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## Patient-centered outcomes in an interdisciplinary clinic for complex children with autism

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### Abstract

**Objective:** To compare perspectives of caregivers of children with autism receiving care at the Neurobehavior Healthy Outcomes Medical Excellence (HOME) Program, an interdisciplinary clinic that provides primary care and behavioral/mental health services for patients with autism and other developmental disabilities, with those responding to the 2016 National Survey of Children's Health (NSCH). We focused on ratings related to shared decision making, care coordination, family-centered care, and care within a medical home.

**Methods:** We administered a subset of items from the 2016 NSCH to caregivers of children with autism enrolled in HOME and compared responses to the same items from a nationally representative group of caregivers of children with autism who completed the 2016 NSCH. We compared the proportions that reported receiving shared decision making, care coordination, family-centered care, care within a medical home, and unmet needs among the two study groups using Poisson regression, controlling for age, sex, race/ethnicity, payor, autism severity and intellectual disability.

**Results:** Compared with the NSCH cohort (n=1,151), children enrolled in HOME (n=129) were older, more often female, had severe autism, and had co-occurring intellectual disability. Caregivers perceived that children receiving care within HOME more often received family-centered, coordinated care within a medical home compared with a national sample of children with autism. HOME enrollees also reported increased access to behavioral treatments and adult transition services with less financial burden compared to the national sample.

**Conclusion:** An interdisciplinary clinic model may best serve children with autism, especially those with higher severity symptoms and co-occurring conditions.

### Keywords

Autism; Medical home; Shared decision making; Care coordination; Patient-centered outcomes

## INTRODUCTION

Children with autism spectrum disorder (hereafter referred to as “autism”) have deficits in social communication and repetitive behaviors while often having co-occurring medical, behavioral, and psychiatric conditions [1]. Their needs span the sectors of medical, behavioral and mental health systems and thus they benefit from interdisciplinary care [2, 3]. Without high quality outpatient services, children with autism are more likely to engage in severe maladaptive behaviors, such as physical aggression, leading to disproportionately high utilization of inpatient care [4–6]. Compared with children with other disabilities, however, parents of children with autism report more difficulty accessing needed medical, behavioral and mental health care services and have lower satisfaction with outpatient services [7–9]. Specifically, families of children with autism describe difficulties in accessing rehabilitative therapies and subspecialists, including mental health providers [10]. To address this need, there is a growing interest in pediatric and lifespan integrated service delivery frameworks, particularly the inclusion of behavioral health care [11]. Current research suggests that desired health care outcomes, such as decreased emergency department visits and hospitalizations, and higher family satisfaction with care can be achieved through the provision of integrated, family-centered care through a medical home [12].

A medical home is an interdisciplinary health care delivery model characterized by continuous, comprehensive medical care for patients that emphasizes shared decision-making between families and providers [13, 14]. This model of care specifically benefits children with autism. Families of children with autism who receive care within a medical home have lower out-of-pocket medical expenses and less emergency department utilization for chronic disease management [15, 16]. Despite the benefits, less than half of children with autism receive care within a medical home and those with more severe autism are even less likely to receive this type of care [17]. Within the traditional framework in which services are siloed rather than integrated, children with autism have difficulty accessing high-quality primary and mental health care, which leads to disproportionately high inpatient health care utilization [5, 6, 8, 16]. In order to address these complex needs, interdisciplinary outpatient programs are needed in order to support families of children with autism, improve outcomes and prevent costly inpatient health care utilization.

The Neurobehavior Healthy Outcomes Medical Excellence (HOME) Program at the University of Utah is an outpatient clinic for children and adults with developmental disabilities and co-occurring psychiatric and behavioral conditions that utilizes the medical home model [18]. HOME is staffed by an interdisciplinary team consisting of primary care providers, psychiatrists, behavioral specialists, therapists, dieticians, and case managers who are co-located in the clinic in order to meet the medical and mental health care needs of people with autism and other developmental disabilities across the lifespan. HOME currently serves over 1,200 patients and functions as its own health maintenance organization, receiving funding through a capitated per-member per-month prepayment from state Medicaid and through private insurance from patients who have additional coverage [19]. HOME providers deliver care within the clinic and HOME covers care outside the clinic from paneled specialty providers, as well as any needed inpatient care. HOME

assumes financial risk for costs over the prepayment and has remained financially viable for 20 years, providing value-based care for eligible children and adults with developmental disabilities and co-occurring mental health conditions. Because of the unique funding structure, HOME is able to provide patients and families a unique form of care that includes prolonged visits, visits that are attended by multiple team members simultaneously and care coordinators for every enrollee.

We have previously shown that patients enrolled in HOME are more likely to receive evidence-based outpatient care with a reduction in hospital bed days [18]. We have not yet however analyzed how caregivers of our patients with autism perceive their care and how their perceptions compare with caregivers of children with autism not enrolled in HOME. We hypothesized that the caregivers of children with autism enrolled in HOME would be more likely to report shared decision-making with their providers and care that is coordinated, family-centered and meets the standard of a medical home compared with a national cohort of caregivers of children with autism. Because HOME is a lifespan, interdisciplinary, and Medicaid funded clinic with co-located primary care providers, behavioral health providers, psychiatrists, and care coordinators, we also hypothesized that caregivers of children enrolled in HOME would be less likely to report unmet healthcare needs and improved access to services important for children with autism (mental health, medical subspecialists, adult transition services).

## METHODS

### Data Sources

To evaluate the model of care offered by the Neurobehavior HOME Program, we compared survey responses between caregivers of children with autism enrolled in HOME and a nationally representative sample of caregivers of children with autism utilizing items from the 2016 National Survey of Children's Health (NSCH), a combined version of the previous NSCH and the National Survey of Children with Special Health Care Needs. The 2016 NSCH, a mail and web-based survey conducted by the Census Bureau, assesses caregiver reported physical and mental health, access to quality health care, and the child's family, neighborhood, school, and social context among parents of children age 0–17 across the US. We selected against limiting the reference cohort to children with autism living in Utah as the NSCH dataset would have filtered to an unacceptably low number (n=30). No other available state cohort is currently available to make a similar comparison.

We obtained de-identified data from the 2016 NSCH through an online request submitted to the Data Resource Center for Child & Adolescent Health [20]. We used an identical subset of items from the 2016 NSCH that were administered to both study groups, including demographic information about child and caregiver, autism status and severity, presence of co-occurring conditions, functional status, health care service access, impact of child's health on family, shared decision-making, and medical home access. For HOME participants, the survey was administered via mail or electronically through Research Electronic Data Capture (REDCap), a secure, web-based software platform designed to support data collection for research studies [21]. Survey respondents did not receive compensation or incentives for completion of NSCH or HOME surveys.

## Independent Variables

We compared survey responses between two study groups: caregivers of children with autism (ages 2–21) enrolled in HOME and a nationally representative group of caregivers of children with autism (age 2–17 years), presumed not to be enrolled in HOME. For HOME participants, we included caregivers of individuals up to 21 years (rather than cutoff for the NSCH group at 17 years) because individuals between the ages of 18–21 enrolled in HOME are cared for by the same pediatric primary care providers who care for children under 18 years and are not transitioned from pediatric to adult providers until the age of 22. With the use of conditional branching logic, NSCH responders who reported receiving no medical or mental health care in the last 12 months were not asked to reflect on their child's experiences and unmet need. Due to many NSCH survey items specific to the care over the past 12 months, we excluded caregivers in HOME who had not brought their child for a visit during the study period (n=46). Children in both groups were identified as having autism based on affirmative responses to two items from the NSCH: *“Has a doctor or other health care provider EVER told you that this child has Autism or Autism Spectrum Disorder (ASD)?”* and *“Does this child CURRENTLY have the condition?”*

## Recruitment of HOME Participants

We recruited caregivers of individuals with autism who were under the age of 22 and were continuously enrolled in HOME during 2017. Individuals with autism were identified based on the identification of an autism ICD code (299.xx, F84.x) from a review of HOME electronic health records. Caregivers were given information regarding the study objectives by email along with a link to the study's REDCap electronic informed consent form. Only caregivers who signed the electronic consent were eligible to access and participate in the study. Potential participants were informed that their responses would be kept confidential and anonymous and that non-participation would not in any way affect their child's care at HOME. We emailed electronic surveys to families with email addresses on file (235 of the 300 families) and the remainder received the identical informed consent form and survey in print format. For those invited via email, we sent two follow-up reminder emails to non-responders. For those invited via mail, only one initial letter was sent out due to study budget constraints. We subsequently invited all eligible caregivers during clinic visits between November 2018 to May 2019 with all surveys completed during this time period. For caregivers who participated in clinic, we administered the consent and survey via REDCap on study iPads. Families asked in clinic were given the same opportunity to decline study participation as families participating in the online survey. Across all three recruitment methods (electronic, print, in-person), the same informed consent form and survey were used.

## Outcome Variables

The survey administered to HOME participants consisted of questions identical to a subset of items from the 2016 NSCH questionnaire. Individual survey items were grouped to form the following composite outcome variables: Shared Decision-Making, Family-Centered Care, Effective Care Coordination, and Care Within a Medical Home. The individual survey items that were grouped to form each of the composite variables are listed in table 1. For

each item within the composite variables of shared decision-making and family-centered care, respondents answered “always”, “usually”, “sometimes”, or “never”. Shared decision-making and family-centered care were defined as present with responses of “usually” or “always” on *all* of the individual items. For each item of the effective care coordination composite variable respondents answered “very satisfied”, “somewhat satisfied”, “somewhat dissatisfied” or “very dissatisfied”. Effective care coordination was defined as present with responses of “very satisfied” on *all* individual items. The presence of a medical home was defined by a composite variable based on the presence of *all* of the following: having a personal doctor or nurse, having a usual source for sick care, experiencing family-centered care, having no problems getting needed referrals and experiencing effective care coordination when needed.

In addition to composite variables, we included other individual NSCH items in the HOME survey that relate to unmet healthcare needs for children with autism. Specifically, these items addressed access to needed healthcare and mental health services, referrals for specialty care and health insurance coverage and costs.

### Data Analysis

Descriptive statistics of child characteristics and co-occurring conditions were summarized for the two cohorts (HOME and NSCH). We then compared the proportions of each group that reported receiving shared decision-making, care coordination, family-centered care, care in a medical home, and unmet needs with the chi-squared test. Anticipating that there would be significant differences between the two groups, we also modeled the receipt of composite variables (shared decision-making, care coordination, family-centered care, and care within a medical home) and individual unmet needs items using multivariable binary Poisson regression with robust standard errors [22] in order to control for child characteristics (age, sex, race/ethnicity, insurance, autism severity, and intellectual disability [ID]) and parent characteristics (highest educational level). Survey items, such as access to mental health care, specialist referrals, and transition to adult care, were separately evaluated. Statistical significance was determined at  $p=0.05$ . The current study was exempt from Institutional Review Board (IRB) review by our institution.

## RESULTS

Among 300 children with an autism diagnosis enrolled in HOME during the study period, 254 had visits during 2017. After offering participation to caregivers of these individuals, 129 (51%) completed surveys. The NSCH cohort consisted of 1,151 responses from caregivers of children with autism who completed the 2016 NSCH.

Children in the HOME cohort were older compared with those in the NSCH (16.6 years [95% CI 15.7–17.2], SD 4.4 vs 11.1 years [95% CI 10.8–11.3] SD 4.2,  $p>0.001$ ). The HOME cohort also had a higher proportion that were female (28.7% vs. 19.0%,  $p=0.009$ ), had severe autism (31.8% vs. 9.5%,  $p<0.001$ ), and co-occurring intellectual disability (66.7% vs. 17.4%,  $p<0.001$ ) (table 2). Additionally, a higher proportion of pediatric patients enrolled in HOME had co-occurring anxiety (86.4% vs. 48.0%,  $p<0.001$ ), behavioral problems (84.1% vs. 62.1%,  $p<0.001$ ), attention deficit disorder/attention deficit

hyperactivity disorder (67.2% vs. 48.6%,  $p < 0.001$ ), depression (45.5% vs. 18.7%,  $p < 0.001$ ), and epilepsy (22.1% vs. 7.0%,  $p < 0.001$ ) (table 3). Reported ethnicities between the two cohorts were not different ( $p > 0.05$ ).

In our unadjusted analysis of the main outcomes, a higher proportion of parents in HOME reported shared decision-making (71.0% vs. 51.4%,  $p < 0.001$ ), family-centered care (92.0% vs. 78.1%,  $p < 0.001$ ), effective care coordination (70.2% vs. 55.7%,  $p = 0.002$ ), and care within a medical home (53.2% vs. 36.3%,  $p < 0.001$ ) compared with families in the NSCH cohort (figure 1). In the unadjusted analysis, children enrolled in HOME more often reported access to behavioral treatment for autism (table 4). Among respondents of children older than 12 years of age, more HOME respondents reported their providers having discussed transition to adult care and fewer reported problems paying for medical bills.

After controlling for child characteristics (age, sex, race/ethnicity, insurance, autism severity, and ID) and parent education level in multivariable analysis, caregivers of children in HOME were still more likely to report shared decision-making, family-centered care, effective care coordination, and care within a medical home than caregivers of children participating in the NSCH (Figure 2). Specifically, HOME respondents were 1.25 times more often to experience shared decision-making (95% CI [1.03–1.52],  $p = 0.024$ ), 1.22 times (95% CI [1.11–1.32],  $p < 0.001$ ) more likely to receive family-centered care, and 1.41 times (95% CI [1.20–1.66],  $p < 0.001$ ) more likely to report effective care coordination compared with NSCH respondents. HOME families were also 1.62 times more likely to report receipt of care within a medical home than NSCH families (95% CI [1.28–2.04],  $p < 0.001$ ). When controlling for child characteristics (age, sex, race/ethnicity, insurance, autism severity, and ID) when comparing unmet needs, HOME respondents were more likely to access autism specific behavioral treatment, have more than 20 minutes with their healthcare provider during their child's last check up, and were less likely to have frustration getting needed services and paying healthcare bills (table 4).

## DISCUSSION

To our knowledge, this is the first study demonstrating the effects of an established interdisciplinary clinic serving as a medical home for individuals with autism. Our comparison of the care received in the HOME program with the care received by a nationally representative cohort of children with autism is important because it highlights the differences in aspects of care (shared decision-making, family-centered care, effective care coordination, and care within a medical home) that are associated with improved child and family outcomes. HOME was established with a goal of implementing a medical home model of care [18]. Visits at HOME are scheduled for one hour, are often attended by multiple team members at the same time, and are done by providers with interest and expertise in the care of individuals with disabilities. Children with autism across the country typically access a healthcare system that mandates short visits that are done by providers that lack self-efficacy in the care of children with autism and who experience many barriers in providing evidence-based services [23]. Given the contrast in models, it is not surprising that data from this study demonstrate the success of HOME in regard to a variety of patient-centered outcomes. States seeking to improve patient-centered care should consider



establishing similar programs that integrate primary care with mental and behavioral health services for children with autism and other developmental disabilities.

Consistent with our hypothesis, a higher proportion of HOME caregivers reported family-centered care than NSCH caregivers. Family-centered care is present when caregivers feel unrushed, listened to, respected, and informed [24]. Families who report family-centered care are more likely to report a higher quality primary care experience and have their health care needs met [9, 25].

With regards to care coordination, each HOME enrollee is designated a case manager that works directly with families, HOME providers, and outside specialists to streamline care and connect families to available resources. Having a co-located and integrated team as well as a case manager available for families likely contributes to the higher reported care coordination in the HOME cohort than care experienced by the NSCH cohort. Care coordination prevents fragmentation of care but lack of payment for these services has limited its success in the current healthcare system [26]. Children with autism are less likely to receive care coordination, which adversely affects health care outcomes [16]. HOME emphasizes care coordination activities that are led by a non-physician case manager, a more cost-effective means to provide this service. The funding structure of HOME enables one case manager per 200 patients. This implementation of case management has been associated with a decrease in hospitalization of HOME enrollees [18].

Shared decision-making involves patient education and consideration of family preferences and goals, thereby encouraging patient adherence and higher caregiver satisfaction [18, 27]. Parents of children with autism have previously reported less shared decision-making with their child's provider than desired, although this is improved if care is received within a medical home [28]. The results from our study suggest that the HOME's model of care (prolonged visits, interdisciplinary team) allows adequate time for respectful back-and-forth dialogue between providers and caregivers about treatment decisions.

Families of children with autism have long lagged behind children with other special health care needs in access to the medical home model of care [17]. In the NSCH cohort, 36% of families reported receiving care in a medical home compared with 53% of HOME caregivers with children with autism. Achieving this higher proportion is significant in that it equals the current percentage of US children *without* disabilities that receive care in a medical home (50%) [29]. Our data suggest that achieving this level of care may be more feasible within programs such as HOME. We identified that families enrolled in HOME reported fewer unmet healthcare needs and decreased family financial stress. Previous studies have indicated that compared to families of children with other disabilities, families of children with autism are more likely to experience unmet healthcare needs and that care within a medical home can mitigate some of this adversity [5, 7, 13, 16, 30]. Our findings further support the notion that care within a medical home can decrease unmet healthcare needs and ease the financial burden of raising a child with autism. The medical home composite outcome we utilized was similar to previous operationalized definitions and consisted of a caregivers' perception of having a personal doctor or nurse for their child, a source for sick care, no difficulties getting referrals, and the results of the care coordination and family-



centered care composite outcomes. The perception that these needs are only met 53% of the time for families of children with autism enrolled in HOME indicates that even interdisciplinary clinics that focus on children with developmental disabilities can benefit from further quality improvement. Therefore, even though HOME aspires to provide 100% of enrollees with care consistent with a medical home, this has been an elusive goal for providers across the country. Caregivers in our study, as in the national sample, often report that they are not receiving care consistent with the strict definition of a medical home. The results of our study demonstrate that HOME provides this level of care to a significantly higher proportion of individuals with autism than the national sample.

As the demographic data demonstrates, HOME focuses on providing care for children with autism who need and benefit the most from a resource intensive program: older patients with higher severity autism and a higher burden of co-occurring psychiatric and medical conditions. Because the resources needed to maintain programs like HOME are intensive, limiting enrollment to children with higher severity symptomatology ensures services remain available to those needing a higher level of support while those with lower service needs remain in traditional models of care. Because the investment in creating programs like HOME is significant, focusing on the subpopulation of older children with higher severity autism, intellectual disability and psychiatric co-morbidities targets these resources to those who benefit the most.

Current barriers to establishing more interdisciplinary programs include assembling the number of trained providers and having a financial structure that supports interdisciplinary care, prolonged visits, and case management. The capitated payment structure utilized by the HOME program allows longer clinic appointments (one-hour) in order to meet the needs of the patients and their families as well as a team of case managers to provide care coordination. This model allows for the team to better address concerns associated with more severe autism and intellectual disability, such as aggressive behavior and co-occurring conditions such as epilepsy, ADHD and anxiety.

### Limitations

This study does have its limitations. The HOME cohort was smaller in number, had higher severity autism and a higher prevalence of co-occurring psychiatric, developmental and medical conditions compared with the NSCH cohort. This is likely due to referral bias inherent to the aims of the program. That said, we controlled for these child characteristics in multivariable analysis and the significant differences in the main outcome variables remained. The study also presumes that caregivers participating in the HOME survey did not also partake in the NSCH. If families in the NSCH cohort did receive care at HOME, however, we predict it would have biased the findings towards a type II error. The difference in age ranges between the two cohorts may have affected responses. However, as we compared the proportion (rather than the absolute number) of a given response to survey items, having more in a given age category would likely not influence responses a significant amount. Given the nature of utilizing a voluntary survey as the primary form of data collection, there is a risk of a participation bias such that HOME respondents may have been either very dissatisfied or satisfied with their care in the program. Lastly, the cross-sectional

study design of this project prevents capturing perception of the interdisciplinary clinic over time.

In conclusion, compared with a national sample of caregivers of children with autism, those whose children received care in a Medicaid-funded interdisciplinary program were more likely to engage in shared decision-making with their providers and receive family-centered, coordinated care within a medical home, a process of care associated with improved child, family and healthcare system outcomes. Caregivers also experienced improved access to needed services for their children and less financial stress in paying healthcare bills. States should consider investing Medicaid funds in interdisciplinary medical home programs for children with autism, focusing on older children with more severe core symptoms, intellectual disability and psychiatric comorbidity who are less likely to receive high-quality ambulatory care in traditional healthcare settings.

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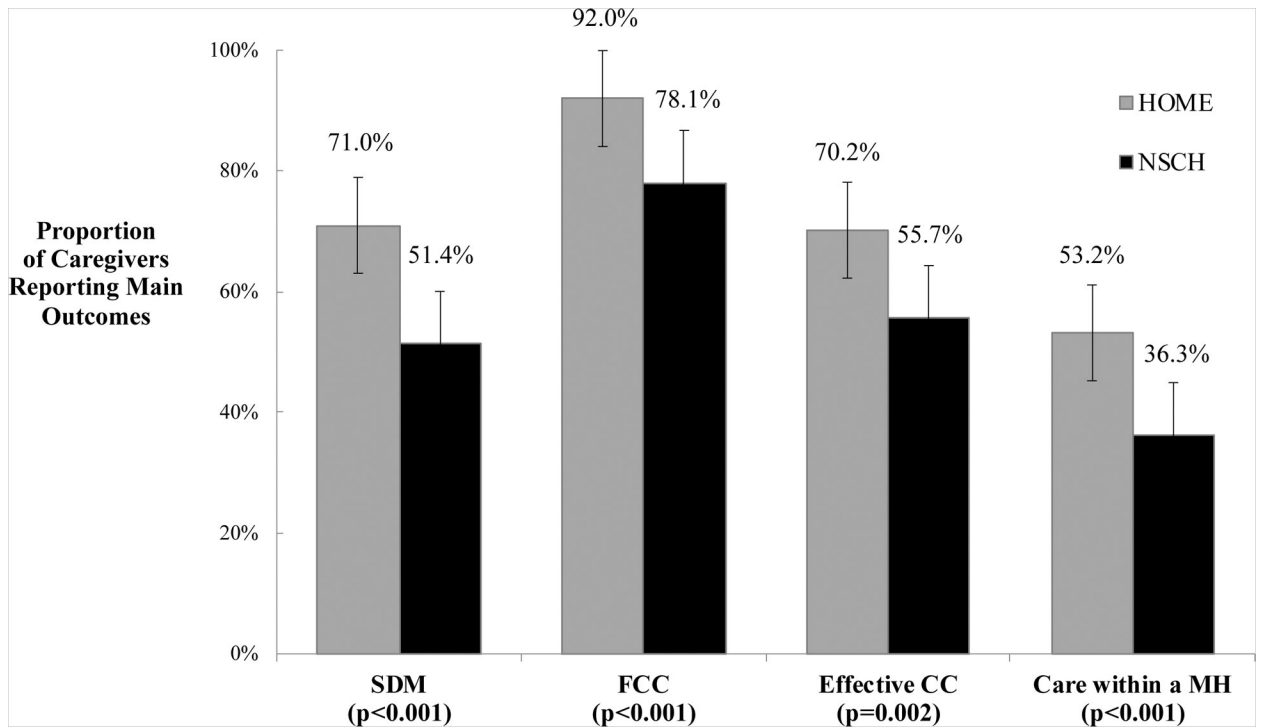
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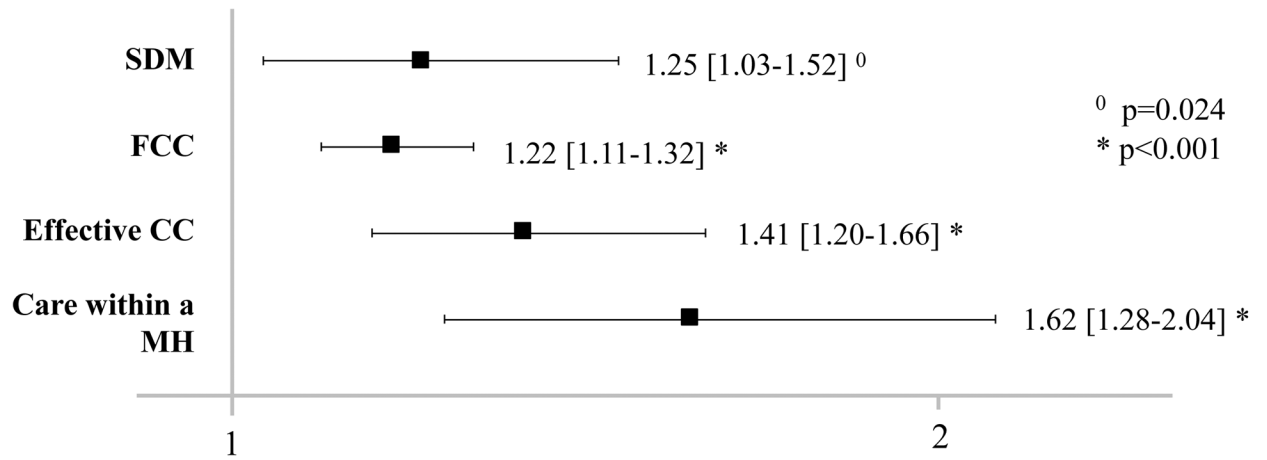
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**Figure 1.**

Chi-Squared Analysis of Frequencies of Responses from Parents of Children Enrolled in HOME vs. NSCH

CC: care coordination, FCC: family-centered care, HOME: Healthy Outcomes Medical Excellence Program, MH: medical home, NSCH: National Survey of Children's Health, SDM: shared decision-making



**Figure 2.**  
Poisson Regression of Composite Outcomes of Caregivers with Children Enrolled in HOME vs. NSCH

Incidence rate ratios (boxes). 95% confidence intervals (lines).

CC: care coordination, FCC: family-centered care, HOME: Healthy Outcomes Medical Excellence Program, MH: medical home, NSCH: National Survey of Children's Health, SDM: shared decision-making

**Table 1.**

## Individual Survey Items Grouped to Form Composite Outcomes

|   |
|---|
| <p><b>Shared Decision Making</b></p> <p><i>During the past 12 months, how often did this child's doctors or other health care providers:</i></p> <p>Discuss with you the range of options to consider for his or her health care or treatment?</p> <p>Make it easy for you to raise concerns or disagree with recommendations for the child's health care?</p> <p>Work with you to decide together which health care and treatment choices would be best for this child?</p>  |
| <p><b>Family Centered Care</b></p> <p><i>During the past 12 months, how often did this child's doctors or other health care providers:</i></p> <p>Spend enough time with this child?</p> <p>Listen carefully to you?</p> <p>Show sensitivity to your family's values and customs?</p> <p>Provide the specific information you needed concerning this child?</p> <p>Help you feel like a partner in this child's care?</p>   |
| <p><b>Effective Care Coordination</b></p> <p>Does anyone help you arrange or coordinate this child's care among the different doctors or services that this child uses?</p> <p>During the past 12 months, have you felt that you could have used extra help arranging or coordinating this child's care among the different health care providers or services?</p> <p>If yes, during the past 12 months, how often did you get as much help as you wanted with arranging or coordinating this child's health care?</p> <p>During the past 12 months, did this child's health care provider communicate with the child's school, child care provider, or special education program?</p> <p>Overall, how satisfied are you with the communication among this child's doctors and other health care providers?</p> |
| <p><b>Care Within a Medical Home</b></p> <p>Do you have one or more persons you think of as this child's personal doctor or nurse?</p> <p>Is there a place that this child usually goes when he or she is sick or you or another caregiver needs advice about his or her health?</p> <p>How much of a problem was it to get referrals?</p> <p>Effective care coordination composite</p> <p>Family-centered care composite</p>   |



**Table 2:**

Comparison of Child/Caregiver Characteristics Between Healthy Outcomes Medical Excellence (HOME) and National Survey of Children's Health (NSCH) respondents.

| Child Characteristics   | HOME<br>N (%) | NSCH<br>N (%) | P-value |
|---|---------------|---------------|---------|
| Sex of child  | N=129         | N=1,151       | 0.009   |
| Male  | 92 (71.3)     | 933 (81.1)    |         |
| Female  | 37 (28.7)     | 218 (18.9)    |         |
| Age category (years) of child   | N=129         | N=1,150       | <0.001  |
| 2–6   | 1 (0.8)       | 142 (12.4)    |         |
| 5–12  | 18 (14.0)     | 422 (36.7)    |         |
| 13–21   | 110 (85.3)    | 586 (51.0)    |         |
| Race/ethnicity of child   | N=129         | N=1,151       | 0.113   |
| Hispanic  | 11 (8.5)      | 126 (11.0)    |         |
| White, Non-Hispanic   | 103 (79.8)    | 802 (69.7)    |         |
| Black, Non-Hispanic   | 6 (4.7)       | 83 (7.2)      |         |
| Asian, Non-Hispanic   | 1 (0.8)       | 49 (4.3)      |         |
| Other   | 8 (6.2)       | 91 (7.9)      |         |
| Insurance of child  | N=122         | N=1,118       | <0.001  |
| Private Only  | 0 (0)         | 602 (53.8)    |         |
| Public Only   | 69 (56.6)     | 344 (30.8)    |         |
| Both Private and Public   | 53 (43.4)     | 144 (12.9)    |         |
| No coverage   | 0 (0)         | 28 (2.5)      |         |
| Autism Severity   | N=126         | N=1,142       | <0.001  |
| Mild  | 24 (19.1)     | 587 (51.4)    |         |
| Moderate  | 62 (49.2)     | 447 (39.1)    |         |
| Severe  | 40 (31.8)     | 108 (9.5)     |         |
| Intellectual Disability   | N=126         | N=1,147       | <0.001  |
| Yes   | 84 (66.7)     | 199 (17.4)    |         |
| No  | 42 (33.3)     | 948 (82.7)    |         |
| How often child's health conditions affect child's ability to do things | N=125         | N=1,112       | <0.001  |
| Usually/always  | 99 (79.2)     | 451 (40.6)    |         |
| Sometimes/never   | 26 (20.8)     | 661 (59.4)    |         |
| Highest level of education by caregiver respondent                      | N=121         | N=1,120       | 0.003   |
| Less than high school   | 3 (2.5)       | 48 (4.3)      |         |
| High school, GED, vocational  | 29 (23.9)     | 197 (17.6)    |         |
| Some college and/or technical school                                    | 48 (39.7)     | 318 (28.4)    |         |
| College degree or higher  | 41 (33.9)     | 557 (49.7)    |         |
| Parent sex  | N = 122       | N = 1,134     | <0.001  |
| Female  | 108 (88.5)    | 832 (73.4)    |         |
| Male  | 14 (11.5)     | 302 (26.6)    |         |
| Parental age  | N = 116       | N=1,126       | 0.058   |

| <b>Child Characteristics</b> | <b>HOME</b>  | <b>NSCH</b>  | <b>P-value</b> |
|------------------------------|--------------|--------------|----------------|
|                              | <b>N (%)</b> | <b>N (%)</b> |                |
| Mean (SD)                    | 45.6 (9.4)   | 43.9 (9.0)   |                |

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**Table 3:**

Comparison of Comorbidities Between Healthy Outcomes Medical Excellence (HOME) (n=129) and National Survey of Children's Health (NSCH) (n=1,151) Respondents.

| <b>Comorbidities</b> | <b>HOME<br/>N (%)</b> | <b>NSCH<br/>N (%)</b> | <b>P-value</b> |
|----------------------|-----------------------|-----------------------|----------------|
| Anxiety              |                       |                       | <0.001         |
| Yes                  | 108 (86.4)            | 550 (48.0)            |                |
| No                   | 17 (13.6)             | 596 (52.0)            |                |
| Behavior Problems    |                       |                       | <0.001         |
| Yes                  | 106 (84.1)            | 713 (62.1)            |                |
| No                   | 20 (15.9)             | 435 (37.9)            |                |
| ADD/ADHD             |                       |                       | <0.001         |
| Yes                  | 86 (67.2)             | 558 (48.6)            |                |
| No                   | 42 (32.8)             | 591 (51.4)            |                |
| Depression           |                       |                       | <0.001         |
| Yes                  | 56 (45.5)             | 214 (18.7)            |                |
| No                   | 67 (54.5)             | 933 (81.3)            |                |
| Epilepsy             |                       |                       | <0.001         |
| Yes                  | 27 (22.1)             | 80 (7.0)              |                |
| No                   | 95 (77.9)             | 1068 (93.0)           |                |

ADD/ADHD = attention deficit disorder/attention deficit hyperactivity disorder

**Table 4.**

Comparison of Unmet Needs Between Healthy Outcomes Medical Excellence (HOME) and National Survey of Children's Health (NSCH) Respondents.

| Item  | Univariable Analysis |               |         | Multivariable Analysis <sup>a, b</sup> |           |         |
|---|----------------------|---------------|---------|--|-----------|---------|
|   | HOME<br>N (%)        | NSCH<br>N (%) | P-value | APR <sup>c</sup>                       | 95%CI     | P-Value |
| Received behavioral treatment for autism              | N=128                | N=1,141       | <0.001  | 1.26                                   | 1.11–1.43 | <0.001  |
| Yes   | 103 (80.5)           | 710 (62.2)    |         |  |           |         |
| No  | 25 (19.5)            | 431 (37.8)    |         |  |           |         |
| Needed healthcare but not received                    | N=129                | N=1,150       | 0.818   | 1.01                                   | 0.98–1.05 | 0.418   |
| Yes   | 12 (9.5)             | 117 (10.2)    |         |  |           |         |
| No  | 114 (90.5)           | 1,033 (89.8)  |         |  |           |         |
| Frustrated in efforts to get services                 | N=126                | N=1,146       | 0.138   | 0.48                                   | 0.25–0.91 | 0.025   |
| Usually/always  | 12 (9.5)             | 172 (15.0)    |         |  |           |         |
| Sometimes/never                                       | 114 (90.5)           | 974 (85.0)    |         |  |           |         |
| Problem seeing a specialist                           | N=91                 | N=443         | 0.660   | 1.07                                   | 0.76–1.50 | 0.702   |
| Not a problem   | 53 (58.2)            | 269 (60.7)    |         |  |           |         |
| Small/big problem                                     | 38 (41.8)            | 174 (39.3)    |         |  |           |         |
| How long doctor in room with you during last check up | N=118                | N=1,005       | <0.001  | 1.72                                   | 1.37–2.16 | <0.001  |
| More than 20 mins                                     | 80 (67.8)            | 280 (27.9)    |         |  |           |         |
| Less than or equal to 20 mins                         | 38 (32.2)            | 725 (72.1)    |         |  |           |         |
| Problems paying for healthcare bills                  | N=121                | N=830         | <0.001  | 1.11                                   | 1.05–1.18 | <0.001  |
| Yes   | 17 (14.0)            | 254 (30.6)    |         |  |           |         |
| No  | 104 (86.0)           | 576 (69.4)    |         |  |           |         |
| Insurance covers needed services                      | N=123                | N=1,117       | 0.050   | 1.03                                   | 0.97–1.10 | 0.314   |
| Usually/always  | 112 (91.1)           | 943 (84.4)    |         |  |           |         |
| Sometimes/never                                       | 11 (8.9)             | 174 (15.6)    |         |  |           |         |
| Insurance covers mental or behavioral health needs    | N=121                | N=877         | 0.620   | 0.88                                   | 0.76–1.01 | 0.060   |
| Usually/always  | 85 (70.2)            | 635 (72.4)    |         |  |           |         |
| Sometimes/never                                       | 36 (29.8)            | 242 (27.6)    |         |  |           |         |
| Are healthcare costs reasonable?                      | N=121                | N=831         | <0.001  | 1.32                                   | 1.14–1.54 | <0.001  |
| Usually/always  | 101 (83.5)           | 438 (52.7)    |         |  |           |         |
| Sometimes/never                                       | 20 (16.5)            | 393 (47.29)   |         |  |           |         |

<sup>a</sup>Covariates included in multivariable model: age, sex, race/ethnicity, autism severity, intellectual disability, insurance, parent education

<sup>b</sup>NSCH group is referent

<sup>c</sup>Adjusted prevalence ratio