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Participation of Children with Special Health Care Needs in School and the Community

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Abstract

Objective—Children with special health care needs (CSHCN) are at risk for decreased participation which can negatively impact their lives. The objectives of this study were to document the presence of participation restrictions for CSHCN compared to other children and to determine how personal and environmental factors are associated with participation restrictions for CSHCN.

Methods—The 2007 National Survey of Children's Health (NSCH) was analyzed to evaluate two participation outcomes for children aged 6–17 years: school attendance and participation in organized activities, and two participation outcomes for children aged 12–17 years: working for pay and volunteering. Adjusted prevalences of participation restrictions were calculated for

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Contributors' Statement Page

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children with and without special health care needs. Logistic regression was used to identify factors independently associated with participation restrictions for CSHCN.

Results—After adjustment for sociodemographic characteristics, a larger proportion of CSHCN (27.9%) reported missing more than 5 days of school than other children (15.1%). In contrast, no differences were found for participation in organized activities, working for pay or volunteering. CSHCN with functional limitations were more likely to experience all four types of participation restrictions compared to other CSHCN and non-CSHCN. For CSHCN, the odds of certain participation restrictions were higher for those with functional limitations, in fair/poor health, with depressed mood, living at or near the federal poverty level and living in homes not headed by two parents.

Conclusions—CSHCN with functional limitations and those with worse health status are at elevated risk of experiencing participation restrictions than other children. Social disadvantage furthers the likelihood that CSHCN will experience participation restrictions.

Keywords

Children with special health care needs; participation; functional limitations; disability; poverty

INTRODUCTION

Children and youth with special health care needs (CSHCN) are those who have ‘a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.’¹ Although there is a broad spectrum of condition severity among CSHCN, these children are all at risk for or have compromised functional status.² One of the consequences of chronic health conditions and compromised function is often restricted participation in educational and social activities.^{2–4}

Participation in these activities is the context in which children and youth make friends, learn social skills and competencies, and develop their sense of purpose.^{5,6} Additionally, participation in developmentally appropriate activities can enhance quality of life and, when restricted, can negatively impact opportunities later in adulthood.⁷ While both overall health and functional status can greatly influence participation, neither are the direct causes of restricted participation, per se. There is a dynamic interdependence between the person and their environment that enables participation and⁸ a multitude of personal factors and characteristics of the social and physical environment, some of which may be amenable to intervention, affect a child’s participation in life events.⁹ Therefore, it is important to evaluate the factors associated with participation among CSHCN to reduce their likelihood of restricted participation.

The health services literature is replete with studies addressing participation restrictions for children with specific disabilities,^{4,10–18} however, these studies are not directly applicable to CSHCN generally. CSHCN have a broad range of health conditions and consequences, but might not be limited in their abilities to do the things that other children typically do.^{11,19} Additionally, no studies have examined the relationship between CSHCN status, health

status and social characteristics to determine possible influences on participation. Measuring factors that impact participation is an important first step in developing clinical interventions and formulating policy recommendations to maximize participation by CSHCN. To supplement the sparse health services literature related to participation for this population as a whole, we sought to identify factors associated with participation restrictions. Our first objective was to compare participation rates between CSHCN and non-CSHCN. Our second objective was to evaluate the impact of health and functional status on participation rates among CSHCN. Finally, we sought to identify personal and environmental factors that may be amenable to intervention in order to guide the development and implementation of practices and programs to maximizing participation for CSHCN.

METHODS

Conceptual Framework and Model

For this study, we framed our investigation of participation and the contextual factors that influence it based on the World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF). The WHO defines three levels of functioning: the body, the person, and the person within a social context.^{2,3,20} Individuals with difficulties related to body functioning have impairments; those with whole person level dysfunction have activity restrictions; and individuals with difficulty functioning in society are considered to have participation restrictions.^{2,3,9,20,21} Activities that are complex and require societal involvement are considered participation activities.²² Using this definition of participation, we identified four domains of participation using items from the National Survey of Children's Health (NSCH): school attendance, participation in organized activities, working for pay and volunteering. These serve as our study outcomes, or dependent variables. In the ICF, factors that affect participation can fall into 2 categories – personal and environmental.²³ These factors, or independent variables, can act as barriers or facilitators to participation.^{3,9}

The selection of personal and environmental factors for our empirical analysis was guided by the ICF and the ecological model of human development which highlights the role of personal and environmental factors in the interaction between the child and their world.²⁴ The ecological model nests the child in increasingly larger spheres of influence.²⁵ Using this model, a child's participation may be impacted by various factors, such as functional limitations, as well as family resources, the accessibility of community activities, and social norms. While not all potential influencing factors can be analyzed in a single study, the ecological model provides a frame of reference for variable selection. An additional value of this model for understanding participation in childhood is that it recognizes how the nexus of personal and environmental factors can influence a child's development and participation in activities differently over time.²⁴ For example, a child with cerebral palsy who is limited in his/her ability to ambulate may be able to participate on a soccer team as a preschooler, but develops a participation restriction when the skills required exceed his/her abilities and no adaptive programs exist. For this child, it is the interaction with the environment that leads to his/her participation restriction, not just the presence of his/her functional limitation. Using the language of the ecological model, the community sphere may not have the resources to

facilitate participation for this child. Covariates for these analyses were selected based on relevance to both the ecological model previous findings in the disability literature that examined demographic, health and social correlates of participation and social engagement.^{4,6,8,15,17,23,26,27}

Dataset

The data presented in this study are from the 2007 NSCH. This survey is a nationally representative random-digit-dial telephone survey that uses the State and Local Area Integrated Telephone Survey (SLAITS) mechanism and was conducted by the National Center for Health Statistics at the Centers for Disease Control and Prevention (CDC) between April 2007 and July 2008. The NSCH was designed and funded by the Maternal and Child Health Bureau (MCHB) to provide national and state-specific prevalence estimates of a variety of child health indicators for children aged 0–17 years. Interviews were conducted in English, Spanish, and four Asian languages; all data are parent-reported²⁸ For additional details regarding the survey administration, readers are advised to review the methodology report published by the NCHS.²⁸ The sample for this study was limited to subjects aged 6–17 years because the participation questions were asked only of school aged children. Our final sample size was 64,076 children. The National Center for Health Statistics (NCHS) provided the survey weights to estimate population totals and account for sample biases.²⁸

Measures

Dependent Variables—To evaluate differences in participation, we identified two domains for all school-aged children (ages 6–17 years) and two additional domains exclusively for adolescents (ages 12–17 years). These four areas were broadly defined as (1) school attendance, (2) participation in organized activities (3) working for pay, and (4) volunteering. A restriction in school attendance was defined as whether or not a child had missed more than 5 days of school due to illness or injury in the past twelve months. This cut point represents a substantial participation restriction given that less than one-fifth of all children miss that many days of school in a year.²⁹ Restriction in participation in any organized activity was determined by negative responses by the parent to all three questions concerning participation in sports team or sports lessons, clubs or organizations, or any other organized events or activities. For youth aged 12–17 years, parents were asked if their child had earned money in the past week through any work including regular jobs, babysitting, cutting grass, or other occasional work. Those reporting no paid work were classified as not working. The question regarding volunteering was also limited to those aged 12–17 years and assessed any involvement by the youth in community service or volunteer work at school, church, or in the community in the past twelve months.

Independent Variables—The independent variables for these analyses were selected based on the ICF, the ecological model and previous disability research, as well as the authors' hypotheses. We were particularly interested in the relationship between health and functioning and participation, as well as the family and community factors that may influence participation. The presence of a special health care need (SHCN) and the presence of a functional limitation among those with CSHCN were the primary covariates of interest.

Special health care needs were identified using the CSHCN Screener.³⁰ Children qualify as having a SHCN if they have a health condition that has lasted or is expected to last at least 12 months and is associated with one of five consequences: 1) needing or using medicine prescribed by a doctor; 2) needing or using more medical care, mental health or education services than typical children do; 3) being limited or prevented in any way in their ability to do the things that most children of the same age can do; 4) needing or using special therapies, such as physical, occupational, or speech therapy; and/or, 5) needing or using treatment or counseling for an ongoing emotional, behavioral or developmental condition.^{28,30} We used item 3 from the Screener to identify children with functional limitations; thus CSHCN who are limited or prevented in any way in their ability to do the things that most children of same age can do due to a condition that has lasted or is expected to last at least 12 months are considered to have functional limitations. CSHCN with functional limitations may also qualify on any of the other 4 criteria. Other sociodemographic and health-related factors that have been shown to be associated with either special health care needs or participation limitations included the child's age, sex, race/ethnicity, poverty status as measured by the Federal Poverty Level (FPL), region, perceived neighborhood safety, reported health status, presence of depressive symptoms, and family structure. We classified neighborhoods as safe if the survey respondent reported that their neighborhood was usually or always safe for children. Depressive symptoms were identified by parent report that their child was "unhappy, sad, or depressed" and diagnosis by a health care provider was not required for this covariate. Family structure was coded as two-parent biological or adoptive, two-parent step, single mother, and other.

Analysis

The Chi-square (χ^2) statistic was used to test the overall associations between the presence of a SHCN and among the subset of CSHCN with functional limitations and each of the four participation outcomes. For school attendance, the percentage of CSHCN missing more than 5 days of school was calculated by the cumulative presence of the following risk factors – presence of a functional limitation, not being in excellent or very good health, and living below 200% of the FPL. The sociodemographic and health-related variables included in the multivariate models were selected based on the significance of their bivariate associations with our outcomes. Logistic regression was then used to ascertain the independent effects of the contextual variables of interest on participation. Only factors significant at the $p < 0.05$ level in the bivariate analysis were included in the final regressions. We used the multiple imputation files provided by the National Center for Health Statistics for the missing income data. Analyses were conducted using SAS-callable SUDAAN 9.1 in order to account for the complex sampling design of the NSCH (Research Triangle Institute, Research Triangle Park, NC). The PREDMARG option in SUDAAN was used in the logistic regression procedure to calculate mean predicted marginals which provided the adjusted estimates of participation by SHCN status and functional limitation status after adjusting for possible confounders. Analysis used weighted data, with standard errors adjusted for the complex, multistage sample design.

This study was deemed Exempt by the University of California San Francisco's Committee on Human Research.

RESULTS

The demographic characteristics of the study population are presented in Table 1. Boys are overrepresented among CSHCN, as are children living in households with incomes below 100% of the FPL.

Our first objective was to compare participation rates for CSCHN and non-CSHCN. As shown in Table 2, in the unadjusted analyses, CSHCN more commonly missed more than 5 days of school and fewer CSHCN participated in organized activities or volunteered. After adjustment for personal and environmental factors, higher percentages of CSHCN missed more than a week of school (27.9% vs. 15.1%) than non-CSHCN but there were no statistically significant differences in participation in organized activities, working for pay or volunteering.

As shown in Table 2, CSHCN with functional limitations more commonly experienced participation restrictions than other CSHCN and non-CSHCN. After adjustment, 25.4% of CSHCN without limitations missed more than 5 days of school compared to 37.6% of CSHCN with functional limitations. While 18.9% of non-CSHCN and 19.3% of CSHCN without functional limitations did not participate in organized activities, substantially more (25.0%) of CSHCN with limitations had this participation restriction. A similar pattern was observed for engaging in paid work and volunteer activities. While 64.3% of non-CSHCN and 62.1% of CSHCN without limitations did not work for pay, significantly more CSHCN with functional limitations did not (73.0%). Similar proportions of children with and without SHCN reported not volunteering (21.5% and 21.6%, respectively) compared to 28.3% of CSHCN with limitations.

Our second objective was to evaluate the relationship between SHCN and health status. To do so, participation was stratified by reported health status and presence of functional limitations. As shown in Table 3, CSHCN with functional limitations were more likely to experience participation restrictions than other CSHCN for all measures of participation even when health status was taken into account. For example, nearly twice as many CSHCN with functional limitations who were in excellent/very good health (28.7%) reported not being involved in organized activities compared to other CSHCN in excellent/very good health (15.2%). For both CSHCN with functional limitations and CSHCN without limitations, health status was also found to be associated with participation restrictions. An incremental relationship exists for all measures of participation (except school attendance for CSHCN without limitations) such that CSHCN in fair/poor health had more participation restrictions than CSHCN in good health and CSHCN in good health had more restrictions than CSHCN in excellent/very good health. Notably, the relationship between poorer health status and participation was more pronounced for the non-mandated forms of participation (organized activities, working for pay and volunteering) than school attendance. For example, 15.2% of CSHCN without functional limitations in excellent/very good health did not participate in organized activities in comparison to 51.9% of those in fair/poor health. Similarly, among CSHCN with limitations, 28.7% in excellent/very good health did not participate in organized activities compared to 45.4% in fair/poor health. The most marked

participation restriction was among CSHCN with functional limitations in fair/poor health, of whom 91.2% did not work for pay.

To further address school attendance (a mandated participation activity), we calculated the percent of CSHCN who missed more than 5 days of school by number of risk factors (having a functional limitation, not being in very good or excellent health, and living below 200% of the FPL) (Table 4). More than 21% of CSHCN with none of the 3 risk factors missed more than 5 days of school compared to 14.3% of non-CSHCN who missed more than 5 days. As the number of risk factors increased, the percentage of CSHCN who were reported to miss more than 5 days of school increased: 32.1% of CSHCN with one risk factor missed more than 5 days, compared to 40.9% of CSHCN with 2 risk factors and 59.0% of CSHCN with all 3 risk factors.

Our final objective was to identify personal and environmental mediators of participation. We used logistic regression to identify factors independently associated with participation. Adjusted odds for each of the four types of participation for CSHCN are presented in Table 5. The presence of functional limitations was independently associated with increased odds of participation restrictions for all 4 of the participation outcomes. Similarly, the odds of school, organized activities and working for pay participation restrictions were higher when the child's health status was deemed fair/poor. For example, when compared to CSHCN in excellent or very good health, the adjusted odds of being limited in the ability to participate in organized activities among CSHCN in fair/poor health were 2.28 compared to 1.41 for those in good health.

There were also several non-health related factors that were statistically associated with participation. Male gender was associated with decreased odds of missing school (0.71) and increased odds (1.55) of not volunteering. Those classified as Hispanic or Black had decreased odds of missed school compared to Whites. Conversely, Hispanics had increased odds of not participating in organized activities, AOR=1.60. No racial differences were noted for working for pay or volunteering. Poverty status was associated with restrictions in all types of participation such that children living in or near poverty had increased odds of participation restrictions. This finding was most pronounced for participation in organized activities. Compared to CSHCN living above 400% of the FPL, the adjusted odds of having an organized activity participation restriction were 5.11 for those living below the FPL and 3.05 for those living between 100–199% of the FPL. Region of the country was not associated with any participation outcomes in the adjusted analyses. CSHCN with frequent depressive symptoms had higher odds of participation restrictions in organized activities (AOR=2.81) and volunteering (AOR=1.65). Family structure was also associated with participation restrictions. Compared to having two biological/adoptive parents, children living with single mothers had increased odds for restrictions in organized activities (1.38) and volunteering (1.47). Similarly, children living in step-families had participation restrictions in organized activities (1.89) and volunteering (2.64).

DISCUSSION

This paper describes participation outcomes for CSHCN compared to children without SHCN and delineates factors associated with participation restrictions for CSHCN including health and functional status. As expected, CSHCN experienced greater school attendance restrictions than other children. School attendance was more commonly restricted among CSHCN with the additional risk factors of living in or near poverty, not being in very good or excellent health, and having a functional limitation. Over 50% of CSHCN with all three risk factors missed more than a week of school per year. On a positive note, we found no differences between CSHCN and other children for the other 3 measures of participation. This indicates that, in general, CSHCN are keeping up with their peers in terms of participating in organized activities, working for pay and volunteering. Although, among CSHCN, reported health status was strongly associated with participation outcomes. In addition, when the subset of CSHCN with functional limitations was considered, the participation restrictions were substantial. These results suggest that participation may be fostered by maximizing health and function through focused medical interventions and providing accommodations. Existing legal mechanisms may be leveraged to enhance participation for CSHCN with functional limitations who may experience social or environmental barriers to participation.^{15,31,32} If the environment and social worlds of children are accommodating, and children receive adequate health care to address their chronic health conditions, the strong links between functional status, health status and participation restrictions may be broken.

The existing literature regarding participation for children with disabilities indicates that these children are at risk for participation restrictions due to a multitude of factors that can act as barriers.^{6,26,33–35} Our study is the first to examine barriers to participation in life activities for all CSHCN. Our findings show that participation restrictions are mediated by personal and environmental factors, some of which may be amenable to intervention.⁹ We found that personal factors, including reported health status, the presence of functional limitations and depressed mood, were associated with participation restrictions. Similar to studies for children with disabilities,^{14,27} we also found that family-level (environmental) factors, including family structure and poverty status were associated with participation restrictions. Poverty is associated with a host of negative consequences for children, including poor health outcomes.^{36,37} There is strong evidence that poverty negatively affects participation in key developmental activities in childhood as well as outcomes later in life.¹⁰ Our results showing reduced participation among CSHCN living in poverty is well-aligned with negative outcomes identified by other researchers.^{10,36,37} All of these factors, which may be amenable to intervention directly through health and social policies to maximize health, deserve attention to diminish the impacts of functional limitations and support families in need.

Our research and the research of others points the need to support mechanisms that address the health and well-being of CSHCN, as well as those mechanisms that mitigate social disadvantage and optimize the life chances of CSHCN and their families.^{33,34} Applying the ADA and IDEA to address barriers in the built and social environment may mitigate the influence of functional limitations on participation because even with optimal clinical care,

CSHCN with functional limitations still face hurdles to participation.^{33,38,39} Additionally, policies and activities that support the MCHB's community-based system of services for CSHCN can improve health and related outcomes for children,⁴⁰ and thus may positively impact participation.

Pediatric practices and other community providers could potentially influence participation outcomes through the delivery of care in a medical home which is designed to provide family-centered care, care coordination, and improved access to community supports.^{27,41–44} This may be especially beneficial for CSHCN with functional limitations because they less frequently receive care in a medical compared to other CSHCN.⁴⁵ Within provider–family encounters, pediatricians and other health care professionals may impact participation by directly addressing the health and functional status of CSHCN through the delivery of comprehensive health care and by providing access to community resources.^{33,46} Furthermore, by directly addressing participation in clinical encounters, providers could encourage participation and help address barriers to participation when they are identified.

Limitations

This study has notable limitations. First, the NSCH is a cross-sectional study which does not allow for the establishment of a causal relationship between the contextual factors and our participation outcomes. There also may be causal feedback loops that we cannot detect; for example, depressed mood might be a cause of participation restrictions, vice versa or both. Second, while the selection of independent variables was guided by theory and past research, we were limited to variables available in the NSCH data set. Other unmeasured personal and environmental variables, including social attitudes and barriers related to the built environment, also influence participation. Furthermore, three of our participation outcomes are voluntary. This means that personal, family and cultural factors may heavily influence participation. Lastly, our measures of health status and functional limitations are subjective and do not allow for a detailed assessment of chronic health conditions, specific types of disability, or existing accommodations. Although we were not able to assess participation of children with specific chronic conditions and different types of disabilities, we note that the non-categorical approach used by the CSHCN Screener identifies children across the range of diverse childhood chronic conditions, disabilities and special needs, allowing a comprehensive assessment of health issues and provides a robust assessment of outcomes.

Conclusions

This research demonstrates that the presence of a SHCN, per se, does not necessarily limit a child's ability to participate in key developmentally appropriate social activities. Rather, it is health status and presence of functional limitations that impact the ability of CSHCN to participate. It also shows that socioeconomic and demographic factors may either impede or enhance participation for CSHCN. While this study cannot elucidate the underlying etiologies of participation restrictions, many important factors were found to be associated with limited participation including poverty status. Addressing the factors amenable to intervention by child health care professionals in the medical home and the broader health care system, as well as through social and public policy may lead to improved participation

for CSHCN. As participation is a vital part of social life and development, it is of utmost importance to eliminate barriers to successful participation for CSHCN.

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Abbreviations

CSHCN	Children with Special Health Care Needs
IDEA	Individuals with Disabilities Education
ADA	Americans with Disabilities Act
WHO	World Health Organization
ICF	International Classification of Functioning
NSCH	National Survey of Children's Health
CDC	Centers for Disease Control and Prevention
MCHB	Maternal and Child Health Bureau
FPL	Federal Poverty Level
NCHS	National Center for Health Statistics
SHCN	Special Health Care Needs

References

1. McPherson M, Arango P, Fox H, et al. A new definition of children with special health care needs. *Pediatrics*. Jul; 1998 102(1 Pt 1):137–140. [PubMed: 9714637]
2. Lollar DJ, Simeonsson RJ. Diagnosis to Function: Classification of Children and Youths. *Developmental and Behavioral Pediatrics*. Aug; 2005 26(4):323–330.
3. World Health Organization. [Accessed July 5, 2010] Towards a Common Language for Functioning, Disability and Health. 2002. <http://www3/who.int/icf/beginners/bg.pdf>
4. Ehrmann LC, Aeschleman SR, Svanum S. Parental reports of community activity patterns: a comparison between young children with disabilities and their nondisabled peers. *Research in developmental disabilities*. Jul-Aug;1995 16(4):331–343. [PubMed: 7480959]
5. Murphy NA, Carbone PS. Promoting the participation of children with disabilities in sports, recreation, and physical activities. *Pediatrics*. May; 2008 121(5):1057–1061. [PubMed: 18450913]
6. King G, Law M, King S, Rosenbaum P, Kertoy MK, Young NL. A conceptual model of the factors affecting the recreation and leisure participation of children with disabilities. *Physical and Occupational Therapy in Pediatrics*. 2003; 23(1):63–90. [PubMed: 12703385]
7. King G, Tucker MA, Baldwin P, Lowry K, LaPorta J, Martens L. A life needs model of pediatric service delivery: services to support community participation and quality of life for children and youth with disabilities. *Physical and Occupational Therapy in Pediatrics*. 2002; 22(2):53–77. [PubMed: 12216367]

8. Hammel J, Magasi S, Heinemann A, Whiteneck G, Bogner J, Rodriguez E. What does participation mean? An insider perspective from people with disabilities. *Disability and Rehabilitation*. 2008; 30(19):1445–1460. [PubMed: 18923977]
9. Simeonsson RJ, Leonardi M, Lollar D, Bjorck-Akesson E, Hollenweger J, Martinuzzi A. Applying the International Classification of Functioning, Disability and Health (ICF) to measure childhood disability. *Disability & Rehabilitation*. Jun 3–17; 2003 25(11–12):602–610. [PubMed: 12959334]
10. McConachie H, Colver AF, Forsyth RJ, Jarvis SN, Parkinson KN. Participation of disabled children: how should it be characterised and measured? *Disability and Rehabilitation*. Sep 30; 2006 28(18):1157–1164. [PubMed: 16966237]
11. Msall ME, Avery RC, Tremont MR, Lima JC, Rogers ML, Hogan DP. Functional disability and school activity limitations in 41,300 school-age children: relationship to medical impairments. *Pediatrics*. Mar; 2003 111(3):548–553. [PubMed: 12612235]
12. Mu K, Royeen CB. Facilitating participation of students with severe disabilities: aligning school based occupational therapy practice with best practices in severe disabilities. *Phys Occup Ther Pediatr*. 2004; 24(3):5–21. [PubMed: 15257966]
13. Noreau L, Lepage C, Boissiere L, et al. Measuring participation in children with disabilities using the Assessment of Life Habits. *Developmental Medicine & Child Neurology*. Sep; 2007 49(9): 666–671. [PubMed: 17718822]
14. Soreff B, Ratzon NZ, Rosenberg L, Leitner Y, Jarus T, Bart O. Personal and environmental pathways to participation in young children with and without mild motor disabilities. *Child: care, health and development*. Aug 9.2011
15. Barr M, Shields N. Identifying the barriers and facilitators to participation in physical activity for children with Down syndrome. *Journal of intellectual disability research : JIDR*. Nov; 2011 55(11):1020–1033. [PubMed: 21554468]
16. Law M, Anaby D, DeMatteo C, Hanna S. Participation patterns of children with acquired brain injury. *Brain injury : [BI]*. 2011; 25(6):587–595.
17. Clarke MT, Newton C, Griffiths T, Price K, Lysley A, Petrides KV. Factors associated with the participation of children with complex communication needs. *Research in developmental disabilities*. Mar-Apr;2011 32(2):774–780. [PubMed: 21129915]
18. Palisano RJ, Chiarello LA, Orlin M, et al. Determinants of intensity of participation in leisure and recreational activities by children with cerebral palsy. *Developmental Medicine & Child Neurology*. Feb; 2011 53(2):142–149. [PubMed: 20964676]
19. Stein RE, Westbrook LE, Silver EJ. Comparison of adjustment of school-age children with and without chronic conditions: results from community-based samples. *Journal of Developmental and Behavioral Pediatrics* Aug. 1998; 19(4):267–272.
20. Stucki G, Cieza A, Melvin J. The International Classification of Functioning, Disability and Health (ICF): a unifying model for the conceptual description of the rehabilitation strategy. *Journal of Rehabilitation Medicine*. May; 2007 39(4):279–285. [PubMed: 17468799]
21. Jette AM, Haley SM, Kooyoomjian JT. Are the ICF Activity and Participation dimensions distinct? *Journal of Rehabilitation Medicine*. May; 2003 35(3):145–149. [PubMed: 12809198]
22. Nagi SZ. A Study in the Evaluation of Disability and Rehabilitation Potential: Concepts, Methods, and Procedures. *American Journal of Public Health and the Nation's Health*. Sep.1964 54:1568–1579.
23. Fougeyrollas P, Noreau L, Bergeron H, Cloutier R, Dion SA, St-Michel G. Social consequences of long term impairments and disabilities: conceptual approach and assessment of handicap. *International Journal of Rehabilitation Research*. Jun; 1998 21(2):127–141. [PubMed: 9924676]
24. Sontag JC. Toward a comprehensive theoretical framework for disability research: Bronfenbrenner revisited. *The Journal of Special Education*. 1996; 30(3):319–344.
25. Bronfenbrenner, U. *The ecology of human development : experiments by nature and design*. Cambridge, Mass: Harvard University Press; 1979.
26. Bult MK, Verschuren O, Jongmans MJ, Lindeman E, Ketelaar M. What influences participation in leisure activities of children and youth with physical disabilities? A systematic review. *Research in developmental disabilities*. Sep-Oct;2011 32(5):1521–1529. [PubMed: 21388783]

27. Law M, King G, King S, et al. Patterns of participation in recreational and leisure activities among children with complex physical disabilities. *Developmental Medicine & Child Neurology*. May; 2006 48(5):337–342. [PubMed: 16608540]
28. Blumberg SJ, Foster EB, Frasier AM, et al. Design and operation of the National Survey of Children's Health, 2007. National Center for Health Statistics. *Vital Health Statistics*. 2009; 1:1–136.
29. National Survey of Children's Health 2007. Child and Adolescent Health Measurement Initiative. NSCH; 2007. <http://www.nschdata.org/DataQuery/DataQueryResults.aspx> [Accessed March 22, 2011]
30. Bethell CD, Read D, Stein REK, Blumberg SJ, Wells N, Newacheck PW. Identifying Children With Special Health Care Needs: Development and Evaluation of a Short Screening Instrument. *Ambulatory Pediatrics*. 2002; 2(1):38–48. [PubMed: 11888437]
31. National Dissemination Center for Children with Disabilities. [Accessed June 6, 2010] IDEA -the Individuals with Disabilities Education Act. <http://www.nichcy.org/laws/idea/pages/Default.aspx>
32. Hurwitz KA. A review of special education law. *Pediatric Neurology*. Sep; 2008 39(3):147–154. [PubMed: 18725058]
33. Law M, Petrenchik T, King G, Hurley P. Perceived Environmental Barriers to Recreational, Community, and School Participation for Children and Youth With Physical Disabilities. *Archives of Physical Medicine and Rehabilitation*. 2007; 88(12):1636–1642. [PubMed: 18047879]
34. Murphy NA, Carbone PS. the Council on Children With Disabilities. Promoting the Participation of Children With Disabilities in Sports, Recreation, and Physical Activities. *Pediatrics*. May 1; 2008 121(5):1057–1061. [PubMed: 18450913]
35. Rosenberg L, Ratzon NZ, Jarus T, Bart O. Perceived environmental restrictions for the participation of children with mild developmental disabilities. *Child: care, health and development*. Sep 9.2011
36. Wood D. Effect of Child and Family Poverty on Child Health in the United States. *Pediatrics*. Sep 1; 2003 112(3):707–711. [PubMed: 12949326]
37. Bauman LJ, Silver EJ, Stein REK. Cumulative Social Disadvantage and Child Health. *Pediatrics*. Apr 1; 2006 117(4):1321–1328. [PubMed: 16585330]
38. Teitelbaum J, Burke T, Rosenbaum S, Olmstead VLC. the Americans with Disabilities Act. implications for public health policy and practice. *Public Health Report*. May-Jun;2004 119(3): 371–374.
39. Perenboom RJ, Chorus AM. Measuring participation according to the International Classification of Functioning, Disability and Health (ICF). *Disability and Rehabilitation*. Jun 3–17; 2003 25(11–12):577–587. [PubMed: 12959331]
40. Perrin JM, Romm D, Bloom SR, et al. A Family-Centered, Community-Based System of Services for Children and Youth With Special Health Care Needs. *Archives of Pediatric and Adolescent Medicine*. Oct 1; 2007 161(10):933–936.
41. Committee on Children with Disabilities of the American Academy of Pediatrics. Role of the pediatrician in family-centered early intervention services. *Pediatrics*. May; 2001 107(5):1155–1157. [PubMed: 11331701]
42. Committee on Early Childhood and Adoption and Dependent Care American Academy of Pediatrics. The Pediatrician's role in family support programs. *Pediatrics*. Jan; 2001 107(1):195–197. [PubMed: 11134461]
43. American Academy of Pediatrics Council on Children with Disabilities. Care coordination in the medical home: integrating health and related systems of care for children with special health care needs. *Pediatrics*. Nov; 2005 116(5):1238–1244. [PubMed: 16264016]
44. Schor EL. American Academy of Pediatrics Task Force on the Family. *Family Pediatrics: Report of the Task Force on the Family*. *Pediatrics*. 2003; 111(6):1541–1571. [PubMed: 12777595]
45. Houtrow AJ, Okumura MJ, Hilton JF, Rehm RS. Profiling health and health-related services for children with special health care needs with and without disabilities. *Acad Pediatr*. Nov-Dec;2011 11(6):508–516. [PubMed: 21962936]

46. Forsyth R, Colver A, Alvanides S, Woolley M, Lowe M. Participation of young severely disabled children is influenced by their intrinsic impairments and environment. *Developmental Medicine & Child Neurology*. 2007; 49(5):345–349. [PubMed: 17489807]

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Table 1

Demographic Characteristics of Study Population (N=64 076)

	Children with Special Health Care Needs		Children without Special Health Care Needs	
	Unweighted Sample Size, n	Weighted Proportion of Sample (SE)	Unweighted Sample Size, n	Weighted Proportion of Sample (SE)
Age in years				
6–11	6199	47.6 (1.0)	21 593	48.8 (0.6)
12–17	8850	52.4 (1.0)	27 434	51.2 (0.6)
Sex				
Male	8652	59.1 (0.97)	24 640	48.8 (0.6)
Female	6379	40.9 (0.97)	24 314	51.2 (0.6)
Race/ethnicity				
Non-Hispanic White	10 655	61.8 (1.1)	33 134	55.9 (0.6)
Hispanic	1 431	15.3 (1.0)	5 926	20.6 (0.6)
Non-Hispanic Black	1 545	15.8 (0.7)	4 905	14.8 (0.4)
Non-Hispanic Multi-racial	749	4.4 (0.4)	2 027	3.6 (0.2)
Other	457	2.8 (0.4)	2 156	5.1 (0.3)
Household Poverty Status				
At or above 400%	5 615	29.0 (0.9)	18 908	30.3 (0.5)
200–399%	4 906	31.3 (1.0)	16 978	32.5 (0.6)
100–199%	2 575	20.1 (0.8)	8 057	21.0 (0.5)
Below 100%	1 953	19.6 (0.8)	5 084	16.6 (0.5)
Region				
Northeast	2 738	17.8 (0.7)	8 663	17.1 (0.3)
Midwest	3 629	23.6 (0.7)	11 735	21.7 (0.3)
South	5 342	39.0 (0.9)	16 040	36.3 (0.5)
West	3 349	20.6 (1.1)	12 589	24.9 (0.6)
Family Structure				
Two Parent Biological or Adopted	8 846	55.2 (1.0)	33 192	64.9 (0.6)
Two Parent Step Family	1 586	10.8 (0.7)	4 486	10.0 (0.4)
Single Mother	3 234	25.6 (0.9)	7 689	18.4 (0.5)

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	Children with Special Health Care Needs		Children without Special Health Care Needs	
	Unweighted Sample Size, n	Weighted Proportion of Sample (SE)	Unweighted Sample Size, n	Weighted Proportion of Sample (SE)
Other	1 304	8.5 (0.6)	3 344	6.7 (0.3)

Table 2
 Unadjusted and Adjusted Prevalence of Children Aged 6–17 Years Not Participating in Selected Activities by the Presence of a Special Health Care Need and Functional Limitation: National Survey of Children’s Health, 2007

	Missing More than 5 Days of School in the Last Year			Not Participating in Any Organized Activity			Not Working for Pay in the Last Week ^c			Not Volunteering in the Last Year ^c		
	Unadjusted	Adjusted ^a	se	Unadjusted	Adjusted ^a	se	Unadjusted	Adjusted ^b	se	Unadjusted	Adjusted ^b	se
Special Health Care Need^a												
No	14.3	15.1	0.4	18.3	18.9	0.5	64.2	64.3	0.7	21.0	21.5	0.7
Yes	31.0	27.9	0.9	22.8	20.7	0.9	65.0	63.9	1.4	25.4	23.0	1.3
Functional Limitation												
No	27.0	25.4	1.0	19.5	19.3	1.0	61.6	62.1	1.5	22.5	21.6	1.4
Yes	45.3	37.6	2.2	34.3	25.0	1.8	77.9	73.0	2.3	36.3	28.3	2.7

^a Adjusted for age, sex, race/ethnicity, poverty, region, neighborhood safety, child’s overall health, depressive symptoms, family structure

^b Adjusted for sex, race/ethnicity, poverty, region, neighborhood safety, child’s overall health, depressive symptoms, family structure

^c Children Aged 12 – 17 years

Table 3

Unadjusted Prevalence of CSHCN Aged 6–17 Years Not Participating in Selected Activities by Functional Limitation and Overall Health Status: National Survey of Children’s Health, 2007

	Missing More than 5 Days of School in the Last Year		Not Participating in Any Organized Activity		Not Working for Pay in the Last Week ^a		Not Volunteering in the Last Year ^a							
	Without Limitation	With Limitation	Without Limitation	With Limitation	Without Limitation	With Limitation	Without Limitation	With Limitation						
Perceived Overall Health Status	%	se	%	se	%	se	%	se						
Excellent or very good	23.4	1.1	31.9	2.7	60.2	1.7	70.7	3.2	21.1	1.5	27.8	3.5		
Good	38.2	2.6	55.6	3.6	27.3	2.3	62.7	4.0	74.5	3.7	25.4	38.7	4.0	
Fair or poor	42.8	5.6	55.9	5.8	51.9	5.8	78.3	1.5	91.2	1.9	34.6	45.4	7.6	
	p<.001		p<.001		p=.032		p=.022		p<.001		p=.135		p=.041	

^aChildren aged 12–17 years, se=standard error

Table 4

The percentage of CSHCN Aged 6–17 Years Who Missed More than 5 Days of School in the Last Year by Cumulative Number of Risk Factors* (N=14,820)

	No Risk Factors		One Risk Factors		Two Risk Factors		Three Risk Factors	
	%	SE	%	SE	%	SE	%	SE
5 of Fewer Days	78.9	1.3	67.9	1.7	59.1	2.4	41.0	4.2
More Than 5 Days	21.1	1.3	32.1	1.7	40.9	2.4	59.0	4.2

* Risk factors include having a functional limitation, not being in excellent or very good health, and living in a family <200 the Household Poverty Status. Children who didn't go to school or were homeschooled were excluded from this analysis.

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Adjusted Odds of CSHCN Aged 6–17 Years Not Participating in Selected Activities in the Past 12 Months: National Survey of Children’s Health, 2007^a

Table 5

	Missing More than 5 Days of School		Not Participating in Any Organized Activity		Not Working for Pay in the Last Week ^b		Not Volunteering in the Last Year ^b	
	AOR	95% CI	AOR	95% CI	AOR	95% CI	AOR	95% CI
PERSONAL FACTORS								
Age in years								
6–11	0.96	0.80	1.16	0.93	1.44	N/A	n/a	N/A
12–17	1.00		1.00			N/A	n/a	N/A
Sex								
Male	0.71	0.59	1.16	0.94	1.43	0.72	1.10	1.21
Female	1.00		1.00				1.00	
Race/ethnicity								
Non-Hispanic White	1.00		1.00				1.00	
Hispanic	0.61	0.43	1.60	1.13	2.28	0.91	2.33	0.90
Non-Hispanic Black	0.62	0.46	1.28	0.97	1.71	0.82	1.65	0.59
Non-Hispanic Multi-racial	1.17	0.80	1.08	0.62	1.88	0.73	2.57	0.88
Other	0.68	0.43	1.17	0.63	2.14	0.76	2.29	0.49
Functional Limitation								
No	1.00		1.00					1.00
Yes	1.71	1.39	1.47	1.15	1.87	1.31	2.00	1.60
Child’s Overall Health								
Excellent/Very Good	1.00		1.00					1.00
Good	2.25	1.81	1.41	1.12	1.79	0.77	1.40	1.16
Fair/Poor	2.73	1.91	2.28	1.55	3.37	1.57	3.61	1.58
Depressive Symptoms								
Never/Rarely/Sometimes	1.00		1.00					1.00
Usually/Always	1.20	0.84	2.81	1.84	4.30	0.55	1.47	1.65
ENVIRONMENTAL FACTORS								
Household Poverty Status								

	Missing More than 5 Days of School		Not Participating in Any Organized Activity		Not Working for Pay in the Last Week ^b		Not Volunteering in the Last Year ^b	
	AOR	95% CI	AOR	95% CI	AOR	95% CI	AOR	95% CI
At or above 400%	1.00		1.00		1.00		1.00	
200–399%	1.33	1.04	2.02	1.41	1.20	0.90	1.48	1.02
100–199%	1.58	1.20	3.05	2.13	1.43	1.01	1.52	1.04
Below 100%	1.58	1.17	5.11	3.53	2.18	1.47	2.10	1.39
Region								
Northeast	1.00		1.00		1.00		1.00	
Midwest	1.06	0.86	1.04	0.76	0.84	0.65	1.19	0.87
South	1.01	0.81	1.22	0.90	0.80	0.61	0.87	0.63
West	1.06	0.75	1.31	0.89	0.94	0.65	0.87	0.55
Safe Neighborhood								
Always/Usually	1.00		1.00		1.00		1.00	
Never/Sometimes	0.87	0.67	1.02	0.76	0.94	0.65	1.08	0.74
Family Structure								
Two Parent Biological or Adopted	1.00		1.00		1.00		1.00	
Two Parent Step Family	0.77	0.55	1.89	1.32	0.84	0.56	2.64	1.73
Single Mother	1.16	0.92	1.38	1.07	0.85	0.63	1.47	1.05
Other	0.70	0.53	1.30	0.85	2.03	1.35	1.47	0.95

^a Adjusted for all other variables in the table

^b Children aged 12–17 years

Bolded numbers are statistically significant