



Predictors of Unmet Family Support Service Needs in Families of Children with Special Health Care Needs

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Abstract

Objectives This study describes rates of perceived and unmet need for family support services (care coordination, respite care, and family mental health care) among a national sample of children with special health care needs (CSHCN), distinguishing children with emotional, behavioral, or developmental problems (EBDPs) from children with primarily physical chronic conditions. It also examines if a child having EBDPs is associated with perceived and unmet family support service needs and investigates public versus private health insurance's moderating effect on this association.

Methods Using data from the National Survey of Children with Special Health Care Needs (2005/2006 and 2009/2010), this cross-sectional study uses multi-level, fixed effects logistic regression.

Results When compared to CSHCN with no EBDPs, parents of CSHCN with EBDPs report greater need for all family support services and greater rates of unmet need for all support services. This pattern of greater need for CSHCN with EBDPs versus those without is similar among those with public and private health insurance. Among CSHCN with family support needs, however, the pattern differs. For CSHCN with EBDPs, having public insurance is associated with lower probabilities of unmet needs compared to private insurance. For CSHCN without EBDPs, having public insurance has a mixed effect on probability of reporting unmet need.

Conclusion Having EBDPs and public insurance is associated with increased perceived need, but public insurance also confers particular benefit for children with EBDPs.

Keywords Child behavioral health · Children with special health care needs · Medicaid · Health services · Health financing

Significance

Among children with special health care needs (CSHCN), those with emotional, behavioral, or developmental problems (EBDPs) have greater need for family mental health and care coordination services. CSHCN with EBDPs who have public health coverage have lower odds of unmet behavioral health care needs due to costs. This study demonstrates that for all CSHCN, having EBDPs is also associated with greater odds of reporting need for respite care. EBDPs are associated with having unmet family mental health, care

coordination, and respite needs among privately insured CSHCN. Public coverage is associated with reductions in unmet respite need for CSHCN with EBDPs.

Objectives

Children with special health care needs (CSHCN) have an ongoing physical, developmental, behavioral, or emotional condition that requires levels of health care or other support service use that are greater than the majority of other children (McPherson et al., 1998). Among this group of children, common conditions include asthma, allergies, anxiety, Attention Deficit Hyperactivity Disorder (ADHD), and behavioral disorders (Kenney & Chanlongbutra, 2020). A minority of CSHCN have more disabling conditions, such as developmental or intellectual disabilities, diabetes, cerebral palsy, epilepsy, and brain injuries (Child and Adolescent Health Measurement Initiative, 2012b). Parents of CSHCN

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experience significant strain and stress related to caring for their child's special needs, and the enormous burden of caregiving can decrease a parent's ability to provide care, impacting the health of the child, the parents, and overall family functioning (Nygård & Clancy, 2018).

Approximately 30% of CSHCN have emotional, behavioral, or developmental problems (EBDPs). These problems can consist of various concerns, including anxiety, depression, autism, or cognitive or intellectual delays (Blanchard, et al., 2006). Families of children with EBDPs may be particularly at risk for negative family experiences. Compared with parents of children with other types of special needs, those whose children have emotional or behavioral concerns experience greater financial strain and employment impacts (Vohra et al., 2014), are more likely to end their relationship in separation or divorce (Wei & Yu, 2012), and siblings often exhibit adjustment difficulties (Kilmer et al., 2010). Compared to families of children with only physical health care needs, those with EBDPs are also more likely to report more difficulty navigating and engaging with health service systems (Nageswaran et al., 2011; Vohra et al., 2014).

To manage these challenges, parents of CSHCNs with EBDPs report the need for family support services: care coordination, respite services, and therapeutic and peer support (Lutenbacher et al., 2005). Care coordination is associated with reductions in unmet mental and specialty care needs, more timely receipt of services, better provider-family relationships and service engagement, and greater use of shared decision-making (Cordeiro et al., 2018). Respite is time-limited care for a disabled child provided to give time off for the caregiver; it can relieve stress and increase coping for parents and caregivers and can reduce out of home placements for the child (Strunk, 2010). Therapeutic and peer support can reduce mental health symptoms in parents (Silverstein et al., 2018).

Unfortunately, though families whose children have EBDPs express the greatest need for family support services, this group of families is more likely to report that these needs are unmet (Brown et al., 2014; Inkelas et al., 2007; Nageswaran, 2009). These specialty services are often inaccessible due to cost and availability barriers (Lutenbacher et al., 2005). Commercial or private health insurance—often provided through parents' employers or paid for out-of-pocket by families—rarely provides payment for these types of specialized, community-based services (Graaf & Snowden, 2020). Though mental health parity legislation and the essential health benefits mandated under the Affordable Care Act (2010) aimed to increase behavioral and other specialized health care coverage under private insurance, many private insurance carriers were exempt as large group or self-insured plans (Uberoi, 2015). Further, state control of implementation resulted in significant variation in coverage across states (Grace et al., 2014). Neither law required coverage for family-focused services such

as case management, respite, or parent peer support (Bailey & Davis, 2012). Nor were the Affordable Care Act's (ACA) coverage mandates aimed at increasing access to these services for CSHCN (Keller & Chamberlain, 2014). Even the ACA's support for care coordination models is geared primarily towards the adult population—particularly in behavioral health (Voursney & Huang, 2016). In contrast, public Medicaid insurance benefits—most often conferred as a result of poverty or disability—often cover a rich array of specialty and behavioral health services for children and families, including care coordination or case management, parent support or family therapy, and respite care (Howell, 2004).

Given the differences in benefits and coverage for family support services between public and private insurance, several studies demonstrate that children with EBDPs who have public coverage have lower odds of unmet behavioral health care needs and fewer experiences of encountering cost barriers to needed care (Graaf & Snowden, 2019; Thomas et al., 2016). However, research focusing on access to family support services for CSHCN with EBDPs is limited with mixed findings (Brown et al., 2014; Inkelas et al., 2007; Lutenbacher et al., 2005; Nageswaran, 2009).

This study describes rates of perceived and unmet need for family support services among a national sample of CSHCN, distinguishing children with EBDPs from children with primarily physical conditions. It examines if a child having EBDPs is associated with perceived and unmet family support service needs and investigates the moderating effect of health insurance type on this association. The hypothesis is that having EBDPs and public insurance will be associated with increased perceived need, but that public insurance will confer particular benefit for children with EBDPs and be associated with the greatest reduction in unmet need for this group of CSHCN. The study uses the Behavioral Model for Vulnerable Populations, which indicates the individual and family-level factors associated with health care use. These factors include predisposing characteristics such as age and race; enabling characteristics such as insurance, income, and education; need such as condition type and severity; and context such as supply of services and urbanicity that lead to health service use (Andersen, 1995). This model guides our focus on the interaction of health insurance type and EBDPs, controlling for other model components to assure fully specified modeling.

Methods

Data and Sample

This study draws data from two waves of the National Survey of Children with Special Health Care Needs (NS-CSHCN), conducted from 2005 to 2006 and 2009 to 2010 (Blumberg

et al., 2008; Bramlett et al., 2014). The 2005/2006 and 2009/10 NS-CSHCN both capture comprehensive state- and national-level parent-reported information on children and youth's health status and health care service experiences with special health care needs (CSHCN) and their families. They include detailed information on family support services not available in the more current 2016–2020 National Surveys on Children's Health. The interview completion rate for 2005/2006 and 2009/2010 was 68.7% and 83.65%, respectively, and survey data are weighted to reflect the population of non-institutionalized children ages 0–17 years at the state and national levels.

The analysis dataset includes only children identified as CSHCN through the Children with Special Health Care Needs Screening Tool (Bramlett et al., 2009). The CSHCN Screener is a parent-report survey tool developed and validated to specifically identify children who meet the federal Maternal and Child Health Bureau's definition of SHCN, based on a health-consequences model. To qualify as a CSHCN through this tool, a child must experience one or more of the following health consequences due to a medical, behavioral, or other health condition that has lasted (or is expected to last) for at least twelve months: need for or use of prescription medications; elevated need for or use of medical, mental health, or educational services; functional limitations; need for or use of special therapies; or emotional, developmental, or behavioral conditions that require treatment.

Data from both years of the survey were pooled, for a total initial sample size of 80,965. Changes to the survey made between data collection waves that affected the current study were minimal (Child and Adolescent Health Measurement Initiative, 2012a). To adjust for the addition of cell-phone sampling in the later wave of data collection, recommended adjustments to data stratification and weighting were made (Bramlett et al., 2014). Analysis included only the subsample of children insured continuously for the past twelve months with either public or private insurance. Children whose parents responded "Don't Know" or "Refused to Answer" regarding the child's sex were excluded (<0.01%). These criteria yielded a final analytical sample of 74,221. This study was deemed exempt from human subjects' oversight by the *omitted for blinding*.

Independent Variables

Insurance Type captures type of health coverage at the time of the interview: "Private insurance" for children with *only* insurance provided through an employer, union, or the military, and "Public insurance" for children with any type of Medicaid, CHIP, Medicare, or Medigap coverage (where eligibility is conferred based on complex rules regarding

poverty or disability of the child or sometimes the parent), either alone or in conjunction with private insurance.

Emotional, Behavioral, or Developmental Problem. If a parent reported on the Children with Special Health Care Needs Screening Tool that a child had any ongoing emotional, developmental, or behavioral problem for which they need treatment or counseling, the child was coded as having an EBDP.

Dependent Variables

Family Support Services. *Perceived Care Coordination Need* is a binary variable representing families who reported that they could have used extra help coordinating their child's care among different health care or service providers in the last twelve months. *Unmet Care Coordination Need* is a binary variable that identifies when a parent reported "never" or "sometimes" getting as much help as they wanted with arranging their child's care during the past twelve months.

Perceived Respite Need is a binary variable that identifies when a parent reported a need for respite services in the past twelve months. *Unmet Respite Care Need* is a binary variable that identifies when a parent reported unmet respite care needs in the past twelve months.

Perceived Family Mental Health Need is a binary variable capturing children whose parents reported a need for family mental health services in the past twelve months. *Unmet Family Mental Health Need* is a binary variable that identifies when a parent reported any unmet family mental health service need in the past twelve months.

Control Variables

Selection of control variables for models was guided by the Behavioral Model for Vulnerable Populations (Gelberg et al., 2000). We control for other need (condition severity), predisposing (age, sex, race) and enabling factors (income, family language, household structure, parent education), and context (urbanicity, supply of mental health facilities, state mental health spending per capita, and year).

Child control variables include child predisposing characteristics: race/ethnicity (White only, Black Only, Hispanic-Black or White, and Other), sex (male or female), age (0–3 years, 4–12 years, and 3–17 years) and additional child need: condition severity [condition affects child's ability to do things very little or sometimes (0) or usually (1)]. Family-level enabling characteristics include income level (0–199% FPL, 200% FPL or greater), parent language (English or not), parent education level (less than high school, and high school or more), and household structure [less than two adults (0) or two or more adults in the household (1)].

Context was captured with urbanicity (living in states with few metropolitan statistical areas (MSAs) was classified as non-urban (MSA = 0) and living in states with large numbers of MSAs was classified as urban (MSA = 1) (Dusing et al., 2004). State Mental Health Authority expenditures per capita for 2009 drawn from the Centers for Mental Health Services (CMHS) Uniform Reporting System and captures the size of the local mental health safety net (Frank et al., 2003). To further control for the influence of provider supply (Cook et al., 2013), the total number of mental health providers and facilities, drawn from the Substance Abuse and Mental Health Data Archive's (SAMHDA) 2010 National Mental Health Services Survey (N-MHSS), captures the size of the mental health treatment network in each state. Year of data collection is binary to control for trends of system expansion over time (2005 = 0, 2009 = 1) (Mark et al., 2011).

Analysis

Descriptive analyses identified key characteristics of the full sample and by EBDP status. Descriptive analysis also examined reported sample size and proportional differences of parent report of perceived and unmet needs for CSHCN with public insurance, with EBDPs, and by EBDP and insurance status.

Fixed effects logistic regression models estimated the association between health insurance type, child EBDP status, their interaction, and perceived and unmet family support needs. Unmet need models were estimated among the samples of children with reported need for each type of family service, respectively. Models controlled for predisposing, enabling, need, and contextual factors. Because some state Medicaid plans provide coverage for care coordination and family peer support while others do not, models with random effects for states were also generated. Results were similar to fixed effects models; thus, final models used fixed effects for parsimony. For ease of interpretation of the model results, we calculated marginal effects for insurance type, EBDP status, and their interactions (regression model results are presented in the supplement). Margins reflect predicted probabilities of outcomes associated with each of the factors, controlling for all other covariates. Wald-tests estimate significance of differences in predicted probabilities between groups. All models used survey sampling weights to adjust for the complex survey design. Analyses were conducted in Stata 16 MP.

Results

Table 1 displays the characteristics of the analytic sample. Most of the sample is White (62%), speaks English (96%), and has family incomes above 200% of the FPL (57%) with private insurance (55%). Descriptive results portray the proportions of parents reporting need and unmet need for each family support service. Much larger proportions of parents of children with EBDPs report perceived need for care coordination (34%), respite (13%), and family mental health (31%) when compared to parents of children with no EBDPs (12%, 3%, and 4%, respectively). This larger proportion holds for parent report of unmet family support needs as well.

Table 2 displays unadjusted proportions of CSHCN with and without EBDPs, and with private and public insurance, who report need and unmet need for family support services. Rates of unmet need are expressed as proportions of the whole sample and proportions of those with need. The proportions reporting need vary across subgroups, with CSHCN with EBDPs having higher rates of reported need, and CSHCN with EBDPs who have public insurance reporting need most frequently. This is the case for each type of family support service. Among those reporting need, 72–85% report unmet need for care coordination, 32–57% for respite, and 14–23% for family mental health services.

Table 3 illustrates adjusted rates of need and unmet need for each service (adjusted predicted probabilities from our logistic regressions; see “Appendix” for outcomes from logistic regressions). These characterize the effect sizes for differences between CSHCN with and without EBDPs and for CSHCN with private insurance versus public insurance. This table shows that for CSHCN with private insurance, the probability of reporting need for all family support services is significantly higher for those with EBDPs than for those without (Care Coordination = 0.28 vs. 0.11, Respite Care = 0.05 vs. 0.01, Family Mental Health = 0.26 vs. 0.03). For CSHCN with public insurance with and without EBDPs, the pattern is similar. The marginal effect of public (vs. private) insurance for CSHCN with EBDPs is 0.00 for care coordination need ($p < 0.89$), 0.13 for respite need ($p < 0.00$), and 0.02 for family mental health need ($p < 0.07$).

Among CSHCN with family support needs, the pattern reverses regarding probabilities of unmet need. For CSHCN with EBDPs, having public insurance is associated with lower probabilities of reporting unmet need. The marginal effect of public (vs. private) insurance is -0.06 for unmet care coordination needs ($p < 0.01$), -0.12 for unmet respite needs ($p < 0.00$), and -0.01 for unmet family mental health needs ($p < 0.85$). For CSHCN without EBDPs, having public insurance has a mixed effect on probability of reporting unmet need. The marginal effect of public (vs. private) insurance is -0.07 for unmet care coordination needs ($p < 0.01$), 0.05 for unmet

Table 1 Children with special health care needs sample characteristics

| | Full Sample | | Non-EBDP | | EBDP | |
|--|-------------|----------------|------------------|----------------|------------------|----------------|
| | n = 79,393 | | n = 56,837 (70%) | | n = 24,128 (30%) | |
| | N | % ^a | N | % ^a | N | % ^a |
| Insurance type | | | | | | |
| Only private | 47,942 | 55 | 37,713 | 64 | 11,121 | 44 |
| Any public | 20,671 | 32 | 15,604 | 36 | 11,379 | 56 |
| Severity | | | | | | |
| Mild or moderate | 30,550 | 36 | 26,594 | 44 | 3956 | 16 |
| Severe | 50,415 | 64 | 30,243 | 56 | 20,172 | 84 |
| Race | | | | | | |
| White only | 56,639 | 62 | 40,495 | 62 | 16,613 | 61 |
| Black only | 7343 | 16 | 5713 | 16 | 2501 | 16 |
| Hispanic (black or white) | 8383 | 14 | 5716 | 14 | 2779 | 15 |
| Other | 7028 | 8 | 4913 | 8 | 2235 | 7 |
| Household income | | | | | | |
| 0 to 199% FPL | 28,929 | 43 | 18,683 | 39 | 10,836 | 51 |
| 200% of FPL and above | 50,464 | 57 | 38,154 | 61 | 13,292 | 49 |
| Parent education level | | | | | | |
| High school or less | 16,135 | 30 | 10,643 | 29 | 5866 | 0 |
| More than high school | 63,182 | 70 | 46,140 | 71 | 18,234 | 100 |
| Age group | | | | | | |
| 0–3 years | 7284 | 11 | 6451 | 14 | 1004 | 5 |
| 4–12 years | 43,163 | 55 | 30,453 | 54 | 13,567 | 56 |
| 13–17 years | 28,946 | 34 | 19,933 | 33 | 9557 | 39 |
| Sex | | | | | | |
| Male | 47,367 | 59 | 32,467 | 57 | 15,822 | 64 |
| Female | 31,882 | 41 | 24,257 | 43 | 8274 | 36 |
| Adults in household | | | | | | |
| One | 10,946 | 17 | 6,845 | 15 | 4504 | 22 |
| Two or more | 67,851 | 83 | 49,992 | 85 | 19,624 | 78 |
| Language | | | | | | |
| Survey in english | 76,573 | 96 | 54,862 | 96 | 23,215 | 95 |
| Survey not in english | 1972 | 4 | 1349 | 4 | 667 | 5 |
| Urban/rural residence | | | | | | |
| Rural resident | 24,609 | 18 | 17,225 | 18 | 7384 | 17 |
| Urban resident | 56,287 | 82 | 39,566 | 82 | 16,721 | 83 |
| Year | | | | | | |
| 2005 | 39,902 | 48 | 28,987 | 49 | 11,736 | 45 |
| 2009 | 39,491 | 52 | 27,850 | 51 | 12,392 | 55 |
| Care coordination (CC) need | | | | | | |
| Perceived care coordination need | 13,206 | 19 | 5854 | 12 | 7352 | 34 |
| Unmet care coordination need | 10,504 | 15 | 4469 | 6 | 6035 | 8 |
| Respite care (RC) need | | | | | | |
| Perceived respite need | 4356 | 6 | 1309 | 3 | 3126 | 13 |
| Unmet respite need | 2103 | 3 | 460 | 1 | 1683 | 7 |
| Family mental health (FMH) need | | | | | | |
| Perceived family mental health need | 9195 | 12 | 2080 | 4 | 7313 | 31 |
| Unmet family mental health need | 2157 | 3 | 390 | 1 | 1806 | 8 |

Data Source: NSCSHCN, National Survey of Children with Special Health Care Needs, 2005/2006 & 2009/2010

^aPercentages are weighted

Table 2 Unadjusted perceived and unmet need for family support services by EBDP status and type of health insurance

| | Total sample | Need | Portion of total sample with need (%) | Unmet need | Portion of sample with need who have unmet need (%) | Portion of total sample with unmet need (%) |
|-----------------------------|--------------|--------|---------------------------------------|------------|---|---|
| Care coordination | | | | | | |
| Total sample | 72,096 | 13,206 | 18 | 10,504 | 80 | 15 |
| Public insurance | 24,481 | 5374 | 22 | 4079 | 76 | 17 |
| Private insurance | 47,615 | 5628 | 12 | 4581 | 81 | 10 |
| No EBDP | 51,031 | 4818 | 9 | 3624 | 75 | 7 |
| No EBDP & public insurance | 14,160 | 2049 | 14 | 1479 | 72 | 10 |
| No EBDP & private insurance | 36,871 | 2769 | 8 | 2145 | 77 | 6 |
| EBDP | 21,065 | 6184 | 29 | 5036 | 81 | 24 |
| EBDP & public insurance | 10,321 | 3325 | 32 | 2600 | 78 | 25 |
| EBDP & private insurance | 10,744 | 2859 | 27 | 2436 | 85 | 23 |
| Respite care | | | | | | |
| Total sample | 72,096 | 3956 | 5 | 1883 | 48 | 3 |
| Public insurance | 24,481 | 2824 | 12 | 1234 | 44 | 5 |
| Private insurance | 47,615 | 1132 | 2 | 649 | 57 | 1 |
| No EBDP | 51,031 | 1151 | 2 | 405 | 35 | 1 |
| No EBDP & public insurance | 14,160 | 755 | 5 | 245 | 32 | 2 |
| No EBDP & private insurance | 36,871 | 396 | 1 | 160 | 40 | 0 |
| EBDP | 21,065 | 2805 | 13 | 1478 | 53 | 7 |
| EBDP & public insurance | 10,321 | 2069 | 20 | 989 | 48 | 10 |
| EBDP & private insurance | 10,744 | 736 | 7 | 245 | 33 | 2 |
| Family mental health | | | | | | |
| | n | n | % | n | % | % |
| Total sample | 72,096 | 8071 | 11 | 1689 | 21 | 2 |
| Public insurance | 24,481 | 3909 | 16 | 885 | 23 | 4 |
| Private insurance | 47,615 | 4162 | 9 | 804 | 19 | 2 |
| No EBDP | 51,031 | 1785 | 3 | 297 | 17 | 1 |
| No EBDP & public insurance | 14,160 | 696 | 5 | 146 | 21 | 1 |
| No EBDP & private insurance | 36,871 | 1089 | 3 | 151 | 14 | 0 |
| EBDP | 21,065 | 6286 | 30 | 1,392 | 22 | 7 |
| EBDP & public insurance | 10,321 | 3213 | 31 | 739 | 23 | 7 |
| EBDP & private insurance | 10,744 | 3073 | 29 | 653 | 21 | 6 |

Data Source: NSCSHCN, National Survey of Children with Special Health Care Needs, 2005/2006 & 2009/2010

respite needs ($p < 0.34$), and -0.01 for unmet family mental health needs ($p < 0.88$).

Conclusions for Practice

Parents of CSHCN with emotional, developmental, and behavioral health concerns reported greater need for family support services and greater rates of unmet need for support services when compared to CSHCN with no EBDPs. Public insurance is associated with decreased rates of unmet care coordination need for all CSHCN and reduced rates of

unmet respite need for those with EBDPs. Results are consistent with the hypothesis that having EBDPs and public insurance will be associated with increased perceived need but that public insurance will benefit children with EBDPs. Critically, results are consistent with the hypothesis that public insurance will be associated with the greatest reduction in unmet need for CSHCN with EBDPs regarding respite care; among CSHCN with EBDPs with need for respite care, having public insurance is associated with a lower probability of experiencing unmet respite need. Although findings for unmet family mental health and care coordination needs were not all significant, children with both EBDPs

Table 3 Marginal effects of EBDP status and type of health insurance on perceived and unmet need for family support services

| | Perceived care coordination need (N = 68,817) ^a | | | | | Unmet care coordination need (N = 10,649) ^b | | | | | | |
|------------|---|----------|------------------|----------|------------|--|--------|------------------|--------|------------|-------|------|
| | Private insurance | | Public insurance | | Difference | Private insurance | | Public insurance | | Difference | | |
| | Margin | <i>p</i> | Margin | <i>p</i> | Margin | <i>p</i> | Margin | <i>p</i> | Margin | <i>p</i> | | |
| No EBDP | 0.11 | | 0.14 | | 0.03 | 0.00 | 0.80 | | 0.73 | | -0.07 | 0.01 |
| EBDP | 0.28 | | 0.28 | | 0.00 | 0.89 | 0.84 | | 0.78 | | -0.06 | 0.01 |
| Difference | 0.17 | 0.00 | 0.15 | 0.00 | | | 0.05 | 0.01 | 0.05 | 0.02 | | |
| | Perceived respite need (N = 70,267) ^a | | | | | Unmet respite need (N = 3,858) ^c | | | | | | |
| | Private insurance | | Public insurance | | Difference | Private insurance | | Public insurance | | Difference | | |
| | Margin | <i>p</i> | Margin | <i>p</i> | Margin | <i>p</i> | Margin | <i>p</i> | Margin | <i>p</i> | | |
| No EBDP | 0.01 | | 0.06 | | 0.05 | 0.00 | 0.30 | | 0.35 | | 0.05 | 0.34 |
| EBDP | 0.05 | | 0.18 | | 0.13 | 0.00 | 0.55 | | 0.43 | | -0.12 | 0.00 |
| Difference | 0.04 | 0.00 | 0.12 | 0.00 | | | 0.25 | 0.00 | 0.08 | 0.04 | | |
| | Perceived family mental health need (N = 70,234) ^a | | | | | Unmet family mental health need (N = 7,862) ^d | | | | | | |
| | Private insurance | | Public insurance | | Difference | Private insurance | | Public insurance | | Difference | | |
| | Margin | <i>p</i> | Margin | <i>p</i> | Margin | <i>p</i> | Margin | <i>p</i> | Margin | <i>p</i> | | |
| No EBDP | 0.03 | | 0.05 | | 0.02 | 0.00 | 0.17 | | 0.16 | | -0.01 | 0.88 |
| EBDP | 0.26 | | 0.28 | | 0.02 | 0.07 | 0.23 | | 0.22 | | -0.01 | 0.85 |
| Difference | 0.22 | 0.00 | 0.23 | 0.00 | | | 0.06 | 0.02 | 0.06 | 0.02 | | |

Data Source: NSCSHCN, National Survey of Children with Special Health Care Needs, 2005/2006 & 2009/2010

Adjusted for condition severity, race, age, sex, rurality, parent income, education and language, number of adults in household, year, number of mental health facilities and total state mental health authority spending per capita

^aAmong children publicly or privately insured all year

^bChildren with need for care coordination and publicly or privately insured all year

^cChildren with need for respite and publicly or privately insured all year

^dChildren with need for family mental health and publicly or privately insured all year

and public insurance also have lower predicted probabilities of unmet needs for these services. Future analyses should explore these trends to identify which families experience important gains from these public insurance benefits.

These findings are consistent with prior research demonstrating that rates of perceived and unmet need for family mental health and care coordination services are greater for CSHCN with behavioral health needs (Inkelas et al., 2007; Miller et al., 2018). This study expands this pattern to respite care. Though prior research on unmet care coordination and respite needs has not directly compared probabilities between CSHCN with EBDPs and those without (Brown et al., 2014; Nageswaran, 2009), these findings are consistent with research demonstrating that families whose children have EBDPs have more challenges accessing needed health services (Nageswaran et al., 2011). Results are also consistent with prior findings that CSHCN with public insurance are less likely to have unmet respite needs (Nageswaran, 2009) and that CSHCN with EBDPs who have public insurance are less likely to have unmet mental health needs than those with private coverage (Graaf & Snowden, 2019).

Limitations

Consideration of these findings must be in the context of several study limitations. First, secondary data limits the possible confounding variables that could be adjusted for in our analyses, such as transportation. Second, the cross-sectional nature of the data prevents any causal claims in associations identified here. Third, several measures used are based solely on caregiver report and recall; this may have led to inaccurate reporting of need or service use. Lastly, it is important to keep in mind that this study's data collection occurred before the ACA passage.

Implications for Future Research

The finding that reductions in the probability of unmet respite need are significantly and negatively related to public insurance for children with EBDPs (see Table 3)—but not for children without EBDPs—raises questions for further exploration. Families of children without EBDPs may be more likely to have public insurance through income

eligibility rather than categorical eligibility through disability or specialized waiver programs. Standard public health insurance programs—not crafted specifically for children with specialized care needs—are unlikely to offer respite care coverage (Koyanagi et al., 2008). Further, because CSHCN who don't have EBDPs may be less complex or burdensome to care for—and because there is often less stigma attached to medical concerns than behavioral concerns (Serchuk et al., 2021)—these families may have access to a network of community and family supports who can provide informal respite care, making insurance coverage for the service less critical. More in-depth examination of formal and informal resources available to families with CSHCN—and how these differ for those with and without EBDPs—is required to uncover these relationships' nuances and is critical to understanding the adequacy and effectiveness of systems of care for CSHCN.

Implications for Policy

A recent call to more assertively address parent mental health concerns by reducing silos between child and adult behavioral health care underscores the importance of improving access to effective interventions to support families of children with behavioral health needs (Biel et al., 2020). Findings here suggest that private health coverage is not meeting the family support needs of CSHCN with EBDPs and that richer home and community-based service (HCBS) arrays, which states may choose to offer through state funds, federal block grants, or the joint state and federally funded Medicaid program, may do so more effectively. Though children did not experience the coverage gains (moving from no insurance to some) achieved for adults through the ACA (Garrett & Gangopadhyaya, 2016), opportunities for states to broaden HCBS coverage available through Medicaid increased under the ACA. This has spurred many states to enrich their HCBS offerings since 2009/2010. (Harrington et al., 2012). The findings reported here highlight the value of the richer HCBS service array for CSHCN with EBDPs and provide a rationale for their expansion across states.

The likelihood that many CSHCN with EBDPs are accessing Medicaid through optional state programs based on severity of medical or behavioral health need means that public insurance may not cover a parent or sibling. If the rest

of the family is privately insured, limits or co-pays associated with mental health services in these plans may contribute to unmet family mental health need. Further, because states choose the Medicaid income and need eligibility criteria for their residents, adults are not eligible for Medicaid coverage regardless of their income level in many states. These eligibility standards are particularly restrictive today in states that declined the option to expand the income eligibility limits of Medicaid under the ACA. Thus, though public programs may insure a child, many parents continue to go uninsured. Lack of insurance or inadequate private insurance may continue to inhibit access to family mental health care.

The mental health component of the Essential Benefits mandate under the ACA may also hold power to expand family support services for CSHCN with EBDPs—particularly for family mental health needs—by improving mental health coverage under commercial private insurance plans. However, exemptions for plans in existence prior to the ACA, large group plans, and a lack of national standards for insurance benefits limits potential impact of the policy (Keller & Chamberlain, 2014). The need to understand the availability of formal family support services and the role that public and private health coverage now play in facilitating access to these supports under current policy is vital. Since the ACA, the required nationally representative data that captures access to family support services for CSHCN is currently unavailable.

The Maternal and Child Health Bureau and the Health Resources and Services Administration should revise the National Survey of Children's Health to examine the extent to which public and private systems of care are meeting the family support needs of CSHCN in the wake of the ACA. These agencies dropped data collection about in-home health, respite, and family mental health services for CSHCN when merging the National Survey of Children with Special Health Care Needs into the National Survey of Children's Health in 2016. Without national data about these services—which are critical components of a community-based system of care for CSHCN—it will continue to be unclear how these systems have developed over time and how they have changed in response to the sweeping health care reforms ushered in under the ACA.

Table 4 Multivariable Logistic Regressions of Perceived and Unmet Need for Family Support Services by EBDP Status and Type of Health Insurance

| | Perceived Care Coordination Need (N=68,817) ^a | | | | Perceived Respite Need (N=70,267) ^a | | | | Perceived Family Mental Health Need (N=70,234) ^a | | | |
|---|--|------------------|--------|-------|--|------------------|--------|-------|---|------------------|--------|--------|
| | AOR | P>t ^e | 95% CI | | AOR | P>t ^e | 95% CI | | AOR | P>t ^e | 95% CI | |
| No EBDP & private insurance (baseline) [*] | 0.070 | 0.000 | 0.054 | 0.091 | 0.001 | 0.000 | 0.001 | 0.002 | 0.015 | 0.000 | 0.011 | 0.021 |
| Public insurance (among no EBDP) | 1.290 | 0.000 | 1.130 | 1.472 | 5.571 | 0.000 | 4.318 | 7.188 | 1.494 | 0.000 | 1.228 | 1.818 |
| EBDP (among Private Insurance) | 3.368 | 0.000 | 3.038 | 3.734 | 5.016 | 0.000 | 3.967 | 6.341 | 10.700 | 0.000 | 9.385 | 12.200 |
| EBDP & public insurance | 0.782 | 0.002 | 0.671 | 0.912 | 0.743 | 0.041 | 0.559 | 0.988 | 0.754 | 0.007 | 0.614 | 0.926 |
| | Unmet care coordination need (N=10,649) ^b | | | | Unmet Respite Need (N=3858) ^c | | | | Unmet Family Mental Health Need (N=7862) ^d | | | |
| | AOR | P>t ^e | 95% CI | | AOR | P>t ^e | 95% CI | | AOR | P>t ^e | 95% CI | |
| No EBDP & private insurance (baseline) [*] | 2.192 | 0.003 | 1.300 | 3.698 | 0.132 | 0.000 | 0.052 | 0.336 | 0.077 | 0.000 | 0.036 | 0.167 |
| Public insurance (among no EBDP) | 0.706 | 0.010 | 0.540 | 0.921 | 1.264 | 0.348 | 0.775 | 2.062 | 0.958 | 0.870 | 0.576 | 1.594 |
| EBDP (among private insurance) | 1.365 | 0.014 | 1.066 | 1.749 | 2.974 | 0.000 | 1.885 | 4.693 | 1.487 | 0.029 | 1.041 | 2.123 |
| EBDP & public insurance | 0.963 | 0.820 | 0.697 | 1.331 | 0.473 | 0.009 | 0.271 | 0.826 | 1.018 | 0.947 | 0.609 | 1.699 |

Data Source: NSCSHCN, National Survey of Children with Special Health Care Needs, 2005/2006 & 2009/2010

ORs adjusted for condition severity, race, age, sex, parent income, education and language, number of adults in household (<2, 2 or more), number of mental health facilities and total state mental health authority spending per capita, urbanicity, and year

^{*}Baseline odds

^aAmong children publicly or privately insured all year

^bChildren with need for care coordination and publicly or privately insured all year

^cChildren with need for respite and publicly or privately insured all year

^dChildren with need for family mental health care and publicly or privately insured all year

^eOverall P value (Design-based F-test; 1 df)

Appendix

See Table 4.

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

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