Maternal and Child Health Journal (2021) 25:1156–1163
https://doi.org/10.1007/s10995-021-03150-2

Health Service and Functional Measures of Benefit of a Medical Home in Children with Autism

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Accepted: 19 April 2021 / Published online: 29 April 2021

Abstract

Objectives A medical home is a model of patient-centered, comprehensive care recommended by the American Academy of Pediatrics for all children. The aims of this study were (1) to determine if the presence of a medical home is associated with improved health service outcomes of children with autism, and (2) to determine if the presence of a medical home is associated with improved key functional outcomes in children with autism.
Methods This study used data from the 2016–2017 National Survey of Children's Health. We used a medical home construct of 14 survey questions as the main independent variable in logistic regression models estimating cross-sectional association, and also evaluated the interaction between medical home and demographic and household characteristics, including race, income, household composition, and autism severity in regression for outcomes.
Results Overall, the presence of a medical home was associated with increased parent reporting of shared health care decision-making, receipt of preventive pediatric care, and reduced frustration in accessing services. Some functional outcomes were also positively associated with the presences of a medical home in children with parent-reported mild autism symptoms; children who had a medical home visited the ED less often than children without a medical home. This did not persist for children with moderate or severe parent-rated autism.
Conclusions for practice Based on parent-reported, cross-sectional data from a large, nationally representative sample of families with a child with autism, the presence of a medical home was positively associated with some improved health services and functional outcomes.

Keywords Autism · Medical home · Health services

Abbreviations

ASD	Autism spectrum disorders
CDC	Centers for disease control and prevention
CSHCN	Children with special health care needs
NPL	National poverty level

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Significance Statement

What is known on this subject? A medical home is a recommended approach to care for all children, and the association of the medical home with child outcomes has been mixed to positive but is generally associated with favorable impacts on child health.

What this study adds? This study looks at the association of a medical home on outcomes of children with autism. It adds to the paucity of literature in this area and finds provision of care within a medical home is positively associated with both improved health services and functional outcomes.

Introduction

The concept of a medical home was first described by the American Academy of Pediatrics (AAP) in 1967 (Sia et al., 2004). It is a way to provide team-based care integrated across all healthcare needs, from primary to specialty care, that addresses care quality and cost. The AAP states care through the medical home should be accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally competent (Medical Home Initiatives for Children with Special Needs Project Advisory Committee, 2002). These characteristics make up the core of the medical home, but the medical home should extend beyond these tenets to improve care and quality of life more broadly. Thus care should include a provision of preventive care, assure ambulatory and inpatient care for acute illness, provide care over an extended time period, assist with referrals, create a central medical record, and interact with schools and early intervention services (Medical Home Initiatives for Children with Special Needs Project Advisory Committee, 2002). The medical home is desirable for all children, but is more often utilized for children and youth with special health care needs (CYSHCN) who have an increased need for services and resources beyond that of typically developing children (Damiano et al., 2006; Long et al., 2012).

Autism spectrum disorders are a life-long set of developmental disabilities that often include persistent difficulties in social communication and social interaction across contexts; restricted, repetitive patterns of behavior, interests or activities; symptoms that present in early childhood; and an impact on every day functioning (American Psychiatric Association, 2013). Children with autism have complex health needs and increased prevalence of co-occurring health conditions, suggesting they could benefit from care provided within a medical home (Kogan et al., 2008; Rast et al., 2020). Several prior studies have examined the presence of a medical home in children with autism. In general, these studies suggest children with autism less often have a medical home compared to other CYSHCN (Kogan et al., 2008). Possible reasons for this disparity include increased need for a variety of healthcare services and lack of specialty knowledge in pediatricians about autism (Levy et al., 2016). However, the medical home may address this concern, as some studies have suggested that children with autism with a medical home have fewer unmet specialty care needs and better access to needed services (Cooley et al., 2009; Farmer et al., 2014; McAllister et al., 2009; Soman & Larson, 2009).

Additional studies have assessed the impact of a medical home on CYSHCN not specific to autism and found positive results. Reduction in emergency department (ED) visits and out of pocket expenses have been linked to the receipt of care within a medical home, as has the increase in well-being indicators, including daily reading, sufficient sleep, increased parental coping skills, reduced screen time and reduced school absences (Arauz Boudreau et al., 2012; Long et al., 2012; Porterfield & DeRigne, 2011; Romaire et al., 2012; Willits et al., 2012). Other studies have shown mixed results when assessing associations with the presence of a medical home, including the presence of a medical home not being a significant predictor of vaccination coverage in infants (Allred et al., 2007). Several studies have shown contradictory findings on missed school in youth with a medical home (Long et al., 2012; Strickland et al., 2009; Willits et al., 2013). These findings emphasize the importance of understanding what health services a medical home is actually providing to CYSHCN when considering the effect of medical home on improved health outcomes. And what areas of care provision may need focus for improvement.

The medical home offers promise of more wholistic and comprehensive healthcare that may improve quality of life measures beyond the provision of primary healthcare. Visits to the ED often result in increased health care costs and treatment by a physician unfamiliar with the child and potentially the child's health and mental health conditions and drive-up unnecessary health care costs. Specialty treatment within an ED setting is often suboptimal, particularly for pediatric and mental health concerns, and the most common problems that children with autism present at the ED are epilepsy and psychiatric conditions (Iannuzzi et al., 2015). Comprehensive primary care should lead to reduced emergency care, as conditions are identified and treated before they escalate to that level. Missing school is a major interruption for all children, especially children with autism who need more support and resources (Lee et al., 2008). Management of health concerns that lead to missed school could ameliorate the same. The medical home is an ideal model to address these concerns, but it is unclear in children with autism if receiving care within a medical home does.

The goals of this study are to determine whether, among children with autism, the presence of a medical home is associated with improvements in primary care service delivery expected to occur in a medical home setting, and to evaluate whether having a medical home was associated with better functional outcomes in this population. A few previous studies have examined the medical home in children with autism, but this study is unique in the examination of functional outcomes and the use of the most recent national data.

Methods

This study used data from the National Survey of Children's Health (NSCH), combining data from study years 2016–2017 (Child and Adolescent Health Measurement Initiative (CAHMI), 2019). The NSCH, designed by the Health Resources and Services Administration's Maternal and Child Health Bureau and conducted by the US Census Bureau, is a cross-sectional, nationally representative survey designed to provide national information estimates on the health and well-being of children from parent or caregiver report (The United States Census Bureau, Associate Director of Demographic Programs, & National Survey of Children's Health, 2018).

Children with autism were identified through parent-report. All survey respondents were asked if "a doctor or other health care provider ever told you that this child has autism or autism or Autism Spectrum Disorder (ASD)? Include diagnoses of Asperger's Disorder or Pervasive Developmental Disorder (PDD)." If yes, they were asked if the child currently has the condition. This analysis was limited to the 1711 children with a current diagnosis of autism. A comparison group of CYSHCN without autism was included (n = 14,717) to compare medical home outcome associations. CYSHCN are identified in the survey from a five-question screener developed to flag children with ongoing health needs and elevated service utilization (Bethell et al., 2015).

The principal independent variable in this analysis was whether a child received care in a medical home, constructed based on answers to 14 survey questions coded to determine if the child's care meets the requirement for the AAP definition of care provided through a medical home (Child and Adolescent Health Measurement Initiative (CAHMI) & Data Resource Center for Child and Adolescent Health 2018). All children had to have a personal doctor or nurse, a usual source of sick and well care, and family-centered care to meet the medical home criteria. If children saw more than one provider in a year, they must have experienced effective care coordination, and if they needed a referral, they must have had no problem receiving it. Children who did not see more than one provider and did not need a referral qualified for a medical home if they met the first three elements.

Outcome variables in this study were four items related to receipt of health services expected to improve in a medical home setting and two functional outcomes. The four health service receipt items, all of which were dichotomous, were: (1) child's health care provider worked with the family to decide which health care and treatment choices would be best for the child if decisions were needed (shared decision making), (2) the child had at least one preventive health visit in the past 12 months, (3) the parent was never frustrated in efforts to get services for the child in the past 12 months, and (4) the child received health care transition services. Shared decision making was only asked of parents who reported that there were any decisions needed about this child's health care services or treatment, such as whether to start or stop a prescription or therapy services, get a referral to a specialist, or have a medical procedure in the past 12 months (n = 895). Health care transition consisted of several survey questions that asked if the child spoke privately to their provider without an adult in the room, discussed transition to adult health care, and worked with their provider to gain health skills and understand changes to health care for children ages 12–17 (n = 887) (Child and Adolescent Health Measurement Initiative (CAHMI) & Data Resource Center for Child and Adolescent Health 2018). The two functional outcomes considered were number of hospital ED visits in the past 12 months and days of school missed in the past 12 months due to illness or injury (only asked of parents of children age six and older n = 1470).

Several variables previously found to be associated with the presence a medical home were considered as potential confounders (Allred et al., 2007; Arauz Boudreau et al., 2012; Long et al., 2012; Porterfield & DeRigne, 2011; Romaire et al., 2012; Strickland et al., 2009; Turchi et al., 2009; Willits et al., 2013). Sociodemographic characteristics included age, race, ethnicity, and highest parental level of education in the household. Health related information included parent-rated autism severity for children with autism; functional limitations; presence of an emotional, developmental, or behavioral problem; and insurance type. Functional limitations and presence of an emotional, developmental, or behavioral problem were questions from the NSCH screener survey. Parents were asked, "Is this child limited or prevented in any way in his or her ability to do the things most children of the same age can do?" (functional limitations) and "Does this child have any kind of emotional, developmental, or behavioral problem for which he or she needs treatment or counseling?" Household information included primary language spoken in the household, household income as percent of the federal poverty level, household composition, and number of children and CYSHCN in the household.

Statistical Analysis

The distribution of covariates was compared across children with and without a medical home. Bivariable logistic regression models were used to test the statistical significance of these individual associations.

The prevalence of each outcome was presented for children with autism and CYSHCN with and without a medical home. Significant difference in the prevalence of outcome by medical home status was determined using bivariable logistic regression models. Separate multiple logistic regression models were used to estimate crude and adjusted associations between medical home status and each dichotomous outcome. Shared decision making was excluded from this analysis due to the high prevalence of shared decision making among children with a medical home and limited power to examine associations. An ordinal ED visit survey question was recoded as never having visited the ED in the past 12 months versus ever in the past 12 months. The ordinal days of school missed survey question was recoded as a dichotomous outcome at four days when preliminary analyses suggested there was no difference in zero or 1–3 days of school missed associated with presence of a medical home. Effect modification was evaluated by adding interaction terms between covariates and the medical home variable. Differences between groups and interactions terms were evaluated using an adjusted Wald test, appropriate for survey set data, at the 0.05 level.

All analyses were done in Stata 15 to control for the complex sampling procedure of the NSCH (StataCorp, 2017). An adjusted weight was used to account for combining two years of data. All variables were missing fewer than 5% of observations and we did not perform missing data estimation procedures.

Results

Of children with current autism, 31.1% received care within a medical home, lower than the percentage of CYSHCN who had a medical home (44.9%). Table 1 shows the distribution of demographic characteristics of children with autism by presence of a medical home. Children who received care within a medical home were more often White non-Hispanic (58.8% versus 39.7%), primarily spoke English at home (92.8% versus 80.9%), from high income households, publicly insured (48.7% versus 33.3%), and had better overall health and less often had functional limitations (52.5% versus 65.9%) than children without a medical home.

Figure 1 presents the prevalence of each outcome by medical home status in children with autism and CYCSN. In children with autism, shared decision making, preventive health visits, and reduced frustration in access to services were more common among children with a medical home than children without a medical home. Nearly all children with autism with a medical home experienced shared decision making (98.8%). Similarity, shared decision making and reduced frustration in access to services were more often reported for CYSHCN with a medical home than those without one. Regardless of medical home status, few children with autism received health care transition.

The presence of a medical home was associated with increased odds of two of the three examined health service receipt items in children with autism: preventive health visits and reduced frustration in access to services, but not health care transition services. As seen in Table 2, the highest magnitude association was for frustration in accessing services, in which children with a medical home had 4.46 times the odds of little parent-reported frustration to access services as children without a medical home. The functional outcomes are also shown in Table 2. For children with autism, there was a significant interaction between each outcome and parent-reported autism severity. The results depict the odds ratio for the presence of a medical home and ED visits for each level of severity. For children with parent-reported mild autism severity, children with a medical home had 2.29 times the odds of never visiting the ED in the past 12 months as children without a medical home. For children with moderate/severe autism severity, the relationship did not persist. Similarly, there was a significant interaction with medical home status and missed days of school, but the odds ratio was not significant in this outcome.

For CYSHCN, visiting the ED in the past year depended on parent-reported overall health. Children with excellent or very good health with a medical home had 1.28 times the odds of never visiting the ED compared to children without a medical home. There was no such association in children with worse health. There was no association with the medical home and missed school for CYSHCN.

Discussion

Families of children with autism find themselves navigating an array of systems and services that can be challenging and overwhelming (Cheak-Zamora & Teti, 2014). The medical home affords an opportunity to address the services and systems needed to maximize the potential of children with autism and assists in care integration of necessary services (Turchi & Antonelli, 2014).

The results of this study suggest some areas in which the medical home may provide support to children with autism. The medical home was associated with increased shared decision making and preventive health services, and reduced frustration in access to services. And in children with mild parent-reported autism severity and CYSHCN with better overall health, the medical home was associated with a reduction in ED visits. However, the medical home was not associated with more health care transition services, with fewer missed days school, or ED visit reduction in children with more complex needs. Previous studies have found that unmet service needs and a high number of total services, a proxy of the complexity of a medical condition, are negatively associated with the presence of a medical home (Cheak-Zamora & Farmer, 2015). The current study found that in children with more severe autism, the medical home did not have the same associations of ED visit or potentially missed school reduction as children with mild autism severity. Both the barriers to medical home access and the barriers to high quality care within a medical home for children with high service needs must be addressed in the policy and medical communities when considering medical home implementation and training to specifically meet the needs of patients and families of children with autism.

Practice transformation to a medical home requires financial, human, and material resources. Policies and payment structures that incentivize transformation could promote the creation of medical home practices (Edwards et al., 2014).

Table 1 Child and family characteristics of children with current autism by medical home status

Child has a medical home		No (n = 1067)		Yes (n = 644)	
		Percent	95% CI	Percent	95% CI
Race/ethnicity	White non-Hispanic	39.7*	(33.0, 47.0)	58.8*	(46.3, 70.3)
	Black, non-Hispanic	16.2	(11.5, 22.5)	9.9	(6.2, 15.5)
	Other, non-Hispanic	7.8	(5.7, 10.6)	6.9	(4.6, 10.3)
	Hispanic	36.2	(27.1, 46.4)	24.4	(12.8, 41.5)
Primary language	English	80.9*	(69.9, 88.5)	92.8*	(87.2, 96.0)
	Other	19.1*	(11.5, 30.1)	7.2*	(4.0, 12.8)
Percentage of national poverty level	0–99% FPL	30.1	(22.3, 39.2)	28.9	(17.1, 44.6)
	100–199% FPL	31.5**	(23.4, 40.9)	16.6**	(11.7, 23.0)
	200–399% FPL	18.3**	(14.5, 22.9)	30.0**	(22.6, 38.6)
	400% FPL or greater	20.1	(16.1, 24.8)	24.5	(18.4, 31.8)
Household composition	Two parents, married	56.8	(48.7, 64.6)	59.6	(46.8, 71.3)
	Two parents, not married	11.0	(6.9, 17.1)	16.3	(5.8, 37.8)
	Mother only household	24.3*	(18.8, 30.8)	14.9*	(10.0, 21.7)
	Other family structure	7.9	(5.1, 12.0)	9.2	(5.3, 15.6)
Autism severity	Mild	41.8	(34.6, 49.3)	52.8	(41.3, 63.9)
	Moderate	48.2	(40.6, 55.9)	39.4	(27.6, 52.5)
	Severe	10.1	(7.0, 14.2)	7.9	(5.0, 12.3)
Overall health	Excellent	23.2	(18.4, 28.9)	37.3**	(28.7, 46.8)
	Very good	36.5	(29.4, 44.4)	30.9	(23.6, 39.2)
	Good	31.2	(22.6, 41.4)	28.2	(16.4, 44.1)
	Poor/fair	9.0	(6.1, 13.0)	3.6*	(1.6, 7.9)
Functional limitations	Yes	65.9	(58.1, 73.0)	52.5*	(41.9, 62.9)
Emotional, behavioral, or developmental condition	Yes	79.5	(71.9, 85.5)	73.7	(65.4, 80.6)
Insurance type	Private only	47.2	(38.7, 55.8)	42.8	(31.2, 55.3)
	Public only	33.3*	(27.2, 40.0)	48.7*	(37.9, 59.6)
	Both Public and Private	13.2	(8.6, 19.6)	8.1	(5.5, 11.7)
	Uninsured	6.3***	(2.7, 14.2)	0.4***	(0.2, 0.9)
Number of children in household	1	31.0	(24.0, 39.0)	29.6	(22.2, 38.3)
	2	34.5	(27.0, 42.9)	42.5	(31.2, 54.6)
	3	25.6	(18.7, 34.1)	20.7	(14.8, 28.2)
	4 and above	8.9	(5.7, 13.6)	7.2	(4.1, 12.2)
Number of children with SHCN	0	6.4	(2.9, 13.8)	6.2	(3.9, 9.9)
	1	60.5	(52.3, 68.2)	66.4	(57.3, 74.5)
	2	24.1	(18.0, 31.5)	20.5	(14.8, 27.8)
	3 and above	8.9	(5.7, 13.6)	6.8	(3.7, 12.2)
Highest level of education	Less than high school	15.6	(7.9, 28.4)	6.5	(3.3, 12.4)
	High school graduate	26.6	(19.4, 35.2)	18.6	(12.5, 26.7)
	More than high school	57.9**	(48.4, 66.8)	74.9**	(65.9, 82.2)

*$p < 0.05$

**$p < 0.01$

***$p < 0.001$

Promotion of the medical home as the standard of care could include payment for medical home accreditation, promoting community partnerships and fostering concepts like shared decision making and family centered care, and recognizing autism as a diagnosis among others warranting care delivered in a medical home. These findings also highlight the importance of shared decision making and the acknowledgement of such within a medical home. Working collaboratively with families with children with autism to ensure access to a medical home is critical to ensure higher quality

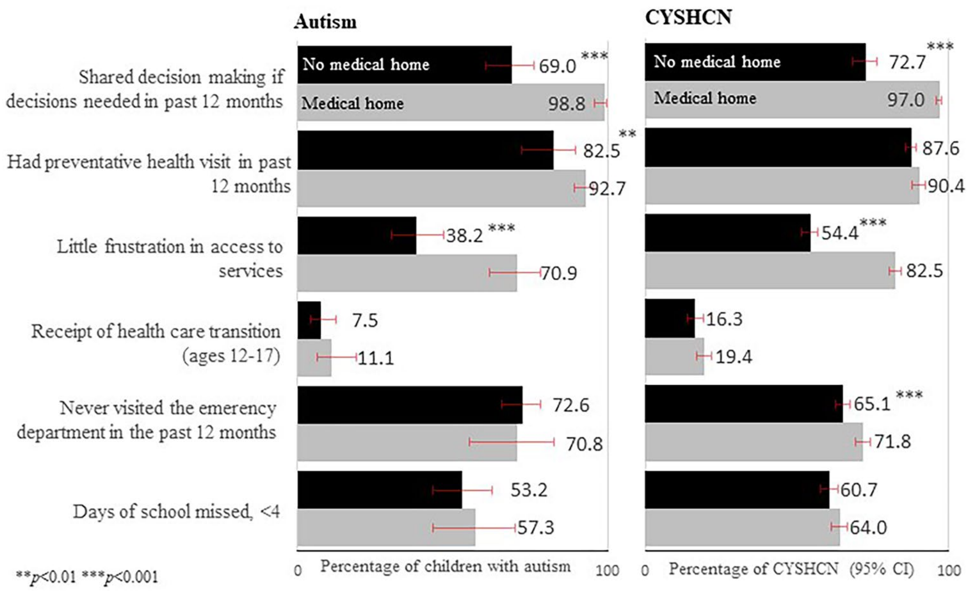

Fig. 1 Prevalence of outcomes for children and youth with autism and special health care needs (CYSHCN) by medical home status

Table 2 Logistic regression odds ratio for presence of a medical home for each outcome of interest in children and youth with autism and other special health care needs (CYSHCN)

Outcome variable	Autism		CYSHCN	
	OR (CI)	OR (CI)*	OR (CI)	OR (CI)*
Had a preventative health visit in the past 12 months	2.71 (1.30, 5.66)	1.86 (1.01, 3.44)	1.35 (0.99, 1.83)	1.07 (0.76, 1.49)
Little frustration in access to services	3.94 (2.30, 6.73)	4.46 (2.89, 6.98)	3.95 (3.31, 4.71)	3.53 (2.95, 4.22)
Receipt of health care transition services ages 12–17 (n = 887)	1.54 (0.65, 3.62)	1.61 (0.75, 3.47)	1.23 (0.95, 1.59)	1.09 (0.83, 1.45)
Never visited the ED in the past year				
Mild autism severity	2.21 (1.14, 4.30)[a]	2.29 (1.20, 4.41)[a]		
Moderate/severe autism severity	0.48 (0.17, 1.33)[a]	0.51 (0.26, 1.00)[a]		
Health excellent or very good			1.43 (1.19, 1.73)[b]	1.28 (1.05, 1.55)[b]
Health good/fair/poor			0.88 (0.61, 1.27)[b]	0.83 (0.58, 1.20)[b]
Days of school missed, fewer than four			1.15 (0.98, 1.36)	1.07 (0.90, 1.27)
Mild autism severity	1.78 (0.99, 3.19)[a]	1.68 (0.93, 3.04)[a]		
Moderate/severe autism severity	0.64 (0.23, 1.78)[a]	0.73 (0.38, 1.42)[a]		

*Model adjusted for race, primary language, percent of national poverty level, household composition, autism severity (in autism models only), overall health, functional limitations, presence of behavioral condition, insurance type, number of children in the household, number of children in the household with special health care needs, and highest level of parent education

[a] This model includes an interaction between medical home and parent-reported autism severity; the OR shows the odds of the outcome for children with a medical home compared to those without a medical home at each level of parent-rated severity

[b] This model includes an interaction between medical home and parent-reported overall health; the OR shows the odds of the outcome for CYSHCN with a medical home compared to those without a medical home at each level of overall health

care that promotes shared decision making and family-centered care (Todorow et al., 2018; Turchi & Antonelli, 2014). However, previous studies have noted important barriers to successful shared decision-making that may make this difficult in families with children with autism, including lack of pediatrician knowledge of autism specific treatments and care (Levy et al., 2016; Mohanty et al., 2018).

Another notable finding from this study was the higher prevalence of medical home in children with autism who had public health insurance. This may not be surprising, as various state and federal policies exist to increase the use of the medical home for CYSHCN (Gifford et al., 2019). However, it is important because it highlights the mechanisms through which medical home implementation may occur. Some states use Medicaid managed care organizations as the foundation of medical home initiatives while other states implement multi-payer medical home initiatives that include Medicaid, Medicare, and private insurers. The goal is to provide more comprehensive care, while managing costs for Medicaid. Some states have studied the spillover of medical home benefits administered through Medicaid managed care organizations onto patients in the same practice with commercial insurance. Spillover seems limited in these studies, but the potential for widespread adoption based on Medicaid initiatives still promises increased access for all populations (Hinde et al., 2020).

There are several limitations to this study. Causal inference is limited by cross-sectional survey data, and reverse causation possible. The presence of a medical home is derived from a combination of survey questions and includes children whose parents reported not needing some of the core components of the medical home. If a parent reported not needing one of the components, they were marked as having received that component, even if they may not have had access to it if they had needed it. This may be part of why fewer children with autism meet the medical home criteria, because they may need and try to access more services than the general population. Use of parent report and the potential for recall bias, limited information about parental health and social support, and the lack of geographic information are further limitations.

There are several strengths to this study as well. This survey is one of the largest samples of children with autism and is a nationally representative source or information. The measure for medical home is designed based on the AAP concept of medical home and is used in many studies, allowing for accuracy and consistency of results. The performance of this study is timely, as both Healthy People 2020 and the Patient Protection and Affordable Care Act promote the provision of care within a medical home, and increasingly state Medicaid initiatives are focused on providing care through the medical home model.

Conclusion

This study demonstrates a mixed impact of the medical home, with positive associations of a medical home in some but not all studied health service components for all children with autism, and positive associations in some functional outcomes for only children with mild parent-reported autism severity. For future study, observational evaluation of medical home implementation should be assessed, and understanding barriers and facilitators to providing a medical home for children with autism from the health care provider perspective could inform next steps. Studies should also examine ways to increase the number of children with autism who have access to a medical home, particularly those with more intense service needs. Increasing the number of children with autism who receive care within a medical home is recommended.

Author Contributions JR conceptualized the study, ran analysis, and wrote a rough draft of the submission. She incorporated many edits and approved the final version for submission. CN helped with conceptualization of the study, as well as providing in-depth support for analytic activities and editing of the rough draft. He provided a critical role in the analysis and the drafting of the methods and results sections. He approved the final manuscript as submitted. RT conceptualized the study and provided critical insight into the existing literature on medical home and other related concepts. She provided a critical link to the practical relevance of these findings, and heavily drafted these portions of the submission. Beyond drafting these sections, she was integral to the organization of the submission as a whole, and editing and to improve all sections. She approved the final manuscript as submitted. JP conceptualized the study, provided insight into the link between findings and practice, and helped with critically examining these sections. She approved the final manuscript as submitted.

Funding This project was done with no specific financial support.

Declarations

Conflict of interest The authors have no conflicts of interest relevant to this article to disclose. The authors have no financial relationships relevant to this article to disclose.

Ethical Approval This study was declared exempt from humans subject research by the Drexel University Institutional Review Board.

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