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# Use and Nondisclosure of Complementary Health Approaches among US Children with Developmental Disabilities

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# Abstract

**Background and Objectives**—Many US children use complementary health approaches (CHA), including some modalities that may be ineffective, unsafe, and/or costly. Yet little is known about the prevalence and correlates of CHA use among children with developmental disabilities (DD), as well as parent nondisclosure of CHA used for children with DD to healthcare providers. We, therefore, aimed to profile the use and nondisclosure of CHA among US children with DD.

**Methods**—We analyzed data from the 2012 National Health Interview Survey, which included the most recent Child Complementary and Alternative Medicine Supplement. The study sample was comprised of 2141 children with DD aged 4–17 years.

**Results**—Nearly one-quarter (23%) of US children with DD used CHA. Among those with a personal health provider, 42% of parents did not disclose some or all CHA used to the child's provider. The adjusted odds of using CHA were greater among those with female gender, higher household income, residences not in the South, difficulty accessing care, or comorbid conditions. CHA was most commonly used because "it is natural." Nondisclosure was associated with female gender, older age, no functional limitations, less conventional services use, or use of fewer CHA. The most common reason for nondisclosure was that the child's provider did not ask.

**Conclusions**—CHA use is prevalent among US children with DD, and nondisclosure is likely among those who use CHA. Future intervention targeting education and communication about CHA for parents of children with DD and their healthcare providers may promote disclosure.

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# INTRODUCTION

Developmental disabilities (DD), such as attention deficit/hyperactivity disorder (ADHD) autism spectrum disorder (ASD), and cerebral palsy (CP), affect an estimated 1 in 6 children nationwide.<sup>1</sup> DD include a group of chronic conditions characterized by cognitive, behavioral, and/or physical impairments.<sup>2</sup> DD lack curative treatments,<sup>2</sup> have adverse health impacts for children and their families,<sup>3</sup> and incur substantial costs for families and the health system.<sup>4,5</sup>

Evidence-based treatments to manage DD symptoms exist and are widely recommended (e.g., early intensive behavioral intervention for ASD).<sup>6</sup> These treatments may, however, vary in efficacy, take time to show noticeable positive effects, or may not alleviate all concerning associated symptoms (e.g., gastrointestinal problems for children with ASD). Together with other factors, these circumstances may influence a family's decision to use complementary health approaches (CHA) for their child with DD.

CHA (also referred to as complementary and alternative medicine) encompass a wide array of modalities developed outside of or parallel to mainstream medicine.<sup>7</sup> The National Center for Complementary and Integrative Health currently categorizes CHA as natural products (e.g., specific vitamins, herbal supplements), mind and body practices (e.g., qigong, yoga), and other approaches (e.g., special diets, homeopathy).<sup>7</sup> CHA are typically used with conventional health services.<sup>7</sup> At present, limited evidence exists regarding the efficacy and/or safety for many CHA used to treat DD symptoms in children.<sup>8–13</sup>

The types of CHA most commonly used has been previously assessed among certain condition-based subgroups of children with DD. For example, children with ASD are commonly reported to use special diets (e.g., gluten- and/or casein-free),<sup>14–18</sup> certain natural products (e.g., specific vitamins/minerals, non-vitamin supplements such as probiotics), and/or mind and body practices (e.g., chiropractic or osteopathic manipulation).<sup>14–18</sup> Children with ADHD are reported to frequently use mind and body practices (e.g., chiropractic or osteopathic manipulation, massage therapy), special diets, and/or some natural products (e.g., specific vitamins/minerals, non-vitamin supplements).<sup>19,20</sup> Similarly, children with CP are most commonly reported to use certain mind and body practices (e.g., massage therapy, aquatherapy, hippotherapy).<sup>21,22</sup> Within these subgroups, a minority of children are reported to use unsafe and/or inefficacious CHA, such as chelation or hyperbaric oxygen therapy, in relationship to their DD symptoms. Still, little is known about the types of CHA most commonly used by children with DD overall.

Past research also suggests that the prevalence of CHA use is higher among specific DD subgroups (e.g., ASD, ADHD) than it is among other children.<sup>14,17–20,23–25</sup> That is, the use of CHA in the larger US child population was estimated to be 12.0% in 2007 and 11.6% in 2012.<sup>26</sup> Recent studies using large databases estimate 17.3 percent<sup>23</sup> to 28 percent<sup>14</sup> of children with ASD use CHA and approximately 25 percent of US youth (aged 7–17 years) with ADHD use CHA.<sup>20</sup> We are, however, unaware of previous studies that have estimated the prevalence of CHA use among US children with DD more broadly.

Greater knowledge of what factors are related to CHA use among children with DD is additionally needed. Prior research has identified some correlates of CHA use (e.g., age, symptomatology, parent education), again though, only among certain condition-based subgroups of children with DD.<sup>14,17,18,20,21,23,27</sup> For instance, younger versus older children with ASD or CP have been found to be more likely to use CHA.<sup>18,21</sup> Across these three DD subgroups (i.e., ADHD, ASD, CP) severity of symptoms or comorbidity have also been associated with the use of CHA.<sup>14,17,20,21</sup> Higher parent education versus lower parent education has additionally been associated with CHA use in studies of children with ADHD, ASD, or CP.<sup>17,18,20,21,27</sup> Some research also suggests that the use of certain conventional health services, particularly prescription medication, may be associated with the use of CHA among children with ASD or ADHD.<sup>17,18,20,27</sup> Yet the extent to which a more comprehensive set of factors are associated with the use of CHA among US children with DD has not been determined.

Because CHA are most commonly used along with conventional health services for children, pediatric healthcare providers are recommended to routinely communicate with families about and monitor CHA used for children.<sup>28,29</sup> A critical piece of this communication is a parent's disclosure of CHA used for their child to the child's healthcare provider(s). Limited research has, however, examined how often parent disclosure of CHA used for children occurs and what factors are related to disclosure.

Findings from several studies suggest that nondisclosure of CHA used in pediatric populations, including children with ADHD or asthma, occurs frequently.<sup>19,30,31</sup> Younger child age (< six years old),<sup>30</sup> use of mind and body practices,<sup>30</sup> parent non-CHA use,<sup>30</sup> or high parent-provider relationship quality<sup>31</sup> have been shown to be associated with parent disclosure of CHA used for children. The most frequently reported reason for nondisclosure in one study of children with asthma was that the parent did not think the child's provider needed to know.<sup>31</sup> Disclosure of CHA used for children with ASD has also been explored in two recent qualitative studies. One of these studies identified barriers and facilitators to disclosure of CHA used for children with ASD from parents' perspectives<sup>32</sup> and the other study described the use of CHA as an influence on shared decision-making from the perspectives of parents of children with ASD and primary care pediatricians.<sup>33</sup> Findings from these qualitative studies suggest that disclosure and subsequent discussion of CHA used for children with ASD can be challenging due to a number of factors such as provider attitudes and/or knowledge regarding CHA, as well as parent-provider relationship quality. Taken together, past research provides some indication of the frequency with which parent nondisclosure of CHA used occurs in pediatric healthcare settings; however, further research is needed to better understand parent nondisclosure of CHA used for children including those with DD.

Knowledge regarding the use and nondisclosure of CHA among children with DD is currently limited. Greater understanding regarding the prevalence and correlates of CHA use and nondisclosure for children with DD is needed to improve healthcare delivery and quality, specifically in terms of how information about CHA is transferred between families of children with DD and healthcare providers. Increased knowledge of CHA use and nondisclosure among children with DD may also inform the development of future studies

about pediatric health services utilization and outcomes, as well as intervention studies intended to promote family and provider communication about use of CHA and shared decision making more broadly. For these reasons, this study aimed to determine the prevalence and correlates of CHA use and nondisclosure among US children with DD. This study is novel because it applied the Complementary and Alternative Medicine (CAM) Healthcare Model to comprehensively examine both the use and nondisclosure of CHA among a large and nationally-representative sample of US children with DD, using one of the most extensive data sources presently available on the use and nondisclosure of CHA in the United States.

# METHODS

#### Study Design and Data Source

We analyzed parent-reported data from the 2012 National Health Interview Survey (NHIS). The 2012 NHIS is the most recent NHIS to include the Child Complementary and Alternative Medicine (CAM) Supplement Questionnaire. The supplement, sponsored by the National Center for Complementary and Integrative Health, was intended to provide nationally representative information on CAM use among children aged 4–17 years.<sup>34</sup> The final response rate was 69.7%.<sup>35</sup> The Institutional Review Board at the affiliated university determined that this study did not require review.

#### Sample

Of children aged 4–17 years (n = 10,185) for whom the 2012 NHIS Child CAM Supplement Questionnaire was completed, 2141 were determined to have one or more DD. To determine DD status, we used the Centers for Disease Control and Prevention's current DD definition<sup>2</sup> and relevant past research.<sup>1,3</sup> Specifically, DD status was based on affirmative responses by the child's parent to a series of questions in the 2012 NHIS Sample Child Core asking if the child had ADHD, ASD, cerebral palsy, Down syndrome, intellectual disability, seizures, stammering or stuttering, moderate to profound hearing loss, visual impairment including blindness, learning disorders, or other developmental delays.

#### Predisposing, Enabling, and Healthcare Need Factors

We used the CAM Healthcare Model,<sup>36</sup> a modification to the Behavioral Model of Health Services Utilization (the Behavioral Model),<sup>37</sup> as the theoretical basis for determining factors potentially correlated with the use and nondisclosure of CHA. The CAM Healthcare model includes factors adapted from the Behavioral Model that are theorized to influence the use of CHA with or without conventional health services, and in turn, healthcare outcomes (e.g., quality of life). Factors potentially influencing the use of CHA more specifically include those that predispose an individual to use CHA (e.g., gender, age, education), enable an individual to use CHA (e.g., income, health insurance coverage), or influence their need for CHA (e.g., condition symptoms, perceived health status).

To operationalize predisposing, enabling, and healthcare need factors for this study, we used these definitions to identify relevant variables available in the data source. Predisposing factors included child age, gender, race and ethnicity, parent education, and family structure.

Enabling factors included household income relative to the federal poverty level (FPL), health insurance coverage, household employment, and census region. Healthcare need factors were any problem or delay accessing conventional healthcare (e.g., prescription medication); current use of three or more conventional healthcare services (i.e., office visits, specialty care, emergency department visit, mental healthcare, therapy services, prescription medication, special education, or early intervention); and comorbidity per the 38 chronic conditions asked about in the 2012 NHIS. Additionally, healthcare need factors included functional limitations status based on if the child had any impairment limiting his or her physical abilities (e.g., walking); used special equipment (e.g., wheelchair); *or* had difficulties with emotions, concentration, behavior, or getting along with others that limited his or her daily activities. To account for confounding when examining nondisclosure correlates, the number of CHA used in the past year dichotomized at the median of one was included.

#### Use and Nondisclosure of CHA

Children were determined to have used any CHA if they had at least one affirmative response to items asking, "During the past 12-months, did [child] use...?" They were asked about: chelation, Ayurveda, acupuncture, qigong, hypnosis, biofeedback, energy healing, craniosacral therapy, naturopathy, Tai chi, traditional healers (e.g., Native American Healer), movement therapy (e.g., Pilates), guided imagery, meditation, special diets (i.e., vegetarian or vegan), homeopathy, massage therapy, yoga, chiropractic or osteopathic manipulation, herbal or non-vitamin supplements (e.g., fish oil), specific minerals (i.e., calcium, magnesium, iron, chromium, zinc, selenium, potassium), and specific vitamins (i.e., A, B, C, D, E, H, K). To have been counted as using acupuncture, Ayurveda, biofeedback, chelation, chiropractic or osteopathic manipulation, craniosacral therapy, energy healing therapy, hypnosis, massage, movement and exercise techniques, or naturopathy, the child had to have seen a practitioner for the modality in the past 12-months *or* the child used the given modality in the past 12-months. Per past research, we did not consider children who were only indicated to have used multi-vitamins or multi-minerals in the past 12-months as having used any CHA.<sup>26</sup>

To further characterize CHA use, we additionally examined the reasons for use of CHA that were asked about. In the survey, parents were asked to select up to three modalities that children were reported to have used in the past 12-months that the parent considered to be most important for the child's health. Parents were not able to select multivitamins/minerals, specific vitamins, specific minerals, or chelation in this survey section. Then for each modality selected as being most important for the child's health, 14 reasons for use were subsequently asked about (Figure 1a).

CHA nondisclosure was only assessed among children with a usual source of healthcare and a personal health provider, defined as a health professional who knew the child well and was familiar with the child's health history (e.g., general doctor). To have been asked about CHA nondisclosure, the child additionally needed to have used one or more CHA from the subset of modalities that reasons for use were asked about. The following item was asked for up to three of these modalities, which were reported as being most important for the child's

health, "During the past 12-months, did you let [child]'s personal health provider know about [his/her] use of [modality]?" Nondisclosure of *any* CHA was defined when the parent said "No" for any of the modalities asked about. Because correlates of nondisclosure of *any* versus *all* CHA asked about may differ among children with DD, we also included a nondisclosure of *all* CHA measure (i.e., nondisclosure was reported for all modalities asked about). When any nondisclosure was reported by parents, eight reasons for nondisclosure were subsequently asked about (Figure 1b). We examined six reasons for nondisclosure, collapsing three reasons into a single variable about negative provider reaction, due to low response frequency and content similarity.

# Analysis

To describe the sample and estimate the prevalence of CHA use and nondisclosure among US children with DD, descriptive statistics were first computed for all variables of interest. We also computed CHA use by DD status to further contextualize the prevalence of CHA use for children with DD. Bivariate statistics were then computed to determine differences in the distributions of predisposing, enabling, and healthcare need variables by use and nondisclosure of CHA. Bivariate analysis results informed three multivariable logistic regression models fit to determine adjusted associations of predisposing, enabling, and healthcare need factors with (1) any CHA use, (2) nondisclosure of *any* CHA, and (3) nondisclosure of *all* CHA. Factors that had an unadjusted association with CHA use and/or nondisclosure significant at a P < .10 level were initially included in the respective multivariable model but were only retained if their association remained statistically significant at the P < .05 level. Given sample size constraints, we descriptively examined reasons for CHA use and nondisclosure. We weighted analyses per NCHS guidance<sup>35</sup> and performed all analyses in Stata 14.2.

# RESULTS

## **Population Characteristics**

The sample represented an estimated 12,382,376 US children with DD aged 4–17 years. The most common DD was ADHD (47.4%) followed by learning disabilities (39.5%), other DD (22.9%), visual impairment (15%), moderate or profound hearing loss (11.9%), stuttering or stammering (8.6%), ASD (6.4%), ID (5.9%), seizures (3.4%), and CP (1.4%). The mean child age was 11 years (SD = 3.8 years). Many children with DD were male, non-Hispanic white, had at least one parent with more than a high school education, had a household income level above the FPL, had one or more working adult in their household, had no problems or delays accessing conventional care, and had comorbid conditions (Table 1).

# Use of CHA

Among US children with DD aged 4–17 years, 23.3% (95% CI: 21.0%–25.8%) or an estimated 2,841,436 children reported using any CHA in the past year. By comparison, we found that 19.8% (95% CI: 18.5%–21.1%) of US children without DD aged 4–17 years reported using any CHA use in the past year. The proportion of children with DD reported to use CHA was significantly higher than the proportion of children without DD reported to use CHA (P=.005).

For children with DD, specific vitamins (14.7%), herbal supplements (8.1%), and specific minerals (7.7%) were the most commonly used modalities followed by chiropractic or osteopathic manipulation (3.2%). Certain modalities that can be unsafe, such as special diets (~1%), were infrequently reported to be used by children with DD, and no children with DD were reported to have used chelation. Although bivariate analysis results showed statistically significant associations of CHA use with child age, race and ethnicity, parent education, health insurance, household employment, conventional care use, or functional limitations status, these associations did not remain statistically significant in the multivariable analysis. Multivariable regression results showed higher adjusted odds of CHA use for children with DD who were female, had higher household income, did not live in the South, experienced any problem or delay accessing conventional care, or had one or more comorbid chronic condition (Table 2). Among children with DD who used one or more of the select CHA modalities, the most frequently reported reasons for use were because it is natural, for the child's general wellness or disease prevention, and because it treats the cause not just the symptoms (Figure 1a).

#### Nondisclosure

Among US children aged 4–17 years with DD who used any CHA in the past year and had a personal health provider, nondisclosure of *any* CHA used was reported for an estimated 533,333 or 41.9% (95% CI: 34.2%–50.0%) of children. Nondisclosure of *all* CHA used was reported for an estimated 461,750 or 36.2% (95% CI: 28.3%–45.0%) of children with DD. For children with DD, the most frequently nondisclosed modalities were herbal supplements (i.e., fish oil, melatonin, probiotics), certain mind and body practices (i.e., yoga, tai chi, qigong, chiropractic or osteopathic manipulation), and homeopathy (data not shown). Multivariable regression results demonstrated higher adjusted odds of nondisclosure of *any* CHA used for children with DD who were female or had no functional limitations (Table 3). Higher adjusted odds of nondisclosure of *all* CHA used one modality of CHA (Table 3). The most frequently reported nondisclosure reason was that the child's health provider did not ask (Figure 1b).

# DISCUSSION

This study is one of the first to examine the prevalence and correlates of CHA use and nondisclosure among US children with DD. Our study found higher CHA use prevalence for US children with DD (23.3%) compared to those without DD (19.8%). Prior research utilizing data from other databases among subgroups of US children with DD has shown prevalence of CHA use close to this study, ranging from 17.3%<sup>23</sup> to 28.0%<sup>14</sup> for children with ASD and 10.2%<sup>25</sup> to 24.7%<sup>20</sup> for children with ADHD. Variability in prevalence estimates of CHA use may be due in part to differences in how CHA use is measured (e.g., the exclusion of specific vitamins and/or specific minerals from the definition of CHA), as well as how children are sampled. Consistent measurement and sampling are, therefore, needed in future research intended to determine time trends in CHA use among children with DD.

Being female, higher household income, not living in the South, difficulty accessing healthcare, and comorbidity were each associated with greater odds of CHA use. These findings are consistent with past research suggesting female versus male children with mental health conditions including ADHD<sup>20</sup> are more likely to use CHA. Past research similarly shows that children with ADHD who have higher household income are more likely to use CHA.<sup>20,25</sup> Our study findings regarding regional variation in CHA use among children with DD are also consistent with past research demonstrating children with ADHD<sup>25</sup> or ASD<sup>23</sup> in the South are less likely to use CHA. Past research additionally shows that various markers of elevated healthcare need (e.g., problems accessing care, service use, comorbidity, symptom severity) are associated with greater CHA use in DD subgroups (e.g., ASD, ADHD),<sup>14,20,25</sup> and our study also showed that problems accessing healthcare and comorbidity were associated with greater odds of CHA use among children with DD. Future research is needed to determine how different aspects of healthcare need (e.g., changes in the need for certain conventional DD treatments) may interact over time in relationship to CHA use for children with DD.

The most frequently reported reason for use (i.e., it is natural) among children with DD who used any CHA aligns with some prior research demonstrating parents use CHA because they believe CHA is safer than other treatments (e.g., medication),<sup>24</sup> even though this may not be true. We also found the use of CHA to treat the cause not just the symptoms was another frequently reported reason. A potential rationale for CHA use by children with ASD and other neurodevelopmental disorders—particularly the use of biomedical modalities—is that they are believed to address underlying disease mechanisms (e.g., oxidative stress, immune abnormalities).<sup>13</sup> Our study suggests this belief may contribute to CHA use in children with DD more broadly. Still, *how* these and other beliefs, together, drive patterns of conventional healthcare and CHA use in children with DD remains largely unstudied and an area for future research.

We found nondisclosure was relatively common for some or all modalities reported to be most important for the child's health. Past studies<sup>19,30,31</sup> have found higher nondisclosure rates for other specific populations (e.g., children with asthma). Methodological differences (e.g., nonprobability versus probability sampling) may account for some of this variation or it may be that children with DD are relatively well-connected to the health system and are more likely to disclose CHA use. We also found discrepancies in the factors significantly associated with nondisclosure of any versus all CHA modalities used by children with DD. Specifically, though nondisclosure of any CHA may be more likely for female children or those without functional limitations, nondisclosure of all modalities may most commonly occur among older children, those receiving fewer conventional care services, or those using few CHA modalities. Overall, our study's findings align with past research showing younger age, more severe symptomatology, and routine conventional health services use may prompt disclosure. Gender has not, however, been a characteristic previously identified as potentially influencing nondisclosure among children with DD, suggesting that greater exploration of gender-based differences in family-provider communication about CHA use in children with DD is needed.

Like past research,<sup>30,31,38</sup> the most frequently reported reasons for nondisclosure in this study were that the child's health provider did not ask or that the parent felt the child's provider did not need to know, pointing to a need for improved family-provider communication about CHA and greater education of families and providers about DD treatment options including CHA. Past research shows that some pediatric providers encourage the use of certain CHA (e.g., fatty acids, melatonin) for children with ASD, and that most of these providers inquire about CHA use and would like to receive more training about CHA.<sup>39</sup> Relatedly, limited provider knowledge and/or negative attitudes about CHA may contribute to nondisclosure and ultimately greater discord in shared decision-making between families of children with ASD and their healthcare providers.<sup>32,33</sup> Additional research is needed to determine how family-provider communication and other aspects of pediatric healthcare visits (e.g., visit questionnaires asking about CHA use, provider prompts to ask about CHA in the electronic health record system) could be used to reduce nondisclosure and potentially improve pediatric healthcare quality more broadly (e.g., receipt of routine immunizations, use of antibiotics).

Our findings should be interpreted with several limitations in mind. Foremost, the crosssectional design precludes causal inferences from being drawn. Descriptive results on reasons for CHA use and nondisclosure do, however, provide some insights into the motivations for these behaviors. Future longitudinal and mixed methods research is needed to better understand why families use CHA for children with DD and do not disclose it to their child's health provider. Though the definitions used to construct measures of DD status, as well as CHA use and nondisclosure, are congruent with past research, measurement variability across the entire body of relevant research may contribute to differences in findings. For example, the 2012 NHIS CAM Supplement did not ask about all potential modalities used (e.g., hyperbaric oxygen therapy, essential oils), and this may contribute to differences in estimates of CHA use prevalence across studies. In addition, nondisclosure of CHA used was only assessed for a subset of children in the 2012 NHIS (i.e., those with a usual source of care and personal health provider who used the CHA asked about). Further research is, therefore, needed to better understand nondisclosure among the broader population of children with DD who may not have a health provider and/or use modalities that were not asked about. Although the timeframe of all NHIS items used to assess CHA use and nondisclosure was the past 12-months, the potential for recall bias still exists in terms of under- or over-reporting. Other data sources such as information available from children's electronic health records and/or patient portals may be considered in future research insofar as they may be able to provide additional and potentially more recent insights into CHA use and disclosure among children with DD.

# CONCLUSION

CHA use is prevalent among children with DD nationwide. The most common reason for CHA use ("it is natural") reflects parents' perception that CHA may be safe. This perception may be consistent with current scientific evidence for some CHA used to treat DD, while for other CHA it may not be. Families of children with DD may view healthcare providers as information resources or brokers regarding DD treatment options, including CHA. Healthcare providers may, however, possess limited knowledge of CHA.<sup>39</sup> Increased

education for healthcare providers about CHA is, therefore, needed. Greater knowledge of CHA among healthcare providers may, in turn, help families to better understand the safety and efficacy of CHA along with other DD treatment options. Disclosure of CHA is necessary for shared treatment decision-making to occur. Our study revealed nondisclosure may be common among children with DD. Common reasons for nondisclosure highlight a need for improved family-provider communication about CHA, specifically in terms of providers initiating dialogue about CHA. Provider prompts in electronic health record systems to ask families about CHA reported on intake forms, as well as brief training to enhance providers' family-centered communication in discussing health risks<sup>40</sup> may be used to increase disclosure. Interventions informed by this study's findings may help improve healthcare for children with DD, particularly related to the use and nondisclosure of CHA.

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# Abbreviations

ADHD	attention deficit/hyperactivity disorder
ASD	autism spectrum disorder
CAM	complementary and alternative medicine
СНА	complementary health approaches
СР	cerebral palsy
DD	developmental disabilities
FPL	federal poverty level
NCHS	National Center for Health Statistics
NHIS	National Health Interview Survey

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Figure 1a. It is natural 67 1% For child's general wellness or disease prevention 64.4% Treats the cause and not just the symptoms 57.4% Recommended by a family member 56.4% For specific health problems, symptoms, or conditions 50.9% Focuses on the whole person, mind, body, and spirit 49.0% To improve child's memory/concentration 36.0% Part of child's upbringing 35.6% To improve child's immune function 34.8% Recommended by a medical doctor 32.2% To improve child's energy 28.1% Recommended by a friend 25.0% To improve child's sports/athletic performance 23.0% Recommended by a co-worker of child's family 5.2% 0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100% Weighted Relative Frequency Figure 1b. Child's provider did not ask about CHA Parent did not think child's provider needed to know 45 Child not using CHA modality at the time it was asked about 26 Parent did not think child's provider knew as much as them 11 Parent concerned about negative reaction from child's provider Provider did not give parent enough time to tell

#### Figure 1.

**Figure 1a.** Weighted Relative Frequencies of Reasons for Use of CHA among US Children with DD aged 4-17 years (n = 255)

20

30

40

50

60

Unweighted Frequency

70

80

90

100

**Figure 1b.** Unweighted Frequencies of Reasons for Nondisclosure of CHA used for US Children with DD aged 4–17 years (n = 95)

0

10

# Table 1

Characteristics of US Children with DD aged 4–17 years (n = 2,141)

	п	%
Predisposing characteristics		
Age, years		
4–9	757	36.50
10-12	498	24.70
13–17	886	38.80
Gender		
Female	798	36.70
Male	1,343	63.30
Race/ethnicity		
White, non-Hispanic	1,107	59.12
Hispanic	504	18.89
Black, non-Hispanic	342	14.15
Other race, non-Hispanic	188	7.83
Highest parent education level		
High school diploma or GED	753	32.32
More than high school	1,385	67.68
Family structure		
2 parent biological/adoptive	683	35.62
2 parent with step parent	160	9.14
Single mother	413	16.83
Other family structure	884	38.40
Enabling resources		
Household income level		
0–99% FPL	590	27.72
100–199% FPL	554	24.63
200-399% FPL	551	25.59
400% FPL	446	22.06
Health insurance coverage		
Public insurance or uninsured	1,217	54.90
Any private insurance	914	45.10
Household employment		
1 adult working	1,771	84.81
No adults working	370	15.19
Census region		
Midwest	436	22.58
Northeast	359	15.78
South	816	40.05
West	530	21.59
Healthcare need factors		

	n	%
Problems or delays getting care		
No problems or delays	1,729	80.57
1 problem or delay	412	19.43
Conventional care use		
2 services	1,132	52.05
3 or more services	1,009	47.95
Chronic condition comorbidity		
1 chronic condition	512	23.61
2 of 38 chronic conditions	1,629	76.39
Functional limitations status		
No functional limitations	1,430	66.73
Functional limitations	707	33.27
Overall health status		
Excellent or very good	1,466	69.60
Good, fair, or poor	675	30.40

Note. Percentages were computed using weighted analyses.

Data source: 2012 National Health Interview Survey

## Table 2

Bivariate<sup>*a*</sup> and Multivariable Associations<sup>*b*</sup> of CHA Use with Predisposing, Enabling, and Healthcare Need Factors among US Children with DD aged 4–17 years (n = 2,103)

	0/	OD (05% CT)	oOD (059/ CD)
Predisposing characteristics	<u>%</u>	<u>OR (95% CI)</u>	<u>aOR (95% CI)</u>
Age, years			
4–9	19.40	1.00	_
10-12	23.83	1.30 (0.91–1.86)	
13–17	25.85 26.68	<b>1.50</b> (0.91–1.80) <b>1.51</b> ( <b>1.12–2.05</b> )	
Gender	20.08	1.31 (1.12–2.03)	
Female	26.85	1 26 (1 04 1 77)	
		1.36 (1.04–1.77)	1.38 (1.06–1.81)*
Male	21.27	1.00	1.00
Race/ethnicity			
White, non-Hispanic	25.11	1.00	
Hispanic	19.39	0.72 (0.52-0.98)	—
Black, non-Hispanic	15.77	0.56 (0.37-0.85)	—
Other race, non-Hispanic	33.13	1.48 (0.96-2.27)	—
Highest parent education level			
High school diploma or GED	16.55	1.00	—
More than high school	26.49	1.82 (1.37-2.40)	
Family structure			
2 parent biological or adoptive	25.60	1.00	—
2 parent with step parent	26.58	1.05 (0.62–1.79)	—
Single mother	20.29	0.74 (0.50–1.09)	—
Other family structure	21.72	0.81 (0.60–1.09)	—
Enabling resources			
Household income			
0–99% FPL	16.09	1.00	1.00
100–199% FPL	17.76	1.13 (0.77–1.66)	1.23 (0.83–1.83)
200–399% FPL	25.85	1.82 (1.28-2.57)	2.09 (1.44–3.03) ****
400% FPL	35.60	2.88 (1.99-4.17)	3.50 (2.35–5.21)***
Health insurance coverage			
Public insurance only/uninsured	17.79	1.00	—
Any private insurance	29.89	1.97 (1.52-2.56)	_
Household employment			
1 adult working	24.52	1.00	_
No adults working	16.50	0.61 (0.43-0.86)	
Census region			
South	16.66	1.00	_
West	31.54	2.30 (1.60-3.33)	2.24 (1.56–3.22) ***
Northeast	25.75	1.73 (1.18-2.55)	
Tormoust	23.13	1.75 (1.10-2.55)	1.52 (1.02–2.26)*

	<u>%</u>	<u>OR (95% CI)</u>	<u>aOR (95% CI)</u>
Midwest	25.66	1.73 (1.23–2.43)	1.69 (1.20–2.39) **
Healthcare need factors			
Problems or delays getting conventional care			
No problems or delays	21.83	1.00	1.00
1 problem and/or delay	29.50	1.50 (1.10-2.04)	1.64 (1.23–2.20)***
Conventional care utilization			
2 conventional care services	20.63	1.00	_
3 or more conventional care services	26.29	1.37 (1.04–1.82)	—
Chronic condition comorbidity			
1 chronic condition	17.09	1.00	_
2 of 38 chronic conditions	25.27	1.64 (1.16-2.32)	1.71 (1.18–2.48)**
Functional limitations			
No functional limitations	21.54	1.00	_
Functional limitations	26.91	1.34 (1.02–1.77)	
Overall health status			
Excellent or very good	23.13	1.00	_
Poor, fair, or good	23.75	1.04 (0.78–1.37)	—

<sup>*a*</sup>Bolded values indicate the unadjusted association was significant at a P < .10 level and was initially included in the multivariable model. For the multivariable model results:

\*\*\* P<.001,

\*\* P<.01,

\* P<.05

<sup>b</sup>Only the final multivariable model results are shown. Dashes indicate variables were not included or were removed.

Note. All analyses were weighted.

Data source: 2012 National Health Interview Survey

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# Table 3

Bivariate<sup>a</sup> and Multivariable Associations<sup>b</sup> of Nondisclosure with Predisposing, Enabling, and Healthcare Need Factors for US Children with DD aged 4– 17 Years (n = 223)

Lindly et al.

		Nondisclosu	<u>Nondisclosure of Any CHA</u>		Nondisclosu	Nondisclosure of All CHA
	%	OR (95% CI)	aOR (95% CI)	%	OR (95% CI)	aOR (95% CI)
Predisposing characteristics						
Age, years						
4-9	30.85	1.00		24.53	1.00	1.00
10–12	51.34	2.36 (0.98–5.73)		39.39	2.00 (0.81-4.94)	2.32 (0.91–5.92)
13-17	44.75	1.82 (0.89–3.72)		44.11	2.42 (1.17–5.04)	2.40 (1.16–4.97)*
Gender						
Female	55.67	2.76 (1.41–5.40)	2.74 (1.41–5.32)**	43.35	1.72 (0.85–3.47)	
Male	31.26	1.00	1.00	30.78	1.00	
Race/ethnicity						
White, non-Hispanic	42.27	1.00		37.30	1.00	
Hispanic	41.66	0.98 (0.36–2.63)		26.23	0.60 (0.23–1.58)	
Black, non-Hispanic	44.52	$1.10\ (0.32 - 3.80)$		44.52	1.35 (0.38-4.80)	
Other race, non-Hispanic	38.62	0.86 (0.31–2.37)		35.51	0.93 (0.34–2.51)	
Highest parent education level						
High school diploma or GED	38.67	1.00		38.67	1.00	
More than high school	42.39	1.17 (0.44–3.12)		35.83	0.89 (0.33–2.39)	
Family structure						
2 parent biological or adoptive	39.60	1.00		35.04	1.00	
2 parent with step parent	54.03	1.79 (0.50–6.61)		45.22	1.53 (0.43–5.44)	
Single mother	32.96	0.75 (0.22–2.60)		29.50	0.78 (0.21–2.92)	
Other family structure	44.66	1.23 (0.63–2.40)		37.69	1.12 (0.55–2.29)	
Enabling resources						
Household income level						
0-99% FPL	43.03	1.00		37.21	1.00	
100–199% FPL	52.72	1.47 (0.48–4.58)		39.56	1.10 (0.33–3.70)	
200–399% FPL	38.85	0.84 (0.33–2.18)		42.42	1.24 (0.46–3.35)	

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		TINGOTOSTINITOLT			TAUTORINA	
	%	OR (95% CI)	aOR (95% CI)	%	OR (95% CI)	aOR (95% CI)
400% FPL	38.68	0.84 (0.33–2.12)		30.10	0.73 (0.27–1.93)	
Health insurance coverage						
Public insurance or uninsured	48.44	1.00		44.53	1.00	
Any private insurance	38.27	0.66 (0.34–1.27)		31.49	0.57 (0.29–1.14)	
Household employment						
1 adult working	41.87	1.00		36.33	1.00	
No adults working	41.71	0.99 (0.41–2.43)		35.41	0.96 (0.38–2.42)	
Census region						
South	46.56	1.00		42.58	1.00	
West	39.28	0.74 (0.33–1.66)		31.98	0.63 (0.26–1.57)	
Northeast	43.23	0.87 (0.26–2.95)		37.07	0.79 (0.22–2.82)	I
Midwest	39.23	0.74 (0.31–1.76)		34.29	0.70 (0.29–1.73)	
Healthcare need factors						
Problems or delays getting care						
No problems or delays	41.73	1.00		36.56	1.00	
1 problem and/or delay	42.33	1.03 (0.44–2.36)		35.03	0.94 (0.40–2.19)	
Conventional care use						
2 services	50.81	1.83 (0.91–3.69)		49.15	2.50 (1.22–5.12)	$3.08 \left(1.40 - 6.79 ight)^{**}$
3 or more services	36.07	1.00		27.89	1.00	1.00
Chronic condition comorbidity						
1 chronic condition	46.12	1.00		50.67	1.00	
2 of 38 chronic conditions	41.21	0.82 (0.28–2.42)		34.05	0.50 (0.17–1.48)	
Functional limitations status						
No functional limitations	48.49	2.13 (1.08-4.22)	2.11 (1.05–4.22)*	43.18	2.34 (1.15-4.78)	
Functional limitations	30.63	1.00	1.00	24.50	1.00	
Overall health status						
Excellent or very good	44.08	1.00		40.29	1.00	
Poor, fair, or good	36.51	0.73 (0.35–1.52)		26.51	0.53 (0.25–1.16)	
Number of CHA used $c$						
1 modality	43.01	1.12 (0.59–2.13)		45.71	2.91 (1.43–5.94)	$3.64 \left( 1.70  extsf{7.81}  ight)^{**}$

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 $a^{d}$ Bolded values indicate the unadjusted association was significant at a P < .10 level and was initially included in the multivariable model. For the multivariable model results:

 $^{**}_{P<.01}$ ,

 $^{*}_{P<.05}$ 

b Only the final multivariable model results are shown. Dashes indicate variables were not included or were removed.

<sup>c</sup>The number of CHA modalities reported by children with DD ranged from 1-7, with the median number of modalities used = 1.

Note. All analyses were weighted.

Data source: 2012 National Health Interview Survey