

Mothers with Disabilities – Characteristics and Outcomes: An Analysis from the 1994/1995 NHIS-D

Introduction

Societal commitments to recognition of the rights of persons with disabilities and to supporting opportunities for them to fulfill typical social roles and personal aspirations are relatively new and continue to evolve. These commitments, bolstered by philosophies of normalization

In 1994/1995, in the U.S. there were an estimated 174,000 mothers with ID/DD and an additional 1.34 million mothers with one or more substantial functional limitations, but not ID/DD.

and self-determination and expressions of full citizenship in the Americans with Disabilities Act, recognize and honor the rights of women with disabilities to become mothers. At the same time, the prevalence and characteristics of mothers with disabilities, especially mothers with intellectual and/or developmental disabilities (ID/DD), have been difficult to document because most of those mothers and their children live in homes of their own, with their spouse or with other family members, and do not receive supports or services from ID/DD agencies.

About This *Data Brief*

This *DD Data Brief* summarizes findings from the National Health Interview Survey conducted by the U.S. Bureau of the Census, National Center on Health Statistics in 1994 and 1995. In these years, 202,560 people were surveyed using the National Health Interview Survey Disability Supplement (NHIS-D), including 140 mothers with intellectual and/or developmental disabilities (ID/DD) and 1,081 mothers with other substantial functional limitations (FL Only). This *DD Data Brief* examines the characteristics and outcomes for mothers with disabilities and their children, estimates the number of mothers with ID/DD in the U.S. non-institutionalized population, and examines factors that influence developmental outcomes for both mothers with disabilities and their children.

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The National Health Interview Survey (NHIS) provides an opportunity to learn more about parents with ID/DD from a national cross-sectional household survey. The 1994/1995 surveys were designed to collect information about people with disabilities in the non-institutionalized civilian population of the United States, making this a particularly useful dataset for learning more about parents with disabilities and their children.

Methodology

Each year, the NHIS sample includes approximately 108,000 persons in 48,000 households. The annual NHIS core survey asks about basic demographic and health characteristics of all household members. In 1994 and 1995, a two-phase supplement called the National Health Interview Survey Disability Supplement (NHIS-D) was added to gather information specific to the status of individuals with disabilities such as diagnostic, functional, social, and behavioral characteristics; service needs and use; and other related information. The Phase I disability supplement was conducted at the same time as the core NHIS survey and gathered information about every person in the sampled households. It was used to identify individuals with disabilities in the sampled households. Individuals with disabilities were surveyed separately a second time to learn more about in- and out-of-home services; housing and family structures; and physical, emotional and social functioning of sample members. Separate Phase 2 surveys were included for children and adults.

The operational definitions used in this brief to identify individuals with disabilities were described in Larson, Lakin, Anderson et al. (2000). Briefly, individuals were identified as having intellectual disabilities (ID) if a) the household respondent identified that person as having intellectual disabilities, b) intellectual disabilities were given as the reason for general activity limitations in

specific areas (e.g., communication) or as the reason for receiving specific services, and/or c) the person was identified as having a condition that is highly associated with intellectual disability (e.g., Down syndrome, autism) and was concurrently reported to have serious difficulty learning how to do the things that most people of that age were able to do. People were identified as having a developmental disability (DD) if they had significant functional limitations in three or more of seven domains (self-care, language, learning, mobility, economic self-sufficiency, independent living, and self-direction), the limitations were expected to endure longer than a year, and the limitations first occurred before the person was 18 years old.

Individuals were identified as having functional limitations (FL) if they had substantial functional limitations in one or more of the seven areas listed for developmental disabilities, but did not meet the operational definition of either intellectual disabilities or developmental disabilities (either because they had fewer than three functional limitations or because their limitations first occurred during adulthood). This group is referred to as persons with FL Only.

For most of the analyses in this brief, individuals with intellectual disabilities and individuals with developmental disabilities were combined into a single group referred to as people with ID/DD. When only two disability groups are used, the label ID/DD refers to people with intellectual disabilities only, developmental disabilities only or both intellectual and developmental disabilities. However, for Table 1 and Table 5 describing demographic characteristics of mothers and children, four groups of mothers were included:

- Mothers who had intellectual disabilities but did not have three or more significant functional limitations were included in the group labeled ID only.

- Mothers who had developmental disabilities who did not have intellectual disabilities were in the group labeled DD only.
- Mothers who met the criteria for having *both* intellectual disabilities and developmental disabilities were in the group labeled ID and DD.
- Mothers who had functional limitations but not intellectual or developmental disabilities were included in the group labeled FL Only.

Mothers with disabilities were identified from the NHIS-D by selecting mothers between the ages of 18 and 55 with ID/DD or FL Only living in a primary household with one or more children. An item from the Phase 2 NHIS-D that asked if the person had living children was used to identify mothers with disabilities in the sample. The pool of mothers was then matched by household identifiers to children ages 0-17. Only mothers with disabilities living with children ages 0-17 years old were included in this study. In the event that there was more than one mother with ID/DD or FL Only in the household between the ages of 18 and 55, the eldest of the women in the household was included in the analyses. Mothers older than 55 years, men, mothers not living in primary households, and mothers not living with children ages 0-17 were excluded. For the analysis of child outcomes, children who lived in the households of mothers with ID/DD or FL Only were compared to all other children ages 0-17 in the sample.

The two-year time span of the NHIS-D allowed for more reliable sampling of low-incidence disabilities such as intellectual and developmental disabilities. The 1994 and 1995 samples were combined in this analysis to make use of this strength. Population estimates were calculated using the weights provided in the NHIS survey divided by two to account for using both 1994 and 1995 surveys. The relative standard error (RSE) is provided as a measure of the estimates' reliability. RSEs less than 30 are generally

considered reliable. Because the overall sample size of parents with ID/DD was small, sample sizes of five or greater were reported despite having RSEs greater than 30. Caution should be used in interpreting these population estimates. SUDAAN™ was used in all analyses.

Results

Characteristics of Mothers with Disabilities

Based on the 1994/1995 NHIS-D data, in the United States there were an estimated 43,953 mothers with intellectual disabilities, 49,719 mothers with developmental disabilities, 80,638 mothers with both intellectual and developmental disabilities, and 1,340,324 mothers with significant functional limitations, but not ID/DD (see Table 1).

Of these mothers with disabilities, women with both intellectual and developmental disabilities were most likely to report being never married (82%), to be living above the federal poverty guidelines (70%), and to be Black (30%). More than two-thirds of mothers with both ID and DD were between 18 and 40 years old.

Mothers with developmental disabilities only were the most likely to report living below the federal poverty guidelines (58%). More than half (54%) were between 18 and 30 years old. While 42% of mothers with DD only had never married, 26% were married at the time of the survey, and 32% had been married but were now divorced, separated, or widowed.

Most mothers with intellectual disabilities only were 18 to 30 years old (53%) and had never been married (51%). A total of 26% of these mothers were married at the time of the survey while 23% had previously been married. Overall, 73% of these mothers were White, while 27% were Black and the majority (58%) lived in households with incomes that exceeded the federal poverty guidelines.

Table 1: Demographic Characteristics of Mothers with Disabilities

	Total			Mothers with ID Only			Mothers with DD Only		
	Sample Size	Estimated Population	RSE [†] %	Sample Size	Estimated Population	RSE [†] %	Sample Size	Estimated Population	RSE [†] %
Total	1,222	1,514,634	3.5	35	43,953	10.8	40	49,719	16.9
Age									
18-30	304	399,429	6.5	18	23,476	24.5	20	26,941	17.7
31-40	423	508,897	5.8	11	11,467	29.8	13	14,590	44.9
41-50	371	458,668	5.5	^	^	^	6	7,641	55.2
51-55	124	147,641	10.0	^	^	^	^	^	^
Race									
White	933	1,187,081	3.9	22	28,840	20.8	28	36,900	20.5
Black	236	259,159	7.8	10	10,524	32.7	9	9,417	35.0
Other	53	68,394	17.1	^	^	^	^	^	^
Marital Status									
Never married	253	302,373	6.8	20	22,322	23.2	16	20,705	25.9
Married	663	839,304	4.6	8	11,625	37.1	10	13,151	35.7
Formerly married	304	371,783	6.1	8	10,007	33.1	14	15,863	28.6
Economic Status									
Above FPG [‡]	719	924,060	4.1	17	20,485	26.4	17	20,485	24.7
Below FPG [‡]	403	479,300	6.1	14	14,881	29.6	23	28,094	23.2

[†]RSE = Relative Standard Error
[‡]FPG = Federal Poverty Guidelines
 ^ = N < 5
 ** p < .01. *** p < .001.

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Table 1 (continued): Demographic Characteristics of Mothers with Disabilities

	Mothers with ID and DD			Mothers with FL Only			X ²
	Sample Size	Estimated Population	RSE ¹ %	Sample Size	Estimated Population	RSE ¹ %	
Total	65	80,638	13.0	1,081	1,340,324	3.6	
Age							
18-30	24	32,681	21.1	242	316,332	8.7	35.03***
31-40	23	25,851	22.0	376	456,989	4.8	34.1
41-50	14	17,171	28.3	345	426,043	5.8	31.8
51-55	^	^	^	118	140,961	10.5	10.5
Race							
White	47	56,856	15.3	836	1,064,485	4.0	79.4
Black	19	23,783	24.6	199	215,437	8.4	16.1
Other	0	0	0.0	46	60,403	18.6	4.5
Marital Status							
Never married	52	65,807	14.4	165	193,540	8.3	14.5
Married	8	9,490	36.0	637	805,039	4.6	60.1
Formerly married	5	5,342	46.4	277	340,571	6.5	25.4
Economic Status							
Above FPG ¹	44	56,609	15.9	644	828,793	4.2	66.4
Below FPG ¹	14	17,726	28.7	352	418,599	6.5	33.6

¹RSE = Relative Standard Error
¹FPG = Federal Poverty Guidelines
 ^ = N < 5
 ** p < .01. *** p < .001.

Table 2: Functional Limitations of and Supports Received by Mothers with Disabilities

	Mothers with ID/DD		Mothers with FL Only		X ²
	%	RSE [†]	%	RSE [†]	
Economic Self-Sufficiency					
Yes	90.2	9.4	33.0	6.0	100.01***
No	9.8	28.5	67.0	4.3	
Learning Limitations					
Yes	90.2	9.5	14.0	8.9	128.31***
No	9.8	26.5	86.0	3.8	
Self-Direction Limitations					
Yes	42.8	14.3	2.2	9.2	26.14***
No	57.2	28.5	97.8	2.1	
Language Limitations					
Yes	32.1	15.4	1.9	23.1	39.86***
No	67.9	10.7	98.1	3.7	
Receives Supervision for ADL¹/IADL² Activities					
Yes	73.8	11.0	51.0	5.0	21.59***
No	26.2	16.8	49.0	5.2	

†RSE = Relative Standard Error

¹ADL = Activities of Daily Living. ²IADL = Instrumental Activities of Daily Living

*** $p < .001$

Most mothers with functional limitations, but not intellectual or developmental disabilities reported being married (60%) and being older than 31 years of age (76%). Of these mothers, 78% were White, 16% were Black, and 5% were of other racial groups. Two-thirds of these mothers lived in households with incomes that exceeded federal poverty guidelines.

Table 2 combines the groups of mothers with ID and/or DD for further analysis. This was done because of the relatively small sample sizes of the individual groups. Table 2 presents the percentage of mothers with specific functional limitations and whether the mothers reported receiving supervision to complete activities of daily living (ADLs) such as bathing, dressing or eating or to complete instrumental activities of daily living (IADLs) such as cooking, cleaning or shopping. Differences in the limitations and

support needs of the two groups of mothers were statistically significant in every case. For example, while 90% of the mothers with ID/DD reported having substantial functional limitations in economic self-sufficiency, only 33% of mothers with FL Only reported substantial limitations in economic self-sufficiency. Similarly, 90% of the mothers with ID/DD reported learning limitations compared with only 14% of mothers with FL Only. Very few of the mothers with FL Only reported self-direction limitations (2%) as compared to 43% mothers with ID/DD. Similarly, while only 2% of mothers with FL Only reported substantial limitations in expressive or receptive communication, 32% of mothers with ID/DD did so. Finally, about three-quarters (74%) of mothers with ID/DD reported receiving supervision for either ADLs or IADLs as compared with about half (51%) of mothers with FL Only.

Table 3: Social Participation in the Past Two Weeks by Mothers with Disabilities

Activities in Prior Two Weeks	Mothers with ID/DD		Mothers with FL Only		X ²
	% Participating	RSE [†]	% Participating	RSE [†]	
Specific Activities					
Met with friends or neighbors	56.3	12.2	71.2	4.2	9.63**
Talked on phone with friends or neighbors	55.0	12.5	82.7	3.9	33.08**
Met with relatives	61.0	12.0	71.0	4.1	4.16**
Talked on phone with relatives	66.5	11.4	84.7	3.8	17.52**
Attended religious services	36.0	16.1	41.6	5.1	1.40
Attended events (e.g. movies, sports, etc.)	24.5	17.2	29.9	6.6	1.81
Activity Frequency					
Went out of house every day	46.4	13.2	63.9	4.4	10.12**
Left home at least once in past two weeks	95.0	9.2	98.9	3.8	4.55**
Would like to do more activities	50.3	17.1	47.3	5.6	0.22

[†]RSE = Relative Standard Error

** $p < .01$

Table 3 describes participation in social activities during the past two weeks. Mothers with FL Only were more likely than mothers with intellectual and/or developmental disabilities to participate in a variety of social activities in the two weeks prior to the interview. Most mothers with FL Only reported meeting with friends or neighbors (71%), talking on the phone with friends or

neighbors (83%), meeting with relatives (71%), talking on the phone with relatives (85%), and getting out of the house every day (64%). Most reported leaving home at least once in the past two weeks (99%). Less than half reported attending religious services (42%) or going to movies or other events (30%) during the previous two weeks.

Table 4: Health Status of Mothers with Disabilities

Health Status	Mothers with ID/DD		Mothers with FL Only		X ²
	% Reporting	RSE [†]	% Reporting	RSE [†]	
Health Status					
Excellent	11.1	25.8	7.2	11.8	3.61
Good	46.9	13.7	43.3	5.6	
Fair	22.2	19.1	27.3	6.2	
Poor	19.7	21.1	22.2	7.7	
Mental Health Status					
Frequently depressed or anxious	31.8	17.6	32.5	6.1	0.02
Serious trouble coping with day-to-day stresses	30.4	18.2	19.2	8.3	5.12**
Took medication for mental/emotional conditions in past 12 months	24.1	18.9	23.0	7.1	0.06
Received mental health services in past 12 months	29.7 [#]	19.8	18.5 ^{##}	10.9	4.37**

[†]RSE = Relative Standard Error

[#]N = 83. ^{##}N = 463.

** $p < .05$

Table 5: Demographic Characteristics of Children Living with Mothers with Disabilities or in Other Households

Child Characteristics	Total			Not Living with a Mother with a Disability			Mothers with ID Only		
	Sample Size	Estimated Population	RSE [†] %	Sample Size	Estimated Population	RSE [†] %	Sample Size	Estimated Population	RSE [†] %
Total	57,553	70,349,128	1.2 100.0	55,656	68,084,479	1.2 100.0	36	38,372	24.5 100.0
Age									
0-3	12,820	16,116,621	1.4 22.9	12,437	15,649,551	1.5 23.0	17	16,281	34.5 42.4
4-10	23,295	27,808,239	1.3 39.5	22,583	26,987,029	1.4 39.6	7	10,152	48.3 26.5
11-17	21,438	26,424,268	1.4 37.6	20,636	25,447,899	1.4 37.4	12	11,940	34.8 31.1
Race									
White	45,397	55,738,844	1.3 79.2	44,023	54,057,813	1.3 79.4	25	26,837	30.0 69.9
Black	9,622	11,259,139	3.0 16.0	9,174	10,772,259	2.9 15.8	8	7,080	49.7 18.5
Other	2,534	3,351,145	5.2 4.8	2,459	3,254,408	5.1 4.8	^	^	^
Economic Status									
Above FPG [‡]	41,561	53,013,160	1.3 80.5	40,624	51,839,682	1.3 81.3	10	11,829	44.4 35.8
Below FPG [‡]	11,969	12,868,299	2.4 19.5	11,148	11,919,286	2.5 18.7	22	21,172	35.8 64.2
Disability Status of Child									
ID/DD	1,960	2,391,976	3.0 3.4	1,753	2,148,012	3.1 3.2	9	10,830	51.0 28.2
FL Only	1,538	1,862,591	3.1 2.6	1,390	1,682,737	3.1 2.5	^	^	^
None	54,055	66,094,561	1.2 94.0	52,513	64,253,730	1.2 94.4	25	25,008	32.8 65.2

†RSE = Relative Standard Error

‡FPG = Federal Poverty Guidelines

^ = N < 5

** p < .01

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Table 5 (continued): Demographic Characteristics of Children Living with Mothers with Disabilities or in Other Households

Child Characteristics	Mothers with DD Only			Mothers with ID and DD			Mothers with FL Only						
	Sample Size	Estimated Population	RSE [†] %	Sample Size	Estimated Population	RSE [†] %	Sample Size	Estimated Population	RSE [†] %	X ²			
Total	53	68,352	27.2	100.0	51	63,155	22.1	100.0	1,757	2,094,771	4.9	100.0	
Age													
0-3	16	24,561	42.6	35.9	6	8,089	57.1	12.8	344	418,140	8.3	20.0	30.66**
4-10	18	20,692	35.2	30.3	16	18,309	32.5	29.0	671	772,058	6.3	36.9	
11-17	19	23,100	30.0	33.8	29	36,757	24.8	58.2	742	904,573	5.7	43.2	
Race													
White	40	49,159	26.4	71.9	37	42,240	22.1	66.9	272	1,562,796	5.1	74.6	14.36
Black	10	12,026	44.8	17.6	13	19,582	47.6	31.0	417	448,194	10.6	21.4	
Other	^	^	^	^	^	^	^	^	68	83,781	24.9	4.0	
Economic Status													
Above FPG [‡]	12	15,674	35.8	24.9	22	27,053	28.1	45.8	893	1,118,923	6.1	56.9	108.28**
Below FPG [‡]	36	47,336	36.7	75.1	25	32,050	35.4	54.2	738	848,436	7.5	43.1	
Disability Status of Child													
ID/DD	8	8,653	40.9	12.7	14	17,611	30.7	27.9	176	206,871	9.5	9.9	132.46**
FL Only	5	5,195	54.2	7.6	^	^	^	^	137	166,936	11.1	8.0	
None	40	54,505	32.5	79.7	33	40,355	27.0	63.9	1,444	1,720,964	5.3	82.1	

[†]RSE = Relative Standard Error
[‡]FPG = Federal Poverty Guidelines
 ^ = N < 5
 ** p < .01

Mothers with ID/DD were less likely than mothers with FL Only to report getting out of the house each day (46%), meeting with friends or neighbors (56%), meeting with relatives (61%), talking on the phone with friends and neighbors (55%), and talking to relatives on the phone in the prior two weeks (67%). The 36% of mothers with ID/DD attending religious services and 24.5% attending events such as movies or sports in the previous two weeks were not statistically different than the rates reported by mothers with FL Only. Like mothers with FL Only, nearly all mothers with ID/DD reported getting out of the house at least once in the prior two weeks (95%). About one-half of mothers with ID/DD and mothers with FL Only reported that they wanted to do more activities.

Table 4 summarizes the self-reported health and mental health status of mothers with disabilities. There were no statistically significant differences between mothers with ID/DD and mothers with FL Only in their reported health status. Overall, slightly more than half of mothers with disabilities reported being in good or excellent health. There were also no statistically significant differences between these groups in the proportion reporting that they were frequently depressed or anxious (about one-third in each case), or in the proportion who took medication for mental or emotional conditions (about one-fourth). However, mothers with ID/DD were more likely to report having serious trouble coping with day-to-day stresses (30% versus 19%) or to have received mental health services in the past 12 months (30% versus 19%) than mothers with FL Only.

Characteristics of Children Whose Mothers have Disabilities

The final two sets of analyses compare the characteristics of children living with mothers with disabilities with the characteristics of all of the other children included in the

NHIS sample. In 1995, there were an estimated 70.3 million children in the non-institutionalized U.S. population (see Table 5). Of those, an estimated 38,372 lived with mothers who had intellectual disabilities only, 68,352 lived with mothers who had developmental disabilities only, 63,155 lived with mothers who had both intellectual and developmental disabilities, and 2,094,771 lived with mothers who had functional limitations but not intellectual or developmental disabilities. An estimated 3.2% of all children ages birth to 17 years in the United States were living with mothers with substantial functional limitations, including the estimated 169,879 (0.24%) who lived with mothers with intellectual and/or developmental disabilities. Adult children (18 years and older) living with mothers with ID/DD were not included in this analysis.

There were no statistically significant racial differences between children whose mothers had substantial functional limitations and other children. There were, however, significant differences across groups by age of the child, income level of the child's family, and the presence of disabilities amongst the children. Children whose mothers had both intellectual and developmental disabilities were older than the children of other groups of mothers, with 58% between the ages of 11 and 17 years. Children whose mothers had only intellectual disabilities and children whose mothers had only developmental disabilities were more likely to be ages birth to 3 years (42% and 36% respectively) than other groups of children.

Overall, 20% of children in the United States lived in households with incomes that were below the federal poverty guidelines. Children whose mothers had disabilities were much more likely to live in such households (ranging from 43% of children whose mothers had functional limitations only to 75% of children whose mothers had developmental disabilities).

Table 6: Factors Associated with Developmental Outcomes for Children Ages 4 to 17 Years

	Receives Special Education		Has Problems Understanding Materials		Has Problems Paying Attention		Has Problems Communicating		Has Problem Behavior		Child Has ID/DD	
	Odds Ratio	Sig	Odds Ratio	Sig	Odds Ratio	Sig	Odds Ratio	Sig	Odds Ratio	Sig	Odds Ratio	Sig
Intercept	0.1	***	0.0	***	0.1	***	0.0	***	0.0	***	0.0	***
Race												
White	1.0		1.0		1.0		1.0		1.0		1.0	
Other	0.8	**	1.0	NS	1.0	NS	1.2	*	1.1	NS	1.1	NS
Gender of Child												
Male	1.0		1.0		1.0		1.0		1.0		1.0	
Female	0.5	***	0.6	***	0.4	***	0.5	***	0.4	***	0.5	***
Economic Status												
Above FPG ¹	1.0		1.0		1.0		1.0		1.0		1.0	
Below FPG ¹	1.6	***	2.0	***	1.6	***	1.7	***	1.9	***	2.0	***
Marital Status of Mother												
Yes	1.0		1.0		1.0		1.0		1.0		1.0	
No	1.4	NS	1.7	**	1.5	**	1.9	**	1.8	**	1.5	*
Disability Status of Mother												
Not living with mother	1.0		1.0		1.0		1.0		1.0		1.0	
Living with mother with ID/DD	4.8	***	8.5	***	6.5	***	7.5	***	5.7	***	7.2	***
Living with mother with FL Only	3.2	***	4.3	***	3.7	***	4.3	***	3.4	***	3.5	***
R²	0.01	***	0.01	***	0.02	***	0.01	***	0.02	***	0.01	***

NS = No statistically significant difference

¹FPG = Federal Poverty Guidelines

* p < .05. ** p < .01. *** p < .001.

Overall, an estimated 6.0% of children in the United States had intellectual or developmental disabilities and/or functional limitations. Overall, an estimated 3.4% of children in the United States had ID/DD and 2.6% of children had FL Only. However, children whose mothers had ID/DD or other substantial functional limitations were much more likely themselves to have ID, DD or FL. Overall, 28% of children whose mothers had both intellectual and developmental disabilities, 28% of children whose mothers had intellectual disabilities only, 20% of children whose mothers had developmental disabilities only, and 18% of children whose mothers had functional limitations only themselves had ID, DD or FL Only. Nearly 30% of children whose mothers had intellectual disabilities only or both intellectual and developmental disabilities had intellectual and/or developmental disabilities themselves. By contrast, 13% of children whose mothers had developmental disabilities only, and 10% of children whose mothers had functional limitations only, had intellectual and/or developmental disabilities themselves.

Factors Associated With Child Outcomes

Table 6 shows factors associated with developmental outcomes for school-aged children, including receiving special education, having problems understanding materials, having problems paying attention, having problems communicating with others, exhibiting problem behavior at school, and being identified as having intellectual and/or developmental disabilities. For each outcome, several possible predictors are tested, including race, gender of the child, family income level, marital status of the mother, and disability status of the mother. Outcomes for children aged three and younger, such as having a family service plan, were not analyzed due to small sample sizes. Logistic regressions were used to calculate the odds ratio of a particular outcome. The outcome variables were

selected from Phase 1 of the NHIS, as they would be available for all children in the sample.

All of the identified factors were associated with at least one of the child outcomes. However, the identified factors together accounted for only 1% to 2% of the variability in whether a child would experience a particular outcome.

The factors associated with receiving special education services once the other factors were statistically controlled were as follows: children who were White were 25% more likely to receive special education services; boys were twice as likely as girls to receive special education; and children who lived in households with below poverty level incomes were 60% more likely to receive special education services. With regard to their mothers' disability status, children whose mothers had functional limitations only were 3.2 times more likely to receive special education services, and children whose mothers had intellectual and/or developmental disabilities were 4.8 times more likely to receive special education services as children whose mothers did not have ID/DD or substantial functional limitations.

The factors associated with the other child outcomes followed the same pattern as for special education with two exceptions. First, race was only associated with the outcome of having problems communicating with others. Specifically, children who were Black or of another race were more likely than children who were White to have reported problems communicating with others. Second, the marital status of the child's mother was associated with all developmental outcomes other than receiving special education. Specifically, children whose mothers were not married were between 50% and 90% more likely to report problems at school or to have intellectual or developmental disabilities than children whose mothers were married.

When compared with children whose mothers did not have substantial functional limitations (and controlling for race, gender, and poverty), children of mothers with ID/DD were reported to be 8.5 times more likely to have problems understanding learning materials, 6.5 times more likely to have attention problems, 7.5 times more likely to have communication difficulties, 5.7 times more likely to have behavior problems, and 7.2 times more likely to be identified with ID/DD themselves. Risks for children of mothers with FL Only were also higher in each of the developmental outcomes, ranging from 3.4 to 4.3 times higher, depending on the outcome.

Discussion

Based on estimates from the NHIS-D, there were in 1994/1995 about 2.26 million children living with mothers who had either ID/DD or other substantial functional limitations. Raising any child 17 years and younger in the contemporary U.S. is challenging. The challenges are exacerbated when mothers have intellectual, developmental, or substantial functional limitations themselves. While several factors were associated with developmental outcomes experienced by school-aged children, having a mother with an intellectual and/or developmental disability was the strongest predictor of children having poorer outcomes. Children whose mothers had ID/DD were more than eight times as likely to be reported to have problems understanding material in school and more than seven times as likely to have problems communicating as children who were not living with a mother identified as having functional limitations. They were more than five times as likely to have problem behavior, six times as likely to have problems paying attention, and four times as likely to need special education. Children living with mothers with ID/DD were seven times more likely to be identified as having ID/DD themselves.

Mothers with ID/DD were themselves limited in social activities and general well-being, even when compared with mothers who also had substantial functional limitations, but not ID/DD. For example, they were less likely than mothers with functional limitations to report participation in a variety of social activities, including having contact with relatives, friends and neighbors. This outcome likely reflects increased levels of social isolation not just for these mothers, but also for their children. It may contribute to lower levels of informal support in meeting the challenges of parenting. Many of the mothers with disabilities reported feeling anxious and depressed and receiving mental health care and treatment, but mothers with intellectual or developmental disabilities were more likely to report serious difficulty coping with day-to-day stresses and to receive mental health services.

The children of mothers with ID/DD were more likely to live in poverty or with a never-married mother than were other children. Children of mothers with both ID and DD were less likely to live in poverty than were children of mothers with ID only, DD only or FL Only. Other analyses using the NHIS-D suggest that the reason for this is that adults with both ID and DD are much more likely than adults in the other groups to live with parents or siblings. As a result, the family income was based not just on the income of the person with both ID and DD, but also on the income of the family members with whom they live (Larson, Lakin, Anderson, & Kwak, 2001).

Children of mothers with ID/DD were at significant risk for generally undesirable educational and developmental outcomes, including needing special education, having problems understanding material in school, having behavior problems, having problems communicating, and having problems paying attention.

A mother's disability status was the single strongest predictor for the child receiving special education, having problems understanding material, having problems paying attention, having problems communicating, having problem behavior, and/or being identified as having ID/DD. It was much stronger than economic, racial or marital status factors. Mothers with functional limitations but not ID/DD were also more likely to have children with adverse outcomes, but less so than mothers with ID/DD.

Given the number of mothers with ID/DD and the challenges facing them and their families in terms of social isolation, the mothers' mental health, and the increased risk for negative outcomes for the children, the need for support services for parents with ID/DD, including parenting education, is obvious. The problems faced by these mothers and children pervade all aspects of family life. Accordingly, support services must be comprehensive, be family-centered, address the needs of both parent and child, and be provided on an ongoing basis to meet the substantial, complex, and ever-changing challenges of parenting.

Based on the 1994/1995 NHIS-D, there were an estimated 174,000 mothers with intellectual and/or developmental disabilities in the United States, and 1.34 million mothers with other substantial functional limitations. Given the continued commitment to independent living and self-determination, it seems reasonable to assume that this group has at minimum increased proportionally with growth in the population of people with ID/DD as a whole. Many mothers with ID/DD reported limitations of direct relevance to their ability to independently raise their children, including 90% who reported substantial limitations in learning and economic self-sufficiency. These and other reported limitations and service needs have direct implications on the need for support and assistance. Failure to provide such assistance exacerbates the highly at risk status of many tens of thousands of children.

A Final Note

Having a parent with an intellectual and/or developmental disability is clearly a major risk factor for poor outcomes in children. Due to the limits of the questions asked in the NHIS-D, it is impossible to identify mothers with ID/DD who might have been receiving parenting services and supports. It is, therefore, impossible to use the NHIS-D data to suggest that parent training and/or support services would mitigate the increased odds of poor developmental outcomes of children whose mothers have an intellectual and/or developmental disability. At the same time there is little to suggest as an alternative to parent training and support. Policymakers and those who provide supports and services for adults with intellectual disabilities need to recognize the important but extremely difficult role of parents with intellectual and/or developmental disabilities. Training, assistance, and accommodation are needed to help mothers with ID/DD overcome the burdens of functional limitations, intellectual impairments, mental health challenges, and limited economic resources or poverty in meeting their children's needs. Both education and long-term supports for families and children are essential to giving mothers with ID/DD improved odds for overcoming such burdens to provide stable, nurturing, and stimulating environments for their children.

References

- Larson, S.A., Lakin, K.C., Anderson, L., Kwak, N. Lee, J.H., & Anderson, D. (2000). Prevalence of mental retardation and/or developmental disabilities: Analysis of the 1994/1995 NHIS-D. *DD Data Brief* 2(1). [Minneapolis, MN: University of Minnesota, Institute on Community Integration, Research and Training Center on Community Living.]
- Larson, S., Lakin, C., Anderson, L., & Kwak, N. (2001). Demographic Characteristics of Persons with MR/DD Living in Their Own Homes or with Family Members: NHIS-D Analysis. *MR/DD Data Brief* 3(2). [Minneapolis, MN: University of Minnesota, Institute on Community Integration, Research and Training Center on Community Living.]

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- Problems in Defining Mental Retardation and Developmental Disability: Using the National Health Interview Survey. (2005)
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