

## **Coordinating Care for Children with Chronic Conditions in Primary Care**

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### I. Introduction

#### A. Nature of the research problem

Growing numbers of children and adolescents have chronic health conditions that affect their daily lives and require complex health care services from a variety of providers. Despite different etiologies and physiologies, the chronic conditions of children create an array of similar problems for most families.<sup>1</sup> These families typically need a range of services (eg, specialized therapies, counseling, home health care, school-based services, family education) that are often poorly coordinated if available, and families either forgo services or find them only at high personal cost.<sup>2</sup> In contrast to families' needs, primary care pediatric practices are mainly organized around acute and preventive care, with generally little capacity to address chronic care.<sup>3</sup>

The Vanderbilt study of children with chronic health conditions and their families documented these challenges and helped to formulate the notion of commonalities among families raising children with dissimilar chronic conditions.<sup>4</sup> A main recommendation from the study was the development of a system of care for all children with special health care needs (CSHCN). An ideal system would integrate services, connect children with appropriate resources, improve communication, develop registries, enhance financing, coordinate with school and the community, support families in providing care, coordinate medical care, assess and improve quality, and assure access to a range of health care services including quality primary, specialty, tertiary, and home care.<sup>5</sup> The medical home model encompasses these ideals.<sup>6</sup>

In recent years, a number of states, mainly through leadership from the state Maternal and Child Health programs, have experimented with new programs to coordinate care for children with special health care needs (CSHCN). Massachusetts developed one such program, emphasizing the integration of state MCH care coordination staff with community-based primary care services, and thus meeting several goals of the Federal MCH-CSHCN program, including public-private partnerships and efforts to improve the health status of CSHCN.

This research project represented a collaboration with the Massachusetts Department of Public Health (MDPH) to evaluate the state program, the Massachusetts Medical Home Project (MMHP). This program placed state-employed care coordinators in local primary care practices to improve care and outcomes for children with chronic health conditions and their families and to help the practices evolve into medical homes.

#### B. Purpose, scope, and methods of the investigation

The principal objective of this project was to describe the effects of the MMHP in comparison with standard community practice without care coordinators in place. The research focused on three main family outcomes of interest:

- a. access to care and unmet health needs,
- b. satisfaction with services,
- c. mental and physical health of parents

Additionally, we expected that 1) higher rates of met needs would be associated with increased satisfaction; 2) households enrolled in the MMHP would report significantly higher levels of care coordination than households in the comparison practices; and 3) parents (in the care coordination practices) reporting higher ratings on their assessment of care coordination services at time 2 would experience greater improvement in outcome scores.

#### C. Nature of the findings

This study provides some important information regarding the workings and effects of the Massachusetts Medical Home Program. As with other studies of care coordination, the Time 2 cross-sectional data provide evidence that the families referred to the coordinators for services have substantially greater needs than comparison families, resulting in (likely appropriate) selection bias in the coordinators' caseloads. The cross-sectional data at Time 2 suggest that, in general, the coordination (intervention) households were doing better than the comparison households. However, analyses examining change in the two populations over time show somewhat different findings, although the small numbers preclude strong conclusions. Here, intervention families, starting from a less-well-functioning baseline, had more improvement in key scores than did the comparison families, as indicated below, although real differences in the two populations at Time 1 limited the strength of the analyses.

The MMHP, in assigning care coordinators to community pediatric practices, represents a first step in developing medical homes for children with special health care needs. This evaluation provides some evidence of the effectiveness of the project in meeting its stated goals. The cross sectional analyses of the survey data suffer from the same limitations of similar previous analyses: the selection bias in families referred for care coordination and the inability to control for unknown differences between the two groups of families obscure these results.

## II. Review of the Literature

Epidemiology. The 2001 National Survey of Children with Special Health Care Needs indicated that 12.8% of children and youth under age 18 years had a special health care need, defined as needing more health, medical and related services than children of the same age.<sup>7</sup> A number of studies have documented the effects of childhood chronic conditions on parental health and functioning. Cadman et al. found about a doubling of mental health conditions among parents of children with chronic conditions compared to other parents.<sup>8</sup> Mothers of children assisted by technology had significantly poorer mental health than other mothers.<sup>9</sup> Numerous other studies have documented higher rates of depression and other mental health conditions in parents of children with chronic conditions.<sup>10, 11, 12</sup>

Care coordination. Despite different etiologies and physiologies, disabilities among children create an array of similar problems for most families. Most work on medical home and care for CSHCN in primary care practice indicates the difficulty of providing the full range of services based only on traditional office staffing. Such services instead typically require the addition of non-physician staff, although the models of staff experience vary substantially. Care coordination is the single element of the medical home model that exceeds the capability of most pediatric practices.<sup>13</sup>

Much of the research on case management and care coordination has come from fields other than child health – mainly from community mental health and social work.<sup>14</sup> Care coordination was applied to children with special health care needs over two decades ago, often with initial goals similar to those for other human service clients. The medical home model had an early pilot in the Pediatric Home Care program (PACTS) at Albert Einstein College of Medicine<sup>15, 16</sup> in which 219 families with children with chronic conditions were randomly assigned to an intervention or to standard care in resident-run continuity clinics. The intervention included primary care by a pediatrician and nurse clinician, counseling, home visits, care coordination within and outside the medical center, parental/self-care education and support, social services, advocacy, 24-hour telephone access, and other services. The intervention had important impacts on family mental health, with increased satisfaction with services, improved child psychological adjustment, and reduced psychiatric symptoms of the mother, with some

reductions persisting at 4-5 year follow-up.<sup>17</sup> Households with relatively less severely ill children and with fewer community resources benefited most from the program.<sup>18</sup> Children receiving Pediatric Home Care had slightly more hospital admissions (significant only at one year). The authors attributed this finding to the selection bias of sicker children remaining with the study through one year and the greater medical supervision that identified more medical problems.

### III. Study Design and Methods

A. Study Design: We carried out a one-year longitudinal study examining change in families with CSHCN receiving care coordination through the MMHP compared with families with CSHCN in a similar community practice. All families were surveyed at study entry and again at 12 months after the initial survey to determine changes over time in key dependent variables. The main research focused on a longitudinal study of care coordination and changes in parent/child outcomes, using a difference-in-differences approach. In 2005 and 2006, we surveyed parents of children entering the care coordination (CC) program in each CC site, as well as parents of children with special health care needs in a comparison site. The difference-in-differences approach provides a strong method for examining changes in key variables while controlling for temporal or maturational changes through the comparison group.<sup>19</sup> The study was approved by MDPH and by the IRBs at Partners Health Care, Baystate Medical Center, Children's Hospital Boston, Greater Lawrence Family Health, and the University of Massachusetts Medical Center (Worcester).

B. Population Studied: The study population included households of CSHCN receiving care coordination services in one of six practice sites where the MDPH had assigned care coordinators. We used one comparison site where no care coordinators were included in the practice.

C. Sample Selection: We sought participation in the survey of all children/households entering care coordination in the six treatment sites. Each of the original MMHP sites estimated that it had enrolled 100 households in the MMHP by the end of the first year. Thus, we expected to recruit 100 families per care coordination practice as the primary sample, with a rolling entry over the first year. We also provided an incentive of \$10 to households to participate. For new households entering care coordination, we requested survey participation from each new family as the care coordinators enrolled them – ie, a rolling enrollment both in the project and in the study.

For the comparison practice, we used previously described methods<sup>20</sup> to identify children with SHCN. Specifically, we applied a list of ICD-9 codes to children ages 2-18 years in the practice to determine presence of a chronic condition and randomly selected from those identified.

#### D. Tests and Measurements.

*Parent Survey Measures:* We derived survey questions from existing surveys of general populations or surveys specific to families of children with special health care needs. The sources included NSCSHCN<sup>21</sup>, CAHPS<sup>22</sup>, Family Voices survey 1998-1999<sup>23</sup>, Special Care Coordination survey of MDPH<sup>24</sup>, MPOC<sup>25</sup>, Stein Impact of Illness<sup>26</sup>, and the SF-12.<sup>27</sup>

The survey queried access to and coordination of care, satisfaction with services, and parent mental and physical health; as well as family/child sociodemographics, health insurance coverage, and the child's overall health status.

To determine access to care we used two questions regarding the frequency of the child's visits to a primary care physician and/or specialist. Higher rates indicated better access. For met needs, we developed a score per child calculated as 1 minus the percent of services rated as needed but for which parents report difficulties in getting.

We considered coordination of care as an additional element of access, used several indicators of coordination of care, including:

**Primary Care Physician Office Help.** This measure assessed how helpful the family perceived the staff at the primary care physician's office to be. This measure (PCP Help) consisted of 12 questions on a 1-to-6 scale and included, for example, how well did the staff "Help you to understand your child's health insurance plan benefits?" Higher scores represent improved outcomes.

**Overall Care and Concern.** This 18-item measure derived from the MDPH Special Care Coordination Survey and from the NSCSHCN assessed whether the families believed their primary care physician's office staff provided overall care, concern, and culturally appropriate support and. Questions included, for example, "Their ability to answer questions or give medical advice by phone" and "Their caring and concern for your child". As with PCP Help measure, the Overall Help measure response options included a 1-to-6 scale, from Excellent to Very Poor.

**Family-Professional Partnership.** A third measure tapped whether the families reported having a Family-Professional Partnership with their health care provider. This measure consisted of 5 questions on a 1-to-6 scale.

**Revised Measure of Processes of Care.** As the main measure of the activities within the child's health care provider's setting, we used a revised 15-item version of the Measure of Processes of Care (MPOC), which includes two factors: Enabling and Partnership and Coordinated and Comprehensive Care. This measure was originally developed as a 56-item measure to examine various aspects of care for children with developmental disabilities and their families in a multidisciplinary care center.

To assess parent satisfaction with services, we used one question from the National Survey of Children with Special Health Care Needs,<sup>28</sup> dichotomized into very and somewhat vs somewhat dissatisfied or very dissatisfied.

For parent mental and physical health, we used the SF-12, Version 2, a well-standardized measure of adult mental and physical health.

*Main comparison:* The primary comparison examines child/family outcomes by care coordination vs none.

*Control variables:* We controlled for family income and parent rating of the child's overall health status (from the CAHPS) as excellent, very good, good, fair, or poor. Given the high correlation of race/ethnicity with income, we did not include race/ethnicity in the final models.

#### E. Statistical Techniques and Data Analysis.

Hypothesis 1) (*households enrolled in the MMHP will report more positive improvement in the three main outcomes than comparison group households, controlling for clinical and demographic factors*): The main longitudinal analysis used a quasi-experimental design, with a difference-in-differences strategy. Initial analyses determined bivariate relationships between presence of coordination and each dependent variable, controlling for income and health status. For the main analysis, we compared changes in dependent variables (access to care and coordination of care, unmet needs, parent satisfaction with services, parent mental and physical health) from baseline to one-year follow-up among households surveyed in the six care coordination practices with changes among households in the comparison practice.

To examine hypothesis 1b (*higher rates of met needs will also be associated with increased satisfaction*), we performed a correlation analysis using only the Treatment group sample at time 2.

To examine hypothesis 1c (*households enrolled in the MMHP will report significantly higher levels of care coordination than households in the comparison practices*), we used chi-square analysis to examine whether the treatment and control

groups differed significantly in reporting whether they had a care coordinator. To examine whether levels of reported care coordination differed between the two groups, we performed t-tests on the MPOC aggregate score and its factors, followed by regression analyses with control variables.

The evaluation of hypothesis 2 (*whether parents in the care coordination practices reporting higher ratings on their assessment of care coordination services at time 2 will experience greater improvement in outcome scores*) involved several analyses. First, ratings of care coordination were assessed by three questions (how often does the care coordinator help you organize your child's care, did you receive all the care coordination services you needed, and how satisfied have you been with the services). For satisfaction, we dichotomized into "Very Satisfied" or "Somewhat Satisfied" and determined whether the two groups differed significantly on all of the outcomes (by t-tests). Additionally, with the sample limited to the households in the care coordination practices, regression analyses were conducted to examine change scores for each of the dependent variables, as factors of the total MPOC score and each of its factors at Time 2.

#### IV. Findings

*Final Sample:* In total, there were 245 Time 1 Surveys (118 Treatment, 127 Control) and 130 Time 2 Surveys (61 Treatment, 69 Control), representing a 52% follow up rate for the care coordination families and 54% for the control families. Despite our efforts to recruit a generally comparable comparison group, the two groups differed in important ways. Families receiving care coordination had lower incomes ( $X^2=44.80$ ,  $p < .01$ ), higher Latino population ( $X^2 =21.14$ ,  $p < .01$ ), and public insurance ( $X^2 =42.95$ ,  $p < .01$ ) (Table 1). These families reported that their children's overall health was poorer than for the children in the families that did not receive care coordination, ( $X^2 =35.19$ ,  $p < .01$ ). Parent education did not differ significantly between the two groups. We adjusted for these differences in our analyses. Race, income, and insurance were highly correlated. Therefore, in the multiple regression analyses, we included only income to avoid multicollinearity.

#### Main Hypothesis Findings

The unadjusted and adjusted cross-sectional analyses at time 2 are included in Tables 2 and 3 as are the unadjusted difference-in-difference analyses (Table 4). In summary, in cross sectional analyses from the follow-up survey (61 families in care coordination group, 69 comparisons), after controlling for child's overall health and family income, multiple regression analyses revealed that for six of the dependent variables, (financial impact, MPOC, help provided by primary care physician, communication with other services, PCP access, and specialist access), the overall models were significant (see Table 3). Examination of the independent variables revealed that the group variable (Treatment or Control) was significantly associated with both the PCP access ( $t=2.49$ ,  $p<.05$ ) and specialist access ( $t=3.48$ ,  $p<.05$ ) models. For financial impact and communication with other services, family income was a significant independent variable; for PCP Help and for the MPOC, as well as for the access measures, the Child's Overall Health was a significant independent variable.

To look at family change over time, we carried out difference-in-differences analyses wherein changes before and one year after the initiation of care coordination are compared with changes in the same timeframe for the comparison families. After controlling for the child's overall health and family income, the overall model was significant for two of the dependent variables: Parent Mental Health ( $R^2 = .12$ ,  $p < .01$ ) and Physical Health ( $R^2= .15$ ,  $p < .001$ ) (Table 5). Within these models, however, Group (Treatment or Control) was not a significant independent variable. For Mental Health,

the child's overall health was significant and for Physical Health, the family income was significant. With respect to PCP access, the overall model was marginally significant ( $F=2.52$ ,  $p=.06$ ), and income was shown to be the only significant variable in the model ( $t=2.50$ ,  $p<.05$ ).

With regard to the various dimensions of care coordination, for the dependent variable, PCP Help, Group was a significant variable, with the Treatment group reporting better PCP help ( $t=-1.97$ ,  $p<.05$ ), but the overall model was not significant. For overall care and support, family-professional partnership, and the MPOC, neither the overall models nor the individual variables were significant.

Hypothesis 1b Findings:

In analyses to examine whether higher rates of met needs were associated with increased satisfaction *in the Treatment group*, correlation analysis showed a significant relationship ( $r=.47$ ,  $p<.001$ ). The parents who reported having greater needs met also reported greater satisfaction.

Hypothesis 1c Findings:

Chi-square analyses showed that the families enrolled in the MMHP reported significantly higher levels of care coordination than the comparison families ( $\chi^2=49.57$ ,  $p<.001$ ). In t-test analyses, we found a significant difference in levels of care coordination, as reflected by the aggregate MPOC score, between the two groups, with the Treatment Group reporting higher levels of care coordination, ( $t=-2.42$ ,  $p=.02$ ). The comparison between the two groups on the MPOC factors (Enabling and Partnership and Comprehensive and Coordinated Care) did not reach statistical significance although the Treatment group did report higher levels of each (see Table 2). In analyses controlling for the child's overall health and the family's income, however, there was no significant difference between the two groups (see Table 3) on either the aggregate MPOC score or its factors.

Hypothesis 2 Findings:

T-tests revealed that the group of families that reported being "Very Satisfied" with their care coordination services (as opposed to "Somewhat Satisfied") reported better scores on several of the outcomes, including: Measure of Processes of Care, Family Professional Partnership, Overall Care and Support Provided, PCP Help Provided, Satisfaction with Services, Communication among Providers, and Communication with Other Services. (See Table 7).

In terms of whether the families who reported that their care coordinator "Usually/Always" helped organize their child's services, (as compared with those who reported that they "Never/Sometimes" helped), there was a significant difference reported on the outcome measure, communication with other services. That is, the families who reported that they had better help in organizing their child's care also reported that their doctors and other providers did a better job of communicating with other entities such as schools and child care providers ( $t=3.01$ ,  $p<.01$ ). There were no other significant differences between the two groups on any of the other outcome measures.

Difference-in-differences analyses were performed to determine whether parents in the care coordination practices who reported higher ratings on their assessment of care coordination services at time 2 experienced greater improvements in outcome scores, and none of the results reached statistical significance.

*Findings summary:* This analysis provides some important information regarding the workings and effects of the Massachusetts Medical Home Program. As with other studies of care coordination, the Time 2 cross-sectional data provide evidence that the families referred to the coordinators for services have substantially greater needs than comparison families, resulting in (likely appropriate) selection bias in the coordinators'

caseloads. The cross-sectional data at Time 2 suggest that, in general, the coordination (intervention) households were doing better than the comparison households. However, the difference-in-differences analysis, comparing change in the two populations over time, show somewhat different findings, although the small numbers preclude strong conclusions. Here, intervention families, starting from a less-well-functioning baseline, had more improvement in key scores than did the comparison families, as indicated below, although the real differences in the two populations limited the strength of the analyses.

The MMHP, in assigning care coordinators to community pediatric practices, represents a first step in developing medical homes for children with special health care needs. This evaluation provides some evidence of the effectiveness of the project in meeting its stated goals, although the limited number of households responding over time and the persistent differences in the families who are selected for care coordination limit the power of the findings and provide mainly indirect evidence that coordination led to changes in outcomes.

The cross sectional analyses of the survey data suffer from the same limitations of similar previous analyses: the selection bias in families referred for care coordination and the inability to control for unknown differences between the two groups of families obscure these results. The difference-in-differences analyses are promising but the small number of surveyed families referred for care coordination and the greater than expected attrition of initially enrolled families resulted in limited power to demonstrate unequivocal improvement associated with care coordination.

## V. Discussion and Interpretation of Findings

### A. Conclusions to be drawn from the findings

The two samples differed substantially, both at time 1 and time 2. These differences, unexpected based on earlier piloting, limited the ability of the research to provide clear answers regarding the direct impact of the care coordination efforts. Thus, many analyses did not yield significant results. The intervention (care coordination) and comparison groups were significantly different on several variables. Intervention group children had poorer health, were more likely to be racial minorities, were economically poorer, and were more likely to have public insurance coverage. These differences were probably also associated with other unmeasured differences that contributed to the programmatic and analytical challenges.

In cross sectional analyses adjusting for child's health and family income at time 2, families in the care coordination group, as opposed to comparison families, reported better access to primary care providers (PCPs) and specialists ( $\beta$  coefficients  $p < .05$ , model  $p < .0005$ ,  $R^2 = .19$  and  $.27$  respectively)(Table 3) These results have important policy and programmatic implications. The difference-in-differences models, however, were significant only for the mental and physical health of the respondent with group membership (care coordination or comparison group) not a significant variable.

Analyses of the sub-group of care coordination families that reported being very satisfied with care coordination services yielded additional results of interest. In cross sectional analyses adjusting for child health and family income, very satisfied treatment families reported more satisfaction with help from the PCP ( $\beta$  coefficient  $p < .05$ , model  $p < .002$ ,  $R^2 = .26$ ), higher satisfaction with access to PCPs ( $\beta$  coefficient  $p < .01$ , model  $p < .009$ ,  $R^2 = .18$ ), and more satisfaction with access to specialists ( $\beta$  coefficient  $p < .01$ , model  $p < .0002$ ,  $R^2 = .28$ ).

As predicted, treatment families reporting higher rates of met needs also reported higher rates of satisfaction. And families in the coordination group reported higher levels of coordinated services than those in the comparison sample.

## B. Explanation of study limitations

The study faced many challenges including small sample size, attrition of families, non-comparable study groups, variably implemented intervention, and multiple overlapping care coordination services. We discuss these in turn.

Many fewer families than expected enrolled in care coordination during the initial study year and as a result, fewer than expected were eligible to enroll in the study. Much of the problem in initial enrollment reflected major and frequent changes in the organization and leadership of the MMHP. These changes led to rediscussion and reframing of the care coordinators' responsibilities and reporting mechanisms. Although the MGH team played important roles in advising the state health department leaders about potential programmatic changes, each change delayed enrollment of households, and the changing expectations between care coordination staff and department leadership also led to substantially smaller numbers of eligible enrollees than the original projections. We attempted to compensate for lower enrollment per site by adding new sites to the project, but even this expansion was insufficient to compensate for far fewer active families per site. The smaller than expected new enrollment in care coordination reflects constrained availability of coordinator time (generally only one per site assigned part time), smaller coordinator caseload due to intensity of family needs, and also an over-optimistic projection from sites about their capacity.

Loss of families who enrolled in the study but did not respond to follow up efforts at time 2 was comparable to that in other studies. Our efforts to contact these families with repeated survey mailings, up to eight telephone calls, and updates from care coordinators about families' whereabouts helped to achieve over 50% follow up of a mobile population.

In spite of our effort to identify comparison families who would be comparable to the care coordination group, the study and comparison groups represented families who were very different on many known variables. (In an earlier cross-sectional pilot, the state coordinators enrolled families much more comparable to those in this study's comparison group. The changes in the MDPH program led, however, to increased recruitment of very poor families, many from racial and ethnic minority groups.) Selection of comparison group families involved using an administrative database to identify children with chronic conditions and asking practice pediatricians to confirm children's eligibility and appropriateness for the study. However, this method is unable to capture many of the factors that are taken into consideration when families are recommended for care coordination: family economic position, family supports, language barriers, or stability and complexity of the child's health conditions. These additional factors lead to an appropriately-biased enrollment of families into care coordination, but they add to the challenges of conducting research.

The care coordination intervention varies by site according to the training and skills of the coordinators. Although MDPH is attempting to develop standard policies and procedures, this variability is inevitable when employees are housed in local practices and must accommodate the practice culture. Our sample size was insufficient to permit site-specific analyses.

Finally, care coordination is available from many sources, and few families of children with special health care needs lack access to any coordinators. Thus, this study is not an evaluation of care coordination per se, but rather an assessment of an additional care coordination services for some families compared with "standard" care coordination for others. The observation of multiple sources of care coordination may be peculiar to a relatively well-resourced state like Massachusetts.

### C. Comparison with findings of other studies

Several studies have examined the effects of care coordination on outcomes for CSHCN. Although the specific elements of the care coordination varied, condition-specific interventions often showed positive effects. Enhanced care for children with asthma – including self-care instruction, written care plans, and regular phone follow-up by a specially trained nurse – resulted in reduced emergency room visits and lower hospital admissions.<sup>29</sup> Socially disadvantaged pregnant women were randomized into an intervention involving home visits and pediatric office support or standard care. Those in the intervention groups were more likely to have a prenatal visit to a pediatrician and to use a primary care practice as the usual source of care for the newborn.<sup>30</sup> Improvements in the percent of low-birth weight newborns among high risk, Medicaid-enrolled women were the result of a care coordination intervention involving needs assessments, referrals to community resources, development of written plans, and follow-up.<sup>31</sup> Children with chronic conditions enrolled in a program in which professionals of various disciplines were integrated into specialty clinics to provide care coordination (among other services) had reduced hospital admissions, lower length of stay, and lower costs.<sup>32</sup> An evaluation of a program to provide some family support through the assignment of experienced parents to parents of children with newly-diagnosed chronic conditions indicated improvements in aspects of both child and parent mental health.<sup>33,34</sup>

### D. Possible application to actual MCH health care delivery situations

MCH supports care coordination efforts in a variety of ways (e.g., in state service delivery programs, in the core objectives, or through the medical home), and this study provides no evidence to change this program emphasis. It does indicate appropriate domains for focus in measuring the impact of care coordination. While families in this study report some positive effects of care coordination, the results are not strong enough to provide definitive evidence supporting specific care coordination methods or the household most appropriate for care coordination.

### E. Policy implications

These findings continue to support the provision of care coordination in primary care settings, although the study limitations indicate the need for continued research in larger studies to provide stronger policy guidelines for MCH. All but one analysis in which group assignment was significant did favor care coordination; the findings support care coordination although improving policy will require even more intense and systematic study. This study maximized the opportunity to examine an important state experiment – ie, a single real-world effort by a state to improve services for children with special health care needs. The data, while promising, also indicate the importance of studying this intervention in varied sites and using varied methods.

### F. Suggestions for further research

Implementing care coordination requires substantial resources. The Massachusetts experience led to substantial growth in leadership understanding of the complexity of coordination and the sizeable difficulties in managing a program using diverse personnel in very diverse clinical settings. Regularizing training and reporting required a major investment of time by program leadership and especially by the dedicated group of coordinators. This work led to reconsideration of the definition of care coordination cases and activities and much group learning about methods and outcomes of coordination. All of these topics merit substantially more investigation and study to describe what happens and provide better standards of care. Families,

providers, advocates, and various policy makers strongly support care coordination. We believe that conducting a thorough evaluation of care coordination should be a high priority for MCHB and other parties. In light of the challenges of identifying truly comparable families for a comparison group, we suggest conducting such an evaluation as a cluster randomized trial in several similar programs, pediatric practices, or medical homes that are thoroughly committed to participation. Such a study design has many advantages: it will allow inferences of causation rather than the weaker inference of association; a randomly assigned family sample should yield a comparable control group; and the intervention itself can be clearly defined and evaluated for fidelity of implementation. Such a study will help answer the ongoing controversy about the effectiveness of care coordination in meeting the many needs of families and children with special health care needs.

#### VI. List of products

Project report: Massachusetts Medical Home Report: Report of an Evaluation; prepared for the Massachusetts Department of Public Health, February 14, 2006.

Table 1. Demographic Characteristics of Completed Survey Respondents (Time 2)

Characteristic	Care Coordination N = 61	Comparison group N =69	t or $\chi^2$ <sup>a</sup>	P-value
Age			1.48	0.14
1-5	24	17		
6-10	18	26		
11-15	12	17		
16-20	6	5		
Missing	1	4		
Gender (Male)	38	46	0.05	0.83
Missing	5	3		
Child's Overall Health			35.19	<.0001
Excellent	5	31		
Very Good	13	22		
Good	21	9		
Fair	18	4		
Poor	4	2		
Missing	0	1		
Education			3.98	0.26
Less than high school	9	6		
High School or GED	24	22		
Some College	16	22		
College graduate	5	12		
Missing	7	7		
Race			21.14	0.0002
White	20	46		
Black	4	4		
Other	4	4		
Latino	33	11		
Missing	0	4		
Insurance			42.95	<.0001
Private	2	38		
Public	58	28		
None	1	2		
Missing	0	1		
Income			44.80	<.0001
< \$10k	20	2		
\$10-19,999	13	7		
\$20-29,999	5	8		
\$30-39,999	5	1		
\$40-49,999	3	7		
> \$50K	2	29		
Missing	13	15		

<sup>a</sup> Where the cell numbers were < 5, Fisher's Exact Tests were run to verify chi-square results.

Table 2. Unadjusted Cross-sectional Comparison of Care Coordination and Non-Care Coordination Households, Time 2

Outcome Variable	Care Coordination Mean score	Comparison group No Care Coordination Mean Score	t	Significance of t
PCP Access	3.32	2.48	-4.29	<b>&lt;.0001</b>
Specialist Access	3.25	1.89	-6.27	<b>&lt;.0001</b>
Unmet Needs	0.13	0.09	-1.27	0.20
PCP Help Provided	25.06	32.53	2.25	<b>0.05</b>
Overall Care and Support Provided	30.24	28.99	-0.44	0.66
Family/Professional Partnership	16.49	17.13	0.38	0.71
Measure of Processes of Care	79.55	68.88	-2.42	<b>0.02</b>
Factor 1 – Enabling and Partnership	40.27	37.45	-1.34	0.18
Factor 4 – Coordinated and Comprehensive Care	41.29	38.17	-0.96	0.34
Communication among providers	2.48	2.67	0.74	0.46
Communication with other services	2.94	4.19	4.20	<b>&lt;.0001</b>
Satisfaction with Services	1.55	1.56	0.06	0.95
Parental Mental Health	43.26	45.97	1.92	<b>0.06</b>
Parental Physical Health	43.00	42.17	-0.80	0.42

Note: Results from T-tests (unadjusted)

Table 3. Adjusted Cross-sectional Comparison of Care Coordination and Non-Care Coordination Households, Time 2

Outcome Variable	Group <sup>a</sup> t-value	Child's Overall Health	Income	F Value	p	R-Square
PCP Access	<b>2.49**</b>	<b>2.55**</b>	1.50	6.60	<b>0.0005</b>	0.19
Specialist Access	<b>3.48***</b>	<b>2.72***</b>	1.89	10.66	<b>&lt;.0001</b>	0.27
Unmet Needs	0.67	1.65	0.11	1.82	0.15	0.05
PCP Help Provided	-1.51	<b>2.22*</b>	1.64	3.77	<b>0.01</b>	0.12
Overall Care and Support Provided	-0.77	<b>2.56**</b>	0.85	2.28	0.08	0.07
Family/Professional Partnership	-1.47	<b>2.34*</b>	-0.57	2.15	0.10	0.05
Measure of Processes of Care	1.55	-0.96	-0.53	1.38	0.25	0.05
Factor 1 – Enabling and Partnership	1.86	-1.91	0.09	1.86	0.14	0.07
Factor 4 – Coordinated and Comprehensive Care	1.09	<b>-2.45*</b>	-0.14	2.07	0.11	0.08
Communication among providers	0.08	1.59	<b>2.04*</b>	1.99	0.12	0.05
Communication with other services	-0.96	-0.71	<b>2.87**</b>	8.32	<b>&lt;.0001</b>	0.19
Satisfaction with Services	-0.89	<b>1.97*</b>	-0.09	1.34	0.27	0.04
Parental Mental Health	-0.29	-0.87	1.49	2.22	0.09	0.06
Parental Physical Health	-0.04	-0.07	-1.21	0.65	0.58	0.02

\*p ≤ .05; \*\*p ≤ .01; \*\*\* p < .001; a: Group: Coordination=1; Comparison=0

Note: Results from multiple regression, controlling for child's health and family income

Table 4. Difference-in-Differences Analyses (unadjusted), Participants in Care Coordinator Sites Versus Participants in Control Site

Outcome Measure	Means for participants				Difference-in-Differences	SE	95% Confidence Interval	
	Care Coordination		Comparison				Lower	Upper
	Pre-Intervention	Post-Intervention	Pre-Intervention	Post-Intervention				
PCP Access	3.44	3.26	2.42	2.48	0.25	0.20	-0.15	0.64
Specialist Access	3.27	3.25	1.82	1.84	0.03	0.25	-0.45	0.52
Unmet Needs	0.14	0.13	0.11	0.08	-0.02	0.05	-0.13	0.08
Primary Care Physician's Help	25.38	24.84	24.71	31.67	<b>7.50*</b>	3.14	0.16	14.84
Overall Care and Support	26.97	30.45	23.98	28.06	0.60	2.77	-4.88	6.07
Family/Professional Partnership	15.19	16.59	15.56	17.13	0.18	1.75	-3.29	3.64
Measure of Processes of Care	82.56	81.09	70.23	69.23	0.47	4.53	-8.51	9.46
Communication among providers	2.32	2.40	2.52	2.62	0.02	0.29	-0.56	0.60
Communication with other services	2.88	2.85	3.78	4.15	0.39	0.37	-0.34	1.12
Satisfaction with Services	1.56	1.56	1.53	1.58	0.05	0.18	-0.31	0.41
Parental Mental Health	43.06	43.26	47.31	45.97	-1.54	1.73	-4.97	1.88
Parental Physical Health	47.77	43.00	52.82	42.17	<b>-5.88**</b>	2.01	-9.87	-1.90

\*p < .05; \*\* p < .01

Table 5. Difference-in-Differences (adjusted), Care Coordinator Sites Versus Participants in Control Site

Outcome Variable	Group t-value	Child's Overall Health	Income	F Value	p	R-Square
PCP Access	-0.05	0.86	<b>2.50**</b>	2.53	0.06	0.08
Specialist Access	0.23	0.19	1.85	1.33	0.27	0.05
Unmet Needs	1.01	-0.57	0.60	0.38	0.77	0.01
PCP Help Provided	<b>-1.97*</b>	1.11	-0.36	1.39	0.25	0.06
Overall Care and Support Provided	0.06	1.65	<b>1.93***</b>	1.93	0.13	0.06
Family/Professional Partnership	-1.05	0.95	-1.26	0.98	0.40	0.02
Measure of Processes of Care	0.07	-0.35	0.24	0.09	0.96	0.003
Communication among providers	-0.71	1.11	-0.35	0.48	0.70	0.01
Communication with other services	-0.89	-0.21	-0.55	0.41	0.75	0.01
Satisfaction with Services	-1.18	0.93	-0.84	0.67	0.57	0.02
Parental Mental Health	-1.13	<b>2.97**</b>	-1.41	4.58	<b>0.005</b>	0.12
Parental Physical Health	0.50	1.73	<b>-2.11*</b>	5.77	<b>0.001</b>	0.15

\* $p \leq .05$ ; \*\*  $p < .01$ ; \*\*\*  $p = .06$

Group: Coordination=1; Comparison=0;

Results from multiple regression analyses, controlling for child's health and family income

Table 6. Unadjusted Comparison of “Very Satisfied” and “Somewhat Satisfied” with Coordination of Care, Time 2

Outcome Variable	Very Satisfied Mean score N = 29	Somewhat Satisfied Mean Score N = 11	t	Significance of t
PCP Access	3.42	3.4	-0.03	0.97
Specialist Access	3.38	2.81	-1.32	0.20
Unmet Needs	0.07	0.12	1.05	0.30
PCP Help Provided	20.03	31.64	3.10	<b>.004</b>
Overall Care and Support Provided	24.89	38.91	2.76	<b>0.01</b>
Family/Professional Partnership	13.69	21.27	2.61	<b>0.01</b>
Measure of Processes of Care	93.48	72.55	-2.50	<b>0.03</b>
Communication among providers	2.16	2.9	2.22	<b>0.03</b>
Communication with other services	2.54	3.5	2.07	<b>0.05</b>
Satisfaction with Services	1.28	2.48	3.68	<b>0.0008</b>
Parental Mental Health	42.51	40.47	-0.67	0.51
Parental Physical Health	42.96	44.15	0.55	0.59

Note: Results from T-tests (unadjusted)

Table 7. Cross-Sectional Comparison of Very Satisfied Care Coordination Families with Non-Care Coordination Families, Time 2

Outcome Variable	Care Coordination Mean score N = 27	Comparison group No Care Coordination Mean Score N = 66	t	Significance of t
PCP Access (frequency of visits)	3.42	2.48	-3.82	<b>0.0003</b>
Specialist Access (frequency of visits)	3.38	1.89	-5.45	<b>&lt;.0001</b>
Unmet Needs	0.07	0.09	0.42	0.68
PCP Help Provided	20.04	32.53	3.29	<b>0.002</b>
Overall Care and Support Provided	24.89	28.99	1.17	0.25
Family/Professional Partnership	13.69	17.13	1.92	<b>0.06</b>
Measure of Processes of Care	92.68	68.88	-4.57	<.0001
Communication among providers	2.16	2.67	1.93	<b>0.06</b>
Communication with other services	2.54	4.19	5.41	<b>&lt;.0001</b>
Satisfaction with Services	1.28	1.56	1.94	<b>0.06</b>
Parental Mental Health	42.51	45.97	1.91	<b>0.06</b>
Parental Physical Health	42.96	42.17	-0.57	0.57

Note: Results from T-tests (unadjusted)

Table 8. Adjusted Cross-Sectional Comparison of Very Satisfied Care Coordination Families with Non-Care Coordination Families, Time 2

Outcome Variable	Group t-value	Child's Overall Health	Income	F Value	p	R-Square
PCP Access	<b>2.46**</b>	1.60	1.09	4.26	<b>0.009</b>	0.18
Specialist Access	<b>3.12**</b>	<b>2.06*</b>	1.31	7.72	<b>0.0002</b>	0.28
Unmet Needs	-0.52	1.48	0.90	1.00	0.40	0.05
PCP Help Provided	<b>-1.98*</b>	<b>2.27*</b>	<b>2.31*</b>	5.68	<b>0.002</b>	0.26
Overall Care and Support Provided	-1.24	<b>2.33*</b>	<b>1.89***</b>	3.88	<b>0.01</b>	0.16
Family/Professional Partnership	-1.85	<b>2.65**</b>	1.78	4.58	<b>0.006</b>	0.18
Measure of Processes of Care	<b>2.58**</b>	<b>-0.70</b>	-1.48	5.57	0.002	0.23
Communication among providers	-1.44	<b>2.65**</b>	1.50	3.70	<b>0.02</b>	0.15
Communication with other services	-1.62	0.50	<b>3.06**</b>	7.38	<b>0.003</b>	0.27
Satisfaction with Services	-1.16	<b>2.02*</b>	<b>2.05*</b>	3.77	<b>0.02</b>	0.16
Parental Mental Health	0.02	0.24	<b>2.93**</b>	3.44	<b>0.02</b>	0.16
Parental Physical Health	-0.54	0.58	-1.76	1.35	0.27	0.07

\*p < .05; \*\*p < .01; \*\*\*p = .06

Group: Coordination=1; Comparison=0

Results from multiple regression analyses, controlling for child's health and family income

Table 9. Difference-in-Differences Analyses (unadjusted) of Very Satisfied Care Coordination Families with Non-Care Coordination Families, Time 2

Outcome Measure	Means for participants				Difference-in-Differences	SE	95% Confidence Interval	
	Care Coordination		Comparison				Lower	Upper
	Pre-Intervention	Post-Intervention	Pre-Intervention	Post-Intervention				
PCP Access	3.67	3.42	2.42	2.49	0.31	0.26	-0.2	0.82
Specialist Access	3.48	3.44	1.82	1.83	0.06	0.30	-0.53	0.64
Unmet Needs	0.11	0.07	0.11	0.08	0.01	0.07	-0.12	0.14
Primary Care Physician Help	20.67	19.71	24.71	31.67	<b>7.92***</b>	4.19	-0.52	16.35
Overall Care and Support	22.04	24.89	23.98	28.06	1.23	3.27	-5.26	7.73
Family/Professional Partnership	12.15	13.69	15.56	17.13	0.04	2.08	-4.10	4.17
Measure of Processes of Care	87.33	95.67	70.23	69.23	<b>-9.33**</b>	5.81	-20.92	2.25
Communication among providers	2.30	2.13	2.52	2.62	0.27	0.38	-0.48	1.02
Communication with other services	2.96	2.52	3.78	4.15	0.81	0.46	-0.10	1.71
Satisfaction with Services	1.54	1.29	1.52	1.58	0.30	0.24	-0.18	0.78
Parental Mental Health	42.95	42.51	47.31	45.97	-0.91	2.33	-5.55	3.73
Parental Physical Health	45.96	42.96	52.82	42.17	<b>-7.65</b>	2.75	-13.11	-2.18

\*p < .05; \*\*p=.058; \*\*\*p =.065

Table 10. Difference-in-Differences; Very Satisfied Care Coordination Families with Non-Care Coordination Families, Time 2 (adjusted)

Outcome Variable	Group t-value	Child's Overall Health	Income	F Value	p	R-Square
PCP Access	-0.45	0.30	1.33	1.07	0.37	0.05
Specialist Access	-0.08	0.18	1.02	0.50	0.69	0.03
Unmet Needs	0.19	0.22	1.15	0.48	0.70	0.03
PCP Help Provided	-1.31	.99	0.18	0.75	0.53	0.06
Overall Care and Support Provided	0.21	1.60	<b>2.41*</b>	2.78	<b>0.05</b>	0.13
Family/Professional Partnership	0.21	1.13	<b>2.38*</b>	2.29	0.09	0.10
Measure of Processes of Care	0.72	-0.00	-0.21	0.35	0.79	0.02
Communication among providers	-1.56	<b>1.97*</b>	-0.75	1.56	0.21	0.08
Communication with other services	-1.24	0.05	0.53	1.28	0.29	0.07
Satisfaction with Services	-0.71	1.32	1.81	2.05	0.12	0.10
Parental Mental Health	-1.18	1.70	-1.51	2.01	0.12	0.10
Parental Physical Health	0.14	1.43	<b>-1.95**</b>	3.41	<b>0.02</b>	0.16

\*p < .05; \*\*p = .06; Group: Coordination=1; Comparison=0

Results from multiple regression analyses, controlling for child's health and family income

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