Functional Disability and School Activity Limitations in 41300 School-Age Children: Relationship to Medical Impairments

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ABSTRACT. ***Objective.*** **Our purpose was to examine the contribution of medical impair-ments to functional disability and school activity limitations in 41300 schoolage children participating in the 1994-1995 National Health Interview Survey.**

Methods. **The 1994 and 1995 National Health Interview Survey and Disability Interview Supplement samples provide *International Classification of Diseases, Ninth Revision* medical impairment codes for children with functional limitations or school activity limitations in a nationally representative US sample. Functional limitations were distributed as follows: mobility 12.4/1000 (95% confidence interval [CI]: 11.1-13.6), self-care 8.8/ 1000 (95% CI: 7.7-9.8), communication 52.9/1000 (95% CI: 50.2-55.5), and learning 104.6/1000 (95% CI: 100.7-108.4). Functional disability status was classified as 4.1% mild, 5.9% major, and 1.9% multiple. School activity limitations included 4.1% needing or receiving special education, 0.7% unable to attend, and 0.9% limited attendance. We categorized *International Classification of Diseases, Ninth Revision* impairment codes reported in conjunction with medical usage as physical disorders (*n* = 1251; eg, leukemia, diabetes), asthma (*n* = 916), neurodevelopmental disorders (*n* = 802; eg, cerebral palsy, epilepsy, mental retardation, autism, blindness, deafness), and learning-behavior disorders (*n* = 806; eg, attention-deficit/hyperactivity disorder, learning disability, anxiety) for children with functional or school activity limitations. Of children with multiple functional disabilities, 29.9% had neurodevelopmental disorders, 27.1% had learning-behavior disorders, 18.1% had physical disorders, 4.2% had asthma, and 20.8% did not have an identified medical impairment because they had not received medical services in the past year. Among children requiring special education, physical disorders accounted for 9.4%, neurodevelopmental disorders for 16.7%, learning and behavior disorders for 17%, asthma for 3.4%, and 53.4% did not have an identified medical impairment because they had not received medical services in the past year.**

Conclusions. **Chronic health impairments, neurodevelopmental disorders, learning-behavior disorders, and functional limitations in essential activities are required to understand the complexity of disability in school-age children. A large number of children with functional disability or school activity limitations have not received ongoing medical services. *Pediatrics* 2003;111:548-553; *childhood disability, functional limitations, chronic health conditions, neurodevelopmental disorders, learning-behavior disorders, special education needs, epidemiology.***

ABBREVIATIONS. NHIS-D, National Health Interview Survey Disability Supplement; ICD-9, International Classification of Diseases, Ninth Revision; CI, confidence interval.

Children with disability are a heterogeneous population distributed between complex medical conditions including chronic illness; developmental disabilities and related disorders requiring special education services; children with attention and behavioral disorders; and children with functional limitations in essential activities of selfcare, mobility, communication, and learning.[1-5] A model for describing the multidimensional aspects of disablement and enablement has been proposed by the National Center of Medical Rehabilitation Research, building on models from the Institute of Medicine and the World Health Organization.[6-8] This model involves 5 domains: pathophysiology, impairment, functional limitations, difficulty with maintaining a social role (disability), and societal limitations. In children, this model allows for an explicit focus on essential functional activities of selfcare, mobility, communication and learning, and social role difficulties in school or play, or medical supports required for chronic illness. In addition, because the domains of this model are not linked in a determinant way, functional strengths (activities), social participation, and environmental facilitators that promote access are also included.[9]

The 1994 and 1995 National Health Interview Survey involved a Disability Supplement (NHIS-D) that

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Portions of this article were previously presented at the Academic Pediatric Societies Meeting; May 15, 2000; Boston, MA; and the American Academy of Cerebral Palsy and Developmental Medicine Meeting; September 21, 2000; Toronto, Ontario, Canada.
Received for publication Jan 28, 2002; accepted Aug 1, 2002.
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included questions about school activity limitations; functional limitations in self-care, mobility, communication, learning, and behavior; and chronic medical impairments of 1-year duration.[10, 11] We have previously reported population estimates of functional limitations in mobility, self-care, communication, and learning-behavior in 21 415 children 5 to 17 years of age in the 1994 NHIS-D.[12] The purpose of this report is to characterize medical impairments in the 1994 and 1995 NHIS-D survey, develop a summary classification of these impairments, and evaluate their contribution to functional disability status and school activity limitations. We hypothesized that measures of medical impairments involving chronic medical, neurodevelopmental, and behavioral disorders would be required to understand summary measures of functional disability and school activity limitations.

METHODS

Medical Impairment

For a medical impairment to be reported about a child in the NHIS-D supplement interview, the child must have a play or school activity limitation; have a functional limitation in self-care, mobility, communication, seeing, hearing, or learning; or receive special education services, rehabilitation therapies, medical devices, or medical usage in the past year. If there is a positive response to any of these limitations, then the respondent is asked which medical condition is associated with the limitation. As medical usage was the most common area for identifying impairments and was not a measure of functional limitations, we examined impairments reported because of medical usage and linked them to both functional limitations and school activity limitations. Because the categories of medical usage for which impairments were reported were very broad, we have a clear indicator of impaired children who are linked to the health care services in the past year.

Medical impairment codes for the NHIS-D overlap with codes from the *International Classification of Diseases, Ninth Revision* (ICD9)[13] Codes from NHIS-D were initially reduced to 10 categories: life-threatening (eg, malignancies, respiratory arrest, congestive heart failure, neurodegenerative disorders, acquired immunodeficiency syndrome); chronic medical disorders requiring ongoing complex medical management (eg, sickle cell anemia, type 1 diabetes, cystic fibrosis, chronic renal failure, inflammatory bowel disease, systemic lupus erythematosus); medical conditions that were episodic (eg, allergies, headache, eczema, sinusitis); intermediate medical conditions (eg, scoliosis not requiring surgery); injury (eg, fracture, sprains, lacerations, burns); asthma; neurosensory disorders (eg, cerebral palsy, spina bifida, epilepsy, visual and/or auditory disorders); mental retardation, autism, and related developmental disorders; genetic disorders (eg, cleft lip and palate, congenital heart disease, limb reduction disorders); learning and attention disorders; and behavior-motional-mental health disorders (eg, anxiety, depression, substance use).

Because certain of these impairment classifications occurred at a low prevalence, 4 summary groupings were calculated: physical, neurodevelopmental, learning-behavior, and asthma. The physical disorders category included life-threatening, chronic, episodic, intermediate medical, and injury impairments. The neurodevelopmental disorder category included neurosensory, genetic,

TABLE 1. Frequency of Medical Impairment Based on Medical Usage

Impairment Classification	Examples (*ICD-9* Code)	Frequency No Weights	Frequency Weighted	Dimension
Physical				
Life-threatening	Leukemia (204), heart failure (428), respiratory arrest (799.1)	131	132.9	P1
Chronic complex disorders	Type 1 diabetes (250), cystic fibrosis (277), sickle cell anemia (283.6)	224	231.2	P2
Episodic	Chronic sinusitis (473), allergic rhinitis (477), headache (784)	633	657.6	P3
Intermediate medical	Scoliosis (737)	199	209.5	P4
Injury	Fractures (800–829), burns (940–949)	64	63.6	P5
Subtotal P		1251	1294.8	
Neurodevelopmental				
Neurosensory	Cerebral palsy (342–43), seizures (345), vision (368–9), hearing (389), communication disorders (315.3)	500	508.8	ND1
Mental Retardation/Autistic Spectrum Disorder	Developmental disabilities (317–319, 758), autism, pervasive developmental disorders (299)	116	112.7	ND2
Genetic	Cleft palate (749), multiple congenital anomalies (759)	186	188.0	ND3
Subtotal ND		802	809.4	
Learning-behavior				
Attention-deficit/learning disorder	Attention-deficit/hyperactivity disorder (314), learning disabilities (315)	638	682.9	LB1
Behavior disorders	Anxiety (300), depression (296.2), substance use (303–304)	168	167.1	LB2
Subtotal LB		806	849.9	
Asthma	Recurrent wheezing (493)	916	928.2	
No impairments	No medical impairment	37 525	37 418.0	None
Total		41 300	41 300	

P indicates physical; A, asthma; ND, neurodevelopment; LB, learning-behavior. Weighted data from 1994–1995 NHIS Disability Supplement for Children.

TABLE 2. Impairment Categories and Severity of Functional Disability for Children 5 to 17 Years

Condition	*N*	None	Mild	Major	Multiple
Life-threatening P1	132.9	54.3%	6.4%	21.9%	17.4%
Chronic complex P2	231.2	69.6%	12.4%	10.3%	7.7%
Episodic P3	657.6	74.8%	7.4%	9.1%	8.6%
Intermediate medical P4	209.5	62.4%	8.6%	13.3%	15.7%
Injury P5	63.6	37.6%	14.5%	23.3%	24.6%
Subtotal P	1294.8	67.9%	8.8%	12.0%	11.3%
Neurosensory ND1	508.8	43.6%	10.6%	21.2%	24.8%
MR/ASD ND2	112.7	0%	1.9%	29.1%	69.1%
Genetic ND3	188.0	51.0%	11.0%	18.3%	19.7%
Subtotal ND	809.4	39.1%	9.5%	21.6%	29.8%
AD/LD LB1	682.9	12.1%	15.1%	49.6%	23.2%
Behavior LB2	167.1	12.1%	12.6%	38.8%	36.6%
Subtotal LB	849.9	12.1%	14.6%	47.5%	25.8%
Asthma	928.2	77.4%	8.1%	10.9%	3.6%
Any medical impairments	3882	52.0%	10.0%	21.5%	16.5%
None	37 418	91.7%	3.5%	4.3%	0.4%
All cases	41 300	88.0%	4.2%	5.9%	2.0%

MR/ASD indicates mental retardation/autistic spectrum disorder; AD/LD, attention-deficit/learning disability; P, physical; ND, neurodevelopmental; LB, learning and behavior; *N*, weighted data from 1994–1995 NHIS Disability Supplement for Children.

mental retardation, and autistic spectrum disorders. The learningbehavior disorder category included learning, attention, and behavior impairments. Asthma was maintained as a distinct category both because of its high prevalence and because it offers opportunities to examine the impact of medical management on activity limitations. Children who were identified as having no impairment either had no impairment believed to be associated with the functional or school activity limitation or had not received medical services in the past year. Table 1 lists impairment categories based on medical usage, and examples of conditions within categories, as well as several ICD-9 codes.

Functional Limitations

NHIS-D questions that characterized functional activities were assigned to 4 domains: mobility, self-care, communication, and learning-behavior. The various items for each type of limitation within each functional area were summed. Overall, mobility scores ranged from 0 to 18, self-care ranged from 0 to 33, communication ranged from 0 to 8, and learning-behavior scores ranged from 0 to 9. We have previously demonstrated excellent Cronbach a coefficients for these categories.[12] As these detailed ordinal scales are highly skewed, with few cases at the highest levels, we divided the scales into ordinal measures of level of severity where 0 indicates no limitation, 1 indicates mild limitations, 2 indicates more severe limitations, and 3 indicates most severe limitations (with the last 2 categories combined for self-care and mobility).

Functional disability status was classified on the basis of severity of functional limitation across domains. Children with mild disability included children with mild limitations in 1 or more functional domains. Children with major disability included children with moderate to severe functional limitations in 1 domain with 0 to 3 mild limitations in other domains. Children with multiple disabilities included children with moderate to severe limitations in 2 or more functional domain areas with 0 to 2 types of mild limitations in other domains. Children without functional limitations in mobility, self-care, communication, or learning-behavior were considered to be nondisabled. Children with either major or multiple functional disability status were considered to have a severe disability.

School Activity Limitations

Activity limitations included limitation in school activities ranging from inability to attend school, receiving or needing special education services, or limited school attendance. Children attending school regularly without needing or receiving special education services were considered to be functionally independent in school.

Data Analysis

Descriptive statistics of functional limitations, functional disability status, and school activity limitations were performed using SUDAAN.[14] The percentage contribution of medical impairment categories to functional disability status and school activity limitation were calculated in cross-tabulations. In categorizing a medical impairment for contributing to functional disability status, conditions that cause the most severe limitations were counted and we used the most severe condition for analyses.

The NHIS-D oversampled minorities in areas with high densities of Hispanics and blacks. Therefore, all cases did not have an equal probability of selection, and prevalence estimates could be biased. The NHIS recommended using weights to measure prevalence accurately. We used these weights in most of our analysis, adjusting the NHIS weight by a constant factor (n = 41300).

Rates of functional limitations, functional disability status, and activity limitations were initially analyzed for the 1994 NHIS-D wave and then for the combined 1994-1995 NHIS-D cohort. By combining the 2 survey waves, we were able to obtain a far greater number of sample cases, enhancing the reliability of estimates, especially of variables with a low prevalence in the population.

RESULTS

Demography

The NHIS-D 1994 and 1995 cohorts involved

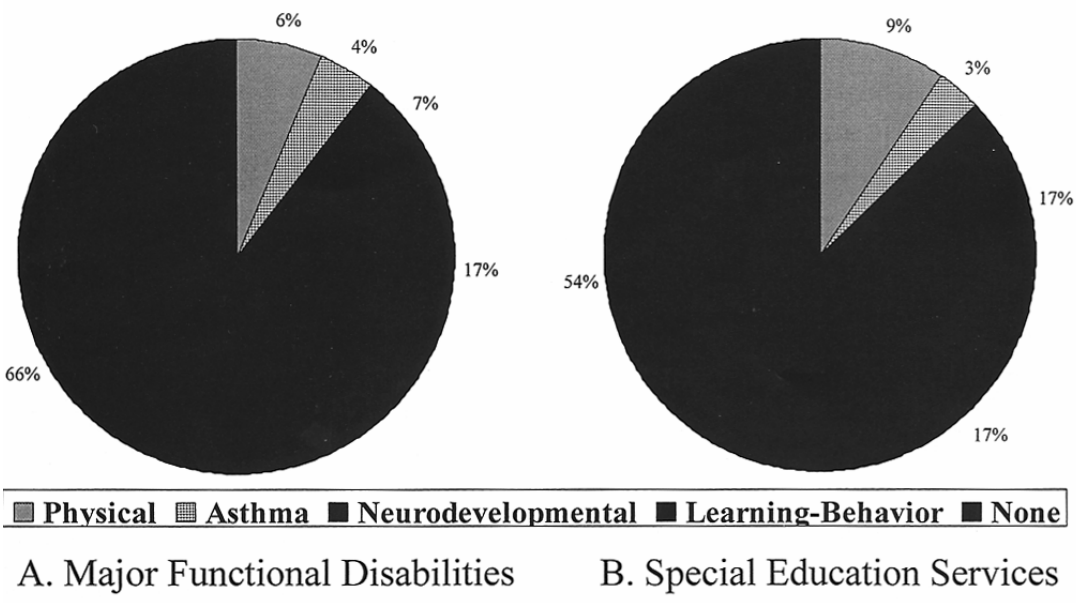

Fig 1. Proportionate contributions of summary medical impairment categories to major functional disabilities (A) and special education services (B).

218 646 people in 84 944 households of which 41300 were children 5 to 17 years of age; 64.2% were white, 19.2% were Hispanic, and 16.6% were black. Overall, 12% of children had some functional limitation and these limitations were distributed as follows: mobility 12.4/1000 (95% confidence interval [CI]: 11.113.6), self-care 8.8/1000 (95% CI: 7.7-9.8), communication 52.9/1000 (95% CI: 50.2-55.5), and learning 104.6/1000 (95% CI: 100.1-108.4). Of the children with functional limitations, 7.9% had severe functional disability (ie, multiple [1.9%] or major [5.9%]) and 4.1% had mild functional disability.

Table 1 describes the frequency of medical impairment categories based on medical service usage and several *ICD-9* codes. Asthma, neurodevelopmental disorders, and attention-deficit/hyperactivity disorder occurred with the highest frequency. Physical disorders account for 33% of children with identified medical impairments, asthma for 24%, neurodevelopmental disorders for 21%, and learning behavior disorders for 21%. As can be seen in Table 1, the weights do not change prevalence estimates of medical impairments significantly.

Table 2 describes for each category of medical impairment the proportion of children with functional limitations of various levels of severity. Ninety-eight percent of children with mental retardation/ autistic spectrum disorder and behavior disorders had severe functional disabilities (major or multiple). Among children with a complex chronic medical impairment, asthma, or episodic impairments, approximately 15% to 18% had a severe functional disability. In contrast, children without an indicated medical impairment as a cause of their functional limitations have a 4.7% occurrence of severe functional disability. Severe functional disabilities occurred in 23.3% of children with physical disorders, 51.4% of children with neurodevelopmental disorders, 73.3% of children with learning and behavior disorders, and 14.5% of children with asthma.

Figure 1A illustrates the percentage contribution of physical, neurodevelopmental, learning-behavior, and asthma categories to major functional disability status. Almost 2 in 3 children with major functional disability did not report a medical impairment. This means that they had not received any medical services in the past year despite having a major limita- tion in mobility, self-care, communication, or learning. Among children with multiple functional disabilities, approximately 1 in 5 had no identified medical impairment. This indicates that a significant number of children with multiple functional challenges also had not received medical services in the past year. Of those with multiple functional disabilities, 29.9% had a neurodevelopmental disorder, 27.1% had a learning-behavior disorder, 18.1% had a physical disorder, and 4.2% had asthma.

Table 3 describes the relationship of medical impairment categories to school activity limitations. Eighteen percent to 20% of children with life-threatening conditions, complex chronic disorders, or asthma are unable to attend school or have limited school attendance. One third of children with learning-behavior disorders and 34.5% of children with neurodevelopmental disorders need or receive special education services. Among children with no identified medical impairment, 2.4% need or receive special education services and 97% have no school limitations. In contrast, among children with any identified medical impairment, 20.1% need or receive special education services and 69% have no school limitations. This suggests that there is not a 1-to-1 correspondence between medical impairments and

school disability.

Additional analysis examined the percentage contributions of physical, neurodevelopmental, learning-behavior, and asthma categories to the inability to attend school or having limited school attendance. Physical disorders account for 24.2% of children un able to attend school and 22.2% of children with limited attendance. Neurodevelopmental disorders account for 14.1% of children unable to attend school and 8.9% of children with limited school attendance. Learning-behavior disorders account for 9.2% of children unable to attend school and 2.4% with limited school attendance. Asthma accounts for 17.5% of children unable to attend school and 30.6% of children with limited attendance. Children without any identified medical impairments account for 35% of children not attending school and 36% of children with limited attendance. Again, this indicates the large number of children not receiving medical services in the past year despite having attendance limitations.

Figure 1B illustrates the percentage of children with physical, neurodevelopmental, learning-behavior, or asthma disorders needing or receiving special education services. Approximately 1 in 3 children receiving special education services had a neurodevelopmental or a learning-behavior disorder, 9.4% had a physical disorder, and 3.4% had an asthma disorder. More than half of the children needing or receiving special education services had not had any contact with medical services in the past year.

DISCUSSION

Our results demonstrate that chronic health impairments, neurodevelopmental disorders, learning and behavior disorders, and functional limitations in the essential activities of self-care, mobility, communication, and learning are required to understand the complexity of disability status in school-aged children. Previous population studies that attempted broadly to describe childhood disability have used noncategorical approaches, medical checklists, and combined medical checklists and activity limitations. [1,2,1s-1s] Several studies have used survey datato focus on specific health conditions, access to care, poverty, racial disparities, adolescent health insurance, unmet health needs of children with complex disorders, and validating a methodology for identifying childhood chronic conditions. 19-26 We used the National Center on Medical Rehabilitation Research model and focused on summary measures of functional limitations and school activity limitations and their relationship to medical impairments based on medical usage as it was the conceptual framework for understanding the components of childhood disability at the time of the study. In this way, we could also understand gaps in children not receiving medical services in the past year.

Stein and Silver [15] examined 30 032 children aged 0 to 17 years in the 1994 NHIS-D and found functional limitations in 9.6%. Overall, 14.8% of children were identified as having any functional limitation, complex or compensatory dependence (medication, equipment), or service use beyond routine. These authors did not attempt to examine the contribution of specific impairments to functional disability or preschool activity limitation. Some of the differences in rates of functional limitations between their study and ours include different categorization of certain areas (eg, special education, adaptive, self-care, motor devices) as a compensatory modality and not a functional limitation. In addition, the Stein and Silver cohort includes preschool children who have reported lower rates of learning and behavior disorders and special education services compared with school-age children. Our rate of functional limitations at 12% thus is between their rates of 9.6% and 14.8%.

Newacheck and Halfon[16] examined 99 513 children younger than 18 years in the 1992-1994 NHIS and found 6.5% with school activity or play activity limitations. We found 5.7% with school activity limitations. Asthma, neurodevelopmental, and speech-language-learning disorders accounted for 70% of activity disability in the 1992-1994 NHIS. More specific, communication and learning impairments accounted for 26.2%, asthma accounted for 26.7%, and neurodevelopmental-behavior disorders (ie, mental, neurologic) accounted for 16.1%. In our analysis, asthma, neurodevelopmental, and learning-behavior disorders accounted for >40% of children unable to attend school and 37.4% of children receiving or needing special education services. Some of the difference in our results reflect how asthma, neurodevelopment, and behavior interfere with play activities.

In an earlier study, Newacheck and Stoddard[17] examined the impact of children with multiple chronic illness in 17 710 children younger than 18 years in the 1988 NHIS. In this cohort, 4.4% had 2 or more chronic impairments. Both school absence and functional limitations increased as the number of chronic conditions increased. When a child had no chronic limitations, 3.1% had activity limitation. In our study, when a child had no impairment, 3% had a school activity limitation. We also found higher rates of school activity and functional limitations in children with more complex physical, neurodevelopmental, and learning-behavior disorders.

Newacheck et al [18] examined a non-categorical definition of a child with special health care needs using methods similar to Stein. Overall, they found that 18% of children aged 0 to 18 years old had special heath needs among the 30 032 children in the 1994 NHIS-D. Of these, 11% had medical insurance with gaps in gaining access to many special services. Almost 2 in 3 children with major functional limitations and 1 in 2 children in special education had not received medical services in the past year, thus suggesting that there were barriers for these children in being involved in a medical home and gaining access to comprehensive care.

Our approach has been to examine function broadly and include communication, behavior, and learning functional limitations as well as self-care,

mobility, and devices. Because school is the major role for children aged 5 to 17, we also focused on school activity limitations as they are indicators of school disability. We have used summary measures of functional limitations and categories of medical impairments to understand the contribution of physical, neurodevelopment, learning-behavior, and asthma on functional disability and school disability. We would describe our framework as biofunctional whereby we link function and medical impairment to childhood disability and family ecology.[27]

There are several limitations in identifying the complexity of child disability in health surveys.[28] Certain programs (eg, special education supports) occur independent of medical diagnosis. Both developmental and behavior disorders may be underidentified and underserved by educational and health professionals. In addition, although medical impairments (eg, epilepsy) increase a child's risk for functional limitations, there is not a 1-to-1 correspondence between a medical impairment and a child's functional performance. In contrast to adults, for whom neurologic and muscular skeletal impairments increase the risk of mobility and self-care limitations, these limitations are more rare, although not insignificant, among children.

Overall, the 1994-1995 NHIS-D allows for the examination of medical, developmental, learning, and behavior impairments on functional and school disability indicators. Recent revision of the International Classification of Functioning has taken place with suggestions for measuring environmental facilitators and community participation.[9] This will allow for understanding the role of the family and school supports in promoting competencies for children with special health care needs. Future studies will need to examine the relationship of family ecology (eg, adults in household, parental education, income, ethnicity) on functional disability and school activity limitations. In this way, we can begin to understand factors on a population basis that optimize functional status, promote child and family well-being, and lessen health discrepancies for children with disabilities.

ACKNOWLEDGMENTS

This work was supported in part by National Institute of Child Health and Human Development/National Center of Medical Rehabilitation Research Grants 1 R03 HD35376 ("The Demography of Child Disability and Rehabilitation") and 1U01 HD37614 ("NICHD Family and Child Well Being Network"), Brown University Department of Pediatric Research Grant 7899, and Maternal Child Health Grant 5T-77 MC 00016-04 ("Leadership Education in Behavioral-Development Pediatrics").

We thank Judith daSilva for secretarial support on this project. This paper is dedicated to Elizabeth Burke Bryant and Catherine Walsh of Rhode Island KIDS Count for efforts to enhance children's well-being and prevent disability.

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