

# Autism-Specific Primary Care Medical Home Intervention

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**Abstract** Forty-six subjects received primary medical care within an autism-specific medical home intervention ([www.autismmedicalhome.com](http://www.autismmedicalhome.com)) and 157 controls received standard primary medical care. Subjects and controls had autism spectrum disorder diagnoses. Thirty-four subjects (74%) and 62 controls (40%) completed pre and post surveys. Controlling for pre-survey medical home status, subjects had 250% greater odds of receipt of a medical home at the study end compared to controls ( $p = 0.021$ ). Compared to controls, subjects receiving the intervention reported significantly more satisfaction ( $p = 0.0004$ ), greater shared decision making ( $p = 0.0005$ ) and fewer unmet needs ( $p = 0.067$ ). However, subjects reported no change in family stress ( $p = 0.204$ ).

**Keywords** Autism · Medical home · Care coordination · Primary care

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## Abbreviations

ASD Autism spectrum disorder  
CSHCN Children with special health care needs

## Introduction

The medical home has potential to improve the health and quality of life of children with autism spectrum disorder (ASD). Medical care meeting the criteria of a comprehensive and coordinated medical home is associated with better health status, timeliness of care, family centeredness, and improved family functioning for children with special health care needs (CSHCN) (Homer et al. 2008). Specifically for children with ASD, medical homes are associated with improved health and decreased financial burdens on the family (Kogan et al. 2008).

National survey data demonstrate that children with ASD are less likely to obtain health care in a manner consistent with a “medical home” or care that is comprehensive, coordinated or family-centered compared to children with other special health care needs (Brachlow et al. 2007; Kogan et al. 2008; Carbone et al. 2009). Medical care can be specifically challenging for children with ASD whose families report particularly low physician satisfaction and experience significant stress. Furthermore, ASD treatments often lack conclusive evidence and ASD requires immense care coordination across service sectors such as educational supports, county services, behavioral therapists, medical therapists, subspecialty doctors and primary care providers.

Parents of children with ASD report less satisfaction with their child’s health care compared to parents of

CSHCN (Kogan et al. 2008). Parents of children with ASD rated their primary care physicians as worse at managing the child's medical condition, answering questions regarding their child's condition and understanding how the child's condition affects the family compared to parents of children with physical disabilities and mental retardation (Liptak et al. 2006b).

In addition to dissatisfaction with health care, parents of children with ASD have a high burden of stress related to their child's condition (Autism Speaks 2009). Families of children with ASD had greater negative impacts on their quality of life (e.g., less likely to attend religious services or participate in organized activities and more likely to miss school or feel concerned about their children) compared to both parents of children with Attention Deficit Disorder/Attention Deficit Hyperactivity Disorder and typical controls (Lee et al. 2008). Despite the stress, parents of children with ASD are often resilient in their coping strategies (Gray 2006).

Shared decision making (SDM) occurs when decisions are made collaboratively by the physician and patient, and has not specifically been studied in ASD. Shared decision making is useful when medical decisions are of low certainty, frequently the case with the many treatments and therapies in ASD that lack conclusive evidence. SDM utilizes patients as "expert" contributors to their care (Tuckett et al. 1985). Families of children with ASD are likely to be successful in this role as they have contributed to the medical understanding of ASD; secured research funding, constructed clinical research networks, suggested new avenues for research, popularized empirically based therapies; and anticipated paradigmatic shifts in the understanding of ASD (Silverman and Brosco 2007). Engaging patients in decision-making is consistent with the patient-centered medical home and has been associated with positive outcomes such as improved satisfaction, (Roter and Hall 1992; Frosch and Kaplan 1999) improved health outcomes, (Greenfield et al. 1988; Kaplan et al. 1989; Stewart 1995) and improved parental confidence in managing a child's condition (Clark et al. 1998).

This paper evaluates an ASD-specific medical home intervention. We found no previous reports of primary care based "medical home" intervention evaluations for children with ASD in the literature. The purpose of this study was to evaluate the impact of this ASD-specific primary care medical home on unmet healthcare needs, health care satisfaction, family stress and shared decision making.

## Methods

This intervention study used a quasi-experimental pre-test, post-test control group design (Shadish 2001). Subjects

( $n = 46$ ) voluntarily enrolled in and experienced greater than two clinic visits within the ASD-specific medical home between January 2009 and May 2010, and were ages 0–18 years. Subjects learned about this opportunity through community promotion (e.g., University sponsored parent forums, family support groups, community behavioral intervention providers). ASD diagnoses were confirmed through review of DSM-IV criteria and clinical observation by a trained pediatrician. The control group ( $n = 157$ ) consisted of patients ages 0–18 years receiving standard healthcare within the same healthcare system as the intervention between January 1, 2008 and December 31, 2008. Controls were identified by an ICD-9 diagnosis code of ASD (299.00 or 299.01: includes autism, pervasive developmental disorder and Asperger's disorder) in their medical record and parents confirmed these ASD diagnoses. Controls were invited to participate via a mailed survey. We included only those who completed both the initial and follow-up survey. The University of Minnesota institutional review board approved the study.

## Treatment Intervention

The ASD-specific medical home intervention was created and implemented November 1, 2008–October 31, 2010 and funded through a medical home demonstration grant from the Minnesota Department of Human Services. The medical home was created as part of a private general primary care clinic which is associated with, but geographically separate from, the University of Minnesota. Subjects received their well and acute care from this clinic experiencing 2–7 visits during the study period. The implementation team consisted of five parents of children with ASD, a general pediatrician, a nurse care coordinator and a scheduling care coordinator. Monthly meetings and quarterly state-wide collaborative meetings facilitated continuous quality improvement through plan, do, study, act (PDSA) cycles. Major ASD-specific accomplishments included: ASD care plan (organized document of each child's care), change monitoring log (tool for collecting treatment trial data; recognizes that each child with ASD is an individual and no one treatment works for all), coordination with outside resources (creation of ASD-specific resource list and ASD dentist list), tools to improve appointments (clinic pictures and stories written in "ASD social story" format, ASD-specific toys and longer duration visits). Detailed information and downloadable tools can be found at [www.autismmedicalhome.com](http://www.autismmedicalhome.com).

## Survey Instrument

We developed a survey instrument to collect information from caregivers (henceforth referred to as parents) of

children with ASD consisting of 13 items regarding demographics and 27 questions regarding access, usage, satisfaction and family stress related to medical care.

A variety of sociodemographic variables were assessed (Table 1). Functional ability was measured by the frequency and degree to which the child's condition affected his or her ability to do things done by most other children of the same age on a Likert Scale (1 = No limitations, 10 = Very limited). Race and ethnicity categories were based on National Center for Health Statistics guidelines and utilized to assess the generalizability of results.

We assessed the extent to which participants endorsed care consistent with the medical home based on the following components from the American Academy of Pediatrics medical home definition: (American Academy of Pediatrics Medical Home Initiatives for Children With Special Needs Project Advisory Committee 2002) comprehensive care, coordinated care, and family centered and compassionate care. Culturally accessible care was not assessed due to the homogeneity of the subjects. Access to care was assessed through the unmet needs, and comprehensive and coordinated care constructs; these constructs evaluated access to subspecialty and outside services which have been shown to be problematic for children with autism (Brachlow et al. 2007; Kogan et al. 2008).

Primary outcome measures included unmet needs, satisfaction, family stress and shared decision making. Unmet needs was an average score for those who reported needing, but not receiving any of the following three items: (a) health care, (b) family support services, and (c) specialty doctors, therapies and outside services, each reported on a 1–7 Likert scale ranging from “never” to “always.” Satisfaction was a measure of a parent's satisfaction with the single item, “overall quality of health care your child has received” on a scale from 1 (“not at all”) to 7 (“very much so”). Family stress was measured by the single item, “family's overall stress as a result of caring for the child” on a scale from 1 (“no stress”) to 7 (“great stress”). Shared Decision Making was measured using items from the Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey instrument. (Agency for Healthcare Research and Quality, United States Department of Health and Human Services 2010) Questions assessed parent's perceptions of whether the medical team: (a) provided more than one treatment choice, (b) talked about the reasons for and against each choice, (c) gave sufficient information about each choice and (d) asked for parents' participation in health care decision-making. The instrument consisted of questions on Likert scales ranging from 1 (“not at all or never”) to 7 (“very much so or always”). The final shared decision making score was the mean value for these four items.

## Survey Administration

We conducted pilot testing on a convenience sample of 7 parents of children with ASD to assess clarity and ease of administration. The survey took approximately 10 min to complete and is available on request to the author. For subjects in the ASD-specific medical home, the pre survey was administered in conjunction with their initial clinic visit (January 2009–May 2009). A post-survey was mailed to subjects' homes 1 year later (January 2010–May 2010). For controls receiving standard healthcare, pre and post surveys were sent by mail in May 2009 and May 2010. Non-respondents received a second mailing 1–2 months after the first mailing. Respondents received a \$10 gift card upon completion of the survey. A consent information letter explaining the purpose, potential risks/benefits and contact information of the study accompanied the surveys.

## Data Analysis

### *Demographics*

Fisher's exact test for categorical variables and a two-sample *t* test for continuous variables were used to determine whether differences existed between the subject and control groups at baseline.

### *Medical Home*

Logistic regression was used to determine the odds that subjects and controls reported receiving care consistent with the medical home model at the study end. Cochran-Mantel-Haenszel tests with continuity corrections were used to test for differences in medical home components among subjects and controls. We controlled for pre-intervention medical home status to reduce potential bias introduced by the non-random assignments to subject or control groups (Table 2).

### *Impact of Intervention*

Multiple linear regressions were used to determine the effect of the medical home intervention on the dependent measures: unmet needs, satisfaction, family stress, and shared decision making. In order to control for potential differences between the subjects and controls caused by non-random assignment, pre-survey measures of the dependent variable and demographic characteristics were included in the regression models. The demographic characteristics included were age, gender, parent educational attainment, and family income. Duration of diagnosis was not included because of a disproportionately high number of missing among respondents; age was also

**Table 1** Demographics

Variable	Controls N (%)	Subjects N (%)
Gender*		
Male	57 (0.934)	24 (0.727)
Female	4 (0.066)	9 (0.273)
Survey respondent		
Mother	54 (0.871)	29 (0.853)
Father	6 (0.097)	5 (0.147)
Other	2 (0.032)	0 (0.000)
Household income		
0–20,000	6 (0.097)	4 (0.121)
20–60,000	22 (0.335)	6 (0.182)
60–100,000	19 (0.306)	8 (0.242)
100–150,000	11 (0.177)	10 (0.303)
150–200,000	3 (0.048)	2 (0.061)
>200,000	1 (0.016)	3 (0.091)
Language spoken at home		
English	59 (0.983)	30 (0.938)
Spanish	1 (0.017)	0 (0.000)
Other	0 (0.000)	2 (0.063)
Respondent education		
Some US	1 (0.016)	0 (0.000)
HS grad/GED	17 (0.274)	5 (0.147)
College grad	30 (0.484)	14 (0.412)
Graduate/prof.	14 (0.226)	15 (0.441)
Living arrangements		
2 Parents, 1 house	45 (0.726)	29 (0.879)
2 Parents, 2 houses	6 (0.097)	1 (0.030)
1 Parent, 1 house	3 (0.129)	3 (0.091)
Other	3 (0.048)	0 (0.000)
Insurance		
Private	21 (0.350)	19 (0.559)
Public	13 (0.217)	4 (0.118)
Both	26 (0.433)	11 (0.324)
Diagnosis		
Autism	35 (0.614)	16 (0.533)
PDD-NOS	11 (0.193)	12 (0.400)
Asperger syndrome	10 (0.175)	2 (0.067)
ASD other	1 (0.018)	0 (0.000)
Duration of diagnosis*		
0–6 months	0 (0.000)	3 (0.097)
6–12 months	1 (0.016)	3 (0.097)
1–2 years	10 (0.161)	9 (0.290)
>2 years	51 (0.823)	16 (0.516)
Race/ethnicity		
Asian	4 (0.066)	5 (0.161)
Black	2 (0.033)	2 (0.065)
White	52 (0.852)	21 (0.677)
Other	3 (0.049)	3 (0.097)
Age*	10.781 (3.811)**	5.889 (2.861)**
Functional ability	6.339 (2.360)**	6.185 (2.617)**

\*  $p < 0.05$  for differences between controls and subjects

\*\*Mean (standard deviation)

thought to be a reasonable proxy for duration of diagnosis. All analyses were conducted by using SAS 9.2 (SAS Institute Inc., Cary, NC).

## Results

### Response Rates

Thirty-four (74%) of subjects and 62 (40%) of controls completed both pre and post surveys.

### Demographics

Subjects were significantly more likely to be female and younger and have a shorter duration of diagnosis than the controls. While not statistically significant, both household income and education level were higher for subjects.

### Medical Home

At the outset of the intervention, none (0%) of the subjects and only 16% of the controls endorsed having a medical home, whereas 1 year later 35% of the subjects and 18% of the control group reported having a medical home.

At the end of the intervention period, controlling for pre-survey medical home status, subjects had 250% greater odds ( $p = 0.021$ ) of reporting that their care met criteria of a medical home compared to controls.

**Impact of ASD-Specific Medical Home Intervention:** At the end of the study, subjects reported both significantly higher satisfaction (6.49 vs. 4.98,  $p = 0.0004$ ) and shared decision making (5.89 vs. 4.03,  $p = 0.0005$ ) compared to controls. Subjects in the intervention group reported fewer unmet needs compared to controls (5.95 vs. 5.17,  $p = 0.067$ ), though this approached marginal statistical significance. The unmet needs affect was attributable primarily to family supports, specialty doctors, therapists and outside services. Family stress related to the child's condition was not significantly lower among the intervention group (5.27 vs. 5.68,  $p = 0.204$ ) (Table 3).

## Discussion

This study reports evaluation findings from an ASD-specific primary care medical home demonstration project. Our findings suggest that paying specific attention to the unique needs of children with ASD increases the likelihood of receiving care that meets medical home criteria as well as satisfaction and shared decision making for children with ASD.

**Table 2** Medical home algorithm summary

	Subjects		Controls	
	Study start	Study end	Study start	Study end
Medical home endorsement*	0 (0%)	12 (35%)	10 (16%)	11 (18%)
Specialty doctor referral	22 (65%)	22 (65%)	47 (76%)	42 (68%)
Coordinating specialty care*	5 (15%)	20 (59%)	17 (27%)	18 (29%)
Inter-doctor communication	5 (15%)	22 (65%)	30 (48%)	41 (66%)
Time with child*	11 (32%)	31 (91%)	49 (79%)	48 (77%)
Doctor attentiveness*	14 (41%)	34 (100%)	51 (82%)	50 (81%)
Sensitivity to values	20 (59%)	33 (97%)	54 (87%)	56 (90%)
Information on child’s health*	14 (41%)	33 (97%)	50 (81%)	50 (81%)

\*  $p < 0.05$  for differences between controls and subjects

**Table 3** Differences between subjects in ASD-specific medical home and controls in standard medical care

Dependent variable	<i>N</i>	Subjects <sup>a</sup>	Controls <sup>a</sup>	<i>p</i> Value
Satisfaction <sup>b</sup>	83	6.49	4.98	0.0004
Shared decision making <sup>b</sup>	87	5.89	4.03	0.0005
Unmet health care needs <sup>b</sup>	83	5.95	5.17	0.0670
Family stress <sup>c</sup>	86	5.27	5.68	0.2040

<sup>a</sup> Adjusted for age, gender, parent education level, income level, and pre-survey results

<sup>b</sup> On a Likert scale one (negative outcomes) to seven (positive outcomes)

<sup>c</sup> On a Likert scale one (positive outcomes) to seven (negative outcomes)

In all analyses, we controlled for differences in age, gender, income and education found between subjects and controls. It is likely that subjects were younger because they had more recent diagnoses and, thus, were more likely to be searching for fitting health care and willing to change their health care providers. Families with greater incomes or education may have had greater opportunities to learn about the ASD-specific medical home intervention trial at University forums, family support groups or from therapists. Controls had slightly fewer females and subjects slightly more females compared to national averages of 12–24% females in children with ASD (CDC 2009). Families of females, who have a higher proportion of cognitive impairment, (CDC 2009) may have been more likely to seek out a medical home, yet there was no significant difference in reported functional ability between subjects and controls. The lack of demographic variation limits the generalizability of the findings yet is similar to the general population of Minnesota (U.S. Census 2000).

This intervention provides a step towards resolving the ASD medical home discrepancy; only a quarter of children with ASD have medical homes compared to nearly one half of children with other special health care needs (Liptak

et al. 2006a; Brachlow et al. 2007). Subjects in this study receiving the ASD-specific medical home were more likely to report gaining a medical home from intervention start to completion compared with controls. The lower rates of baseline medical home endorsement for subjects and controls in this study compared to previous national rates of medical homes among children with ASD (26%) (Brachlow et al. 2007) are likely due to a stricter medical home scoring system. Also, subjects, few of whom endorsed a medical home and its components at baseline may represent families who were particularly “displeased” with their current healthcare. These families may have sought out the intervention and were willing to change health care providers. If this is the case, then it is critical that future efforts “target” this specific population in order to improve rates of medical homes for children with ASD. The intervention in this study built upon the conventional medical home; quality improvement processes resulted in ASD-focused tools and processes ([www.autismmedicalhome.com](http://www.autismmedicalhome.com)).

Since parents of children with ASD report dissatisfaction with their child’s health care (Liptak et al. 2006a; Kogan et al. 2008), it is important that satisfaction of health care received was significantly increased in subjects compared to controls. Additionally, in a review of medical home studies, the parent-provider relationship or a family-centered care education training for the physician were associated with increased satisfaction within the medical home (Homer et al. 2008). Future improvements in autism care should be attentive to family needs.

Shared decision making, a process of parent-provider collaboration, was increased with this study intervention. Shared decision making has not been studied specifically in ASD, but has been associated with improved patient satisfaction (Tuckett et al. 1985) and is said to be particularly useful when treatment decisions are of low certainty (Whitney 2003), frequently the case in ASD. Hence, shared decision making may have been the “pathway” to increased satisfaction for subjects in the intervention.

Furthermore, SDM actively involves parents and parents of children with ASD have a particularly strong track record of achievements in advancing ASD care (Silverman and Brosco 2007). Shared decision making is “actionable” and could be evaluated in future research regarding the care of children with ASD.

While not significant, subjects reported having fewer unmet needs. Unmet needs are important because children with ASD have less comprehensive and coordinated care (Brachlow et al. 2007) and greater unmet needs compared to CSHCN (Kogan et al. 2008). The ASD-specific medical home attempted to provide comprehensive and coordinated care through a dedicated nurse care coordinator, area ASD resource and dental lists and professional connections with area educational, county and specialty medical services.

Subjects in the intervention did not report a significantly different change in family stress compared to controls. Decreasing family stress is important as previous studies have described the significant emotional and financial stress faced by families of children with ASD. Intervention tools, such as social stories and longer appointments, may have reduced stress within the clinic. However, the survey assessed stress related to the child’s condition and not stress specifically related to the clinical experience. It is likely that the medical home intervention was not able to significantly address stress arising from outside of the clinic.

Both unmet needs and family stress may be influenced by multiple factors and require supports that are outside the primary care medical home. For example, previous studies suggest that the lack of medical homes for children with ASD may have more to do with difficulty accessing specialty care than quality primary care (Sheldrick and Perrin 2010). Our findings suggest that a truly comprehensive medical home for children with ASD requires collaboration beyond the primary care setting.

## Conclusions

This study suggests that medical home quality improvement processes targeting children with ASD are associated with care that is more likely to meet medical home criteria, improved healthcare satisfaction and improved shared decision making. Future studies could randomly assign children with well-established ASD diagnoses to medical home intervention or standard healthcare. Similarly, ASD-specific medical home tools and/or medical home teams involving parents of children with ASD could be promoted in randomly selected primary care practice settings compared to control settings. This work provides preliminary support that ASD-specific quality improvement efforts can eliminate medical home disparities and improve medical care for children with ASD.

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