

Children with Disabilities: Social Roles and Family Impacts in the NHIS-D

Introduction

The social roles of children can be defined by relationships with family and friends and by participation in school and other activities that promote their development and growth. Also of great importance is the child's role in the family and the degree and length of dependence on his/her

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parents for care and support. Children with disabilities often require levels and types of care and support beyond that needed by other children of the same age.

In this *DD Data Brief*, we will present information about the association between disability status and the social roles, relation-

ships, and family circumstances of children. These data are drawn from the 1994-1995 National Health Interview Survey Disability Supplement (NHIS-D).

Methodology

In both 1994 and 1995, a special Disability Supplement was developed for the ongoing National Health Interview Survey (NHIS) to provide a national picture of the physical, emotional, functional, and health status and social and economic circumstances of Americans with disabilities. A major strength of the two-year supplement was that combining the two years' samples (as was done in this report) assured a sufficient sample to yield reliable estimates of persons in low-incidence disability catego-

About This *Data Brief*

This issue of *DD Data Brief* uses the 1994-1995 Child Disability Follow-Back Survey (DFS) of the National Health Interview Survey (NHIS) to examine the characteristics of children between the ages of 6 and 17 who were identified as having functional limitations or a disability-related diagnosis. Four disability groups were defined: children with a) developmental disabilities only, b) intellectual disabilities only, c) intellectual disabilities and developmental disabilities, and d) other disabling conditions or impairments. These groups were described in terms of each group's ability to perform the social roles expected of children (e.g., relationships with family and friends, participation in school and other activities). Summary statistics are provided on demographic characteristics, special education and other services, impact of the child's disability on the family, and perceptions of disability. Findings from the Personal Adjustment and Role Skills Survey (PARS) questions are also included.

In this issue the term "intellectual disability" (ID) is used in place of "mental retardation" (MR) in response to the growing commitments to avoid using the latter term because of the stigma associated with that label. The name of this publication has been changed for the same reason.



ries, including intellectual disabilities (ID) and developmental disabilities (DD). Because few studies of persons with ID/DD have been census-based household surveys, there is relatively little information about the characteristics, needs, and service use patterns of children with ID/DD who are not included in formal service systems.

This *DD Data Brief* is based on the data gathered in the Phase 2 disability supplement administered to people who were identified in Phase 1 of the NHIS-D to have conditions or functional limitations that may be indicative of a disability or need or use of disability-related services or programs. Children identified with one of these conditions or functional limitations, or as participants in disability-related programs (e.g., SSI) were administered the Child Disability Follow-Back Survey (DFS). In this study, children were defined as persons between the ages of 6 and 17, inclusive.

Four groups of children were identified. The first group was made up of children who had three or more functional limitations and were thereby classified as having a developmental disability, but they did not meet the operational definition for intellectual disabilities. The second group met the operational definition of intellectual disabilities but not that of developmental disabilities (i.e., they did not have three or more functional limitations). The third group had both intellectual disabilities and developmental disabilities. The fourth group had one or two substantial functional limitations, but did not meet the operational definition of either intellectual disabilities or developmental disabilities. Children were considered to have intellectual disabilities if: a) the household respondent identified that child as having intellectual disabilities, b) intellectual disabilities was 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 child was identified as having a condition which is highly associated with intellectual disabilities (e.g., Down syndrome, autism) and was concurrently reported to have serious difficulty learning how to do the things that most children of that age were able to do. Children were classified with developmental disabilities when they were “unable” to perform or had “serious difficulty” performing in an age-appropriate manner in three or more of five domains –

self-care, language, learning, mobility, and self-direction – and the limitation was expected to endure “longer than a year.” Children with intellectual disabilities and developmental disabilities met the criteria for both the above definitions of intellectual disabilities and developmental disabilities. Children with “other disabilities” had substantial functional limitations in one or two of the five domains included in the definition of developmental disabilities but did not meet the criteria of developmental disabilities and intellectual disabilities. (A detailed description of these definitions and of the NHIS-D data elements used to operationalize them is available in Larson et al., 2001). Children who did not have disabilities could not be included in these analyses because they did not participate in the Phase 2 DFS. Children who were included in the Phase 2 DFS but who did not fall into one of the four identified groups were also excluded. In the case of several demographic variables, data from the Phase I Disability Supplement or the NHIS Core was used to describe children who did not fall into any of the four groups used in this paper.

Population weights provided by the National Center for Health Statistics were applied in all analyses. Both years (1994 and 1995) of the disability supplement were combined and all weighting was done with the original weight factor divided by two. All analyses were conducted using the SUDAAN statistical software package. Where population estimates are provided, the standard error of estimate was calculated using SUDAAN. Standard errors are presented as relative standard errors (RSE). The RSE was computed by dividing the standard error of estimate by the population estimate and multiplying the result by 100.

Results

Population Estimates

Table 1 presents estimates of the U.S. non-institutionalized populations of children in the four disability groups. In 1994/1995, there were an estimated 3,258,817 children between the ages of 6 and 17 with one or more substantial functional limitations. This constituted 7.1% of all school-age children (6-17 years). Of the children with disabilities, an estimated 520,894 children had developmental disabilities only (DD

only); 558,828 children had intellectual disabilities only (ID only); 372,637 had both intellectual disabilities and developmental disabilities (both ID and DD); and 1,806,458 children had at least one significant functional limitation but not intellectual disabilities or developmental disabilities (other disabilities).

Of the estimated 520,894 school-age children (ages 6-17 years) with DD only, an estimated 341,715 (65.6%) were ages 6-12 years and 179,180 (34.4%) were ages 13-17 years. Of the estimated 558,828 school-age children with ID only, an estimated 291,749 (52.7%) were ages 6-12 years and 264,079 (47.3%) were ages 13-17 years. Of the estimated 372,637 school-age children with both DD and ID, 226,354 (60.7%) were ages 6-12 years and 146,873 (39.3%) were ages 13-17 years. Of the estimated 1,806,458 school-age children with other disabilities (i.e., one or two substantial functional limitations), 1,103,716 (61.1%) were ages 6-12 years and

702,742 (38.9%) were ages 13-17 years. By comparison, there were an estimated 45,883,644 total school-age children and youth in the non-institutionalized population; 59.3% were ages 6-12 years and 40.7% were ages 13-17 years.

An estimated 7.1% of school-age children (3,258,817) reported to be “unable” to perform or to have “serious difficulty” with basic age-related activities in the areas of self-care, language, learning, mobility, and/or self-direction because of a condition that would endure for longer than one year, including 7.4% of children 6-12 years old and 7.0% of children 13-17 years old. Children with intellectual disabilities and/or developmental disabilities made up an estimated 3.3% of all non-institutionalized children 6-12 years old and 3.2% of all non-institutionalized children 13-17 years old.

Table 1: Population Estimates of Children with Intellectual Disabilities (ID), Developmental Disabilities (DD), and Other Disabling Conditions, by Age

| Disability Status | School-Age Children by Age Group | | | |
|---------------------------------------|----------------------------------|-------------|------------------|-----------------|
| | 6-12 Years | 13-17 Years | Total 6-17 Years | % of Population |
| DD, but not ID | | | | |
| Estimated Population | 341,714 | 179,180 | 520,894 | 1.1% |
| RSE ¹ | 7.17% | 9.01% | 6.00% | |
| ID, but not DD | | | | |
| Estimated Population | 294,749 | 264,079 | 558,828 | 1.2% |
| RSE | 7.78% | 7.60% | 5.77% | |
| Both DD and ID | | | | |
| Estimated Population | 226,354 | 146,283 | 372,637 | 0.8% |
| RSE | 7.81% | 10.67% | 6.55% | |
| Other Disabilities² | | | | |
| Estimated Population | 1,103,716 | 702,742 | 1,806,458 | 3.9% |
| RSE | 4.04% | 4.78% | 3.19% | |
| Total (DD, ID, or Other) | | | | |
| Estimated Population | 1,966,533 | 1,292,284 | 3,258,817 | 7.1% |
| RSE | 3.21% | 3.70% | 2.65% | |

¹ RSE = Relative Standard Error

² “Other Disabilities” includes children with one or two substantial functional limitations who do not have intellectual disabilities or developmental disabilities.

Family Characteristics

Table 2 presents statistics on the characteristics of the families of school-age children with disabilities.

Family Structure.

The majority of children in each disability group lived in homes with both parents. Children with “other disabilities” were the most likely to live with both parents (66.0%) and least likely to live with only their mothers (24.1%).

Children with both ID and DD were the least likely to live with both parents (57.0%) and most likely to live with only their mothers (32.2%). Only an estimated 2.4% of the children in the four groups lived with only their father, but an estimated 8.4% lived with adult relatives other than their parents. The proportion of children ages 6-17 years with any of these disabilities living in two-parent families (62.9%) compares to an estimated 74.7% of children who do not have disabilities.

Family Size. Relatively few children with disabilities lived in a two-person household (6.5%). Children with both ID and DD were the most likely to be living in a two-person household (10.9%).

Table 2: Family Characteristics of Children with Disabilities, Ages 6-17

| Characteristic | DD not ID | | ID not DD | | ID and DD | | Other Disabilities | | ID, DD, or Other Disability | | X ² |
|---|-----------|-------|-----------|-------|-----------|-------|--------------------|-------|-----------------------------|-------|----------------|
| | % | RSE | % | RSE | % | RSE | % | RSE | % | RSE | |
| Currently Lives with Which Family Member | | | | | | | | | | | |
| Both Parents | 58.3% | 7.5% | 61.1% | 7.4% | 57.0% | 9.0% | 66.0% | 3.9% | 62.9% | 3.1% | 134.69** |
| Mother Only | 28.6% | 11.5% | 27.0% | 9.7% | 32.2% | 10.6% | 24.1% | 6.6% | 26.2% | 5.3% | |
| Father Only | # | # | # | # | # | # | 2.3% | 19.9% | 2.4% | 15.9% | |
| Other Adult Relatives | 10.5% | 20.2% | 8.9% | 15.9% | 8.8% | 22.4% | 7.6% | 10.5% | 8.4% | 8.5% | |
| Family Size | | | | | | | | | | | |
| Two Members | 7.1% | 20.2% | 4.1% | 23.4% | 10.9% | 18.1% | 6.1% | 11.0% | 6.5% | 7.9% | 52.03** |
| Three Members | 20.5% | 1.2% | 15.3% | 12.1% | 20.6% | 13.6% | 21.4% | 6.5% | 20.1% | 5.0% | |
| Four Members | 33.2% | 10.4% | 31.2% | 10.0% | 31.8% | 13.2% | 33.2% | 5.3% | 32.7% | 4.2% | |
| Five Members | 22.0% | 12.3% | 28.6% | 10.1% | 20.0% | 13.3% | 21.6% | 6.4% | 22.7% | 4.9% | |
| Six or More Members | 17.2% | 13.5% | 20.8% | 13.2% | 16.7% | 15.5% | 17.7% | 7.9% | 18.0% | 6.5% | |
| Family Income | | | | | | | | | | | |
| Above Poverty Level | 71.7% | 7.2% | 60.0% | 8.0% | 69.1% | 8.0% | 74.0% | 3.7% | 70.8% | 3.1% | 124.20** |
| Below Poverty Level | 28.3% | 12.9% | 40.0% | 9.7% | 30.9% | 12.3% | 26.0% | 5.8% | 29.2% | 4.7% | |
| Education Level of Parent | | | | | | | | | | | |
| Less Than High School | 19.3% | 13.5% | 23.7% | 12.0% | 22.0% | 13.0% | 15.2% | 7.7% | 18.1% | 5.7% | 133.79** |
| High School Graduate | 41.0% | 9.8% | 42.9% | 8.6% | 40.7% | 11.5% | 39.1% | 5.0% | 40.2% | 4.0% | |
| Some Post-Secondary | 39.8% | 8.3% | 33.4% | 10.3% | 37.3% | 9.3% | 45.8% | 4.6% | 41.7% | 3.8% | |

= RSE greater than 30%
** = p < .01

Children with ID only were least likely (4.1%). Consistently across the disability groups, about one-third of the children were living in a four-person household. Children with ID only were the most likely to be living in households with six or more family members (20.8%), while children with both ID and DD were the least likely (16.7%).

Family Income. Overall, 29.2% of children with disabilities lived in households with incomes below the federal poverty level. By comparison, only 17.3% of children who did not have disabilities lived in households with incomes below the federal poverty level.

The distribution of income levels was different across the disability groups. Children with ID only were the most likely to live in households with incomes below the federal poverty level (40.0%). Children with “other disabilities” were the least likely to be living in households with incomes below the federal poverty level (26.0%). An estimated 30.9% of children with both DD and ID and 28.3% of children with DD only lived in households with incomes below the federal poverty level.

Education Level of Parent. In each of the disability groups, more than one-third of parents had one or more years of post-secondary education. Post-secondary education was most likely among parents of children with “other disabilities” (45.8%) and least likely among children

with ID only (33.4%). Nearly a quarter of children with ID had a parent with less than a high school education (23.7% of parents of children with ID only and 22% of parents of children with both ID and DD). This compares with only 13.5% of parents of children with DD only and 15.2% of parents of children with other disabilities.

Among children ages 6-17 years who do not have disabilities, 11.9% had parents who had not completed high school and 54.7% had parents who had completed one or more years of post-secondary education.

Impact of Child’s Disability on Family

Table 3 presents statistics related to the impact of a child’s disability on the family. Several questions in the Phase 2 Disability Supplement focused on parental accommodations to a child’s disability.

Parents of children with both ID and DD were the most likely to report accommodations because of a child’s disability. Overall, an estimated 52.7% of parents of children with both ID and DD reported that a family member had made one or more of several major accommodations in response to a child’s health status or disability. An estimated 38.4% of parents of children with DD only reported one or more accommodation. Substantially lower rates of major accommodations were reported by parents of children with ID only (23.6%) and parents of children with

Table 3: Impact of Child’s Disability on Family

| Due to child’s health, someone in the family has: | DD not ID | ID not DD | ID and DD | Other Disabilities | Total ID, DD, or Other | χ^2 |
|---|-----------|-----------|-----------|--------------------|------------------------|----------|
| Not taken job | 20.7% | 10.3% | 36.1% | 12.3% | 16.1% | 41.82** |
| Changed work hours | 19.1% | 11.1% | 28.5% | 14.0% | 16.1% | 20.11** |
| Worked fewer hours | 17.7% | 11.5% | 25.8% | 8.4% | 14.7% | 18.37** |
| Quit working | 14.8% | 8.5% | 16.7% | 8.6% | 10.6% | 13.63** |
| Changed sleep patterns | 13.2% | 6.2% | 15.9% | 6.6% | 8.8% | 19.70** |
| Turned down better job | 9.2% | 5.0% | 16.9% | 7.7% | 8.6% | 17.73** |
| Changed jobs | 12.1% | 3.3% | 17.3% | 6.6% | 8.2% | 25.78** |
| Had severe financial problems | 9.8% | 3.7% | 9.1% | 4.8% | 6.0% | 13.80** |
| Reported one or more accommodations | 38.4% | 23.6% | 52.7% | 23.1% | 30.9% | 49.17** |

** $p < .01$

other disabilities (23.1%). Overall, the most common accommodations among the parents of children in the four disability groups were not taking a job because of the need to care for a child with a disability (16.1%), changing work hours (16.1%), working fewer hours (14.7%), and quitting work (10.6%). Overall, fewer than 10% of families reported a change in sleep patterns, turning down a better job, changing jobs, or having severe financial difficulties as the result of their child's disability.

The most common accommodation for parents of children with both ID and DD was not taking a job due to their child's disability (reported by 36.1% of families). Other accommodations among families in this group included 28.5% changing work hours, 25.8% working fewer hours, 17.3% changing jobs, 16.7% quitting a job, and 16.9% turning down a better job. Nearly one in ten of these families (9.1%) reported having severe financial difficulties as a result of their child's disability.

Parents of children with DD only were somewhat less likely than parents of children with both ID and DD to report accommodations due to their child's health but were considerably more likely to report accommodations due to their child's health than parents of children with ID only and parents of children with other disabilities. One in five (20.7%) parents of children with DD only reported not taking a job so they could care for their child. More than 10% reported changing work hours, working fewer hours, quitting work, changing sleep habits, or changing jobs to accommodate a child's disability or health.

Although parents of children with ID only or with "other disabilities" were considerably less likely to make major accommodations due to their child's disability, some did. They reported that they had not taken a job so they could care for their child (10.3% and 12.3%, respectively), or

that they had changed work hours (11.1% and 14.0%, respectively) to accommodate their child's needs. They also reported working fewer hours due to their child's disability (10.5% and 8.4%, respectively), quitting a job because of a child's condition (8.5% and 8.6%, respectively), and turning down a promotion (5.0% and 7.7%, respectively). These groups of parents were much less likely to report having severe financial problems (3.7% and 4.8%, respectively) because of the child's disability.

Perceptions of Disability

Table 4 summarizes parents' reports about perceptions of their child's disability. Parents of children in all disability groups reported that members of the family were more likely to perceive their child as having a disability than were people outside the family. The parents of children with both ID and DD were the most likely to report that the family perceived their child as having a disability (75.6%), followed by parents of children with DD only (47.2%), parents of children with ID only (34.1%), and parents of children with other disabilities (22.8%). Parents of children with both ID and DD were also the most likely to report that others perceive their child as having a disability (71.8%). Parents of children in the other disability groups reported that they thought others perceived their child as having a disability at much lower rates (DD only, 41.6%; ID only, 28.2%; and other disabilities, 18.2%).

Disability-Related Service Use

Table 5 summarizes participation of children with disabilities in special education services, regular and special education school settings, and services received outside of school.

Table 4: Percent of Those Reporting Perceptions of Childhood Disability

| | DD not ID | ID not DD | ID and DD | Other Disabilities | Total ID, DD, or Other | χ^2 |
|------------------------------------|-----------|-----------|-----------|--------------------|------------------------|----------|
| Person Perceives Child as Disabled | 47.2% | 34.1% | 75.6% | 22.8% | 34.7% | 619.52** |
| Others Perceive Child as Disabled | 41.6% | 28.2% | 71.8% | 18.2% | 29.8% | 498.42** |

** $p < .01$

Special Education Services. The majority of children in all groups were reported to receive special education services (72.1%). Participation in special education services was reported to be highest for children with both ID and DD (93.4%) and lowest for children with “other disabilities” (62.0%). Four of five children with DD only (83.1%) and ID only (80.0%) were also reported to receive special education services.

Services Used. Of the special education services identified in Table 5, speech/language therapy was received most often (received by 42.6% of children with one or more of the identified types of disabilities who received special education services). In addition to direct instructional services, 19.4% of children with disabilities who received special education services also received mental health or counseling services. Children with both ID and DD were the most likely to have received these specific therapeutic services. An estimated 64.8% of children with both ID and DD used speech/language services, 29.0% used mental health or counseling services, and 24.6% used physical therapy. A substantial proportion of children with DD only were reported to receive speech/language therapy

(42.6%) and/or mental health or counseling services (32.1%). Among children with ID only and children with “other disabilities,” the only specific therapeutic service received by 25% or more of students was speech/language therapy (38.3% and 36.8%, respectively).

Special Education Settings. Household members reported the settings in which children with disabilities received special education services. Children may have received special education services in more than one setting. There was no statistical difference in the proportion of students in each of the four disability groups that received some or all of their special education services in a regular classroom, with a minority of all four groups receiving special education in regular classrooms. The narrow reported range was 42.5% for children with ID only to 36.9% for children with “other disabilities.” Use of resource rooms was highest for students with “other disabilities” (45.4%), was essentially equal for students with DD only and ID only (36.7% and 37.0%, respectively), and was notably lower for students with both ID and DD (25.1%). Patterns of placement in segregated settings were quite different between the groups.

Table 5: Disability-Related Service Usage by Percentage of Children Ages 6-17

| | DD not ID | ID not DD | ID and DD | Other Disabilities | Total ID, DD, or Other | χ^2 |
|--|-----------|-----------|-----------|--------------------|------------------------|-----------|
| Special Education Services Currently Received | | | | | | |
| Special Education Services | 83.1% | 80.0% | 93.4% | 62.0% | 72.1% | 1177.79** |
| Of Those Receiving Special Education Services, Services Received: | | | | | | |
| Speech/Language Therapy | 42.6% | 38.3% | 64.8% | 36.8% | 42.6% | 53.27** |
| Mental Health or Counseling | 32.1% | 12.1% | 29.0% | 13.9% | 19.4% | 26.94** |
| Occupational Therapy | 14.2% | 5.0% | 7.2% | 23.9% | 10.2% | 70.42** |
| Social Work | 12.9% | 10.4% | 17.2% | 5.1% | 9.6% | 19.84** |
| Physical Therapy | 8.6% | 6.8% | 24.6% | 4.4% | 8.9% | 53.69** |
| Recreational Therapy | 6.7% | 3.9% | 14.0% | 1.7% | 5.0% | 36.94** |
| Of Those Receiving Special Education, Setting Received In (full or part day): | | | | | | |
| Regular Classroom | 38.5% | 42.5% | 41.0% | 36.9% | 39.0% | NS |
| Resource Room | 36.7% | 37.0% | 25.1% | 45.4% | 38.9% | 31.39** |
| Separate Class | 36.1% | 47.3% | 38.8% | 32.0% | 36.9% | 29.49** |
| Special Day School | 11.0% | 7.6% | 28.4% | 4.8% | 10.2% | 41.03** |
| Residential School, Hospital or Institution, or Home | 4.7% | 4.1% | 6.2% | 3.0% | 3.8% | 31.33** |

** $p < .01$

Note: percentages may not equal 100%, as children may receive more than one service or attend school in more than one setting.

Students with ID only had the highest placement rates in separate classes, but relatively low participation in special school, hospital, or home-based programs. Students with “other disabilities” were most likely to receive education in resource rooms and least likely to receive special education services in special classes or special schools, in a hospital, or at home.

Personal Adjustment and Role Skills

The Personal Adjustment and Role Skills (PARS) scale was developed to assess emotional and psychological status (Walker, Stein, Perrin, & Jessop, 1990). The survey was designed to be completed by a parent or other caregiver about children with chronic illness. It has not been validated specifically for children with disabilities other than chronic illnesses. The PARS has 28 total questions about individual adjustment with 4-6 items per subscale. The six subscales are peer relations, dependency, productivity, anxiety/depression, withdrawal, and hostility. Table 6 shows the specific items for each subscale. All items are ranked as occurring “never or rarely,” “sometimes,” “often,” or “always,” with a higher score reflecting better adjustment. Some items were reverse scored. Stein, Westbrook, and Silver (1998) reported mean PARS scores of 97.2 for children without disabilities and 92.6 for children with chronic

illnesses in a national sample of 184 children.

In this study, all four groups of children with substantial functional limitations had lower overall PARS scores than children with chronic illnesses in previously published studies. Overall PARS scores were 77.3 for children with both ID and DD, 78.2 for children with DD only, 85.3 for children with ID only, and 87.3 for children with one or two substantial functional limitations but not ID. Children included in the Phase 2 DFS who did not have one or more substantial functional limitations had scores similar to the scores for children with chronic illnesses from other studies (92.5). This finding may reflect substantial overlap between children with “chronic conditions” in the norming sample and the selection criteria for the Phase 2 DFS (for those without substantial functional limitations).

An analysis of covariance was conducted to assess the differences between the four groups of children on PARS subscales. In each analysis, the highest education of the responsible adult family member, family economic status, and the child’s race, gender, and age were entered as covariates with disability group considered the independent variable. Table 7 shows the estimated marginal means weighted for these factors. After accounting for the covariates, children with developmental disabilities (with or without ID) had significantly lower overall PARS

Table 6: Personal Adjustment and Role Skills (PARS) Subscale Items

Peer Relations

Spent time with friends
Made friends without difficulty
Joined others of his/her own accord
Had many different friends

Dependency (reverse scored)

Wanted help with things he/she could have done on own
Asked for help when he/she could have figured things out
Asked unnecessary questions instead of working on his/her own
Unable to decide things for him/herself

Productivity

Will stay with a task or assignment until finished
Makes full use of his/her abilities
Has done work without being pushed
Kept on a task even though it was difficult

Anxiety/Depression (reverse scored)

Complained about problems

Seemed restless, tense
Said people didn't care about him/her
Seemed sad
Said he/she couldn't do things right
Acted afraid or apprehensive

Withdrawal (reverse scored)

Sat and stared without doing anything
Appeared listless or apathetic
Seemed unaware of things going on around him/her
Showed little interest in things/activities

Hostility (reverse scored)

Done things for attention even when punished for it
Flared up if couldn't have his/her way
Became upset if others don't agree with him/her
Ignored warnings to stop unacceptable behavior
Told lies
Failed to respond to discipline

scores than children with one or two substantial functional limitations (with or without ID).

There were many differences among the four groups on the PARS subscales. On the peer relations subscale, which involves making and spending time with friends, the four groups were all different from each other to a statistically significant degree, with children with both ID and DD having the lowest scores and children with one or two functional limitations but not ID having the highest scores. Children with DD (with or without ID) were similar on dependency, productivity, anxiety/depression, and hostility. Children with both ID and DD had lower scores than children with DD only on peer relations and withdrawal. Children with DD (with or without ID) had lower scores than children with only one or two substantial functional limitations (ID only or other disabilities) on all of the subscales and on the overall score. Children with one or two substantial limitations were similar irrespective of intellectual disability on the anxiety/depression, withdrawal, and hostility subscales. Children with one or two substantial functional limitations and ID had significantly lower scores than similar children without ID on peer relations, dependency, and productivity.

A series of regression analyses were used to assess the contribution of disability group, the child's race, gender, and age, family economic status, and parental education level to variations in PARS scores. Disability group explained significant amounts of variability on each

subscale and on overall PARS scores. Variables contributing significantly to differences in overall PARS score included disability group, economic status, and age. Children with three or more limitations had lower scores than children with one or two limitations; children living in households with incomes below the federal poverty level had lower scores, and younger children had lower scores.

Factors explaining variability in the subscales varied. Disability group contributed significantly to variability within all of the subscales. In addition, for dependency, girls had lower scores than boys, and younger children had lower scores than older children. For productivity, boys had lower scores than girls, and younger children had lower scores than older children. For anxiety/depression, children living in households with incomes below the federal poverty level had lower scores, and girls had lower scores than boys. For hostility, children living in households with incomes below the federal poverty level had lower scores, children whose responsible adult family member had less education had lower scores, and younger children had lower scores. Finally, for withdrawal, children living in households with incomes below the federal poverty level had lower scores, and children who were not white had lower scores.

In summary, for all of the scales on which economic status contributed to variability in scores, children living in poverty had lower scores than children in households earning more

Table 7: Personal Adjustment and Role Skills (PARS): Weighted Mean Scale Scores by Disability Group

| | Total Score Possible | ID and DD | DD not ID | ID not DD | Other Disabilities | Average 1+ Substantial Limitation |
|--------------------|----------------------|-------------------|-------------------|-------------------|--------------------|-----------------------------------|
| Peer Relations | 16 | 8.7 ¹ | 10.4 ² | 11.0 ³ | 11.6 ⁴ | 11.0 |
| Dependency | 16 | 11.2 ¹ | 11.2 ¹ | 12.0 ² | 12.5 ³ | 12.1 |
| Productivity | 16 | 8.4 ¹ | 8.5 ¹ | 9.4 ² | 9.9 ³ | 9.4 |
| Anxiety/Depression | 24 | 18.8 ¹ | 18.2 ¹ | 20.0 ² | 19.9 ² | 19.5 |
| Withdrawal | 16 | 13.2 ¹ | 13.7 ² | 14.5 ³ | 14.6 ³ | 14.3 |
| Hostility | 24 | 17.3 ¹ | 16.6 ¹ | 18.8 ² | 18.7 ² | 18.3 |
| Overall PARS Score | 112 | 78.6 ¹ | 77.6 ¹ | 85.7 ² | 87.2 ² | 84.5 |

*** $p < .001$

$N = 1,836$. Means with different superscripts are significantly different at $p < .05$.

Means are weighted by economic status, race, highest education of the responsible adult, gender, and age.

than federal poverty level incomes. For all of the scales on which age contributed to variability in scores, older children had higher scores than younger children. For all of the scales on which gender contributed to variability in scores, girls had higher scores on one scale (productivity) and lower scores on two scales (dependency and anxiety/depression). For the scale on which race contributed to variability in scores (withdrawal), children who were not white had lower scores. For the scale on which education of the adult contributed to variability in scores (hostility), children whose responsible adult had less education had lower scores.

Conclusion

Estimates from the NHIS-D indicate that 7.1% of all U.S. children between the ages of 6 and 17 have “serious difficulty” or are unable to perform age-appropriately in one or more of the areas of self-care, language, learning, mobility, and self-direction. These patterns of “serious difficulty” were similar among the 26.5 million children ages 6-12 years (7.4% of whom had serious developmental difficulties) and the 18.6 million children ages 13-17 years (7.0% of whom had serious developmental difficulties). Children meeting the operational definition of developmental disabilities and/or intellectual disabilities comprised an estimated 3.2% of children ages 6-17. By contrast, children with significant functional limitations in one or two of the major life activities but who did not meet the criteria for DD or ID made up 3.9% of children ages 6-17.

In most areas examined, children with intel-

lectual disabilities but not developmental disabilities (i.e., those with a label of intellectual disability who had only one or two substantial functional limitations) had the most in common with children with “other” disabilities (who also had only one or two substantial functional limitations). Similarly, children with developmental disabilities only (i.e., those with three or more substantial functional limitations but no intellectual disabilities) had the most in common with children with both intellectual disabilities and developmental disabilities (who had both a label of intellectual disability and three or more substantial functional limitations). These patterns held true across a wide range of services, impacts on family, and adjustment variables. Such an outcome might have been expected since the number of limitations is an indicator of increasingly “severe” impairments, but it does support the assertion that intellectual disability and developmental disability are significantly different concepts (see also Larson et al., 2001).

Parents of children with disabilities reported substantial effects from the child’s disability on the family, particularly the vocational and economic health of the family. An estimated 30.9% of families had made one or more substantial vocational or economic accommodation related to their child’s health or disability. Among families with children with the most severe disabilities (those with both intellectual disabilities and developmental disabilities), over half of all families reported substantial vocational and/or economic accommodations (52.7%). Most significant of these was that in a third of these families, a parent had not taken a job

Table 8: Personal Adjustment and Role Skills (PARS): Significant Predictors (Wald F)

| | Disability Group | Poverty Status | Race | Education of Adult | Gender | Age | Overall Model | R ² |
|--------------------|------------------|----------------|--------|--------------------|----------|----------|---------------|----------------|
| Peer Relations | 40.57*** | 0.55 | 1.29 | 0.69 | 0.52 | 3.21 | 1,565.34*** | 0.079 |
| Dependency | 18.50*** | 0.73 | 0.82 | 1.14 | 4.00* | 92.42*** | 3,394.49*** | 0.100 |
| Productivity | 20.25*** | 0.35 | 1.04 | 0.15 | 13.50*** | 9.34** | 1,469.88*** | 0.059 |
| Anxiety/Depression | 15.84*** | 6.76** | 0.12 | 2.11 | 8.73** | 1.87 | 5,403.62*** | 0.055 |
| Withdrawal | 16.36*** | 16.85*** | 0.98 | 6.40** | 0.76 | 27.98*** | 3,060.15*** | 0.092 |
| Hostility | 11.74*** | 8.51** | 8.26** | 0.87 | 0.05 | 2.01 | 6,979.19*** | 0.082 |
| Overall PARS Score | 32.80*** | 9.32** | 1.58 | 2.12 | 0.07 | 22.60*** | 6,110.41*** | 0.114 |

*** $p < .001$, ** $p < .01$, * $p < .05$
 N = 1,836.

because they had to care for their child with a disability (36.1%). High rates of effects on vocational and economic circumstances were also reported among families whose child had developmental disabilities but not intellectual disabilities (38.4% reported one or more vocational or economic effects). Clearly, raising children with substantial functional limitations places high demands on families—demands which require sensitivity and support from society.

Being a student is, of course, one of the primary roles expected of children. Most children with disabilities were reported to receive special education, but the rates at which they did so varied by disability group. Children with “other disabilities” were least likely to be reported to receive special education (62.0%) while children with both intellectual and developmental disabilities were most likely (93.4%). Many children with disabilities in each group received some or all of their special education supports in “regular” classrooms, giving these children the opportunity to participate in an educational experience similar to that of their peers without disabilities. Children with disabilities also received a number of supports to participate in school settings. Overall, only 10.2% of children living in non-institutional settings received school services in a “special day school” and only 3.8% received school services in a hospital, in an institution, or at home.

Responses of parents to the items on the Personal Adjustment and Roles Skills (PARS) scale suggested that children with disabilities have substantial social and emotional difficulties. Those difficulties are compounded for children whose families have incomes below the federal poverty level, and for children who have three or more substantial functional limitations compared to those with only one or two substantial functional limitations. Some of those difficulties were less pronounced for older children. Children with more significant disabilities appear to need additional supports to engage in activities that are typical for same-age peers and to develop relationships with same-age peers. The supports and services children with disabilities receive (including inclusive educational opportunities) influence their ability to participate in the activities typical of children and to form relationships, motivations, and interests from those activities. Family supports are also important to

children’s opportunities. The financial supports (e.g., SSI) and other services available to children with disabilities may help explain the relatively lower number of parents reporting severe financial distress due to their child’s disability despite substantial effects of the child’s disability on job opportunities, hours worked, job tenure, promotion, and so forth.

There were, unfortunately, no questions in the NHIS that asked parents’ perceptions of the positive contributions children made to the family or their school environments. Instead, questions focused on negative impacts on the family or on supports and services received. Future efforts to measure the impact of childhood disability on the family and on the child should also recognize the positive contributions made by children with disabilities, and that they, too, fulfill important roles in the family and at school.

References

- Bureau of the Census (1997). *Statistical abstract of the United States, 1997*. Washington, D.C.: U.S. Government Printing Office.
- Larson, S.A., Lakin, K.C., Anderson, L, Kwak, N., Lee, J.H. & Anderson, D. (2001). Prevalence of mental retardation and developmental disabilities: Estimates from the 1994/1995 National Health Interview Survey Disability Supplements. *American Journal on Mental Retardation*, 106, 231-252.
- Stein, R.K., Westbrook, L.E. & Johnson, E. (1998). Comparison of adjustment of school-age children with and without chronic conditions: Results from community-based samples. *Developmental and Behavioral Pediatrics*, 19(4), 267-272.
- Walker, D.K., Stein, R.E.K., Perrin, E.C. & Jessop, D.J. (1990). Assessing psychosocial adjustment of children with chronic illnesses: A review of the technical properties of PARS III. *Developmental and Behavioral Pediatrics*, 11(3), 116-121.

DD Data Brief

August 2002, Vol. 4, No. 1

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

The data analyses reported in this *DD Data Brief* were support in part by the National Institute on Disability and Rehabilitation Research (NIDRR), U.S. Department of Education through Cooperative Agreement H133G980082. Support for publication and dissemination of the *Data Brief* series is provided by the NIDRR through Cooperative Agreement H133B980047. Supplemental funding was provided by the Administration on Developmental Disabilities (Grant #90DN0028/03).

The analysis, interpretation, and conclusions 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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