

# BMJ Open Care coordination and unmet need for specialised health services among children with special healthcare needs in the USA: results from a cross-sectional analysis of the national survey of children with special healthcare needs

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## ABSTRACT

**Objective** To report rates of need and unmet need for specialised health services (occupational and speech therapies, durable medical equipment, home healthcare, and mobility and communication aids) from the National Survey of Children with Special Health Care Needs (CSHCN) (2009/2010) and assess the role of care coordination in having needs met. We distinguish between CSHCN with and without emotional, behavioural and developmental disorders (EBDPs) in the USA.

**Design** A cross sectional cohort study of a nationally representative sample of CSHCN from the National Survey of CSHCN for 2009/2010 used logistic regression to assess the relationship between EBDPs and need and unmet need for specialised services. It also estimates the association of care coordination with unmet need for all services, for CSHCN with and without EBDPs.

**Setting** A nationally representative sample of CSHCN in the USA.

**Participants** Children ages 0–17 years of age.

**Results** Across all specialised health services, rates of unmet need were at or below 25%. Need and unmet need for most services was higher among CSHCN with EBDPs than those without. For CSHCN with and without EBDPs, adequate care coordination was associated with greater probability of having needs for therapy, home health and communication aids met.

**Conclusion** Care coordination is essential to reducing barriers to a wide range of healthcare services for CSHCN. Policies requiring adequate insurance coverage for care coordination may play a critical role in ensuring access to specialised health services.

## INTRODUCTION

Children with special healthcare needs (CSHCN) have a persistent physical, developmental, behavioural or emotional condition that requires the use of health and other support services at greater rates than the

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This research uses the most recent, nationally representative data to understand the need and unmet need for rarely examined, highly specialised services among children with special healthcare needs (CSHCN).
- ⇒ This study identifies the key role of care coordination in accessing specialised health services for CSHCN.
- ⇒ This study used caregiver reported data and their perception of need and unmet need for specialised healthcare services.

majority of other children.<sup>1</sup> While there is a spectrum of healthcare needs and disability among CSHCN in the USA, over 40% of CSHCN report two or more chronic medical, emotional, developmental or behavioural conditions.<sup>2</sup>

Almost all CSHCN experience impairment in completing the activities of daily living. Nearly half of CSHCN experience four or more functional impairments including difficulties in self-care, challenges with coordination, difficulties in learning, behaviour, speaking or communicating, and feeling anxious or depressed.<sup>1</sup> To improve health and prolong life, CSHCN require a wide array of specialised health services to address these limitations. Such services may include speech, occupational or physical therapy (ST, OT, PT), home healthcare, mental healthcare and specialist healthcare.<sup>3 4</sup> Rates of unmet service needs vary significantly across service types in the USA, with as few as 6% of CSHCN going with unmet need for vision

care but nearly 25% having an unmet need for communication assistance.<sup>5</sup>

Multiple factors place CSHCN at increased risk for unmet healthcare needs. Greater functional impairment,<sup>6</sup> presence of emotional, behavioural or developmental disorders (EBDPs),<sup>7,8</sup> lower family income,<sup>7</sup> lack of a usual care provider or medical home,<sup>3</sup> and public health insurance or lack of health insurance are associated with greater rates of unmet healthcare needs.<sup>9</sup> Care coordination increases access to necessary services and community support and can allow families to raise their CSHCN with significant medical, behavioural or developmental complexities at home.<sup>10,11</sup>

### CSHCN experiences with specialised healthcare

US national estimates of the need for a wide range of health services, rates of met needs, and factors associated with need and unmet need among CSHCN have been studied broadly for the last 20 years. This research has commonly examined differences across subgroups groups of CSHCN, particularly focusing on those with EBDPs<sup>9,12,13</sup>; children with autism spectrum disorders,<sup>3</sup> mental health disorders,<sup>14</sup> developmental or intellectual disabilities<sup>8,15</sup> or comorbid conditions.<sup>8</sup> These studies examined the differences in experiences related to access to specialty care,<sup>4</sup> mental healthcare,<sup>6</sup> therapy,<sup>3,5</sup> medical homes,<sup>13</sup> and other preventative and routine care.<sup>14,15,11,15</sup> However, existing research mostly omits examination of the most highly specialised services used by CSHCN. Rarely examined are need and unmet need for OT, ST or PT, mobility, communication or vision aids, and home healthcare. Though these services have much lower need and utilisation rates—even for CSHCN with the most complex conditions<sup>5</sup>—they are critical to maintaining children with the most disabling conditions and functional impairments in their homes and communities rather than in institutionally based care.<sup>16</sup> Further, no studies exist that use nationally representative data examining the role of care coordination in accessing these specialised health services.

The current study seeks to answer the following research questions to address these gaps in knowledge. Specifically, in diverse populations of CSHCN in the USA: (1) What is the rate of need and unmet need for specialised health services for CSHCN? (2) How do rates of need and unmet need for each service differ between CSHCN with EBDPs and those without, when adjusted for child and family characteristics? and (3) To what extent is care coordination associated with rates of need and unmet need for CSHCN with and without EBDPs, adjusting for child and family characteristics?

## METHODS

We performed a cross-sectional cohort study of a nationally representative sample of CSHCN, using logistic regression to assess unadjusted and adjusted rates of need and unmet need for supportive and home health services

for CSHCN with and without EBDPs. We also assess the association of care coordination with rates of unmet need for each service for CSHCN with and without EBDPs.

### Patient and public involvement

Patients and members of the public were not involved in the design or execution of this study.

### Data sources

This study used the 2009–2010 National Survey of CSHCN—the most recent nationally representative data examining specialised paediatric health service needs and utilisation. Children who screened as CSHCN numbered 40 342 among the nearly 200 000 households with children sampled nationwide. The children's caregivers completed interviews about the child's health and health service use. Additional information about the development and administration of the survey is detailed elsewhere<sup>17</sup> and data are publicly available.

### Independent variables

We included all CSHCN in the analysis, comparing those with and without EBDPs. In addition, we compared adequate care coordination with those reporting 'never/sometimes' having enough assistance with arranging care. Online supplemental appendix A provides additional details about how EBDP and care coordination variables were constructed, and the values associated with each variable.

### Dependent variables

The outcome variables include need and unmet need for five specialised health services: (1) OT, ST or PT, (2) home health, (3) durable medical equipment (DME), (4) mobility aids and (5) communication aids. All dependent variables in the study were obtained directly from a series of questions about the parents' perception of need for these healthcare services and whether those needs were fully met (see online supplemental appendix A).

### Control variables

Drawing on Gelberg *et al*'s Behavioural Model for Vulnerable Populations,<sup>18</sup> we controlled our analysis for a variety of need, predisposing and enabling factors. Need included condition severity (condition affects the child's ability to do things very little or sometimes, or usually). Predisposing characteristics included the child's race/ethnicity (white only, black only, Hispanic black or white, and other), sex (male or female) and age (0–3 years, 4–12 years and 13–17 years). Enabling child characteristics included insurance type (private, public, public and private, other or uninsured), whether the child had a usual source of healthcare (none, or one or more), and whether they had been uninsured at any time in the prior 12 months. Enabling family covariates include the income level of the family (0%–199% Federal Poverty Line (FPL) or 200+% FPL), parent language (English or not), parent education level (less than high school, or high school or

more) and the number of adults in the household (less than two adults, or two or more adults).

Enabling environmental characteristics included whether a child lived in a non-urban or urban area. Due to data suppression in the publicly available data, this was not available for all children in the state set, so a proxy variable was created. Children living in a state with few metropolitan statistical areas (MSAs) were classified as non-urban, and those living in states with large numbers of MSAs were classified as urban.<sup>5</sup>

### Sample preparation

Total observations in the 2009/2010 NS-CSHCN are 40 242. If parents or guardians responded 'don't know' or 'refused to answer' for control, diagnostic and specialised health service need and unmet need questions, we excluded these observations in models using these variables. Because less than 10% of the data is missing for any model, dropping these observations does not compromise the national representativeness of the data or analytic results.<sup>19</sup>

### Analysis

Descriptive analyses identified sample size and proportions of CSHCN by clinical, demographic, family, and healthcare need and unmet need characteristics. We also estimated proportions and sample sizes of CSHCN with and without EBDPs with need and unmet need for each specialised health service. Multivariable logistic regression assessed adjusted OR (AOR) for need and met need for each specialised health service, comparing CSHCN with and without EBDPs, and assessing the association of adequate care coordination with having needs met for both populations.

Fifteen fixed effects logistic regression models were fitted for the full sample. Five models assessed need for each of the specialised health services specified above, and five models assessed if needs were met for each type of specialised health service. To estimate the association between EBDP with need for each specialised health service, health service need models were fit to the full sample of CSHCN with EBDP as a covariate, controlling for need, predisposing and enabling factors. To estimate the association between EBDP and care coordination with needs for each specialised health services being met, met need models were fit to the full sample of CSHCN, adjusting for EBDP, care coordination, and need, predisposing, and enabling factors. Finally, to assess the association of care coordination with having specialty healthcare needs met specifically for CSHCN with EBDPs, we fit the met needs models on the subsample of CSHCN with EBDPs. We used the survey sampling weights provided in the survey data<sup>17</sup> to adjust for the complex survey design and conducted analyses in Stata V.16 MP.

To better understand differences in need for each subpopulation (CSHCN with no EBDPs and those with EBDPs) and to understand the differences in unmet need for each subpopulation (CSHCN with no EBDPs and those

with EBDPs, with and without adequate care coordination), postestimation analysis generated predicted probabilities of need and met need for each subpopulation.

## RESULTS

### Sample characteristics

Sample characteristics for predictors and covariates are presented in [table 1](#), and [table 2](#) reports nationally representative rates of need and unmet need for the full sample and stratified by EBDP status. Overall, nearly one-third (31.8%) of the sample qualified as having an EBDP. Nearly all parents (85.6%) reported usually having adequate care coordination. CSHCN had the greatest need for OT, ST or PT, with 27% of all caregivers reporting need. For home health services, rates of need were much lower in general (4%). Over 10% of CSHCN needed DME and only 4% of CSHCN needed mobility aids. Communication assistance was the least commonly reported need (2%), but the mostly likely to be unmet (25%). For all services, CSHCN with EBDPs had higher rates of need and unmet need, except for DME. CSHCN with no EBDP had higher rates of need for DME (13% vs 9%), but lower rates of unmet need (3% vs 8%).

[Table 3](#) reports the adjusted rate of need and met need for specialised health services for CSHCN with EBDPs compared with those without. Predicted probabilities of need and having needs met for all services for both populations are presented in online supplemental appendix B. It also reports the association of having an EBDP with having needs for specialised services met, and the adjusted rate of having needs met for CSHCN with no EBDPs who have adequate care coordination. Predicted probabilities for having needs met for each service for CSHCN with and without EBDPs, and with and without adequate care coordination are presented in online supplemental appendix C. Full model outputs for predictors of having needs met are provided in online supplemental appendix D. Having an EBDP was significantly and positively associated with need for OT, ST or PT (AOR=2.17 (95% CI 1.98 to 2.39)), home healthcare (AOR=2.00 (95% CI 1.63 to 2.45)), and communication aids (AOR=2.91 (95% CI 2.22 to 3.83)), and negatively associated with need for DME (AOR=0.57 (95% CI 0.49 to 0.66)). Having an EBDP was negatively associated with having needs met for OT, ST or PT (AOR=0.67 (95% CI 0.48 to 0.93)), home health (AOR=0.28 (95% CI 0.14 to 0.53)), and DME (AOR=0.51 (95% CI 0.32 to 0.82)). Adequate care coordination was significantly associated with increased rates of having needs met for OT, ST and PT (AOR=3.25 (95% CI 2.65 to 3.98)), home health (AOR=4.62 (95% CI 2.64 to 8.11)), DME (AOR=2.10 (95% CI 1.28 to 3.46)) and communication aids (AOR=7.62 (95% CI 2.96 to 9.58)).

[Table 4](#) presents the association of adequate care coordination with having needs for each specialty health service met specifically for CSHCN with EBDPs. For CSHCN with EBDPs, adequate care coordination is associated with increased rates of having needs met for OT, ST

**Table 1** Sample covariate characteristics

	N*	%†		N*	%†
EBDP			Language used		
No EBDPs	27 850	68.22	English	38 686	94.25
EBDPs	12 392	31.78	Another language	1019	4.48
Adequate care coordination			Missing/don't know/refused	537	1.27
Never or sometimes	4953	14.40	Residential location		
Usually	35 289	85.59	Non-urban residence	12 246	17.53
Insurance type			Urban residence	27 927	82.47
Private	23 315	50.71	Missing/don't know/refused	69	>0.01
Public	11 362	34.72	Condition severity		
Dual	2910	7.94	Mild or moderate	14 795	34.29
Other	1443	3.16	Severe	25 447	65.71
Uninsured	1149	3.47	Usual source of care		
Missing, don't know, refused	63	>0.01	Has no source	2619	7.36
Race			Has one or more source	37 545	92.47
White	27 989	59.3	Missing/don't know/refused	78	0.17
Black only	4010	16.1	Uninsured in the last 12 months		
Hispanic (black or white)	4479	16.8	No	37 043	90.50
Other	3764	7.9	Yes	3065	9.28
Age group			Missing/don't know/refused	134	0.02
0–3 years	3655	10.91	Household income		
4–12 years	22 416	55.28	0%–199% Federal Poverty Line	14 621	44.10
13–17 years	14 171	33.81	200% Federal Poverty Line or above	25 621	55.90
Sex			Parent education level		
Male	24 139	59.20	Less than high school	8152	31.01
Female	16 033	40.62	More than high school	32 090	68.99
Missing/don't know/refused	69	0.18	Adults in household		
			Less than two adults	5444	18.11
			Two or more adults	34 798	81.89

Data source: Centers for Disease Control and Prevention, National Centre for Health Statistics, National Survey of CSHCN, 2009–2010.

\*'Don't Know' or 'Refused to Answer' is coded as missing.

†Weighted proportion.

CSHCN, children with special healthcare needs; EBDPs, emotional, behavioural and developmental disorders.

and PT (AOR=3.23 (95% CI 2.49 to 4.20)), home health (AOR=5.59 (95% CI 2.82 to 11.09)) and communication aids (AOR=1.83 (95% CI 1.03 to 3.26)).

## DISCUSSION

This study reports nationally representative rates of need and unmet need for specialised health services for CSHCN in the USA, distinguishing between those with and without EBDPs. This study also assessed the role of care coordination in having these needs met. In general, the needs of CSHCN for specialised health services are being met relatively well—with rates of unmet need across all types of services reported at or below 25%. However,

significant differences exist in needs and rates of unmet need between CSHCN with and without EBDPs. Adjusted rates of need and having needs met for OT, ST, PT, home healthcare and communication aids were higher among CSHCN who reported EBDPs, compared with those who did not. Having adequate care coordination was associated with greater rates of having needs met for OT, ST, PT, home healthcare and communication aids among all CSHCN—with and without EBDPs.

These results are consistent with existing research—that children with more complex needs, EBDPs and functional impairments have a greater need and higher rates of unmet need for healthcare services.<sup>3 5 6 12 20</sup> In addition,

**Table 2** Sample size and unweighted proportions of need and met need for specialised health services for CSHCN, stratified by EBDP status

	Missing		No need		Need		Missing		Unmet Needs*		Need Met*	
	n		n	%†	n	%†	n		n	%†	n	%†
Occupational, speech and physical therapy												
No EBDPs	16		22 497	80	5337	20	19		684	13	4634	87
EBDPs	19		7445	60	4928	40	21		1065	22	3841	78
Total	35		29 942	73	10 265	27	40		1749	18	8475	82
Home health												
No EBDPs	19		27 082	97	749	3	19		44	5	705	95
EBDPs	26		11 579	93	787	7	26		140	19	647	81
Total	45		38 661	96	1536	4	45		184	13	1352	87
Durable medical equipment												
No EBDPs	7		24 657	87	3186	13	0		105	3	3080	97
EBDPs	4		11 401	91	987	9	1		88	8	898	92
Total	11		36 058	89	4173	11	1		193	4	3978	96
Mobility aid												
No EBDPs	2		26 761	96	1079	4	1		56	6	1022	94
EBDPs	3		11 782	95	606	5	3		60	10	543	90
Total	5		38 543	96	1685	4	4		116	8	1565	92
Communication aids												
No EBDPs	9		27 497	99	336	1	1		66	19	269	81
EBDPs	20		11 718	95	653	5	3		173	27	477	73
Total	29		39 215	98	989	2	4		239	25	746	75

Data source: Centers for Disease Control and Prevention, National Centre for Health Statistics, National Survey of CSHCN, 2009–2010.  
 \*Among CSHCN with reported need.  
 †Weighted proportion.  
 CSHCN, children with special healthcare needs; EBDPs, emotional, behavioural and developmental disorders.

the consistency of these findings with earlier studies<sup>5 20</sup> suggests CSHCN's needs are stable over time. Though there are no direct studies on the role of care coordination in accessing these specialised services nationwide, the findings here are consistent with other studies demonstrating the role of care coordination in accessing health, behavioural health and specialised healthcare.<sup>11 21</sup>

Positive indicators of health system functioning for CSHCN in the USA are low rates of unmet need for home healthcare, DME and mobility aids. However, the reported unmet need for OT, ST or PT is relatively high, with almost 20% of children and youth going without needed therapies. Access problems may be rooted in payer systems in the form of insurance limits (eg, session limits, annual or lifetime maximums) associated with these services, particularly in commercial health insurance plans.<sup>6 9</sup> Insufficient reimbursement rates may also serve as a disincentive for provision of care and contribute to these workforces' insufficiencies in numbers and geographical location.<sup>22</sup> The workforce's existing maldistribution may also place children at risk for disparities in accessing these services, particularly in rural areas.<sup>23</sup> Further policy and research are needed to isolate the source of these unmet needs,

as policies that ensure children with complex health-care needs can access these services can improve health outcomes and quality of life.<sup>10</sup>

Though the need for communication aids is extremely low among CSHCN, the rate of unmet need for this service is high (25%). Because the inability to communicate can exacerbate behavioural or emotional problems in children,<sup>24</sup> complicating and straining home life for families<sup>25</sup> and potentially leading to placement in out-of-home care,<sup>26</sup> unmet need for communication aids is particularly problematic. This study demonstrates that adequate care coordination is associated with greater probability of meeting this need—especially for children with EBDPs. Whether it is problems located in the payer source, location of services or simply availability of needed devices, further research is needed to uncover the source of service inadequacy.

The association of adequate care coordination with higher rates of having specialised health service needs met contributes to the growing evidence that this service is essential to reducing barriers to a wide range of health-care services for CSHCN in the USA.<sup>11 21 27–30</sup> Care coordination can help to integrate the fragmented healthcare



**Table 3** Adjusted rates of need and having needs met for CSHCN: associations with EBDPs and care coordination

	OR (95% CI)
Need for occupational, speech or physical therapy	
EBDP	<b>2.17</b> (1.98 to 2.39)
Need for occupational, speech or physical therapy met*	
EBDP	<b>0.67</b> (0.48 to 0.937)
Adequate care coordination	<b>3.25</b> (2.65 to 3.98)
Need for home healthcare	
EBDP	<b>2.00</b> (1.63 to 2.45)
Need for home health met*	
EBDP	<b>0.28</b> (0.14 to 0.53)
Adequate care coordination	<b>4.62</b> (2.64 to 8.11)
Need for durable medical equipment	
EBDP	<b>0.57</b> (0.49 to 0.66)
Need for durable medical equipment met*	
EBDP	<b>0.51</b> (0.32 to 0.82)
Adequate care coordination	<b>2.10</b> (1.28 to 3.46)
Need for mobility aids	
EBDP	0.95 (0.77 to 1.17)
Need for mobility aids met*	
EBDP	0.56 (0.29 to 1.06)
Adequate care coordination	1.62 (0.87 to 3.04)
Need for communication aids	
EBDP	<b>2.91</b> (2.22 to 3.83)
Need for communication aids met*	
EBDP	0.65 (0.36 to 1.17)
Adequate care coordination	<b>2.62</b> (1.52 to 4.51)

Data source: Centers for Disease Control and Prevention, National Centre for Health Statistics, National Survey of CSHCN, 2009–2010. ORs adjusted for child's age, race, sex, urban residence, functional severity, insurance type, lack of insurance in past 12, months, usual source of care, family income, adults in household, parent language and education.

Reference groups are CSHCN with no EBDPs and inadequate care coordination.

Values in bold italics are significant at  $p < 0.05$ .

\*Among CSHCN with reported need.

CSHCN, children with special healthcare needs; EBDPs, emotional, behavioural and developmental disorders.

experienced by families when their CSHCN receives care and supports from a wide range of providers and service sectors (eg, schools, outpatient providers, inpatient care and behavioural healthcare) which often poses barriers to care access or engagement.<sup>31 32</sup> It accomplishes this through activities and communication across and between providers or services systems (eg, primary care, specialty providers, hospital admissions, home and community-based care providers) aimed at keeping all providers working collaboratively and cooperatively towards the same healthcare goals for a given child.<sup>33</sup>

Care coordination has emerged over the last decade as a solution to the fragmented care experienced by families of CSHCN<sup>33</sup> and has been promoted through incentives

**Table 4** Association of care coordination with rates of having specialty healthcare needs met among CSHCN with EBDPs

	AOR (95% CI)
Occupational, speech or physical therapy	<b>3.23</b> (2.49 to 4.20)
Home healthcare	<b>5.59</b> (2.82 to 11.09)
Durable medical equipment	1.81 (0.90 to 3.66)
Mobility aids	1.55 (0.62 to 3.84)
Communication aids	<b>1.83</b> (1.03 to 3.26)

Data source: Centers for Disease Control and Prevention, National Centre for Health Statistics, National Survey of CSHCN, 2009–2010.

ORs adjusted for child's age, race, sex, urban residence, functional severity, insurance type, lack of insurance in past 12, months, usual source of care, family income, adults in household, parent language and education.

Reference groups are CSHCN with no EBDPs and inadequate care coordination.

Values in bold italics are significant at  $p < 0.05$ .

\*Among CSHCN with reported need.

CSHCN, children with special healthcare needs; EBDPs, emotional, behavioural and developmental disorders.

in state and federal policy, including the Affordable Care Act.<sup>34</sup> However, widespread adoption and implementation remain limited due to workforce, funding and logistical concerns.<sup>33</sup> As a result, receipt of care coordination remains inconsistent for families who need it,<sup>35–41</sup> and barriers to care coordination must be identified and addressed.

Because federal mandates require that Medicaid cover any services or supports needed to treat a child diagnosed with any condition,<sup>42</sup> public insurance usually covers a wider array of critical services and supports than private insurance for CSHCN. Indeed, public insurance has been demonstrated to be associated with lower rates of unmet need for a variety of special healthcare services for CSHCN.<sup>6 9 43</sup> Model outputs in online supplemental appendix D underscore this point, as public insurance is significantly associated with reduced rates of having needs met for the most highly specialised services—DME and communication aids. As such, gaining access to Medicaid coverage may enhance access and remove cost related barriers to many services.

HCBS Medicaid waivers may be a key policy mechanism for increasing access to coverage for critical supports for these children, as the majority of these programmes cover all of the specialty health services examined here, including care coordination.<sup>44</sup> However, limits on waiver programme capacity may play some role in unmet needs for this population, as 1915(c) MCBS Medicaid waiver programmes cap enrolment and enrolment capacity vary significantly across states.<sup>45</sup> Expanding the capacity of these programmes may play a critical role in meeting the needs of children with complex medical, developmental or behavioural healthcare needs. In addition, other home and community-based Medicaid programmes—such as

the Katie Beckett option which allows children needing an institutional level of care to qualify for Medicaid regardless of family income levels and for which states are not allowed to cap enrolment—may be a viable alternative for reducing unmet need.<sup>42</sup>

### Strengths and limitations

This study has several limitations. First, this study used caregiver reported data. The caregiver may have different perceptions of need or unmet need for specialised health-care services than clinicians who care for a child.<sup>46</sup> They may also incorrectly recall use of services in the past year. However, studies comparing survey participants' reported service use to utilisation data demonstrate no significant differences.<sup>47</sup> Second, study data collection occurred in 2009–2010. Despite the gap in time, this is the most recent national data about CSHCN's need for and use of highly specialised healthcare services in the United States. The consistency between our findings and those from studies examining CSHCN's need and unmet need for specialised healthcare services in 2001<sup>5</sup> and 2005 suggests that needs have not changed significantly, and that rates of unmet need persist over time. Third, while the data include a large, national sample of CSHCN, some needs and unmet needs for specialised healthcare services represented rare events. As such, there is the possibility of small sample bias of maximum likelihood estimation.<sup>48</sup> In addition, as the data are survey weighed to be nationally representative with finite population parameters, we cannot reduce the effect of the small sample bias using the Firth method.<sup>49</sup>

### CONCLUSION

CSHNC are a heterogeneous population with unique needs for specialised health services. We identified the rate of specialised health service needs and unmet needs and compared them among subpopulations of CSHCN. Medicaid waiver and other home and community-based services programmes in the USA, which are tailored to meet specialised health service needs of children with complex healthcare needs, may contribute to low or moderate rates of unmet needs. Care coordination, which is provided through these programmes,<sup>50</sup> may be playing a critical role in helping to meet these specialised needs. Future exploration of the role of care coordination in ensuring families can access other types of healthcare services—such as mental healthcare—will further clarify the importance of care coordination in access to care for CSHCN.

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**Contributors** GG is the guarantor of the study, having conceived of the study questions, designed and executed the analysis and drafted the majority of the manuscript. KG provided feedback and revisions to the study design, presentation of findings and provided substantial editing and conceptual framing in the manuscript writing process.

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**Ethics approval** Because this study drew on publicly available, deidentified data, this study was exempt from ethics review.

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**Data availability statement** Data are available on reasonable request. This study relied upon publicly available, deidentified data which can be accessed at [https://ftp.cdc.gov/pub/Health\\_Statistics/NCHS/slraits\\_cshcn\\_survey/2005\\_2006/Datasets/](https://ftp.cdc.gov/pub/Health_Statistics/NCHS/slraits_cshcn_survey/2005_2006/Datasets/)

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**Appendix A. Variable Definitions**

<b>Variable</b>	<b>Question</b>	<b>Variable Values</b>
Emotional, Behavioral, or Developmental Problem (EBDP)	<ul style="list-style-type: none"> <li>• “Does (this) child have any kind of emotional, developmental or behavioral problem for which he/she needs treatment or counseling?”</li> <li>• “Has [his/her]’s emotional, developmental, or behavioral problem lasted or expected to last for 12 months or longer?”</li> </ul>	Yes and Yes =1
Adequate Care Coordination	“During the past 12 months, have you felt that you could have used extra help arranging or coordinating [your child]’s care among these different health care providers or services?” & “How often did you get as much help as you wanted with arranging or coordinating [your child]’s care?”	<ul style="list-style-type: none"> <li>• Yes &amp; Never/Sometimes = 0, Not Adequate Care Coordination</li> <li>• Yes &amp; Usually = 1, Adequate Care Coordination</li> </ul>
Health Service Need	“During the past 12 months, was there any time when [child] needed [specialize health service]?” (Y=1/N=0)	<ul style="list-style-type: none"> <li>• No = 0, No Need</li> <li>• Yes = 1, Need</li> </ul>
Unmet Special Health Service Need	[Question asked after “Y” to previous question on perceived need for specialized health service] “Did [child] receive all the [specialized health service] that (he/she) needed?” (Y=1/N=0)	<ul style="list-style-type: none"> <li>• No = 0, Needs not Met</li> <li>• Yes = 1, Needs Met</li> </ul>

### Appendix B. Predicted Probabilities for Need and Met Need for Specialty Health Services among CSHCN with and without EBDPs

		CSHCN with no EBDPs			CSHCN with EBDPs		
		Margin	95% CI		Margin	95% CI	
<b>Occupational, Speech or Physical Therapy</b>	<b>Need</b>	0.22	0.21	0.23	0.36	0.34	0.37
	<b>Need Met</b>	0.87	0.85	0.88	0.82	0.80	0.84
<b>Home Health Care</b>	<b>Need</b>	0.03	0.03	0.04	0.06	0.05	0.07
	<b>Need Met</b>	0.95	0.92	0.98	0.87	0.82	0.91
<b>Durable Medical Equipment</b>	<b>Need</b>	0.13	0.12	0.14	0.08	0.07	0.09
	<b>Need Met</b>	0.96	0.95	0.98	0.94	0.91	0.96
<b>Mobility Aids</b>	<b>Need</b>	0.04	0.04	0.05	0.04	0.04	0.05
	<b>Need Met</b>	0.95	0.94	0.97	0.92	0.88	0.96
<b>Communication Aids</b>	<b>Need</b>	0.01	0.01	0.02	0.04	0.03	0.04
	<b>Need Met</b>	0.82	0.71	0.93	0.71	0.55	0.86

\*Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, National Survey of Children with Special Health Care Needs, 2009–2010.

\*\*Adjusted for child's age, race, sex, urban residence, functional severity, insurance type, lack of insurance in past 12 months, usual source of care, family income, adults in household, parent language and education

<sup>a</sup> Among CSHCN with reported need

### Appendix C. Predicted Probabilities for Having Needs for Specialty Health Services Met among CSHCN with and without EBDPs and Adequate Care Coordination <sup>a</sup>

	CSHCN with no EBDPs						CSHCN with EBDPs					
	With Inadequate Care Coordination			With Adequate Care Coordination			With Inadequate Care Coordination			With Adequate Care Coordination		
	Margin	95% CI		Margin	95% CI		Margin	95% CI		Margin	95% CI	
<b>Occupational, Speech or Physical Therapy</b>	0.72	0.67	0.78	0.89	0.88	0.91	0.64	0.59	0.69	0.85	0.83	0.87
<b>Home Health Care</b>	0.89	0.82	0.97	0.96	0.93	0.99	0.68	0.55	0.80	0.90	0.86	0.95
<b>Durable Medical Equipment</b>	0.94	0.91	0.97	0.97	0.96	0.98	0.89	0.84	0.94	0.94	0.92	0.97
<b>Mobility Aids</b>	0.92	0.87	0.97	0.96	0.94	0.98	0.90	0.83	0.97	0.92	0.88	0.97
<b>Communication Aids</b>	0.53	0.34	0.72	0.86	0.75	0.97	0.60	0.44	0.76	0.72	0.57	0.88

\*Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, National Survey of Children with Special Health Care Needs, 2009–2010.

\*\*Adjusted for child's age, race, sex, urban residence, functional severity, insurance type, lack of insurance in past 12 months, usual source of care, family income, adults in household, parent language and education

<sup>a</sup> Among CSHCN with reported need

**Appendix D. Adjusted Rates of Unmet Need for CSHCN: Associations with EBDPs and Care Coordination (Full Models)**

	<b>Occupational, Speech, and Physical Therapy</b>				<b>Home Health</b>				<b>Durable Medical Equipment</b>				<b>Mobility Aid</b>				<b>Communication Aids</b>			
	<b>OR</b>	<b>p</b>	<b>95% CI</b>		<b>OR</b>	<b>p</b>	<b>95% CI</b>		<b>OR</b>	<b>p</b>	<b>95% CI</b>		<b>OR</b>	<b>p</b>	<b>95% CI</b>		<b>OR</b>	<b>p</b>	<b>95% CI</b>	
EBDP	0.67	0.00	0.55	0.82	0.28	0.00	0.14	0.53	0.51	0.01	0.32	0.82	0.56	0.08	0.29	1.06	0.65	0.15	0.36	1.17
Adequate Care Coordination	3.25	0.00	2.65	3.98	4.62	0.00	2.64	8.11	2.10	0.00	1.28	3.46	1.62	0.13	0.87	3.04	2.62	0.00	1.52	4.51
Severe Impairments	0.67	0.01	0.49	0.91	0.45	0.33	0.09	2.24	1.80	0.12	0.87	3.73	0.35	0.18	0.07	1.65	2.81	0.27	0.44	17.85
<b>Race</b>																				
Black Only	0.79	0.11	0.59	1.06	2.50	0.05	1.00	6.28	1.57	0.23	0.75	3.31	0.54	0.19	0.21	1.37	0.85	0.71	0.37	1.95
Hispanic (Black or White)	1.00	0.99	0.73	1.38	1.71	0.15	0.83	3.53	1.05	0.89	0.53	2.09	0.65	0.36	0.26	1.63	0.82	0.64	0.35	1.90
Other	0.81	0.25	0.57	1.15	0.90	0.85	0.29	2.76	0.97	0.93	0.45	2.07	0.98	0.97	0.33	2.92	1.08	0.88	0.41	2.80
<b>Age Group</b>																				
4 through 12 years	0.97	0.84	0.69	1.35	0.34	0.02	0.13	0.85	0.34	0.00	0.16	0.68	0.38	0.19	0.09	1.63	0.09	0.00	0.02	0.37
13 through 17 years	0.91	0.61	0.63	1.32	0.30	0.02	0.11	0.81	0.42	0.03	0.19	0.93	0.46	0.30	0.11	1.98	0.12	0.00	0.03	0.49
<b>Sex</b>																				
Female	0.93	0.49	0.75	1.14	1.26	0.45	0.69	2.31	0.55	0.01	0.35	0.89	0.93	0.84	0.47	1.86	0.92	0.77	0.55	1.55
<b>Insurance Type</b>																				
Public	1.20	0.24	0.88	1.64	0.88	0.79	0.35	2.21	0.39	0.00	0.20	0.74	0.95	0.92	0.36	2.47	0.52	0.04	0.28	0.96
Dual	1.32	0.10	0.95	1.84	1.17	0.72	0.49	2.77	0.38	0.01	0.18	0.80	0.76	0.61	0.27	2.15	1.13	0.73	0.56	2.28
Other	0.86	0.57	0.51	1.44	0.18	0.06	0.03	1.04	0.52	0.41	0.11	2.52	0.25	0.09	0.05	1.21	0.68	0.59	0.17	2.72
Uninsured	0.72	0.31	0.38	1.36	1.44	0.65	0.30	6.98	0.33	0.03	0.13	0.88	2.45	0.36	0.37	16.32	0.59	0.53	0.11	3.04
Usual Source of Care	1.24	0.26	0.85	1.79	1.85	0.19	0.75	4.57	1.65	0.23	0.73	3.74	0.48	0.27	0.13	1.78	1.33	0.60	0.46	3.86
Uninsured in the Last 12 Months	0.58	0.01	0.38	0.89	0.28	0.01	0.11	0.73	0.38	0.01	0.19	0.76	0.38	0.04	0.14	0.97	0.44	0.12	0.15	1.25
200% FPL or above	0.84	0.24	0.64	1.12	0.83	0.64	0.37	1.83	1.68	0.09	0.92	3.05	0.90	0.79	0.43	1.90	1.25	0.41	0.74	2.14
More than High School	0.88	0.37	0.67	1.16	0.94	0.85	0.48	1.83	0.71	0.30	0.37	1.35	0.95	0.90	0.45	2.02	0.53	0.06	0.27	1.03
Two or More Adults	1.12	0.38	0.86	1.46	0.59	0.12	0.30	1.14	1.10	0.73	0.64	1.91	0.77	0.54	0.34	1.76	0.91	0.78	0.47	1.76
English is not Household Language	0.85	0.64	0.43	1.70	3.60	0.17	0.58	22.37	2.86	0.11	0.80	10.30	0.78	0.76	0.16	3.83	35.47	0.00	5.61	224.27
Urban State Residence	0.92	0.51	0.73	1.17	0.77	0.46	0.39	1.53	0.89	0.72	0.49	1.63	0.94	0.87	0.45	1.96	1.02	0.94	0.55	1.90

\*Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, National Survey of Children with Special Health Care Needs, 2009–2010.

\*\*Reference group is: no reported EBDPs, inadequate care coordination, mild or moderate impairment, white, 0-3 years of age, male, private insurance, no source of usual care, less than 200% FPL, less than two adults in the household, English is household language, and rural state residence