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## A National Profile of Caregiver Challenges of More-Complex Children with Special Health Care Needs

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### Abstract

**Objective**—To profile the national prevalence of more-complex children with special health care needs (CSHCN) and the diversity of caregiver challenges that their families confront.

**Design**—Secondary analysis of the 2005-06 National Survey of Children with Special Health Care Needs (n=40,723).

**Setting**—United States-based population.

**Participants**—National sample of CSHCN.

**Main Exposure**—More-complex CSHCN were defined by incorporating components of child health and family need, including medical technology dependence and care by 2 subspecialists.

**Outcome Measures**—Caregiver challenges were defined by family reported care burden, including hours providing care coordination and home care; medical care use, defined by health care encounters in the last 12 months; and unmet needs, defined by 15 individual medical and a single non-medical need.

**Results**—Of CSHCN, 3.2% (weighted n=324,323) met complex criteria, representing 0.44% of all children in the United States. Families of more-complex CSHCN reported a median of 2 [IQR 1,6] hours a week on care coordination and 11-15 [IQR 6, >21] hours per week on direct home care. Over half (56.8%) reported financial problems, 54.1% reported that a member stopped working because of the child's health, 48.8% reported 1 unmet medical service need, and 33.1% reported difficulty accessing non-medical services.

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The study findings were presented in part at the 2010 Pediatric Academic Societies Annual Meeting, Vancouver, BC, Canada.

**Conclusions**—Extraordinary and diverse needs are common in family caregivers of more-complex CSHCN. Enhanced care coordination support, respite care, and direct home care may begin to address the substantial caregiving burden and the multiple unmet needs that many of these families face.

### Keywords

Children with Special Health Care Needs; Unmet Needs; Medically Complex Children

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### Background

The more-complex subset of children with special health care needs (CSHCN) is clinically recognized by at least one chronic condition resulting in high family-identified service need, medical equipment addressing functional difficulties, multiple subspecialist involvement, and elevated health service use.<sup>1-5</sup> More-complex CSHCN are increasing in number,<sup>6</sup> account for increasing proportions of hospitalized children,<sup>7, 8</sup> and consume a disproportionate amount of health care resources. One study found that 0.5% of a population of children incurred 15% of total health care charges.<sup>9</sup>

Families of all CSHCN report that the medical care system is fragmented and difficult to navigate.<sup>9, 10</sup> The care requirements of children with any level of special needs create additional financial costs and stress for families.<sup>11-13</sup> As medical diagnoses and care needs rise, families report higher rates of unemployment and unmet needs.<sup>14, 15</sup> The challenges of more-complex CSHCN may be especially daunting for families, as specific care requirements typically include multiple and frequent subspecialist visits and hospitalizations, medical equipment such as a tracheostomy or gastrostomy tube, and therapies addressing neurodevelopmental concerns.<sup>16, 17</sup>

Little is known on a national level about the effects of more-complex CSHCN caregiving on families. Prior studies from small cohorts of families suggest that more-complex CSHCN caregiving may contribute to financial, marital, mental and physical health difficulties.<sup>10, 18-21</sup> A better understanding of how families spend their time caring for more-complex CSHCN may inform more actionable and programmatic strategies to help them overcome these difficulties. The objective of this study was to use a nationally-representative sample to describe the diversity of caregiver challenges. We hypothesized that family caregivers would report a high level of home care, unemployment, and unmet health care needs.

### Methods

#### Study design

The study is a secondary analysis of the 2005-6 National Survey of Children with Special Health Care Needs (NS-CSHCN). Funded by the Maternal Child and Health Bureau (MCHB), the NS-CSHCN provides prevalence estimates of CSHCN and describes aspects of health care utilization, health status, and family burden.<sup>22</sup> The NS-CSHCN is a module of the National Immunization Survey, conducted annually by the National Center for Health Statistics, with computer-assisted telephone interviews on a national random population sample.<sup>22</sup> Subjects for NS-CSHCN were identified with the CSHCN Screener, which asks whether the child had a chronic condition lasting 12 months that resulted in any of the following: (1) need for prescription medications, (2) need for more medical care, (3) limited the ability to do things, (4) need for occupational, physical, or speech therapy, (5) emotional/behavioral problems.<sup>23</sup> A positive response to any of the five questions enrolls a child in the NS-CSHCN. The sampling design specifies a goal of 750 CSHCN in each state, enabling a

maximum standard error of 10% for all point estimates greater than 15%.<sup>22</sup> Because the data set is publicly available and de-identified, this study received Exempt status from the Institutional Review Board at the University of Arkansas for Medical Sciences.

### Study population

The criteria for defining the study population were informed by enrollment criteria from geographically diverse clinical programs at tertiary care centers focused on comprehensive care for more-complex CSHCN.<sup>1-5</sup> Such criteria consider family-identified service need, medical equipment use for activities of daily living, the involvement of at least two subspecialists on an ongoing basis, and a past history of elevated health service use such as multiple hospitalizations. The criteria at such programs are typically not based on any specific diagnosis.

Study subjects in the NS-CSHCN were classified as “more-complex” or “less-complex.” Study subjects who were “more-complex” had to meet all four of the following criteria:

1. Positive response to “need for more medical care” than usual item on the CSHCN Screener. This criterion addresses family-identified service need.
2. Positive responses to any of three of the remaining four items (described above) on the CSHCN Screener. We chose this criterion for several reasons. The number of positive responses on the CSHCN Screener correlates with higher health utilization.<sup>24</sup> Further, CSHCN with positive responses inclusive of different items have reported higher levels of complexity.<sup>25</sup> We decided against requiring a positive response on all four items to avoid falsely excluding more-complex CSHCN who were missing one component (e.g. not all more-complex CSHCN have family-identified emotional/behavioral problems).
3. Medical equipment use, defined as the need for a device to maintain activities of daily living. We operationalized equipment use as a positive response to the need for a mobility aid/device, communication aid/device, medical supplies, or durable medical equipment. This criterion was selected to approximate comprehensive care program requirement of medical equipment use to address activities of daily living.
4. Seeing 2 specialists in last 12 months. This criterion was selected to address the requirement of multiple subspecialist involvement.

### Outcomes

The primary study outcome was:

- *Family reported care burden*, assessed by weekly hours spent on care coordination and home care, financial burden out-of-pocket costs, and whether the family member stopped working, cut back on work to care for child, or needed additional income for medical expenses.

Secondary study outcomes were:

- *Medical care use*, including the use of outpatient, emergency room, early intervention / special education services; and the stability of the child’s health care needs and family report of the number of school days missed.
- *Unmet needs*, assessed by specific questions relating to 15 identified medical care needs, including preventive, dental, and specialty care; and a single question on non-medical service needs such as early intervention services, child care, vocational education, rehabilitation, and related community programs.

We examined the demographic, health services, and clinical characteristics of the study cohort in relation to complexity and the study outcomes. Demographics included age, gender, race/ethnicity, census region, insurance type, poverty level, educational level and primary language of household. We examined the presence of a usual source of care and a usual source of preventive care. The specific chronic medical condition of the child may account for some of the variation of health service use;<sup>26</sup> accordingly, we examined whether the family member identified the child as having any of a list of 16 specific conditions.

### Statistical methods

Chi-square was used to compare demographic and diagnosis characteristics between more-complex and less-complex CSHCN. Diagnoses with the largest absolute prevalence differences (defined as being > 15% between more-complex and less-complex CSHCN) were identified. The Mann-Whitney test was used to compare medians or variables with non-normal distributions (e.g., school days missed, hours spent on care coordination). The skewed distribution of these variables led to a categorical large grouping of their highest values; results falling in such categories are reported as the numerical ranges.

The association of more-complex CSHCN with individual diagnoses were verified by logistic regression models that adjusted for significant ( $p < .05$ ) demographics in bivariate analyses. The association of more-complex CSHCN with individual diagnoses and unmet healthcare needs was examined with logistic regression, adjusting for significant ( $p < .05$ ) demographic and diagnosis characteristics in bivariate analyses. Multivariable analysis adjusted for demographic characteristics significant at  $p < .05$  and the diagnoses with the largest absolute percentage difference. All analyses were conducted in Stata 10 using appropriate person-level weights provided in the survey to generate national estimates.<sup>22</sup>

### Results

There were 10,221,439 CSHCN ages 0-17 years (unweighted NS-CSHCN  $n=40,723$ ) in 2006 in the United States. Of children in the survey, 38.8% required more medical care than usual according to the CSHCN Screener; 12.9% had positive responses to three of remaining four Screener items; 25.2% had medical equipment use; and 23.7% saw 2 specialists in the last year. Combining all the study criteria [Figure 1] resulted in a study sample of 324,323 (95% CI 294,064-354,584) more-complex CSHCN. This sample is 3.2% (95% CI 2.9, 3.5) of all CSHCN, or 0.44% of all children in the United States.

### Demographic and Diagnosis Characteristics

Compared with less-complex CSHCN, more-complex CSHCN were more likely to be younger, have public insurance, have lower family income (all  $p < .001$ ), and have a usual source of health care ( $p < .05$ ). No differences were found in gender, race/ethnicity, census region, household education level, primary household language, or usual preventive care source. [Table 1] Compared with less-complex CSHCN, more-complex CSHCN had more mean (SD) diagnoses (4.0 (.13) vs 1.5 (.01),  $p < .001$ ) per child. While less likely to have asthma, more-complex CSHCN were more likely to have each of the remaining 15 of 16 diagnoses provided. More-complex CSHCN had a significantly higher prevalence of mental retardation (61% vs 10%), emotional problem (47% vs 20%), seizure disorder (27% vs 3%), autism (25% vs 5%), cerebral palsy (21% vs 1%), or joint problem (21% vs 4%) (all  $p < .001$ ). [Figure 2]

### Care Burden

Caregivers of more-complex CSHCN reported a median of 2 hours [IQR 1, 6] per week providing care coordination, and between 11-15 hours [IQR 4, 16-20] providing direct home

care per week. Almost half (46%, weighted n=150,021) of families reported >\$1000 in out-of-pocket health care costs in the prior year. A similar proportion reported health care-related financial problems (57%, weighted n=184,043), a family member stopped working due to the child's health (54%, weighted n=175,294), a family member cut working hours to care for child (46%, weighted n=147,753), and that the family needed additional income for medical expenses (49%, weighted n=157,798) [Table 2].

### Medical Care Use and Unmet Needs

Families of more-complex CSHCN reported medians of 11-15 [IQR 6, >21] doctor visits and 10 [IQR 5, 16-20] school days missed in the preceding 12 months. Almost two-thirds of families with more-complex CSHCN (65%, weighted n=210,810) reported variable health care service needs of the child (i.e., needs change all the time or sometimes). [Table 3]

For individual unmet medical needs, families of more-complex CSHCN reported an increased likelihood of receiving needed specialty care [Adjusted Odds Ratio (AOR) 2.0, 95% CI 1.3, 3.1] compared to families of less-complex CSHCN. Families of more-complex CSHCN reported less likelihood of receiving needed prescriptions (weighted n=14,826; AOR .50, 95% CI .26, .97). No differences were seen in the likelihood of receiving thirteen other medical services [Table 4]. Nearly half of more-complex families (49%, weighted n=158,270; AOR 1.9, 95% CI 1.4, 2.5) reported 1 unmet medical service need and 5% (weighted n=17,513; AOR 2.4, 95% CI 1.4, 4.3) reported >5 unmet needs in the prior twelve months. One-third of families of more-complex CSHCN reported difficulties trying to access non-medical services (33%, weighted n=107,350; AOR 2.1, 95% CI 1.6, 2.8). Significantly fewer families of more-complex CSHCN reported being very satisfied with health services (39%, weighted n=127,459; AOR .69, 95% CI .54, .89).

### Discussion

To our knowledge, this is the first report that describes demographics, family care burden, and service needs for the more-complex subset of CSHCN in a large, nationally representative population. Our findings suggest that families of more-complex CSHCN face exceptionally high care demands, high unemployment and underemployment, and large financial burden, and that many more-complex CSHCN have unmet medical needs. Our study criteria were specifically designed to select children with complex medical care needs, and it is not surprising to find a high care burden. However, quantifying this burden is revealing: the majority of families with more-complex CSHCN in our study reported at least 10 doctor visits, >11 missed school days, and out-of-pocket costs of >\$1000 annually. Over 175,000 parents stopped employment in order to stay at home and care for a child with high medical complexity.

Our methodology is novel by describing a population that is not very prevalent but is nevertheless important. By utilizing criteria adapted from clinical services dedicated to more-complex CSHCN and ascertaining such children via family responses as opposed to administrative data focused on diagnostic lists, we focus on attributes that coexist in a distinct population of children within population-level surveys.<sup>26</sup> These attributes are similar to a recently developed definitional framework of more-complex CSHCN, termed "children with medical complexity."<sup>27</sup> The absence of a definitional gold standard<sup>27</sup> makes it difficult to judge the accuracy of our methods to study these children. However, our population estimate (0.44%) is similar to prior prevalence estimates of 0.22% to 0.41% of more-complex CSHCN in the United States, with case ascertainment from health administrative data.<sup>28, 29</sup>

Our criteria captured children with a high prevalence of neurodevelopmental conditions, particularly mental retardation, emotional problems, seizure disorder, autism, and cerebral palsy. This finding is similar to patients typically enrolled in structured clinical programs that care for more-complex CSHCN even though a neurodevelopmental disorder is not generally used as an explicit inclusion criterion.<sup>2, 17</sup> Another identification method using administrative data, known as Clinical Risk Groups (CRGs), has also found a high prevalence of neurodevelopmental disorders in patients with the highest medical complexity.<sup>30</sup> Children with neurodevelopmental disorders tend to have attributes consistent with more-complex CSHCN, such as multisystem comorbidities including gastrointestinal (e.g. feeding/swallowing), musculoskeletal (e.g. spasticity), and respiratory (e.g. difficulty handling secretions), functional status limitations and technology assistance.<sup>31-33</sup>

We found that almost 15,000 more-complex CSHCN were less likely to have received prescription medications when needed. The clinical attributes of more-complex CSHCN suggest that many of them may need consistent compliance with important medications to maintain their health status. For example, children with cerebral palsy who have epilepsy require daily anti-epileptic drug administration to prevent breakthrough seizures. Difficulty receiving prescription medications may be a factor that is contributing to the high resource utilization (e.g., repeated admission for seizure) observed by some more-complex CSHCN.<sup>16</sup>

Aside from prescription medications, we did not find families of less-complex CSHCN having a lower likelihood of any individual unmet medical service need. Access to individual medical services may not be an issue for more-complex CSHCN generally, possibly because their fragile health results in ongoing, frequent contact with the medical system. More notable is our finding that families of more-complex CSHCN were more likely to have multiple unmet medical needs; indeed, almost 5% reported five separate unmet medical needs. This finding likely illustrates the difficulty of navigating services and the essential role of care coordination. We also found that non-medical, community-based services for more-complex CSHCN were relatively lacking. Care models that incorporate improved access to and coordination of community-based services are critical for optimal medical, developmental, and service outcomes, yet these are the services that families of more-complex CSHCN frequently regard as deficient.<sup>34, 35</sup>

Over half of families of more-complex CSHCN in our study report financial difficulties and employment loss. There is a critical need to help such families overcome these life-disruptive problems. Existing policies can help families sustain employment (e.g., the Family Medical Leave Act), but studies show that these policies remain underused.<sup>36</sup> Enhanced home caregiving support may help families maintain their employment status and financial stability.<sup>15</sup> There is a perceived home nursing shortage throughout the U.S. for more-complex CSHCN. Other jurisdictions have adopted cost-effective alternative strategies to mitigate this shortage (e.g., in Victoria, Australia, a workforce of trained, regulated personal care attendants has been created to care for children with tracheostomy requiring home mechanical ventilation).<sup>37</sup>

Our study has several limitations. We recognize that there is tautology between the methods used to extract more-complex CSHCN (i.e., having multiple special needs) and our outcomes (e.g., health care utilization and unmet needs). Our main intent was to quantify these outcomes rather than highlight the relationship between them and our selected cohort of patients. We had no *a priori* hypothesis of the magnitude or proportion of service use in multiple domains that families of more-complex CSHCN would report. Specific inclusion criteria, such as having an emotional problem on the CSHCN Screener, may be associated with a specific study outcome, such as a parent reporting the presence of an emotional



diagnosis or condition. However, we found that of the more-complex CSHCN who did not report an emotional problem on the CSHCN Screener, 42% still identified an emotional condition or problem on the survey, suggesting that tautology does not explain all outcomes.

The NS-CSHCN was not originally designed to focus on high medical complexity. It lacks related clinical information (e.g., illness severity and duration of functional impairment) and utilization information (e.g., hospitalizations) that may help capture more-complex CSHCN. Some study criteria, such as the need for supplies, may have increased sensitivity and decreased specificity; not all medical supplies have direct relationships to activities of daily living. However, the more-complex CSHCN prevalence in our study is similar to prior studies examining the highest resource users.<sup>28, 29</sup> The less-complex CSHCN group in our study likely varies in the level of complexity, and some children in the comparison group likely require a high level of services. However, inclusion of higher levels of complexity in the comparison group would likely lead to a bias toward the null hypothesis, which may strengthen our findings. The survey is cross-sectional and does not permit the determination of causality. Non-medical service needs was characterized as a single question, which did not enable us to specify specific community-based services that may be particularly lacking. Finally, there is no external validation of study responses, although our findings are consistent with clinical experience and prior qualitative literature documenting the pervasive effects of caregiving on the family unit.<sup>20, 38</sup>

Given the rising number of more-complex CSHCN and their substantial impact on health care costs, maximizing health, development, and function of more-complex CSHCN is an important target for the health care system. Hospital-based programmatic models of care for more-complex CSHCN may deliver enhanced care coordination and technical expertise necessary to improve care, health outcomes, and family satisfaction.<sup>39</sup> Comprehensive medical care and care coordination for more-complex CSHCN in a hospital-based clinic may reduce hospitalizations and overall costs.<sup>40</sup> Family training during transition from hospital to home may decrease morbidity and mortality for children who are dependent on respiratory support.<sup>37</sup> A challenge is to bring these clinical initiatives to the primary care setting, including training personnel to manage chronic illnesses and changing reimbursement patterns that de-incentivize comprehensive care.<sup>6</sup>

## Conclusions

More-complex children with special health care needs can be distinguished by exceptionally high demands placed upon their families and the health care system. Families of more-complex CSHCN report multiple unmet needs and many hours devoted to care coordination and home care. Enhanced care coordination support, respite care, and direct home care may begin to address the substantial economic burden and the multiple unmet needs that many of these families face.

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Dr. Kuo had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

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## Abbreviations

<b>CSHCN</b>	children with special health care needs
<b>IQR</b>	interquartile range
<b>NS-CSHCN</b>	National Survey of Children with Special Health Care Needs
<b>MCHB</b>	Maternal and Child Health Bureau

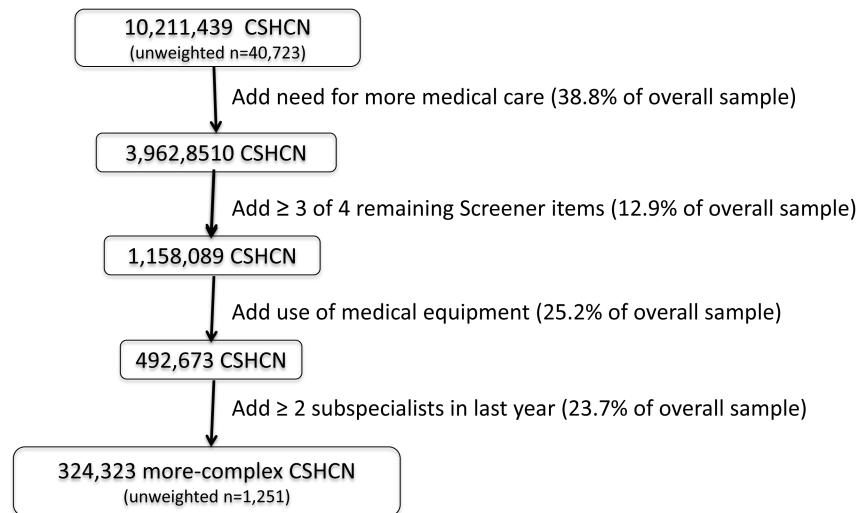
## References

1. Tanios AT, Lyle RE, Casey PH. ACH medical home program for special needs children. A new medical era. *J Ark Med Soc.* Jan; 2009 105(7):163–165. [PubMed: 19170334]
2. Gordon JB, Colby HH, Bartelt T, Jablonski D, Krauthoefer ML, Havens P. A tertiary care-primary care partnership model for medically complex and fragile children and youth with special health care needs. *Arch Pediatr Adolesc Med.* Oct; 2007 161(10):937–944. [PubMed: 17909136]
3. Kelly A, Golnik A, Cady R. A medical home center: specializing in the care of children with special health care needs of high intensity. *Matern Child Health J.* Sep; 2008 12(5):633–640. [PubMed: 17710520]
4. Cohen E, Friedman JN, Mahant S, Adams S, Jovcevska V, Rosenbaum P. The impact of a complex care clinic in a children's hospital. *Child Care Health Dev.* Mar 9; 2010 36(4):574–582. [PubMed: 20337643]
5. Berry JG, Agrawal R, Kuo DZ, et al. Characteristics of Hospitalizations for Patients who Utilize a Structured Clinical-Care Program for Children with Medical Complexity. *J Pediatr.* 2011 epub 21 March 2011.
6. Wise PH. The transformation of child health in the United States. *Health Aff (Millwood).* Sep-Oct; 2004 23(5):9–25. [PubMed: 15495347]
7. Burns KH, Casey PH, Lyle RE, Bird TM, Fussell JJ, Robbins JM. Increasing Prevalence of Medically Complex Children in US Hospitals. *Pediatrics.* Oct; 2010 126(4):638–646. [PubMed: 20855383]
8. Simon TD, Berry J, Feudtner C, et al. Children with complex chronic conditions in inpatient hospital settings in the United States. *Pediatrics.* Oct; 2010 126(4):647–655. [PubMed: 20855394]
9. Ghose R. Complications of a medically complicated child. *Ann Intern Med.* Aug 19; 2003 139(4):301–302. [PubMed: 12965988]
10. Ray LD. Parenting and Childhood Chronicity: making visible the invisible work. *J Pediatr Nurs.* Dec; 2002 17(6):424–438. [PubMed: 12518283]
11. Baker BL, McIntyre LL, Blacher J, Crnic K, Edelbrock C, Low C. Pre-school children with and without developmental delay: behaviour problems and parenting stress over time. *J Intellect Disabil Res.* May-Jun; 2003 47(Pt 4-5):217–230. [PubMed: 12787154]
12. Macias MM, Roberts KM, Saylor CF, Fussell JJ. Toileting concerns, parenting stress, and behavior problems in children with special health care needs. *Clin Pediatr (Phila).* Jun; 2006 45(5):415–422. [PubMed: 16891274]
13. Chevarley, FM. Utilization and expenditures for children with special health care needs. Agency for Healthcare Research and Quality; Rockville, MD: Jan. 2006
14. Bitsko RH, Visser SN, Schieve LA, Ross DS, Thurman DJ, Perou R. Unmet health care needs among CSHCN with neurologic conditions. *Pediatrics.* Dec; 2009 124(Suppl 4):S343–351. [PubMed: 19948598]
15. Okumura MJ, Van Cleave J, Gnanasekaran S, Houtrow A. Understanding factors associated with work loss for families caring for CSHCN. *Pediatrics.* Dec; 2009 124(Suppl 4):S392–398. [PubMed: 19948604]
16. Berry JG, Hall DE, Kuo DZ, et al. Hospital Utilization and Characteristics of Patients Experiencing Recurrent Readmissions Within Children's Hospitals. *JAMA.* 2011; 305(7):682–690. [PubMed: 21325184]

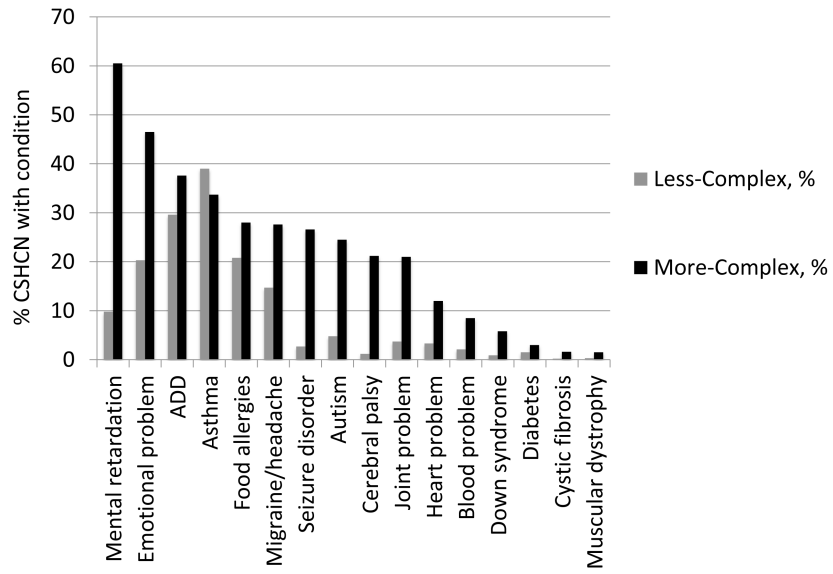


17. Srivastava R, Stone BL, Murphy NA. Hospitalist care of the medically complex child. *Pediatr Clin North Am.* Aug; 2005 52(4):1165–1187. [PubMed: 16009262]
18. Kratz L, Uding N, Trahms CM, Villareale N, Kieckhefer GM. Managing childhood chronic illness: parent perspectives and implications for parent-provider relationships. *Fam Syst Health.* Dec; 2009 27(4):303–313. [PubMed: 20047354]
19. MacKean GL, Thurston WE, Scott CM. Bridging the divide between families and health professionals' perspectives on family-centred care. *Health Expect.* Mar; 2005 8(1):74–85. [PubMed: 15713173]
20. Macdonald H, Callery P. Parenting children requiring complex care: a journey through time. *Child Care Health Dev.* Mar; 2008 34(2):207–213. [PubMed: 18028476]
21. Thyen U, Kuhlthau K, Perrin JM. Employment, child care, and mental health of mothers caring for children assisted by technology. *Pediatrics.* Jun; 1999 103(6 Pt 1):1235–1242. [PubMed: 10353935]
22. Blumberg, SJ.; Welch, EM.; Chowdhury, SR.; Upchurch, HL.; Parker, EK.; Skalland, BJ. Design and operation of the National Survey of Children with Special Health Care Needs, 2005-06. National Center for Health Statistics; Nov 28. 2007
23. Bethell CD, Read D, Stein RE, Blumberg SJ, Wells N, Newacheck PW. Identifying children with special health care needs: development and evaluation of a short screening instrument. *Ambul Pediatr.* Jan-Feb;2002 2(1):38–48. [PubMed: 11888437]
24. Bramlett MD, Read D, Bethell C, Blumberg SJ. Differentiating Subgroups of Children with Special Health Care Needs by Health Status and Complexity of Health Care Needs. *Matern Child Health J.* 2008; 13:151–63. [PubMed: 18386168]
25. Kohen DE, Brehaut JC, Garner RE, et al. Conceptualizing childhood health problems using survey data: a comparison of key indicators. *BMC Pediatr.* 2007; 7:40. [PubMed: 18053253]
26. Andersen RM. Revisiting the behavioral model and access to medical care: does it matter? *J Health Soc Behav.* Mar; 1995 36(1):1–10. [PubMed: 7738325]
27. Cohen E, Kuo DZ, Agrawal R, et al. Children with medical complexity: An emerging population for clinical and research initiatives. *Pediatrics.* 2011; 127:529–38. [PubMed: 21339266]
28. Buescher PA, Whitmire JT, Brunssen S, Kluttz-Hile CE. Children who are medically fragile in North Carolina: using Medicaid data to estimate prevalence and medical care costs in 2004. *Matern Child Health J.* Sep; 2006 10(5):461–466. [PubMed: 16752093]
29. Neff JM, Sharp VL, Muldoon J, Graham J, Myers K. Profile of medical charges for children by health status group and severity level in a Washington State Health Plan. *Health Serv Res.* Feb; 2004 39(1):73–89. [PubMed: 14965078]
30. Neff JM, Sharp VL, Popalisky J, Fitzgibbon T. Using medical billing data to evaluate chronically ill children over time. *J Ambul Care Manage.* Oct-Dec;2006 29(4):283–290. [PubMed: 16985386]
31. Sullivan PB, Lambert B, Rose M, Ford-Adams M, Johnson A, Griffiths P. Prevalence and severity of feeding and nutritional problems in children with neurological impairment: Oxford Feeding Study. *Dev Med Child Neurol.* Oct; 2000 42(10):674–680. [PubMed: 11085295]
32. Sondheimer JM, Morris BA. Gastroesophageal reflux among severely retarded children. *J Pediatr.* May; 1979 94(5):710–714. [PubMed: 156251]
33. Murphy N, Such-Neibar T. Cerebral palsy diagnosis and management: the state of the art. *Curr Probl Pediatr Adolesc Health Care.* May-Jun;2003 33(5):146–169. [PubMed: 12738938]
34. Bodenheimer T, Wagner EH, Grumbach K. Improving primary care for patients with chronic illness. *JAMA.* Oct 9; 2002 288(14):1775–1779. [PubMed: 12365965]
35. 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. *Arch Pediatr Adolesc Med.* Oct; 2007 161(10): 933–936. [PubMed: 17909135]
36. Chung PJ, Garfield CF, Elliott MN, Carey C, Eriksson C, Schuster MA. Need for and use of family leave among parents of children with special health care needs. *Pediatrics.* May; 2007 119(5):e1047–1055. [PubMed: 17473078]
37. Tibballs J, Henning R, Robertson CF, et al. A home respiratory support programme for children by parents and layperson carers. *J Paediatr Child Health.* Jan; 46(1-2):57–62. [PubMed: 19943860]

38. Rehm RS, Bradley JF. Normalization in families raising a child who is medically fragile/technology dependent and developmentally delayed. *Qual Health Res.* Jul; 2005 15(6):807–820. [PubMed: 15961877]
39. Cohen E, Jovcevska V, Kuo DZ, Mahant S. Hospital-based comprehensive care programs for Children with Special Health Care Needs (CSHCN): A systematic review. *Arch Pediatr Adolesc Med.* 2011 in press.
40. Casey PH, Lyle RE, Bird TM, et al. Effect of Hospital-Based Comprehensive Care Clinic on Health Costs for Medicaid-Insured Medically Complex Children. *Arch Pediatr Adolesc Med.* epub Feb 7 2011.



**Figure 1.** Study sample by criteria. All figures weighted unless indicated.



**Figure 2.** Parent-reported diagnoses by complexity (weighted n = 10,221,439).

**Table 1**

Demographics of children with special health care needs by complexity.\*

	Less-Complex, % n=9,897,115	More-Complex, % n=324,323	P
Age			
0-5 yr	21	31	<.001
6-11 yr	37	39	
12-17 yr	42	30	
Gender			
Male	59	59	.81
Female	41	41	
Race/ethnicity			
White/non-hispanic	65	66	.14
Black/non-hispanic	16.	12	
Hispanic/Latino	12	14	
Multiple/other	7	7	
Census region			
Northeast	18	20	.50
Midwest	24	22	
South	39	39	
West	20	18	
Type insurance			
Private	69	58	<.001
Public	28	41	
Uninsured	4	1	
Poverty level			
100%	19	25	<.001
>100-200%	22	27	
>200-300%	16	15	
>300-400%	14	14	
>400%	29	20	
Household education level			
Lower than high school	7	6	.94
High school graduate	23	24	
Higher than high school	70	70	
Primary language			
English	95	93	.13
Other	5	7	
Usual source of health care			
No	5	2	<.05

	<b>Less-Complex, % n=9,897,115</b>	<b>More-Complex, % n=324,323</b>	<b>P</b>
Yes	95	98	
Usual source of preventive care			
No	3	1	.08
Yes	97	99	

All data weighted. Analyses are by Chi-square.

\* More-complex defined as: positive response to “need for more medical care” than usual item and three of the remaining four items on the CSHCN Screener; medical equipment use; and, seeing 2 specialists in last 12 months



**Table 2**

Family reported care burden of children with special health care needs by complexity.

	<b>Less-Complex</b> n=9,897,115	<b>More-Complex</b> n=324,323	<b>Adjusted Odds Ratio (95% CI)</b> / p value
Hours/week providing care coordination, median [IQR]	0 [0, 2]	2 [1, 6]	* <.001
Hours/week providing direct home care, median [IQR]	1 [0, 7]	11 [4,16-20]	<.001
Family paid >\$1000 out of pocket, %	19	46	3.0 (2.3, 3.9)
Child's health care caused financial problems, %	17	57	3.6 (2.7, 4.7)
Family member stopped working due to child's health, %	12	54	2.9 (2.2, 3.9)
Family member cut work to care to child, %	15	46	2.2 (1.7, 2.8)
Needed additional income for med expense, %	15	49	3.0 (2.3, 3.9)

All data weighted. Analyses adjusted for age, insurance, income, usual source of health care, autism, mental retardation, emotional disturbance, cerebral palsy, seizure, joint problems.

\* p values reported for comparisons of medians by Mann-Whitney test.

**Table 3**

Medical care use of children with special health care needs, by complexity.

	<b>Less-Complex</b> n=9,897,115	<b>More-Complex</b> n=324,323	<b>p</b>
Child's health care needs			
change all the time, %	5	32	<.001
change sometimes, %	28	33	
usually stable, %	67	35	
Number of school days missed, median [IQR]	3 [1, 8]	10 [5, 16-20]	<.001
Number of doctor visits, median [IQR]	4 [2, 7]	11-15 [6, >21]	<.001
Number of emergency room visits, median [IQR]	0 [0, 1]	1 [0, 3]	<.001
Received early intervention services, % (<3 years)	19	82	<.001
Received special education services, % (3-17 years)	27	77	<.001

All data weighted. P values were derived from Chi-square for proportions and Mann-Whitney for non-parametric tests.

**Table 4**  
Families of children with special health care needs reporting difficulty with accessing services in last 12 months, by complexity.

Service Needed	Total weighted n	Less-Complex		More-Complex		AOR (95% CI)
		# Less-Complex	% received service	# More-Complex	% received service	
Preventive care	7,938,113	7,647,578	98	290,535	97	1.5 (.65, 3.3)
Specialty care	5,281,140	4,956,878	95	324,262	94	2.0 (1.3, 3.1)
Preventive dental care	8,273,973	8,009,206	92	264,767	87	.82 (.56, 1.2)
Other dental care	2,464,893	2,396,862	98	68,031	96	1.0 (.38, 2.7)
Prescriptions	8,811,327	8,501,168	98	310,159	95	.50 (.26, .97)
Therapies	2,330,249	2,045,493	87	140,048	80	.83 (.59, 1.2)
Mental health care	2,550,503	2,397,218	85	153,285	84	1.1 (.68, 1.8)
Substance abuse counseling	196,311	190,559	79	5,752	83	.48 (.11, 2.2)
Home health services	457,942	365,896	90	73,545	86	1.0 (.41, 2.5)
Eyeglasses/vision care	3,404,342	3,239,572	96	164,770	93	.74 (.37, 1.5)
Hearing aid/care	482,090	407,511	92	74,579	93	1.6 (.58, 4.2)
Respite care	464,223	363,301	53	100,922	51	1.1 (.72, 1.7)
Genetic counseling	577,468	506,555	76	70,913	78	1.3 (.67, 2.7)
Family mental health counseling	1,253,180	1,140,519	81	112,661	80	1.4 (.87, 2.1)
Referrals	3,355,014	3,151,700	79	995,768	70	.79 (.55, 1.1)
1 unmet medical service total	10,221,439	9,897,419	20	324,020	49	1.9 (1.4, 2.5)
5 unmet medical service total	10,221,439	9,897,419	.84	324,020	5	2.4 (1.3, 4.3)
Very satisfied with medical services	9,978,472	9,656,167	60	322,305	39	.69 (.54, .89)
Non-medical services	10,128,214	9,806,137	10	322,077	33	2.1 (1.6, 2.8)

All data weighted. Total n = weighted subjects for which question was applicable (e.g. preventive care needed). Less-Complex and More-Complex n are the total weighted study subjects for each category. Analyses adjusted for age, insurance, income, usual source of health care, autism, mental retardation, emotional disturbance, cerebral palsy, seizure, joint problems.