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Disparities in Quality and Access to Care for Children with Developmental Disabilities and Multiple Health Conditions

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Abstract
Background The Maternal Child Health Bureau identified six indicators of quality and accessibility essential in achieving coordinated, family-centered, community-based care for children with special healthcare needs (CSHCN). Previous research examined associations between children with single conditions and individual indicators. We sought to identify disparities in meeting quality and accessibility indicators for children with different condition types.
Methods The 2009–2010 National Survey of CSHCN is a nationally representative cross-sectional study with caregiver's reports on 40,242 children (0–17 years). Children were categorized into one of seven conditions groups: physical health (PHC), mental health (MHC), developmental disability (DD), physical and mental (PHC and MHC), physical and developmental (PHC and DD), mental and developmental (MHC and DD) and physical, mental and developmental (PHC, MHC, and DD). Unadjusted and adjusted analyses determined associations between condition group and quality and access indicators.
Results Children with DD, alone or in combination with another condition, were significantly less likely to meet each indicator ($p < 0.01$) after adjusting for individual demographic, child's activity limitations and family-related characteristics. Compared with children with PHC, those with all three conditions (PHC, MHC, and DD) had the lowest odds of access to medical home (61 % decreased odds (DO)), community services (67 % DO), and adequate insurance (26 % DO); MHC and DD had the lowest odds of partnering in decision making (51 % DO); DD had the lowest odds of healthcare transition service (66 % DO).
Conclusions Children with DD and multiple conditions experience disparities in quality and access to healthcare services, meeting most indictors half as often as other CSHCN.

Keywords Children with special health care needs · Maternal and child health · Quality of care

Significance

What's known on this subject Access to quality healthcare is associated with better health for children with special healthcare needs (CSHCN). While access is generally high, caregivers report lower rates of quality. Few studies examine differences in access and quality among specific conditions.

What's this study adds This study is the first to show disparities in care for children with developmental disabilities and multiple conditions utilizing Maternal Children Health Bureau's six core outcomes. Children with developmental disabilities and/or multiple conditions meet quality and access indicators half as often as other CSHCN.

The number of children diagnosed with one or more chronic conditions has increased substantially over the last 20 years with nearly 14 million children reported having a chronic condition or special healthcare need (CSHCN) in the latest national survey (Child and 2012). This largely reflects an increase in children with a developmental, emotional or behavioral health diagnosis (Halfon et al. 2012). Increasingly, physicians must address developmental and behavioral problems in addition to physical health needs. This fundamentally differs from historic

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models of care and is a critically challenge for pediatric systems of care (Halfon et al. 2014).

CSHCN are found to have poorer access to and quality of healthcare services compared with children without special healthcare needs (Houtrow et al. 2011; Nageswaran et al. 2008). Further access and quality of care varies greatly based on the child's actual health condition, functioning level, health insurance status, income level, and region of residence (Lollar et al. 2012; Nageswaran et al. 2008; Strickland et al. 2014). Poor access and quality of care for CSHCN is the result of a variety of problems, such as provider shortages, ineffective coordination, and insufficient health insurance coverage (Chiri and Warfield 2012; Krauss et al. 2003; McGrath et al. 2009). Lack of quality care has been shown to influence rates of emergency department utilization, parental satisfaction, family burden, and exacerbated medical issues (Porterfield and DeRigne 2011; Raphael et al. 2011). Similarly, limited access to preventive and primary care can lead to increased utilization of high-cost healthcare services, decreased functional level, family burden, and avoidable death (Coller et al. 2014; DuPaul et al. 2013; Porterfield and DeRigne 2011).

Improving care for CSHCN is a central goal of the U.S. Health Resources and Services Administration's Maternal Child Health Bureau (MCHB) and Healthy People 2020 objectives. In 2000, the MCHB identified six system of care quality indicators, essential to achieve family-centered, community-based, coordinated care for CSHCN (Table 1) (van Dyck et al. 2002). The six quality and access indicators help to ensure all CSHCN receive needed healthcare services as well as works to address barriers to community living for people the chronic conditions (Maternal and Child Health Bureau 2008). MCHB tracks these indicators as performance measures for all state Title V programs and within the National Survey of Children with Special Healthcare Needs (NS-CSHCN).

Several studies found that few CSHCN (17 %) meet all indicators and that the rates at which CSHCN meet each indicator varies, ranging from 79 % for early and continuous screening to 40 % for healthcare transition services (Strickland et al. 2011, 2014). One study, examining predictors of MCHB indictors found that adolescents with mental health conditions, had significantly lower rates on all indicators than those with physical health conditions (Park et al. 2011). This study did not include children with developmental disabilities or multiple health conditions or children below 12 years of age. Similarly, three studies examining one of the six MCHB indicators found that children with mental health conditions or developmental disabilities had lower rates of community-based services, medical home, and healthcare transition services than children with physical health conditions (Cheak-Zamora et al. 2013; DuPaul et al. 2013; Nageswaran et al. 2011). Among these, Nageswaran and colleagues was the only study that included children with multiple conditions within their analysis (2011). Children with a combination of physical, mental and/or developmental condition/disabilities experienced the greatest disparity as they were four times as likely to experience difficulties using services as those with physical health conditions alone, but the impact of different combinations of conditions was not explored. Together these studies point to disparities in healthcare quality and access for children with mental health conditions, developmental disabilities or multiple conditions compared with children with physical health conditions. To date, no study has examined all six indicators across children with physical, mental or developmental conditions and their possible combinations.

This study will further explicate the extent/nature of healthcare disparities across CSHCN related to the six MCHB indicators utilizing the latest national data by: (1) examining differences in prevalence of each indicator for children with physical health conditions (PHC), mental health conditions (MHC), developmental disabilities (DD) and their combinations (seven groups total), and (2) comparing the receipt of each indicator for every condition group after adjusting for demographic, activity limitation and family-related characteristics.

Table 1 MCHB Indicators

Indicator name	Indicator
Partner in decision-making	Family of CSHCN are partners in decision-making for child's optimal health
Medical home	CSHCN receive coordinated, ongoing, comprehensive care within a medical home
Healthcare transition services (HCT)	Youth with special healthcare needs receive services necessary to make a successful transition to adult life (age 12–17 only)
Community-based services	Community-based service system are organized so CSHCN ca use them easily
Adequate health insurance	CSHCN have adequate private and public insurance to pay for the services they need
Early and continuous screening	CSHCN are screened early and continuously for special healthcare needs

MCHB Maternal and Child Health Bureau, *CSHCN* children with special healthcare needs

Methods

Data and Sample

The 2009–2010 NS-CSHCN was utilized in this cross-sectional study. The NS-CSHCN is a nationally representative random digit-dial land-line and cellular telephone interview sponsored by the MCHB and conducted by the Center for Disease Control and Prevention's National Center for Health Statistics. Screening questions identified parents or legal guardians of CSHCN, age 0–17. In-depth interviews about one CSHCN living in the household were completed by 40,242 parents/caregivers. This study was limited to CSHCN with a physical, mental and/or developmental disability and participants with complete information on one or more of the MCHB indicators (n = 34,689). Additional details about the sampling methodology are available at http://www.childhealthdata.org/learn/NS-CSHCN. The Institutional Review Board at the home university approved all study procedures.

Measures

Condition Groups

As done in previous studies using this data, conditions were grouped into categories based on condition/disability type: physical health, mental health and developmental (Cheak-Zamora et al. 2013; Nageswaran et al. 2011). Physical health conditions (PHC) included Allergies, Asthma, Blood Problem/Condition, Cystic Fibrosis, Diabetes, Heart Problem/Condition, Joint Problems, Migraine/Headaches, Muscular Dystrophy, and Seizures. Mental health conditions (MHC) included attention deficit hyperactivity disorder, anxiety, behavioral problems, and depression. Developmental disabilities (DD) included Autism Spectrum Disorder, Cerebral Palsy, Down Syndrome, and Intellectual Disability/Mental Retardation. Children were divided into one of seven mutually exclusive condition groups: physical only (PHC), mental only (MHC), developmental (DD), physical and mental (PHC and MHC), physical and developmental (PHC and DD), mental and developmental (MHC and DD) and physical, mental and developmental (PHC, MHC, and DD).

Outcome Variables

The six MCHB indicators examine and promote, "family-centered, community-based, coordinated care for CSHCN." Each indicator is constructed from two to five subcomponents or questions asked to caregivers of CSHCN (Strickland et al. 2014). The six indicators included (1) being a partner in decision making, (2) having a medical home, (3) receipt of healthcare transition services, (4) access to community-based services, (5) health insurance adequacy and (6) early and continuous screening. Caregivers of CSHCN 0–17 years of age were asked each question in which indicators were derived except for the healthcare transition services questions. As these questions related to appropriate adolescent care there were only asked of caregivers of adolescents between 12 and 17 years of age (n = 14,223).

Control Variables

Variables associated with one or more of the outcome variables within previous studies were included in the analysis to adjust for possible confounders. Table 2 describes all variables and response options. The child's demographic variables included age, gender, and race/ethnicity. Children's activity limitation was measured using a variable accounting for both the frequency at which daily activity was affected (never, moderately, or consistently) and severity of limitation (very little, some, or a great deal). Family demographic variables included federal poverty status, caregiver's highest level of education, family structure (2-parent household versus one-parent or other), and health insurance status.

Analysis

First, descriptive statistics were used to describe the characteristics of the sample and included the percentage of children within each condition group and the percentage who met each MCHB indicator. Second, Chi-square tests of association and post hoc tests for two proportions, using the Bonferroni method, examined the association between condition group and each MCHB indicator. Third, six logistic regression models were constructed to explore the association between each MCHB indicator and condition group adjusting for individual and family demographics and child activity limitations. Adjusted odds ratios (ORs) and 95 % confidence intervals (CIs) were estimated to examine the association between condition group and each MCHB indicator. PHC served as the reference group for all condition group comparisons. SPSS Complex Samples was used for all analyses to account for the multi-stage stratified sampling design of the NS-CSHCN (IBM SPSS Statistics, IBM Corp. Armonk, NY).

Results

The average age of CSHCN within our study was 10.45 (*SD* = 4.53), with a majority white non-Hispanic males living in a two-parent household (Table 2). The majority of

Table 2 Frequency and prevalence of parent-report of child's current disability and child's demographic and activity limitations and family-related characteristics

Characteristic	PHC	MHC	DD	PHC and MHC	PHC and DD	MHC and DD	PHC, MHC, and DD	Total
Unweighted N %	16,913 (48.8)	6157 (17.7)	1070 (3.1)	6710 (19.3)	1144 (3.3)	1174 (3.4)	1521 (4.4)	34,689
Age, mean	9.08	11.55	8.17	11.78	9.17	10.89	11.05	10.45
Sex (male) %	55.1	65.6	69.8	61.1	64.7	76.9	72.4	60.4
Race/ethnicity %								
Hispanic	16.8	13.7	22	14.6	21.2	15.3	15.6	16
White, non-Hispanic	55.4	68.5	58.7	61.3	51.4	65.2	61.3	59.3
Black, non-Hispanic	19.6	12.1	13.3	16.2	18.3	7.3	14.1	16.8
Other, non-Hispanic	8.2	5.7	5.9	8	9.1	12.3	9	7.9
Level of education by parent %								
Less than high school	8.8	11.9	9.1	14.2	10	11	10.6	10.6
High school graduate	19.1	21.7	19.2	22	23.3	16.4	19.4	20.2
More than high school	72.1	66.4	71.7	63.8	66.7	72.6	69.9	69.2
Income %								
<100 % FPL	19.5	22	18.4	29.2	22.2	16.6	27.3	22.2
100–199 % FPL	20.9	23	24.2	23.4	26.5	19.7	24.4	22.2
200–399 % FPL	29.5	28.3	29.6	25.6	26.4	36.2	27.2	28.5
>400 % FPL	30.1	26.7	27.7	21.7	25	27.6	21.2	27.1
Family structure (two parent household) %	70.1	61.5	78.8	56.5	67.1	67.8	60.2	65.5
Insurance coverage %								
Private	57.7	50.7	45	41.5	33.4	40.9	34.3	50.3
Public	30.3	36.1	31.2	44.2	40.8	33.5	42.1	35.2
Both private and public	5.8	6.8	18.8	7.3	21.1	17.4	17.5	8.1
Other comprehensive insurance	2.9	3.5	2.6	2.8	1.8	3.9	4.2	3
Uninsured	3.2	2.8	2.3	4.2	2.8	4.4	1.8	3.3
Activity limitations %								
Never affected	44.1	32.7	8.8	22.3	7.8	6.7	4.4	32.3
Moderately affect, some of the time	42.5	40.1	25.8	43.1	22.6	26.7	21.7	39.5
Consistently affected, often/great deal	13.4	27.3	65.5	34.5	69.6	66.6	73.9	28.1

Datasource 2009–2010 National Survey of Children with Special Health Care Needs (NS-CSHCN), *N* number, *PHC* physical health condition, *MHC* mental health condition, *DD* developmental disability

caregivers had more than a high school education but income was nearly evenly split between all levels. Half of participants had private insurance, over a third had public insurance and few (3 %) were uninsured. Activity limitation was split nearly equally between the three levels.

Condition Group and MCHB Indicators

The largest condition group was children with a PHC only (49 %) and the smallest was children with DD only (3 %) (Table 2). Over 10,500 (30 %) CSHCN had more than one type of condition. Given the large sample size, many demographic differences were observed. Of particular interest were the distinct differences in activity limitation. Nearly three quarters (74 %) of children with all three conditions (PHC, MHC and DD) reported the highest level of activity limitations. Similarly, over 65 % of children with DD (alone or in combination with another condition) reported severe activity limits. Conversely, caregivers of children with PHC were least likely to report their child had significant activity limitations with only 13 % having the most severe limits.

Receipt of each indicator varied among CSHCN by condition type (Table 3). Caregivers were most likely to report receiving early and continuous screening (80 %) and partnering in decision-making (70 %). Less than half of all caregivers reported receiving healthcare transition services (39 %) or access to a medical home (43 %).

Unadjusted Analyses

All six Chi-square tests of condition groups against MCHB indicators were statistically significant ($p < 0.001$) (Table 3). The PHC group most frequently met all indicators while groups with DD met indicators less frequently than groups without DD. Specifically, children with PHC were most likely to receive five of the six indicators, followed by children with MH and those with PHC and MHC. Children with a DD whether alone or in combination with another condition were the least likely to receive each of the six system of care quality indicators. Early and continuous screening was the only indicator that varied from this pattern. Children with all three conditions and those with MHC received screening most frequently while children with PHC and DD received screening services least frequently.

Post-hoc tests for two proportions indicated that while the PCH group and the MCH group both had relatively high percentage of attaining each indicator, these groups were significantly different from each other and all other condition groups across five of the six indicators (Table 3). Interestingly the PHC and DD group and the MCH and DD group were not significantly different from each other across all six indicators and were similar (not significantly different) to other groups with a DD either together or separately. Likewise, the DD group was similar to others groups with a DD in five out of six indicators. Surprisingly, the group with all three conditions (PHC, MHC, and DD) was significantly different than all other groups across three out of the six indicators and was similar to the MCH and DD group across the other three indicators.

Adjusted Analyses

Condition group was a significant predictor in each regression after adjusting for individual, family and activity limitation variables (Table 4). A pattern in which children with DD were less likely to meet the indicator compared with children with PHC only was generally consistent for most indicators (four of the six indicators). Among the individual, family and activity limitation variables, only health insurance type and activity limitations were significant predictors within each regression.

Partner in Decision Making

All condition groups were significantly less likely to report being partners in medical decision making when compared with children with PHC except those with PHC and DD (Table 3). The odds of being partners in decision making was 51 % lower for caregivers of children with MHC and DD compared with those with PHC (OR 0.493; 95 % CI 0.0383, 0.634). The odds of meeting this indicator was 44 and 33 % lower for children with all three diagnosis (OR 0.555; 95 % CI 0.448, 0.688) and those with DD only (OR 0.672; 95 % CI 0.532, 0.847) compared with children with PHC, respectively.

Table 3 Percentage of CSHCN in different condition groups meeting the criteria for six quality and access indicators

	PHC (%)	MHC (%)	DD (%)	PHC and MHC (%)	PHC and DD (%)	MHC and DD (%)	PHC, MHC, and DD (%)	Total (%)	χ2
Families are partners in decision-making	75.1^{a}	70.4^{b}	$62.7^{c,d}$	66.1^{d}	$65.6^{c,d}$	55.2^{e}	56^{e}	70.2	565*
Receiving care with medical home	50.6^{a}	42.1^{b}	31.2^{c}	36.6^{d}	31.5^{c}	26.5^{c}	20.7^{e}	42.9	1058*
Receive health care transition services	47.8^{a}	40.5^{b}	19.1^{c}	34.5^{d}	20.5^{c}	24.9^{c}	21.1^{c}	39.4	463*
Can easily access community resources	72.8^{a}	67.5^{b}	56.3^{c}	54.7^{c}	51.5^{d}	48.7^{d}	33.8^{e}	64.4	1724*
Adequate insurance to pay for services	64.2^{a}	63.4^{a}	$53.8^{b,c}$	55.5^{c}	56.6^{c}	$53.1^{b,c}$	48.9^{b}	60.6	330*
Screened early and continuously for CSHCN	$78.5^{a,b}$	81.4^{c}	71.3^{d}	82.1^{c}	$76.5^{b,d}$	$79.7^{a,b,c}$	$82.3^{a,c}$	79.6	107*

Datasource 2009–2010 National Survey of Children with Special Health Care Needs (NS-CSHCN), *CSHCN* children with special health care needs, *SE* standard error, *PHC* physical health condition, *MHC* mental health condition, *DD* developmental disability

* p value < 0.001; Superscript letters denotes a subset of condition group in one variable categories whose column proportions do not differ significantly from each other at $p < 0.05$ level (Subgroup comparisons were conducted without weight adjustments, all other analysis adjusted for multi-stage stratified sampling design)

Table 4 Receipt of each system of care quality indicator for children with differing disabilities

	Adjusted odds ratios (95 % CI)					
	MHC	DD	PHC and MHC	PHC and DD	MHC and DD	PHC, MHC, and DD
Family shares in decision making (n = 33,731)	0.83 (0.73–0.94)	0.67 (0.53–0.85)	0.76 (0.67–0.87)	0.83 (0.58–1.18)	0.49 (0.38–0.63)	0.56 (0.45–0.69)
Receiving care with medical home (n = 33,009)	0.76 (0.68–0.85)	0.60 (0.47–0.76)	0.70 (0.63–0.78)	0.70 (0.52–0.93)	0.48 (0.38–0.61)	0.39 (0.31–0.48)
Receive health care transition services (n = 14,223)	0.82 (0.69–0.96)	0.34 (0.22–0.54)	0.74 (0.63–0.88)	0.46 (0.27–0.80)	0.43 (0.30–0.62)	0.51 (0.36–0.71)
Can easily access community resources (n = 33,808)	0.87 (0.76–0.98)	0.79 (0.62–0.99)	0.57 (0.51–0.64)	0.69 (0.48–0.99)	0.59 (0.46–0.76)	0.33 (0.27–0.41)
Adequate insurance to pay for services (n = 33,694)	1.05 (0.93–1.18)	0.82 (0.65–1.02)	0.83 (0.74–0.92)	0.96 (0.69–1.33)	0.84 (0.64–1.09)	0.74 (0.61–0.90)
Screened early and continuously for CSHCN (n = 33,728)	1.16 (0.99–1.35)	0.78 (0.61–1.01)	1.29 (1.12–1.48)	1.04 (0.79–1.37)	1.19 (0.88–1.60)	1.39 (1.07–1.79)

CI confidence interval, *PHC* physical health condition, *MHC* mental health condition, *DD* developmental disability

Access to a Medical Home

All condition groups were significantly less likely to have a medical home when compared with children with PHC. The odds of having access to a medical home were 61 % lower for children with all three condition (PHC, MHC, and DD) compared with those with a PHC (OR 0.386; 95 % CI 0.308, 0.483). Similarly, the odds of having a medical home were 52 % lower for children with MHC and DD (OR 0.478; 95 % CI 0.376, 0.608) and 40 % lower for those with DD (OR 0.598; 95 % CI 0.473, 0.757) compared with a child with a PHC.

Receipt of Healthcare Transition Services

Similar to the medical home, all condition groups were significantly less likely to receive healthcare transition services compared with the PHC group. While children with DD alone were the least likely to receive healthcare transition services (OR 0.343; 95 % CI 0.218, 0.538), the odds of receiving healthcare transition services were half as likely for all children with a combination of conditions in which DD was present compared with PHC.

Easy Access to Community-Based Services

Children with all three conditions, were the least likely to have access to community-based services (OR 0.328; 95 % CI 0.266, 0.405), followed by children with PHC and MHC (OR 0.570; 95 % CI 0.507, 0.641) and children with MHC and DD (OR 0.589; 95 % CI 0.456, 0.760). The odds of having access to community-based services were 41–67 % lower for children within these groups compared with those with PHC. This access indicator reflected similar patterns observed for the previous three indicators.

Adequate Health Insurance

Condition group was significantly associated with reporting adequate health insurance for children with all three conditions (OR 0.738; 95 % CI 0.605, 0.900) and PHC and MHC (OR 0.826; 95 % CI 0.738, 0.924). The odds of having adequate health insurance was 17–26 % lower for children with all three conditions and PHC and MHC compared to children with PHC.

Access to Early and Continuous Screening

Unlike all other findings, children with a condition other than PHC were more likely to have access to early and continuous screening. The odds of receiving early and continuous screening were 39 % higher for children with all three conditions compared with children with PHC (OR 1.386; 95 % CI 1.072, 1.792). The odds of receiving this screening were 29 % higher for children with PHC and MHC compared with those with PHC (OR 1.287; 95 % CI 1.118, 1.481).

Discussion

This was the first study to examine all MCHB indicators for children with different condition types. Although the majority of children within our sample had a physical condition (49 %) over 10,000 had multiple conditions (30 %). Children with multiple conditions and/or DD were the most likely to report significant activity limitations which increase reliance on healthcare and community-based services (Newacheck and Kim 2005). Unfortunately, our findings show children with DD alone or in combination with another condition were less likely to receive quality healthcare and had difficulties accessing community-based services. This study demonstrates the disparity in quality of care for children with DD and multiple conditions compared with children with PHC even after adjusting for confounding variables like severity of impairment. Analyzing condition groups separately provides a more accurate picture of how the healthcare system functions for all CSHCN and suggests a duty to consider the unique needs of children with DD and multiple conditions. It further clarifies inconsistent findings in previous research that combined all indicators into one component measure (Beal et al. 2004; Chen et al. 2012).

Although preliminary, our work also demonstrates how disparities in healthcare for different condition groups play out differently across the six indicators. Based on analysis by Chen et al. (2012) and our examination of the indicators, we suggest there may be two separate concepts reflected within the six indicators—quality and access. Indicators reflecting quality would include (#1–3) being a partner in decision making, having a medical home, and receipt of healthcare transition services. Indicators reflecting access would include (#4–6) access to community-based services, health insurance adequacy and early and continuous screening.

Quality Indicators: Decision Making, Medical Home and Healthcare Transition

In general, quality indicators were met by CSHCN less often than access indicators. These three indicators followed the similar partners in the unadjusted and adjusted analyses. Children with DD alone or in conjunction with another condition were least likely to meet all three quality indicators. Similar patterns have been shown in previous research on individual condition groups and individual MCHB indicators including Community-based services, Medical Home and Healthcare Transition (Cheak-Zamora et al. 2013; DuPaul et al. 2013; Nageswaran et al. 2011; Vohra et al. 2014). Research on other measures of quality of care report that caregivers of children with DD express lower satisfaction of the care they receive (Liptak et al. 2006). Children with DD and MHC may lack quality care due to inadequate provider training about these conditions in children and provider knowledge and comfort with treating health issues outside the traditional “medical” realm (Strickland et al. 2014; Vohra et al. 2014). Further, children with multiple conditions, particularly DD, require care from multiple subspecialists requiring significant care coordination and multiple referrals (Nageswaran et al. 2011).

Although the negative effects of poor quality are clear for the general population, little is known about the impact on CSHCN. The lower quality of care for this vulnerable population—children with DD and multiple conditions—must be addressed by further research and targeted interventions (Chen et al. 2012). Interventions such as enhanced care coordination can help these families by ensuring quality services, educating family and involving them in decision making, and providing psychosocial screening and referrals to community services based on the family’s needs (Fedele et al. 2014; Litt and McCormick 2015).

Access Indicators: Community-Based Services, Health Insurance, and Screening

Access-related indictors were met by the majority of CSHCN (60 % or more). While unadjusted analysis of these variables showed significant disparities for children with DD, not all adjusted analyses followed the same patterns. While children with DD and multiple conditions were less likely to have access to community-based services only children with all three conditions and those with PHC and MHC were less likely to have adequate health insurance. Although the patterns across condition groups were different, children with multiple conditions were much less likely to receive all access indicators, except early and continuous screening, compared with children with PHC.

Our results were similar to studies focusing on children with complex medical needs and those with Autism Spectrum Disorder (Kenney and Mann 2013; Kogan et al. 2008; Montes et al. 2009; Vohra et al. 2014)). Nageswaran et al. (2011) found that children with DD, MHC, or multiple conditions reported less “ease of (service) use” compared with children with PHC. Our findings solidify the idea that children with multiple conditions are at greater risk for a lack of access to and insurance coverage for needed services. These children’s need for subspecialty care may make access more difficult due to a fragmented and limited health care system, lack of needed providers, and high out-of-pocket costs (Busch and Barry 2009; Nageswaran et al. 2011). For some conditions, such as Autism Spectrum Disorder, the child’s service needs, although important, may be beyond the scope of the current health care system, particularly in communities with few health care resources. More research is needed to examine what community-based services are unmet and what burden lack of adequate health insurance is putting on families of CSHCN.

System Level Changes

Full implementation of the Patient Protection and Affordable Care Act (ACA) should alleviate some disparities in quality of care by assisting families in obtaining a medical home, increasing reimbursements for care coordination, and implementing chronic care management models. Increasing dependent coverage for youth up to 26 years of age as well as elimination of life-time limits and denial of coverage for preexisting conditions should improve access for many CSHCN as they age. Specific policies, innovative delivery models and targeted outreach efforts must be developed for families with children with DD and multiple conditions to support engagement in available services and increase advocacy for quality of care (Cohen et al. 2011).

Our mixed findings warrant additional examination of the indicator early and continuous screening. The two questions that make up this indicator ask if the child had one “preventative medical” and “preventative dental” visit within the last 12 months (Child and 2012). This indicator may be examining basic service utilization rather than quality or access to care which may explain why children with multiple conditions, and presumably higher service use, were more likely to meet this indicator, yet less likely to meet all other indicators. Families with high medical utilization may have greater difficulty recalling all visits accurately and differentiating a preventative visit from a symptom-based visit (Jobe et al. 1990). Further, few studies have utilized this indicator as a predictor, and of these, most found no association between screening and other quality and access indicators and did not deviate across condition or disability groups of CSHCN (Kenney and Mann 2013). It is important for future studies to examine the validity of this indicator and its utility within our national survey.

Limitations

The current study has several limitations. First, the cross-sectional methodology of this survey does not permit examination of a causal relationship between condition type and MCHB indicator. Second, as with all surveys, caregiver reports were used and are subjective in nature. This may be a particular problem for the reporting of health condition diagnosis as some specific conditions may be difficult to recall or are over-reported. Similarly, the list of chronic conditions included in this study was not exhaustive and may have excluded important although less frequent conditions. Despite these limitations, this study makes a unique contribution by examining the disparity in quality and access to care for children with differing types of conditions using up-to-date data from one of the largest, nationally representative samples of CSHCN.

Conclusion

This is the first study to examine the prevalence of all six MCHB indicators among children with different conditions/disabilities. While many state and federal public health agencies utilize MCHB indicator data to promote policy and community-partnerships, these agencies may miss important disparities across CSHCN by examining them in aggregate. This study demonstrates that children with DD with and without additional conditions experience significant disparities in quality of and access to healthcare services. In most cases, children with a DD had 20–30 % decreased odds to meet the quality indicators compared with children with PHC. Similarly, children with DD and another condition had as much as 40 % decreased odds to meet community-based services and 15 % decreased odds to have adequate health insurance. Further, state and federally funded programs must be evaluated for improved quality and access for all condition groups throughout each phase of program development and implementation rather than within pre and post-measures (Strickland et al. 2011).

Education and training for providers is essential to ensure they understand the needs of people with DD and/or multiple conditions and are working to address quality and access issues. Quality of care has improved greatly in the past decade but these changes have not fully reached children with the greatest need (Cohen et al. 2011). Developmental disabilities, particularly when combined with other type of health conditions, present a substantial challenge for service providers and families in achieving the best care. Practitioners should strive to incorporate quality improvement initiatives such as the medical home model and enhance care coordination for all patients but particularly those with DD and multiple conditions. Further, policy and funding streams must be established to support practitioner’s efforts to provide quality of care to this growing, vulnerable population.

Compliance with Ethical Standards

Conflict of interest The authors declare that they have no conflict of interest.

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