the Department of Education (U.S. Department of Education, 1998). This is because the questions specifically asked about special classes or schools needed because the child had a health impairment. This particular analysis is based on a Phase 1 question asked of all children. In the child Phase 2 survey, more detailed information about special education services received in regular school settings were asked. Those questions will be analyzed in future issues of the *MR/DD Data Brief.*

Services and Supports for Adults with MR/DD

The Phase 2 Disability Supplement inquired about a variety of supports and services individuals may currently be receiving or had received in the past.

Table 10: Residential History: Places Adults with MR/DD in the U.S. Non-Institutionalized Population Have Lived

Type of Facility	%	Est. Pop.	RSE
Facility or group home for people with mental illness	7.4%	113,054	13.4%
Facility for people with mental retardation	5.2%	80,384	23.2%
Nursing home	3.9%	61,607	16.1%
Board and care home	3.7%	56,077	20.2%
Assisted living facility	3.7%	57,269	20.4%
Convalescent home	1.9%	28,854	28.4%
Other long term care facility	2.5%	34,778	25.1%
Any long term care facility	20.8%	324,611	9.4%
Never received long-term care services	78.6%	1,223,120	5.3%

Table 11: Services in Last 12 Months: Adults with MR/DD in the U.S. Non-Institutionalized Population

Service	%	Est. Pop.	RSE
General practitioner/doctor	60.0%	932,220	5.7%
Physician specialist	36.3%	567,802	6.6%
Social worker	11.5%	176,969	12.0%
Physical therapist	7.8%	122,381	13.1%
Occupational therapist	3.8%	59,007	17.2%
Speech therapist or pathologist	3.1%	48,946	23.0%
Personal care attendant	7.8%	123,838	15.8%
Visiting nurse	7.6%	119,234	14.6%
Center for Independent Living	3.1%	47,203	18.2%
Social skills training	10.5%	465,426	13.9%

Residential Services

Table 10 summarizes the types of residential services adults with MR/DD had received during their lifetime. Twenty-one percent of all adults with MR/DD reported receiving residential services at some time in their lives. The most commonly reported previous residential service was in a facility for persons with mental illness (an estimated 7.4% of persons with MR/DD) followed by residential services in a facility for persons with mental retardation (5.2%). Other residential supports used included board and care home (3.7%), nursing home (3.9%), assisted living facility (3.7%), convalescent home (1.9%), and other long-term care facility (2.2%). Respondents' categorizations of previous residential placements may differ from those used by professionals due to unfamiliar terminology, but clearly, the majority of adults with MR/DD (78.6%) had never experienced any kind of out-of-home placement.

Professional Services

Adults with MR/DD had received a variety of medical or professional services during the 12 months prior to the Phase 2 survey (see Table 11). Sixty percent had seen a general practitioner or doctor and 36% had seen a specialist physician. One in 10 (11.5%) had received services from a social worker. Other services used in the previous 12 months included physical therapy (7.8%), occupational therapy (3.8%), personal care attendant (7.8%), visiting nurse (7.6%), Center for Independent Living (3.1%), and social skills training (10.5%).

Social Activities

Adults with MR/DD reported engaging in several

Table 12: Social Activities of Adults with MR/DD in the U.S. Non-Institutionalized Population in Previous 2 Weeks

Activity	%	Est. Pop.	RSE
Get together with friends or neighbors	62.4%	972,626	5.7%
Talk on phone with friends or neighbors	52.4%	817,025	5.9%
Get together with relatives	60.6%	945,768	5.8%
Talk on phone with relatives	55.7%	873,096	6.0%
Go to church or temple services	33.4%	522,644	7.3%
Go to movies, sports events, etc.	27.9%	434,270	7.4%
Go out to eat in a restaurant	50.6%	790,595	6.2%
Out of house every day in last 2 weeks	54.9%	857,513	6.0%
Did not leave home in last 2 weeks	6.2%	96,609	18.3%
Would like to do more activities	27.2%	422,357	7.3%

Table 13: Transportation for Adults with MR/DD in the U.S. Non-Institutionalized Population

Type of Transportation	%	Est. Pop.	RSE
Drives a car	30.8%	480,514	7.1%
Used public transportation (where it was available)	31.9%	323,983	8.5%
Used special bus service (where it was available)	27.2%	240,114	11.6%
Received transportation services	16.4%	248,984	11.8%
Using public transportation is somewhat or very difficult (where available)	43.1%	384,540	8.7%
Impairment prevents or limits use of public transportation (where avail.)	44.4%	282,977	9.5%

different social activities in the two weeks prior to the survey date (see Table 12). Among the most common social activities were getting together with friends or neighbors (62.4%), getting together with relatives (60.6%), talking on the phone to relatives (55.7%) or friends or neighbors (52.4%), and going out to eat in a restaurant (50.6%). Of adults with MR/DD, 54.9% left their house every day in the previous two weeks, but 6.2% never left the house during this time. More than one quarter (27.2%) of adults with MR/DD would like to engage in more social activities than they are currently.

Transportation

Adults with MR/DD use a wide variety of types of transportation (see Table 13). A third (30.8%) reported driving a car. Of those living where public transportation was available, 31.9% used public transportation, 27.2% used special bus services, and 16.4% received other transportation services. Of those living where public transportation was available, 44.4% reported that their impairment prevents or limits their use of public transportation, and 43.1% reported that using public transportation is somewhat or very difficult. The number of people with MR/DD who reported driving a car is surprisingly high. While it is likely that some adults with MR/DD have a driver’s license, it seems likely that at least some of those who reported using a car were actually passengers in a car driven by someone else.

Waiting for Services

While many adults with MR/DD received services of one type or another, a large number of people reported that they were currently on a waiting list for or were waiting to receive services. The largest unmet need, reported by 10.1% of all adults with MR/DD (an estimated 151,390 people), was not a specific “type” of service or

Table 14: Adults with MR/DD in the U.S. Non-Institutionalized Population Waiting for Services

Type of Service	%	Est. Pop.	RSE
Waiting for a Specific Service			
Mental health services	6.3%	98,099	17.2%
Case manager	5.5%	85,434	13.4%
Home, community-based or facility-based long-term care	2.5%	38,675	24.3%
Employment program or day activity center	2.2%	34,913	20.5%
Medical/ancillary services (e.g., OT, PT, Speech)	1.7%	27,125	25.8%
Needs or Tries to Get Help			
Needs additional help with one or more IADLs*	10.1%	151,390	11.0%
Needs help, attempted to hire services unsuccessfully[a]	35.8%	52,433	19.5%
Needs help but stopped receiving it[a]	16.7%	41,155	26.9%

*IADL – Instrumental Activity of Daily Living (Cooking, cleaning, shopping, money management)

[a] Proportion of those who need more help

program, but rather assistance with instrumental activities of daily living (e.g., shopping, cooking, managing money). The proportion of adults waiting for specific services or programs included 6.3% waiting for mental health services, 5.5% waiting for a case manager, 2.2% waiting for employment or day program services, and 1.7% waiting for medical or ancillary services. Another 2.5% (representing an estimated 38,675 adults) reported waiting for long-term care services (either home- or facility-based). Of those individuals who reported needing help, 35.8% said that they tried unsuccessfully to hire someone to help them, and 16.7% said that they received help at one time but stopped receiving it for some reason.

Discussion and Conclusion

This brief contains an initial broad summary of the characteristics and needs of persons with MR/DD derived from analysis of the combined samples of the 1994 and 1995 National Health Interview Surveys and Disability Supplements. The most important feature of the NHIS-D is its focus on persons with MR/DD living in non-institutional settings. This group comprises by far the largest, but least studied, group of persons with MR/DD. Based on the NHIS and other sources of statistics on persons with MR/DD in nursing and MR/DD residential settings of more than three people, it is estimated that 87% of an estimated 1,882,000 adults with MR/DD in the United States live in non-institutional households, 81% in the households represented in the NHIS-D and 6% in MR/DD residential settings with three or fewer residents.

Of the persons with MR/DD sampled in the NHIS-D, an estimated 84% of non-institutionalized individuals with MR/DD live with relatives, 6.7% live with a spouse, 7.0% live alone, and 1.6% live with a non-relative. One in three children and adults under 25 years old with MR/DD live in households with a single parent (33%), a substantially greater proportion than sample members without MR/DD (22%). Almost all of the single parents were mothers. Adults with MR/DD are three times less likely than people without MR/DD to have never married (26.7% vs. 75.5%), and are four times less likely to be currently married (14.1% vs. 60.1%). Almost half of all adults with MR/DD who had ever married were not married at the time of the survey, suggesting marriages are much less stable for persons with MR/DD than for persons without MR/DD

The NHIS demonstrates clearly that the typical shift from living with parents in childhood to establishing an independent household in adulthood (alone or with a spouse) is much less common among adults with MR/DD. While 20% of adults 18 years and older without MR/DD live with relatives, among adults with MR/DD, 60% do. As these relatives age, the presence in the home of an adult with MR/DD brings additional challenges and concerns, particularly when the adult with MR/DD requires help with activities of daily living or instrumental activities of daily living (as 66% of the sample did) or when the adult cannot be left alone for more than two hours at a time (as 29% of the sample reported). Additional attention to this group of people (estimated to number 900,000) and their parents or family members seems particularly warranted. So, too, is attention to the estimated 219,000 parents with MR/DD who struggle to raise families in an increasingly complex world. The NHIS Disability Supplement provides an important opportunity to learn about the status and needs of people with MR/DD of all ages, income levels, and other demographic and social circumstances who are not in institutions.

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