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Access to services, quality of care, and family impact for children with autism, other developmental disabilities, and other mental health conditions

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Abstract

This cross-sectional study examined perceived access to services, quality of care, and family impact reported by caregivers of children aged 3–17 years with autism spectrum disorders, as compared to caregivers of children with other developmental disabilities and other mental health conditions. The 2009–2010 National Survey of Children with Special Health Care Needs was utilized to examine the association between child's special needs condition and three outcomes ($N = 18,136$): access to services (difficulty using services, difficulty getting referrals, lack of source of care, and inadequate insurance coverage), quality of care (lack of care coordination, lack of shared decision making, and no routine screening), and family impact (financial, employment, and time-related burden). Multivariate logistic regressions were performed to compare caregivers of children with autism spectrum disorders to caregivers of children with developmental disabilities (cerebral palsy, Down syndrome, developmental delay, or intellectual disability), mental health conditions (attention deficit hyperactivity disorder, anxiety, behavioral/conduct problems, or depression), or both developmental disabilities and mental health conditions. Caregivers of children with autism spectrum disorders were significantly more likely to report difficulty using services, lack of source of care, inadequate insurance coverage, lack of shared decision making and care coordination, and adverse family impact as compared to caregivers of children with developmental disabilities, mental health conditions, or both.

Keywords

Access to services; autism; autism spectrum disorder health care; burden of autism; developmental disabilities; family impact; mental health condition; quality of care

Introduction

Prevalence of autism spectrum disorders (ASDs) has risen in the past decade by 78% (Centers for Disease Control and Prevention (CDC), 2012a), and currently 1 in 88 children in the United States has ASDs. ASD is associated with restrictive, repetitive, and stereotyped patterns of behavior along with functional and social impairments (American Psychiatric

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Association, 2000). ASD is also associated with extensive physical and neurological comorbidities (Joshi et al., 2010; Kohane et al., 2012; Levy et al., 2010) such as epilepsy, schizophrenia, cranial anomalies, inflammatory bowel disease, sleep disorders, and muscular dystrophy (Kohane et al., 2012; Maski et al., 2011). Some developmental disabilities (DDs) are particularly highly comorbid with ASDs. These specifically include conditions such as cerebral palsy, intellectual disability (ID)/intellectual developmental disorders (IDD), Down syndrome, or developmental delay (CDC, 2012c). The prevalence of comorbid DDs in children with ASDs can be as high as 90% as compared to 82% for children with ID/IDD, 76% for children with developmental delay, and 51% for children with cerebral palsy (Boulet et al., 2009). Similarly, mental health conditions (MHCs) such as attention deficit hyperactivity disorder (ADHD; Furman, 2008), anxiety, behavioral/conduct problems, or depression have also been found to cooccur with ASDs (Stewart et al., 2006; White et al., 2009). Management of such complex and heterogeneous sets of DDs and MHCs in children with ASDs requires provision of services by multiple health-care professionals which may be challenging for the existing DD centers or clinics, a fact supported by many observational studies (Bitsko et al., 2009; Boulet et al., 2009; Krauss et al., 2003; Liptak et al., 2006a).

Although symptoms of cognitive delay and socio-behavioral issues are common in children with ASDs, DDs, and MHCs, children with ASD are unique because of the developmental course of ASDs, their treatment, and management (Volkmar et al., 1999). Caregivers of children with ASDs may face different challenges due to a number of reasons: (1) the complexity of the disorder itself, which requires intensive pharmaco-therapeutic and behavioral interventions needing coordination among multiple educational and health-care providers (Volkmar et al., 1999); (2) extensive developmental and physical comorbidities (Boulet et al., 2009; Kohane et al., 2012; Levy et al., 2010) that need greater medication management and attention by the caregiver as well as the health-care providers; and (3) lack of “gold standard” or evidence base for wide array of pharmacological, biomedical, alternative treatment, and behavioral therapies used by caregivers of children with ASDs (Warren et al., 2011). In addition, the substantial out-of-pocket direct health-care costs and other indirect costs incurred by families of children with ASD also pose a significant financial burden on these families (CDC, 2012b; Kogan et al., 2008).

The complexity of ASD and its impact on the family is evident in the reports of caregivers of children with ASDs; these caregivers have reported greater unmet needs (Chiri and Warfield, 2012; Siklos and Kerns, 2006), issues with access to services (Krauss et al., 2003; Ruble et al., 2005), and dissatisfaction with the quality of care provided (Montes et al., 2009; Spann et al., 2003) as compared to caregivers of children without ASDs. When compared to caregivers of children with DDs, some studies have also observed greater unmet needs (Cadman et al., 2012), problem accessing services (Boulet et al., 2009; Krauss et al., 2003), and poor quality of care (Liptak et al., 2006b) among caregivers of children with ASDs. Primary care physician referral to specialty providers and satisfaction with primary care physician services are also impacted by presence of ASDs. Ming et al. (2011) found that fewer children with ASDs received referrals for specialists from their primary care physicians than children with other neurologic disorders. Liptak et al. (2006a) examined perceptions of parents of children with DDs including ASDs about satisfaction with primary health care. They found that families of children with ASDs expressed greater dissatisfaction

with the communication and coordination of care among primary care physicians as compared to families of children with other DDs. Difficulties in accessing services, dissatisfaction with the service, and poor quality of health care may also lead to negative outlook. For example, families of children with ASDs were also found to be more negative in their comments about the services and were more likely to express unmet needs as compared to families of children with other DDs (Liptak et al., 2006a).

Even among groups of children with special health-care needs (CSHCN), caregivers of children with ASDs report greater unmet health-care needs. Using 2005–2006 National Survey of Children with Special Health Care Needs (NS-CSHCN) data, Kogan et al. (2008) compared the caregivers' health-care experiences and family impact for children with ASDs to caregivers of other CSHCN and caregivers of children with emotional, developmental, and behavioral problems (EDBPs) to caregivers of other CSHCN. This study found that caregivers of children with ASDs and EDBPs are more likely to report poor experiences in accessing services, receiving family-centered care, and an adverse family impact as compared to caregivers of other CSHCN. Even though the study established a significant association between caregivers' negative experiences and child's special needs conditions, it lacked a comprehensive comparison between the ASD and EDBP groups. In addition, the study also did not compare issues reported by caregivers of children with ASDs to those reported by caregivers of children with multiple comorbid conditions such as both DDs/MHCs.

This study attempts to fill the knowledge gap by examining issues with access to services, quality of care, and family impact reported by caregivers of children with ASDs as compared to caregivers of children with DDs, MHCs, or both DDs/MHCs. Identifying health-care disparities across caregivers of children with ASDs and other special needs conditions such as DDs and MHCs will indicate differences in perceptions of caregiver needs and highlight the variations in the extent and type of health-care needs of these children. Such differences, if they do exist, will help inform the health-care providers and policy makers in designing programs that may address core deficits in areas of services provision, care coordination, and shared decision making, leading to improvement in family outcomes for caregivers of children with ASDs, DDs, and MHCs. Due to the complex nature of ASDs, extensive comorbidity burden and health-care needs, and costs associated with the condition (CDC, 2012b), provision of care under the umbrella of DD networks may be inadequate. It is expected that caregivers of children with ASDs will be more likely to have poor access, poor quality of care, and adverse family impact, as compared to caregivers of children with DDs and MHCs.

Methods

Data source

This study uses cross-sectional data from 2009–2010 NS-CSHCN, a computer-assisted random digit dial telephone survey with a complex multistage design representative of the US civilian noninstitutionalized population with children aged 0–17 years. The NS-CSHCN provides child- and household-level data on children with and without SHCN (Maternal and Child Health Bureau, Data Resource Center for Child & Adolescent Health, 2011). A total

of 372,698 children were screened for SHCN in the 50 states and District of Columbia (DC) from 196,159 households. The analyses reported here are based on sample of children who were identified as CSHCN through the survey's CSHCN screener (N = 40,242).

Study population

All special needs children aged 3–17 years with a caregiver-reported current diagnosis of ASDs, DDs, MHCs, or both DDs/MHCs formed the sampled population. The final analytical sampled population (hereafter referred to as sample) was 18,136.

Measures

Key independent variable

Child's special needs condition (ASD, DD, and MHC): ASD was identified from caregiver-reported confirmation to the question "Does the child currently have autism, Asperger's disorder, pervasive developmental disorder, or other autism spectrum disorder?" Children with DDs consisted of those who had cerebral palsy, Down syndrome, developmental delay, or ID/IDD. Children with MHCs consisted of those who had ADHD, anxiety, behavioral/conduct problems, or depression. Based on ASD, DD, and MHC, we adapted the following hierarchical classification of special needs conditions: (1) ASD, (2) DD (without ASD or MHC), (3) MHC (without ASD or DD), and (4) both DD/MHC (without ASD). As evident from the classification, the ASD group included children with ASD alone (n = 372), ASD with DD (n = 694), MHC (n = 739), and both DD/MHC (n = 1220).

Dependent variables

Access to services: Access to services was assessed using four measures: difficulty using services, difficulty getting referrals, lack of source of care, and inadequacy of health insurance coverage. For this study, the services represent those offered by primary care providers, schools, hospital systems, other clinics/health centers, and any other relevant institution. *Difficulty using services* was measured as a binary variable using yes/no responses to the question "During the past year, have you had any difficulties using or delay in services due to lack of eligibility, availability of services, cost issues, problems getting information, getting appointments, or any other reasons?" *Difficulty getting referrals* was measured as a three-category variable and was derived from two questions "Did you need a referral?" and "Among those who needed a referral, whether getting referrals was a big problem, a small problem, or not a problem?" The three categories were as follows: (1) did not need a referral, (2) big/small problem, and (3) no problem. *Lack of source of care* was a binary indicator derived from yes/no responses to the question "Does the child lack a personal doctor/place for routine/sick care or did not receive all specialty care, when needed?" *Inadequacy of health insurance* was derived from the questions "Whether the child has a health insurance?" and "Does the insurance allow the child to see a provider or provide benefits that meet the child's needs?" The variable was grouped into two categories: (1) no insurance/never/sometimes and (2) have insurance/usually/always.

Quality of care: The quality of care was assessed with three binary measures: lack of shared decision making, lack of care coordination, and lack of routine screening or well-child visits. *Lack of shared decision making* was derived from the question “Did the health-care provider discuss, encourage/make it easy to ask questions, or respect your treatment choices?” and was grouped as (1) never/sometimes and (2) usually/always. *Lack of care coordination* was based on the question “Did you receive a family-centered care/received help from different providers (health care, educational, and other), and how satisfied were you with the communication between the different providers?” Lack of care coordination was grouped into (1) did not receive family-centered care/no help from health-care providers/somewhat dissatisfied/very dissatisfied with the communication and (2) received family-centered care/help from provider/satisfied/somewhat satisfied with the communication. *No routine screening* was derived from the question “Number of times the child received a well-child checkup, when he was not sick or injured?” and was grouped into two categories: (1) none and (2) one/more than one.

Family impact: The impact of the special needs condition on the family was assessed using three measures of family burden due to child’s condition: financial burden, employment burden, and time-related burden. *Financial burden* was derived from two questions: “Whether family had financial problems due to child’s condition or the family paid US \$5000, US\$1000–US\$5000, or less than US\$1000 for child’s medical care in the past year, excluding health insurance premiums?” and categorized into two groups: (1) had financial problems/spent US\$1000 for child’s medical care and (2) no financial problems/paid <US \$1000 for child’s medical care. *Employment burden* was derived from a yes/no response to the question “Did the caregiver stop working because of child’s condition?” Time-related burden was asked only to caregivers who provided home-based care and derived from two questions: “Did you provide home-based care?” And for those who provided home-based care, “How many hours did you spend in providing, arranging, and coordinating?” Time-related burden was categorized into three groups: (1) did not provide home-based care, (2) <10 h per week of providing home-based care, and (3) 10 h per week of providing home-based care.

Other independent variables: Demographic variables consisted of child’s age (3–5 years, 6–11 years, and 12–17 years), child’s gender (male, female), child’s race and ethnicity (non-Hispanic Whites, Blacks, Other races, and any Hispanic race), parental marital status (married, single, divorced/widowed/separated, and no parents in the household). Socioeconomic status comprised caregiver income level (100% Federal Poverty Line (FPL), 101%–200% FPL, 201%–400% FPL, and >400% FPL) and caregiver education level (less than high school, high school, and greater than high school). Other variables were as follows: metropolitan statistical area (MSA) status (metro, non-metro, and less than 500,000 area population), geographic region (Northeast, Midwest, South, and West), and type of health insurance (public, private, public/private, other, and none). We also included number of special needs children (one, more than one) in the household, child’s functional ability (never affected, sometimes/very little affected, and always/usually affected), and presence of a physical comorbidity (yes or no).

Statistical analyses

Statistically significant associations between a child's special needs conditions and demographic, socioeconomic status, and other independent and dependent variables were tested with chi-square statistics. Unadjusted and multivariable binary and multinomial logistic regressions were conducted to test the associations between child's special needs conditions (ASDs, DDs without ASDs, MHCs without ASDs, and both DDs/MHCs without ASDs) and measures of access to services, quality of care, and family impact, after controlling for demographic variables, socioeconomic status, number of special needs children in the household, child's functional ability, and presence of a physical comorbidity. The analyses for inadequacy of insurance coverage outcome measure did not include type of health insurance as one of the independent variables. All analyses accounted for the complex survey design of 2009–2010 NS-CSHCN using appropriate clustering, strata, and sampling weights. PROC SURVEYFREQ and SURVEYLOGISTIC procedures were used in the study. Analyses were conducted using SAS 9.3 (SAS Inc.).

Results

Overall, the sample was primarily male (65.0%) and non-Hispanic White (63.1%) children (data not shown in tabular form). Nearly 50% (47.9%) of children were in the age group 12–17 years. Overwhelming majority of caregivers were mothers (76.2%); most of the caregivers were married (57.5%), with greater than high school education (66.7%), and with above 200% FPL income level (52.1%).

Characteristics of the sample by child's special needs condition are summarized in Table 1. In all, 16.1% of the sample were children with ASD; majority of these children were males (79.9%), older (6–17 years; 83.1%), and only a very small proportion (6.2%) had no functional disability (never affected functionally). Of the sample children, 11% had DDs and no ASDs. Children with DDs were primarily in the age group of 6–17 years (73.1%), and 10.1% had no functional disability. Majority of the children in the sample had MHCs and no ASDs (58.3%); these children were primarily in the age group of 12–17 years (55.7%), and 30.1% had no functional disability. There were 14.4% children with both DDs/MHCs; 90.8% of these children were in the age group 6–17 years, and 7.9% had no functional disability.

On further exploration of the data (not shown in tabular form here), it was observed that there were no statistically significant differences in racial composition between ASD and MHC groups. As compared to children with ASDs, those with DDs were less likely (odds ratio (OR) = 0.60, 95% confidence interval (CI) = 0.45–0.81, $p < 0.001$) to be non-Hispanics compared to Hispanic – any race. On the other hand, as compared to children with ASDs, those with both DDs/MHCs were more likely to be non-Hispanic Blacks (OR = 1.81, 95% CI = 1.22–2.67, $0.001 < p < 0.01$), than Hispanic-any race. There were no statistically significant differences in rates of physical co-occurring conditions between children with ASDs and MHCs.

Child's special needs condition and outcomes

Detailed description of the outcome measures and the items used to create the measures are provided in Table 2.

Bivariate analysis—Table 3 summarizes the unadjusted associations between child's special needs conditions and outcomes as measured by access to services, quality of care, and family impact. Numbers and weighted percentages correspond to caregivers who reported problems with the respective outcome measures. Caregiver-reported difficulty using services, difficulty getting referrals, inadequacy of insurance coverage, lack of shared decision making, lack of coordination, financial burden, employment burden, and time-related burden differed by the type of special needs condition.

Access to services—More caregivers of children with ASDs reported difficulty using services (55.0%) than caregivers of children with DDs (43.7%) and MHCs (36.4%). One-third (33.4%) of caregivers of children with ASDs reported insurance coverage as inadequate, as compared to 23.8% of those with DDs and 21.3% of those with MHCs.

Quality of care—Greater proportion of caregivers of children with ASDs reported lack of shared decision making (43.1%), as compared to caregivers of children with DDs (36.4%) and MHCs (31.1%). A significantly greater proportion of caregivers of children with ASDs reported lack of coordination (86.7%) as compared to all other groups (82.2% DDs, 61.0% MHCs, and 80.2% both DDs/MHCs).

Family impact—Financial burden was observed in greater proportion of caregivers of children with ASDs (53.2%) than caregivers of children with DDs (40.7%), MHCs (36.0%), or both (43.0%). Employment burden was observed in greater proportion of caregivers of children with ASDs (38.4%), as compared to caregivers of children with DDs (29.9%), MHCs (11.6%), or both DDs/MHCs (27.0%). Time-related burden was observed in a greater proportion of caregivers of children with ASDs (24.1%) as compared to caregivers of those with MHCs (7.9%) and both DDs/MHCs (18.6%).

Unadjusted and adjusted logistic regression analyses—Tables 4 and 5 display the ORs, adjusted odds ratios (AORs), and 95% CI for unadjusted and adjusted models, respectively, for each measure of the three outcomes: access to services, quality of care, and family impact.

Access to services—Caregivers of children with ASDs were significantly more likely to report difficulty using services as compared to caregivers of children with DDs (AOR = 1.68, 95% CI = 1.30–2.17) and MHCs (AOR = 1.56, 95% CI = 1.31–1.84). Caregivers of children with ASDs were also more likely to report lack of source of care as compared to caregivers of children with DDs (AOR = 1.53, 95% CI = 1.13–2.07), and those with both DDs/MHCs (AOR = 1.32, 95% CI = 1.01–1.73). Caregivers of children with ASDs were more likely to report inadequate insurance coverage as compared to caregivers of children with DDs (AOR = 1.63, 95% CI = 1.20–2.20) and MHCs (AOR = 1.57, 95% CI = 1.30–

1.90). Caregivers of children with ASDs were not different from caregivers of children with both DDs/MHCs in reporting inadequacy of insurance coverage.

Quality of care—Caregivers of children with ASDs were more likely to report lack of shared decision making, as compared to caregivers of children with DDs (AOR = 1.41, 95% CI = 1.10–1.80), MHCs (AOR = 1.53, 95% CI = 1.28–1.82), or both DDs/MHCs (AOR = 1.35, 95% CI = 1.10–1.66). Caregivers of children with ASDs were also more likely to report lack of care coordination as compared to caregivers of children with DDs (AOR = 1.42, 95% CI = 1.06–1.91), MHCs (AOR = 3.31, 95% CI = 2.71–4.04), or both DDs/MHCs (AOR = 1.87, 95% CI = 1.45–2.41). Caregivers of children with ASDs did not differ from caregivers of children in the other three groups, for the number of routine screenings the child had in the past 12 months.

Family impact—Caregivers of children with ASDs were more likely to have financial burden than caregivers of children with DDs (AOR = 1.45, 95% CI = 1.10–1.91) and MHCs (AOR = 1.59, 95% CI = 1.33–1.91). There were no significant differences in report of financial burden between caregivers of children with ASDs and those with both DDs/MHCs. Caregivers of children with ASDs were also more likely to report employment burden, as compared to caregivers of children with DDs (AOR = 1.57, 95% CI = 1.23–2.00), MHCs (AOR = 3.06, 95% CI = 2.51–3.74), and both DDs/MHCs (AOR = 1.73, 95% CI = 1.36–2.20). Time-related burden was also significantly different for the four groups, where caregivers of children with ASDs were more likely to report time-related burden as compared to caregivers of children with MHCs (AOR = 2.87, 95% CI = 2.18–3.78) and both DDs/MHCs (AOR = 1.80, 95% CI = 1.32–2.44).

Discussion

This article set out to examine the association between special needs conditions (ASDs, DDs, MHCs, or both DDs/MHCs) and caregiver-reported issues with access to services, quality of care, and impact of the condition on the family. After adjusting for demographic characteristics, socioeconomic status, number of special needs children in the household, child's functional ability, and presence of a physical comorbidity, overall, caregivers of children with ASDs were more likely to report issues with access to services and quality of care as compared to caregivers of children with DDs, MHCs, or both. Caregivers of children with ASDs were also more likely to report financial, employment, and time-related burden as compared to the other three special needs condition groups. One component of access (getting referrals) and one component of quality (routine screening) were not significantly associated with special needs conditions groups.

In our study, compared to caregivers of children with DDs, MHCs, and both DDs/MHCs, caregivers of children with ASDs were more likely to report difficulty accessing services. A closer examination of the various aspects of this measure indicated that caregivers of children with ASDs had difficulties using services because of eligibility, availability of services, delays in appointments, and difficulty obtaining information about services. For example, 25.8% caregivers of children with ASDs compared to 11.6% caregivers of children with MHCs reported limited availability of services. Caregivers of children with ASDs were

also more likely to report lack of source of care compared to caregivers of children with DDs and those with both DDs/MHCs. Taken together, these findings may highlight access difficulties of children with most complex needs such as children with ASDs due to limited supply of subspecialty care providers in the United States. It is well documented that there is a paucity of pediatric subspecialists' workforce in the United States (Althouse and Stockman, 2011), and this may lead to children not receiving timely care in their region and community of residence.

We also observed significant association between inadequacy of insurance coverage and special needs condition groups. Caregivers of children with ASDs were more likely to report inadequate insurance coverage (when measured as whether the insurance allows to see providers as needed) as compared to caregivers of children with DDs and MHCs. These findings suggest that generous insurance benefits that cover needs of children with ASDs may reduce the caregiver perception of access difficulties. It is also plausible that caregiver-reported insurance inadequacy may decrease over time, as increasing number of states pass legislative mandates for better insurance coverage of behavioral therapies (such as applied behavior analysis) for children with ASDs (National Conference of State Legislatures, 2012).

Except for timely/routine screening (i.e. well-child visits), *quality of care* was poor among children with ASDs (as reported by caregivers) compared to children with DDs, MHCs, and both DDs/MHCs. Caregivers of children with ASDs were more likely to report problems in shared decision making, an important component of family- or patient-centered care (Institute of Medicine (IOM), 2001), as compared to children with DDs, MHCs, and both DDs/MHCs. This study supports prior research by Liptak et al. (2006b), which showed that caregivers of children with DDs and specifically ASDs are more likely to report inability of pediatricians and other primary care providers to understand their concerns, to provide information about their child's condition, and to put parents in touch with other parents of children with similar conditions. Levy and team (*Autism Speaks*, 2012) identified areas which may be barriers to shared decision making based on interviews with 20 primary care providers in a hospital in Philadelphia and 20 parents of children with ASDs. These areas were parent's perception of primary care pediatrician's knowledge and help with autism-related decisions, pediatrician's lack of confidence in their training to advise parents about autism-related treatments, and physicians' discomfort in discussing alternative and complementary medicine. The researchers also suggested that these areas need to be targeted for improving provider-patient shared decision making among caregivers of children with ASDs (*Autism Speaks*, 2012).

Caregivers of children with ASDs were more likely to report lack of care coordination compared to caregivers of children with DDs, MHCs, and both DDs/MHCs. It has to be noted that the care-coordination variable encompasses health-related medical, educational, or social services in the past 12 months. As stated in the introduction (Boulet et al., 2009; Krauss et al., 2003; Liptak et al., 2006a; Volkmar et al., 1999), children with ASDs have extensive health-care needs along with physical, developmental/neurological comorbidities (Boulet et al. 2009; Kohane et al., 2012; Maski et al., 2011) due to which they require services from multiple health-care, educational, and social services providers (Volkmar et

al., 1999). As our care-coordination measure also includes a communication item, one could speculate that caregivers of children with ASDs are also more likely to get in touch with multiple professionals, requiring consistent communication with different types of health-care providers. Enhancing communication skills of both caregivers and the health-care providers and reducing miscommunications among multiple providers may play a significant role in reducing care-coordination problems for children with ASDs. Our study findings also suggest that care coordination may be improved by development of better patient-provider networks and adopting best practices of patient-centered care models.

Impact of the special needs condition on the family was also significantly different across the four special needs conditions. Caregivers of children with ASDs were more likely to report employment burden (leaving a job because of child's condition) compared to all other special needs condition groups analyzed in our study. Employment burden reported by caregivers of children with ASDs highlights that the needs of this group are complex and challenging for the caregivers/families. Such differences are specific to ASDs, rather than being associated with having a child with a special needs condition. Caregivers of children with ASDs were more likely to spend 10 h or more per week in coordinating or arranging home-based care for the child, as compared to caregivers of children with MHCs or both DDs/MHCs. In addition, financial burden was also more likely among caregivers of children with ASDs compared to caregivers of children with DDs and MHCs. All these components may be related. For example, additional time spent on coordinating or arranging home-based care may lead a caregiver to leave job for child care and subsequent loss of income. Loss of income may directly/indirectly add to the financial burden of caregivers of children with ASDs. Impact of ASDs on the family also has implications for caregiver's health-related quality of life. Indeed, some studies have reported that caregivers of children with ASDs not only bear greater financial and time burden associated with child's care but also suffer from poorer health outcomes when compared to the caregivers of children without ASDs (Cidav et al., 2012; Kogan et al., 2008; Wang and Leslie, 2010).

It is interesting to note that caregivers of children with both DDs/MHCs were as likely as caregivers of children with ASDs to report difficulty using services, inadequate insurance coverage, and financial burden. In our study, we observed that children with both DDs/MHCs were more likely to have co-occurring physical conditions as compared to children with ASDs. One could speculate that children with both DDs/MHCs may have extensive health-care needs due to presence of multimorbidity, and this could translate into greater health-care use (Bitsko et al., 2009; Boulet et al., 2009; Gurney et al., 2006). Because of the extensive health-care needs and comorbidity burden common to both the groups, it is possible that caregivers of children with both DDs/MHCs and ASDs share similar experiences in accessing and using services. We also observed that children with both DDs/MHCs were more likely to live in households with lower incomes. Greater use for health-care services of children with both DDs/MHCs due to multimorbidity (Bitsko et al., 2009; Boulet et al., 2009; Gurney et al., 2006) and lower income levels of the households in which children with both DDs/MHCs live may explain absence of significant differences in the likelihood of financial burden among caregivers of children with both DDs/MHCs and ASDs.

This study utilized the most recent NS-CSHCN with a nationally representative sample of CSHCN. To the best of our knowledge, ours is the first study to comprehensively examine caregiver-reported access, quality, and family burden across caregivers of four groups of special needs condition: ASDs, DDs, MHCs, and both DDs and MHCs. Our study also aligns with some goals of Healthy People 2020, such as a focus on increasing the proportion of CSHCN who receive their care in family-centered, comprehensive, and coordinated systems.

However, the limitations of this study need to be considered while interpreting the study findings. This study was limited by the type of DDs and MHCs available in the survey and may not have accounted for other neurologic conditions (e.g. schizophrenia). Our special needs conditions groups (DDs and MHCs) may not be mutually exclusive. ADHD which falls under MHCs in our study may also qualify as a DD. However, DD and MHC categorization used in this study has been used in a previous study by Nageswaran et al. (2011) utilizing the 2005 NS-CSHCN in assessment of difficulty using services across different types of special needs conditions. This study did not establish any validity or reliability of the outcome measures, most of which were adapted from core quality outcomes for CSHCN established by data resource center for child and adolescent health (Maternal and Child Health Bureau, 2011). Therefore, replication of the study results may vary depending on the items used to define the outcome measures. This is a cross-sectional study which does not establish causality of association of type of special needs condition and outcome measures.

Conclusion

Based on our study findings, one can conclude that caregivers of children with ASDs face significant barriers in access to services and face adverse family impact. In addition, children with ASDs also receive poor quality of care compared to caregivers of other special needs conditions (DDs and MHCs). Our findings highlight that children with ASDs form a vulnerable population within the group of DDs that may require greater provider and caregiver attention as compared to children with DDs and MHCs. Our findings also suggest that caregivers of children with ASDs may require services and care that extend beyond that provided by the current health-care system. Public policies and state-level programs are needed to reduce the deficits in health-care services for children with ASDs.

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Table 1

Description of study sample (N = 18,136) by type of special needs condition.

All	ASD		DD, no ASD		MHC, no ASD		DD and MHC, no ASD	
	n	Column weighted %	n	Column weighted %	n	Column weighted %	n	Column weighted %
	2936	16.1%	2036	11.2%	10,688	58.3%	2476	14.4%
Gender ***								
Male	2363	79.9	1176	60.2	6859	62.5	1616	63.4
Female	573	20.1	860	39.8	3829	37.5	860	36.6
Age ***								
3–5 years	415	16.9	539	26.9	341	3.8	183	9.2
6–11 years	1372	47.3	854	44.2	4387	40.6	1116	45.9
12–17 years	1149	35.8	643	28.9	5960	55.7	1177	44.9
Race/ethnicity ***								
Hispanic, any race	310	15.3	269	21.4	1032	14.1	286	15.0
Non-Hispanic Whites	2140	63.5	1354	53.4	7851	66.2	1636	58.1
Non-Hispanic Blacks	203	10.7	207	16.4	914	13.2	297	18.9
Non-Hispanic other	283	10.5	206	8.8	891	6.6	257	8.1
Caregiver education ***								
LT HS	117	7.4	138	12.0	604	12.2	217	16.7
HS	363	16.0	347	24.6	1779	21.0	505	25.5
GT HS	2456	76.7	1551	63.4	8305	66.9	1754	57.8
Poverty level ***								
<100% FPL	459	18.6	431	25.6	1992	23.9	681	34.9
101%–200% FPL	607	21.5	436	26.1	2138	22.3	588	25.8
201%–400% FPL	955	32.0	667	27.6	3225	27.7	719	24.2
>400% FPL	915	28.0	502	20.7	3333	26.1	488	15.1
MSA status								
Non-metro	362	14.7	323	15.6	1592	15.6	432	18.4
Metro	1615	74.6	1069	75.7	5823	74.1	1242	71.3
<500,000 state population	959	10.7	644	8.8	3273	10.3	802	10.3
Region ***								
West	870	24.9	613	23.5	2609	19.4	673	20.5
Midwest	581	18.4	442	22.7	2340	21.7	485	21.6
South	843	33.6	594	35.2	3839	41.5	881	39.4
Northeast	642	23.1	387	18.6	1900	17.4	437	18.6
Marital status ***								
Single	269	9.8	242	17.3	1216	15.0	331	17.5
Married	2095	66.3	1460	64.0	6696	55.5	1446	50.8
Separated/Widowed/Divorced	458	20.2	257	15.9	2010	22.8	488	23.6

All	ASD		DD, no ASD		MHC, no ASD		DD and MHC, no ASD	
	n	Column weighted %	n	Column weighted %	n	Column weighted %	n	Column weighted %
	2936	16.1%	2036	11.2%	10,688	58.3%	2476	14.4%
No Parents in the HH	114	3.8	77	2.8	766	6.8	211	8.1
Number of special children in the HH ***								
One	2373	66.7	1665	68.7	8380	62.2	1863	57.5
Two or more	563	33.3	371	31.3	2308	37.8	613	42.5
Health insurance type ***								
Private	1482	45.1	859	34.3	5988	48.4	887	30.8
Public	829	32.0	701	43.7	3356	38.0	1141	52.3
Both	455	17.5	362	17.3	654	6.6	295	10.5
Other	93	3.0	47	1.5	392	3.4	80	3.0
None	77	2.4	67	3.2	298	3.6	73	3.4
Child's functional ability ***								
Never affected	186	6.2	174	10.1	3521	30.1	208	7.9
Sometimes/very little	786	25.7	630	30.5	4681	42.6	842	33.3
Always/usually	1964	68.1	1232	59.5	2486	27.3	1426	58.8
Co-occurring physical condition ***								
Yes	1468	52.3	1229	66.0	5451	53.9	1470	62.3
No	1468	47.7	807	34.0	5237	46.1	1006	37.7

ASD: autism spectrum disorder; DD: developmental disability (cerebral palsy, Down syndrome, developmental delay, or intellectual disability); MHC: mental health condition (attention deficit hyperactivity disorder, anxiety, behavioral/conduct problems, or depression); LT: less than; GT: greater than; HS: high school; FPL: Federal Poverty Line; MSA: metropolitan statistical area; HH: household; NS-CSHCN: National Survey of Children with Special Health Care Needs.

Based on self-reported data from caregivers (N = 18,136) of children aged 3–17 years who had either ASD, DD, or MHC. All analyses accounted for the complex survey design of 2009–2010 NS-CSHCN. Asterisks represent significant differences in groups based on chi-square tests.

p < 0.001.

Table 2

Description of items used to create outcome measures in the study using 2009–2010 NS-CSHCN.

Outcome measures	Categories	
Access to services		
<i>Difficulty using services</i>		
During the past 12 months, did you have any difficulties or delays getting services for the child with the special needs conditions due to any of the six reasons: eligibility for services, availability of health-care providers, appointments for services, cost of services, obtaining information, or any other reasons?	1	Had difficulty
	2	No difficulty using services (reference)
<i>Difficulty getting referrals</i>		
During the past 12 months, did the special needs child need a referral to see a doctor or receive services and was getting referral a big/small/no problem (three-category variable)?	1	Big/small problem
	2	No problem (reference)
	3	Did not need referral
<i>Lack of source of care</i>		
Usual source of care: Do you have a personal doctor/nurse/ place for routine care/sickness?	1	Lacks usual/specialty source of care/did not receive any specialty care
	2	Has a usual/specialty source of care/received all specialty care needed (reference)
Specialty source of care: During the past 12 months, was there any time the special needs child needed a specialty doctor and did the child receive all/any care?		
<i>Adequacy of health insurance coverage</i>		
Did the child have a health insurance during the past 12 months and does the insurance provide benefits/cover services, or allow to see the health-care provider needed?	1	Does not provide benefits/allows to see providers/no insurance
	2	Provides benefits/allows to see a provider/has insurance (reference)
Quality of care		
<i>Shared decision making</i>		
How often did the health-care providers discuss options of health-care treatments, encourage to raise concerns/questions, make it easy to raise concerns/questions, and consider/respect caregiver treatment choices?	1	Never/sometimes
	2	Usually/always (reference)
<i>Care coordination</i>		
Family Centered Care: Did the child visit a health-care provider or a doctor in the past 12 months. If yes, does the provider: spend enough time with the child with the special needs condition, listen carefully to you, is sensitive to your family values and customs, give specific information to you when needed, or make you feel like a partner in child's care.	1	Did not receive family-centered care/help from health-care providers/somewhat dissatisfied/very dissatisfied with the communication
	2	Received family-centered care/help from provider/satisfied/somewhat satisfied with the communication (reference)
During the past 12 months, did the caregiver need extra help and how often did the caregiver get help in arranging/coordinate among these different health-care providers/services?		
Does anyone in doctor's office/any other person help you arrange/coordinate care among different health-care providers?		
Do doctors or other health-care providers need to communicate with child's school, early intervention program, child care providers, vocational education or rehabilitation program and how satisfied were you with that communication?		

Outcome measures	Categories	
<i>Routine screening</i>		
During the past 12 months, how many times did the child with the special needs conditions need a well-child checkups?	1	None
	2	One/more than one (reference)
Family impact		
<i>Financial burden</i>		
During the past 12 months, did the child’s health conditions cause financial problems and did the family pay <US\$1000, US\$1000–US\$5000, or >US\$5000 for child’s medical care?	1	Yes, had financial problems/spent US \$1000
	2	Had no financial problems/spent <US\$1000 (reference)
<i>Employment burden</i>		
Has the caregiver or any other family member stopped working due to child’s condition?	1	Yes
	2	No (reference)
<i>Time-related burden</i>		
How many hours per week do the caregivers or any other family member spend in providing/arranging/coordinating home-based care for the child with the special needs condition (three category variable)?	1	10 h per week
	2	<10 h per week (reference)
	3	Do not provide home-based care

NS-CSHCN: National Survey of Children with Special Health Care Needs.

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Table 3

Access to services, quality of care, and family impact measures by type of special needs condition (N = 18,136).

All	ASD		DD, no ASD		MHC, no ASD		DD and MHC, no ASD	
	n	Column weighted %	n	Column weighted %	n	Column weighted %	n	Column weighted %
	2936	16.1%	2036	11.2%	10,688	58.3%	2476	14.4%
Access to services								
Difficulty using services ***	1598	55.0	882	43.7	3612	36.4	1215	51.5
Difficulty getting referrals ***	328	11.2	187	11.1	655	7.8	301	12.9
Lack of source of care	536	19.9	297	15.5	1762	19.4	426	18.8
Inadequate insurance coverage ***	965	33.4	412	23.8	2001	21.3	621	29.7
Quality of care								
Lack of shared decision making ***	1167	43.1	616	36.4	2912	31.1	911	38.5
Lack of coordination ***	2469	86.7	1643	82.2	6237	61.0	1966	80.2
No routine screening	318	9.1	188	8.3	1116	10.0	223	8.1
Family impact								
Financial burden ***	1592	53.2	891	40.7	3936	36.0	1077	43.0
Employment burden ***	1031	38.4	577	29.9	1016	11.6	599	27.0
Time burden ***	585	24.1	485	24.7	646	7.9	415	18.6

ASD: autism spectrum disorder; DD: developmental disability (cerebral palsy, Down syndrome, developmental delay, or intellectual disability); MHC: mental health condition (attention deficit hyperactivity disorder, anxiety, behavioral/conduct problems, or depression); NS-CSHCN: National Survey of Children with Special Health Care Needs.

Based on self-reported data from caregivers (N = 18,136) of children aged 3–17 years who had either ASD, DD, or MHC. Difficulty getting referrals and time-related burden were three-category variables. All analyses accounted for the complex survey design of 2009–2010 NS-CSHCN. Asterisks represent significant differences in groups based on chi-square tests. Column percentages are not provided for caregivers who had no reported issues with access to services, quality of care, or adverse family impact.

p < 0.001.

Table 4

Unadjusted ORs and 95% CIs from logistic regressions on measures of access to services, quality of care, and family impact.

Outcome measures	ASD vs MHC		ASD vs DD		ASD vs DD and MHC	
	OR	95% CI	OR	95% CI	OR	95% CI
Access to services						
Difficulty using services	2.13 ***	1.84–2.48	1.58 ***	1.26–1.98	1.15	0.95–1.39
Difficulty getting referrals	1.24	0.96–1.61	1.12	0.79–1.59	0.90	0.67–1.21
Lack of source of care	1.03	0.86–1.24	1.35 *	1.02–1.79	1.07	0.83–1.38
Inadequate insurance coverage	1.85 ***	1.57–2.18	1.61 **	1.20–2.15	1.19	0.96–1.47
Quality of care						
Lack of shared decision making	1.68 ***	1.44–1.97	1.32 *	1.04–1.69	1.21	0.99–1.48
Lack of coordination	4.27 ***	3.56–5.13	1.35 *	1.02–1.78	1.72 ***	1.34–2.20
No routine screening	0.90	0.72–1.13	1.10	0.79–1.52	1.14	0.85–1.52
Family impact						
Financial burden	2.02 ***	1.74–2.34	1.65 ***	1.31–2.08	1.51 ***	1.25–1.82
Employment burden	4.74 ***	3.95–5.68	1.46 **	1.16–1.85	1.69 ***	1.37–2.08
Time burden	3.55 ***	2.75–4.59	1.09	0.78–1.51	1.55 **	1.17–2.06

OR: odds ratios; CI: confidence intervals; ASD: autism spectrum disorder; DD: developmental disability; MHC: mental health condition (attention deficit hyperactivity disorder, anxiety, behavioral/conduct problems, or depression); NS-CSCHN: National Survey of Children with Special Health Care Needs.

Based on self-reported data from caregivers (N = 18,316) of children aged 3–17 years who had either ASD, DD, or MHC. All analyses accounted for the complex survey design of 2009–2010 NS-CSCHN. Multinomial logistic regressions were performed for difficulty getting referrals and time-related burden. In these regressions, the reference groups for the dependent variables were “no difficulty getting referrals” and “no time-related burden.” The reference groups for other dependent variables in the order of appearance are “no difficulty using services,” “presence of a source of care,” “adequate insurance coverage,” “presence of shared decision making,” “satisfactory coordination among and between health care providers,” “routine screening,” “no financial burden,” and “no employment burden.”

p < 0.001;

**
0.001 p < 0.01;

*
0.01 p < 0.05.

Table 5

AORs and 95% CIs from logistic regressions on measures of access to services, quality of care, and family impact.

Outcome measures	ASD vs MHC		ASD vs DD		ASD vs DD and MHC	
	AOR	95% CI	AOR	95% CI	AOR	95% CI
Access to services						
Difficulty using services	1.56 ^{***}	1.31–1.84	1.68 ^{***}	1.30–2.17	1.16	0.95–1.43
Difficulty getting referrals	1.09	0.82–1.47	1.18	0.82–1.70	0.98	0.71–1.35
Lack of source of care	1.09	0.89–1.33	1.53 ^{**}	1.13–2.07	1.32 [*]	1.01–1.72
Inadequate insurance coverage	1.57 ^{***}	1.30–1.90	1.63 ^{**}	1.20–2.20	1.20	0.96–1.49
Quality of care						
Lack of shared decision making	1.53 ^{***}	1.28–1.82	1.41 ^{**}	1.10–1.80	1.35 ^{**}	1.10–1.66
Lack of coordination	3.31 ^{***}	2.71–4.04	1.42 [*]	1.06–1.91	1.87 ^{***}	1.45–2.41
No routine screening	0.95	0.72–1.26	1.08	0.77–1.53	1.23	0.90–1.68
Family impact						
Financial burden	1.59 ^{***}	1.33–1.91	1.45 ^{**}	1.10–1.92	1.23	1.00–1.51
Employment burden	3.06 ^{***}	2.51–3.74	1.57 ^{***}	1.23–2.00	1.73 ^{***}	1.36–2.20
Time burden	2.87 ^{***}	2.18–3.78	1.34	0.97–1.87	1.80 ^{***}	1.32–2.44

AOR: Adjusted odds ratios; CI: confidence interval; ASD: autism spectrum disorder; DD: developmental disability (cerebral palsy, Down syndrome, developmental delay, or intellectual disability); MHC: mental health conditions (attention deficit hyperactivity disorder, anxiety, behavioral/conduct problems, or depression); NS-CSCHN: National Survey of Children with Special Health Care Needs; MSA: metropolitan statistical area.

Based on self-reported data from caregivers (N = 18,136) of children aged 3–17 years who had either ASD, DD, or MHC. All analyses accounted for the complex survey design of 2009–2010 NS-CSCHN. Models were adjusted for child's age, child gender, race and ethnicity, caregiver marital status, caregiver education, caregiver income level, MSA status, geographic region, type of health insurance, number of special children in the house-hold, child's functional ability, and a physical comorbidity. Multinomial logistic regressions were performed for difficulty getting referrals and time-related burden. In these regressions, the reference groups for the dependent variables were "no difficulty getting referrals" and "no time-related burden." The reference groups for other dependent variables in the order of appearance are "no difficulty using services," "presence of a source of care," "adequate insurance coverage," "presence of shared decision making," "satisfactory coordination among health care providers and services," "routine screening," "no financial burden," and "no employment burden."

p < 0.001;

**
0.001 ••p < 0.01;

*
0.01 ••p < 0.05.