Use of Health Care Services Among Children With Disabilities Enrolled in an Accountable Care Organization

Paula H. Song, PhD¹; Deena Chisolm, PhD²; Marisa Domino, PhD¹; Renée Ferrari, PhD¹; Brian Hilligoss, PhD³; Rita Mangione-Smith, MD⁴; Thomas Scheid, MA⁵; Sandra Tanenbaum, PhD⁶; Wendy Xu, PhD⁶

AFFILIATIONS:

¹University of North Carolina at Chapel Hill, Chapel Hill
²Nationwide Children’s Hospital, Columbus, Ohio
³Arizona State University, Tucson
⁴Seattle Children’s Hospital, Seattle, Washington
⁵Voices for Ohio’s Children, Columbus
⁶The Ohio State University, Columbus

PCORI ID: IHS-1310-07863
Organization Receiving the Award: University of North Carolina at Chapel Hill
Original Project Title: Improving Care Coordination for Children With Disabilities Through an Accountable Care Organization
HSRProj ID: HSRP20152230
ClinicalTrials.gov ID: NCT02304380

TABLE OF CONTENTS

ABSTRACT ................................................................................................................................. 4
BACKGROUND.......................................................................................................................... 6
  Health Care Needs of Children With Disabilities ................................................................. 6
  Accountable Care Organizations and the Role of Care Coordination ............................... 6
  Study Relevance ................................................................................................................... 7
  Study Aims ............................................................................................................................. 8
PARTICIPATION OF PATIENTS AND OTHER STAKEHOLDERS ........................................ 9
METHODS ................................................................................................................................ 11
  Overall Study ......................................................................................................................... 11
  Aim 1 Methods ..................................................................................................................... 13
    Table 1. Focus Group and Interview Dates ......................................................................... 14
  Aim 2 Methods ..................................................................................................................... 19
  Aim 3 Methods ..................................................................................................................... 24
  Aim 1 ..................................................................................................................................... 30
    Figure 1. ACO stakeholder interviews participant flow ...................................................... 31
    Figure 2. Caregiver focus groups participant flow ............................................................... 32
    Figure 3. Caregiver interviews participant flow ................................................................. 33
    Table 2. ACO Experiences With Care Coordination Before and After the Policy Change ..................................................................................................................... 34
    Table 3. Themes and Representative Quotes From ACO Stakeholder Interviews .......... 35
    Table 4. Caregiver Experiences With Care Coordination Before and After the Policy Change ..................................................................................................................... 38
    Table 5. Themes and Representative Quotes From Caregiver Focus Groups and Interviews ..................................................................................................................... 39
    Table 6. Subthemes and Representative Quotes From Caregiver Focus Groups and Interviews ..................................................................................................................... 42
  Aim 2 ..................................................................................................................................... 46
    Figure 4. Caregiver survey participant flow ...................................................................... 47
    Figure 5. Medical record abstraction flow ......................................................................... 48
    Table 7a. Demographics and Clinical Characteristics of Children ..................................... 50
    Table 7b. Demographics and Clinical Characteristics of Caregivers ............................... 51
Table 8. Survey Respondents Answering “Yes” to the FECC Quality Measures Examined ................................................................. 52
Table 9. Bivariate Associations Between FECC Quality Measures and Child Demographic and Clinical Characteristics ................................................................. 54
Table 10. Bivariate Associations Between FECC Quality Measures and Caregiver Demographics ........................................................................................................... 56
Table 11. FECC Quality Measures and Caregiver Satisfaction ................................................................. 58
Table 12. Correlations Among FECC Variables Associated With Care Coordination Satisfaction ........................................................................................................... 59
Table 13. Logistic Regression Key Driver Analysis for Predicting Caregiver Satisfaction With Care Coordination ................................................................. 59

Aim 3 .......................................................................................................................................................................... 60
Table 14. Demographic Characteristics of ACO Sample Compared With Controlsa .................. 62
Table 15. Annual Descriptive Statistics on Health Services Use in the ACO Sample Compared With Controls .................................................................................. 63
Table 16. ACO Marginal Effects on Health Services Usea ................................................................. 65
Table 17. ACO Marginal Effects on Health Services Use in Subsamples Based on Region and Diagnostic Groups ................................................................. 68

DISCUSSION .......................................................................................................................................................... 70
Context for Study Results .................................................................................................................................. 70
Generalizability of the Findings ........................................................................................................................ 75
Implementation of Study Results ........................................................................................................................ 76
Subpopulation Considerations .......................................................................................................................... 76
Study Limitations .............................................................................................................................................. 76
Future Research .................................................................................................................................................. 79

CONCLUSIONS ................................................................................................................................................. 80
REFERENCES ...................................................................................................................................................... 81
ACKNOWLEDGMENTS ....................................................................................................................................... 85
APPENDICES ..................................................................................................................................................... 86
Appendix A. Patient Advisory Panel Members .......................................................................................... 86
Appendix B. Detailed Patient and Stakeholder Engagement .................................................................. 88
Appendix C. Project Timeline ........................................................................................................................ 91
Appendix D. Recruitment Materials ............................................................................................................. 92
Appendix E. Interview and Focus Group Guides ....................................................................................... 104
Appendix F. Qualitative Data Codebook ..................................................................................................... 126
Appendix G. Family Experiences With Coordination of Care (FECC) Survey .......................... 139
Appendix H. Family Experiences With Coordination of Care Measure Specifications ........ 159
Appendix I. Ohio Medicaid Managed Care Benefits Package .................................................. 168
ABSTRACT

**Background:** Accountable care organizations (ACOs) are groups of health care providers that work together to coordinate care with the goals of improving both quality of care and efficiency. ACOs are increasingly serving children with disabilities and special health care needs, although the effect of ACOs on their health outcomes and experiences is largely unknown.

**Objectives:** The goal of this research was to assess care coordination provided by an ACO and to measure its effects on the health outcomes and experiences of children with disabilities and their caregivers compared with a traditional health delivery model.

**Methods:** Our quasi-experimental, mixed-methods study design used a policy change that moved Medicaid-eligible children with disabilities from a fee-for-service system into a large pediatric ACO via enrollment in managed care plans. Between June 2015 and May 2016, we conducted 7 focus groups and 33 individual interviews with family caregivers of children with disabilities and surveyed 2062 caregivers to assess experiences with care coordination. Using Medicaid claims data, we examined patterns of health care services use and compared the group of children enrolled in the ACO (n = 17356) with a natural control group of similar children enrolled in non-ACO managed care plans (n = 47026).

**Results:** Caregivers viewed themselves as primary coordinators of their children’s care, even when they acknowledged receiving formal care coordination either through the ACO or other providers and agencies. Caregivers’ engagement in care coordination services varied. Factors that influenced caregiver engagement included logistical challenges related to engagement; limited availability of care coordination services; and poor alignment and/or timing of services offered with the caregiver’s and child’s needs.

About half of the 2062 surveyed caregivers reported that their child saw >1 medical provider during the 12 months before the survey. Of those, 72% indicated someone helped coordinate their child’s care. Caregiver satisfaction with care coordination was positively associated with caregivers reporting (1) that care coordinators asked about the child’s health changes/concerns and (2) that care coordinators were knowledgeable, supportive, and advocated for the child.

The average marginal effect of joining an ACO on adolescent well-child visits was 5.1 percentage points higher in the ACO region as compared with the non-ACO region of the state during the period after the implementation of managed care. Emergency department use increased by 1.6 percentage points in the ACO region over the control group. We observed no difference in primary care visits, hospital utilization, or follow-up to outpatient providers after hospitalization. We found greater rates of access to 3 of the 6 classes of medications by ACO enrollees (antidepressants, anticonvulsants, and antianxiety medications) and a lower use rate of medications for attention-deficit/hyperactivity disorder (ADHD). The probability of follow-up after initial use of ADHD medication increased by 7.2 percentage points in the ACO region. In contrast to trends in the comparison group, access to home health services after ACO
implementation declined by 2.7 percentage points, representing a 40% relative decline over the rate in the non-ACO population.

**Conclusions:** Overall, caregivers did not perceive that becoming part of an ACO increased their access to care coordination services. Caregivers identified needs that were less about medical care and more related to social services. Becoming part of an ACO did not appear to have any negative impacts on quality as indicated by most indicators of health services use. Specifically, participation in the ACO increased access to some primary care services and medication use over children who were transitioned to non-ACO managed plan plans. However, use of home health services declined for children in the ACO.

**Study Limitations:** Our study has several important limitations. The qualitative and survey data were self-reported and primarily retrospective. In addition, our qualitative approach does not allow us to ensure representativeness, although we were purposeful in our sampling to ensure we had the perspectives of both urban and rural family caregivers. The study population includes only 1 state and was largely limited to those who spoke English. We also could not identify in which care coordination program each family participated and therefore cannot draw conclusions about specific care coordination models. Limitations to the claims analysis should also be noted. Claims data do not contain complete information on all conditions experienced by insured populations nor do they capture services that were not reimbursed by Ohio Medicaid. Further, if any factors disproportionately occurred in ACO-enrolled children in the postimplementation period compared with controls, the analysis risks attributing their effect to the implementation of the ACO. Despite these limitations, our study is the first to provide insights into how a Medicaid-funded ACO impacted a population of pediatric patients that have high demands for medical resources.
BACKGROUND

Health Care Needs of Children With Disabilities

Children with disabilities are among the most vulnerable populations. Disability creates a higher risk of poor physical, psychological, and social health. In addition to their primary disabling condition, children with disabilities are also more likely to have multiple chronic conditions and comorbidities, such as cardiovascular disease and mental illness. Consistent with the severity of their health conditions, children with disabilities utilize health care services more frequently and intensively than children without disabilities and face more significant barriers to accessing health care, greater out-of-pocket health care costs, and poorer health outcomes compared with their able-bodied counterparts. Children with disabilities require a wide variety of care and services from health providers, social service agencies, and their families or caregivers. Families and caregivers also generally serve as the main coordinators of care for children with disabilities, and the burden of care and care coordination can be detrimental to family welfare.

Accountable Care Organizations and the Role of Care Coordination

Emerging from the Affordable Care Act, Medicaid accountable care organizations (ACOs) are viewed by several states as a new model of health care delivery that offers significant opportunities to improve the quality and efficiency of care. ACOs are groups of providers that take responsibility for the care of a defined population and share in any savings associated with improved quality and efficiency of the care they provide. One of the key assumptions of the ACO model is that the alignment of financial and quality incentives will result in improved patient outcomes and efficiency. Among other things, policy makers are looking to ACOs to integrate high-risk populations, such as children with disabilities—who were historically excluded from Medicaid managed care arrangements—to achieve the goals of higher quality care and improved efficiency through care coordination. In contrast, traditional fee-for-service arrangements do not provide financial incentives for providers to coordinate care, and although children with disabilities may receive some care coordination services, these tend to be ad hoc and time-limited. In most cases, a parent assumes the responsibility of coordinating
medical services for the disabled child. While the ACO model is touted as a potential solution to the critical need for coordinated care, the existing literature speaks more to the promise of ACOs than to any actual ACO results.\textsuperscript{11,12} At the same time, the ACO model is being actively promoted by policy makers as a way to improve quality and lower costs in state Medicaid programs.\textsuperscript{13-15}

ACOs that choose to serve children with disabilities will find that our study addresses many of the questions they are likely to have about the best ways to improve the health care and health outcomes of these patients and whether they can adequately serve the needs of children with disabilities. This study can help caregivers understand how belonging to an ACO might impact their child’s health outcomes and experiences and whether the ACO model of care delivery is desirable given their own situation, particularly as they face an increasingly common scenario such as this one:

\textit{The parents of a child with cerebral palsy receive a letter from their state Medicaid program that children are being enrolled in an “accountable care organization.” How certain can they be that their child’s care will be improved? What problems might occur?}

\textbf{Study Relevance}

The inclusion of children with disabilities in ACOs supported by state Medicaid programs is on the rise, making our study relevant to and timely for policy makers and providers who make the decisions that will directly affect the nature of health care for these children and their resulting health outcomes. This study filled a significant gap in the literature by comparing the performance of an operating children’s ACO with the past performance of the Medicaid fee-for-service system for children with disabilities, as well as comparing utilization outcomes for ACO-participating children vs those of their non-ACO counterparts.
Study Aims

The 3 study aims were as follows:

- **Aim 1:** Use qualitative methods to identify stakeholder perspectives on care coordination before and after the transition from Medicaid fee-for-service to the ACO model of care for children with disabilities.
- **Aim 2:** To evaluate the quality of care coordination provided by the ACO, implement a novel caregiver and medical record abstraction tool designed to assess care coordination for children with disabilities.
- **Aim 3:** Compare health care quality, utilization, and other patient-centered outcomes for children with disabilities before and after joining the ACO and the impact of care coordination on these outcomes using data collected in aims 1 and 2, along with claims and electronic medical record (EMR) data.
PARTICIPATION OF PATIENTS AND OTHER STAKEHOLDERS

In addition to stakeholders who served as co-investigators on the research team, our research was guided by a patient advisory panel (PAP) comprising 12 Ohio-based members, including the 2 stakeholder co-investigators, 7 family caregivers of patients (ie, parents of children with disabilities), and 5 representatives of statewide advocacy or state health organizations working with this population. Participants were identified and recruited in consultation with the ACO and the stakeholder co-investigators, who suggested potential panel members who had previously served on similar advisory panels. One of the stakeholder co-investigators served as PAP leader and liaison to the research team.

We aimed to maintain a strong patient voice that would be representative of the various disability groups affected and that had experience receiving services through fee-for-service, managed care, and an ACO. To that end, we included caregivers whose children were of different age groups and who needed different types of medical services and care coordination. All family caregivers on the PAP were women who were also mothers of a child with disabilities.

We engaged PAP members throughout the project by providing them with consistent and visible feedback about their participation. The principal investigator and PAP leader jointly developed the meeting agendas. Agendas were emailed to PAP members before each meeting and included guiding questions for PAP discussion and input. Meetings were led by a member of the research team. At every meeting, the research team made sure to actively seek PAP participation and to close the loop on the PAP’s input. At the close of each meeting the PAP leader reiterated that members could reach out to the leader should they have any additional thoughts, questions, or concerns. PAP members appreciated knowing how their input could be reflected in the project work plan or in project communications, and exactly how it was going to be used. PAP members talked about how this process made them feel as though their opinions mattered and that they were respected as “experts.”

Our PAP members were meaningfully involved in the project from the initial stages of proposal development through the implementation process. The final framing of the research
questions and study design was based on suggestions from stakeholders, who believed that a more informative comparative analysis was needed to evaluate how children with disabilities were affected before and after the policy change, in addition to comparing experiences and outcomes for this population in ACO vs non-ACO settings. The PAP also suggested that the analysis needed to be stratified by risk and severity, recognizing the different levels and types of care coordination needs among the broad group of children with disabilities.

The research involved conducting various types of interviews and focus groups, and the PAP provided specific recommendations for helping recruit possible participants, such as ways of approaching families to increase their willingness to participate and using more family-friendly wording. The PAP provided an insightful family perspective on preliminary results about factors that could affect a family’s perceptions of care coordination, such as a lack of services in nonurban areas and an unwillingness to disrupt existing sources of care coordination services.

As preliminary research results became available and were shared at the last 3 quarterly meetings of the PAP, there was specific discussion about what aspects of the research would be most interesting to families as well as possible strategies for sharing this information with them. Members of the PAP participated in the Voices for Ohio’s Children Conference on a panel discussion to share their experiences of being engaged in this research project. This activity generated the research team’s interest in potentially developing a manuscript to share our experience with patients and stakeholders about engagement in research. Finally, ACO stakeholders, including leadership, care coordinators, and clinicians, were invited to several PAP meetings and gave thoughtful, insightful feedback on preliminary results. Appendix A lists the PAP members; Appendix B includes greater detail about patient and stakeholder engagement.
METHODS

Overall Study

Overall Study Overview

The goal of this research was to assess care coordination for and patient-centered outcomes of children with disabilities under an ACO via capitated managed care plans compared with traditional Medicaid fee-for-service. We used multiple methods, including focus groups, interviews, a survey, medical record data, and secondary data analysis of Medicaid claims. A timeline depicting overall study activities can be found in Appendix C.

Overall Study Design

We used a recent policy change in Ohio as a natural experiment to assess the outcomes and experiences of children eligible for the Medicaid category of Aged, Blind, and Disabled (ABD) and their caregivers in an ACO model of care compared with their previous outcomes and experiences in a traditional fee-for-service model. Before the policy change, nearly all children who were Medicaid-eligible ABD in Ohio were enrolled in a traditional fee-for-service plan. After the policy change went into effect in July 2013, those children were required to enroll in managed care. The policy change effectively moved approximately 8000 children living in central and southeastern Ohio into the nation’s largest pediatric ACO due to the subcontractual relationships between the ACO and all the Medicaid managed care plans operating in Ohio. Our study incorporated a mixed-method approach that combined qualitative and quantitative data to consider the same question through several lenses. The qualitative component afforded broad and deep consideration of the views of patients and caregivers and allowed individual patient stories to emerge; the quantitative survey component allowed for statistical analysis to produce information about the group of caregivers as a whole; and the Medicaid claims analysis provided access to historical information embedded in claims data to evaluate the actual impact of the ACO effect on patient outcomes. Together, these different sources of data and methodological approaches afforded a richer, more complete understanding of the transition from fee-for-service to an ACO than any one source would have provided alone. We used a
convergent parallel mixed-methods design, meaning that we collected the qualitative and quantitative data concurrently, with neither privileged over the other.\textsuperscript{16}

All study processes and protocols were approved by the institutional review boards (IRBs) of the University of North Carolina at Chapel Hill, Ohio State University, and Nationwide Children’s Hospital.

**Relationships BetweenManaged Care Organizations and the ACO**

Managed care is a health care delivery system designed to manage the cost, quality, and utilization of care.\textsuperscript{17} Medicaid managed care refers to contracts between state Medicaid agencies and Medicaid managed care organizations (MCOs) to provide health insurance coverage to Medicaid beneficiaries. MCOs are simply health insurance companies that offer managed care plans, such as health maintenance organizations, preferred provider organizations, etc. Accountable care organizations, or “ACOs,” are groups of providers that take responsibility for the care of defined populations and share in any savings associated with improved quality and efficiency of the care they provide.\textsuperscript{8}

In this study, Medicaid MCOs, also referred to as “health care plans,” subcontracted with the ACO to provide medical services for pediatric Medicaid beneficiaries living within 34 of the 88 counties in Ohio. Thus, the ACO assumed financial responsibility for the medical care of all pediatric Medicaid beneficiaries living in those counties, including those who qualified for Medicaid because of their disability.

**Overall Study Population**

Our study population included the following groups: (1) key stakeholders with knowledge about care coordination for children with disabilities before and after the 2013 policy change; (2) caregivers of children with disabilities who were enrolled in the ACO; and (3) ABD-eligible children in the state of Ohio during the claims data analysis time period (2011-2016). We defined children with disabilities as those who were eligible for Medicaid under the
ABD category, and caregivers as the person with primary responsibility for the child’s health care (usually a parent or grandparent).

Aim 1 Methods

**Aim 1:** Use qualitative methods to identify stakeholder perspectives on care coordination before and after the transition from Medicaid fee-for-service to the ACO model of care for children with disabilities.

**Aim 1 Qualitative Approach**

We conducted a phenomenological study of experiences reported by ACO stakeholders and caregivers. Phenomenological studies are concerned with subjective “lived” experiences and the meanings people ascribe to those experiences. A phenomenological approach was appropriate because we aimed to identify the perspectives of ACO stakeholders and caregivers on care coordination, including the particular features of experiences that were salient to their interpretations of care coordination before and after the move into the ACO (ie, before and after July 2013).

**Aim 1 Study Overview and Design**

We conducted key informant interviews with ACO stakeholders to identify care coordination activities and strategies for children with disabilities before and after the policy change. We conducted focus groups with caregivers and patients (youths), and interviews with caregivers, to gather detailed narratives of their lived experiences with care and care coordination before and after the change (Table 1). By design, the data collected were self-reported and, in part, retrospective, relying on caregiver recall about experiences that occurred approximately 3 years before data collection.
Table 1. Focus Group and Interview Dates

<table>
<thead>
<tr>
<th>Dates</th>
<th>ACO stakeholder interviews</th>
<th>Caregiver and youth focus groups (No.)</th>
<th>Caregiver interviews (No.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>March–July 2015</td>
<td>Caregiver interviews</td>
<td>Caregiver interviews</td>
<td></td>
</tr>
<tr>
<td>June and November 2015</td>
<td>Franklin (4)</td>
<td>Franklin (16)</td>
<td></td>
</tr>
<tr>
<td>January–May 2016</td>
<td>Jefferson (1)</td>
<td>Guernsey (7)</td>
<td></td>
</tr>
<tr>
<td>Scioto (1)</td>
<td>Vinton (6)</td>
<td>Union (4)</td>
<td></td>
</tr>
<tr>
<td>Participants, n</td>
<td>24&lt;sup&gt;a&lt;/sup&gt;</td>
<td>35&lt;sup&gt;b&lt;/sup&gt;</td>
<td>33</td>
</tr>
</tbody>
</table>

Abbreviation: ACO, accountable care organization.
<sup>a</sup>12 ACOs, 9 payers, 3 public health administrators.
<sup>b</sup>Includes 2 teen patients.

**Aim 1 Participants and Sampling Strategy—ACO Stakeholder Interviews**

We sampled purposively from 4 groups of ACO stakeholders—ACO leaders, care coordinators, clinicians, and payer representatives—to ensure representation of distinct perspectives on coordination objectives and strategies. We added 3 public health administrators (with a mix of state- and county-level experiences) to provide context on these services. ACO stakeholder participants were not compensated for participation.

We worked with executives at the ACO to identify and select key informants from each of the 4 stakeholder groups and used snowball sampling to identify additional stakeholders. Eligible participants were those with knowledge about and experience with care coordination–related decisions and practices for children with disabilities. Individuals were invited to participate via email.

**Aim 1 Participants and Sampling Strategy—Caregiver and Youth Focus Groups and Caregiver Interviews**

We used the same source population for both the focus groups and interviews, recruiting for focus groups first and then once those were filled, recruiting for the in-depth interviews.
To be eligible to participate, the child (as the participant, or of the caregiver) must (1) have resided continuously in the region served by the ACO, have been continuously enrolled in Medicaid, and have had ABD status for at least 1 year before the policy change; (2) be younger than 18 years of age at the time of data collection; (3) have been, at the time of the policy change, at least 14 years of age for patient focus groups or 2 years of age for caregiver focus groups and interviews; and (4) speak English. We did not conduct focus groups or interviews in languages other than English due to the small numbers of non-English–speaking participants in the population and the need for multilingual research staff and additional resources (such as audio-translation). We included participants in both rural and urban settings and those managing a variety of disabling conditions.

To capture geographic variation in perspectives, we recruited participants from 7 of the 34 counties in the ACO region: the urban county where the ACO is located and 6 rural counties. Rural counties were selected based on density (number of eligible caregivers) and to represent distinct rural regions of the state (Appalachia and southern Ohio), based on feedback from our PAP who advised that there would likely be differences in caregiver experiences in the different regions. In addition, the PAP advised on where they had contacts who could provide a suitable location for conducting the focus groups and interviews.

We recruited participants through the following means: (1) distribution of flyers throughout ACO provider sites and via ACO care coordinators; (2) recruitment email sent through PAP and Voices for Ohio’s Children listserv; and (3) snowball-sampling approaches to identify additional participants based on referrals from other participants.

The initial recruitment strategy was not effective. As a result, we added a question to the caregiver survey to inquire whether participants would be interested in taking part in a focus group or in-depth interview. Most of the surveyed caregivers responded positively, allowing us to successfully recruit an adequate number of participants for both the focus groups and in-depth interviews. We obtained caregiver consent in person before the start of the interview or focus group and before initiating audio recording. For youth, we provided the parent with a study fact sheet via mail or email, contacted them via phone to explain the study,
and then obtained verbal approval for their child’s participation. We obtained the youth’s written assent just before beginning the focus group and audio-recording. Recruitment materials are included in Appendix D.

**Aim 1 Interventions and Comparators or Controls**

Not applicable.

**Aim 1 Study Outcomes**

Not applicable.

**Aim 1 Study Setting**

Most stakeholder interviews were conducted in-person at stakeholders’ workplaces for their convenience, while the remainder were conducted over the phone due to stakeholder constraints. We conducted caregiver and youth focus groups and caregiver interviews in conference rooms of various community organizations, including a hospital, a public library, and a university extension office.

**Aim 1 Time Frame for the Study**

All Aim 1 data were collected between March 2015 and May 2016.

**Aim 1 Data Collection and Sources—Overall**

We developed interview and focus group guides for stakeholders, caregivers, and youth, with questions exploring experiences before and after the policy change (Appendix E).

Interviews lasted roughly 1 hour and focus groups lasted about 90 minutes. All interviews and focus groups were conducted in English, digitally recorded, and professionally transcribed.

**Aim 1 Data Collection and Sources—ACO Stakeholder Interviews**

We conducted in-depth, semistructured interviews with 24 ACO stakeholders in early 2015. We developed an interview guide that included questions in the following domains:
Medicaid Policy Change, Care Coordination, Metrics and Evaluations, Hospitalizations, and Overall Assessment (Appendix E). Most interviews were with individuals, but 2 group interviews were conducted at 2 of the payer organizations at stakeholders’ requests. The same 2 researchers participated in all interviews. One led the interview while the other took notes.

**Aim 1 Data Collection Methods—Caregiver and Youth Focus Groups and Caregiver Interviews**

We conducted a total of six 90-minute caregiver focus groups with a total of 33 participants (Table 1). We developed a focus group guide that included questions in the following domains: Coordinating Care, Accessing Care, Satisfaction and Quality of Care, Hospitalizations, Additional Concerns, and Overall Assessment (Appendix E). One researcher moderated each focus group, ensuring all participants had opportunities to share their thoughts, including thoughts that differed from the majority. One or more additional researchers took notes.

Drawing on themes that emerged from the focus groups, we conducted in-depth, semistructured interviews with 33 caregivers (Table 1). We developed a caregiver interview guide (Appendix E) that included questions in the following domains: You and Your Family, Impact of Disability, and the domains from the focus group guide listed above. One researcher conducted the first interview, while a second researcher observed. The remaining interviews were divided between these 2 researchers. Throughout the process, the 2 researchers conferred so that all interviews would be conducted in roughly the same manner.

**Aim 1 Analytical Approach—All Qualitative Data**

Throughout the data collection process, we discussed what we were learning from the interviews and focus groups to develop a shared sense of the data and to identify emerging themes. The lead qualitative researcher developed a codebook based on the questions in the interview and focus group guides and on the emergent themes that were identified through team discussions during the data collection periods (Appendix F). The rest of the research team
reviewed and edited this codebook. The codebook included code names, descriptions, and other notes regarding usage, following standard qualitative research practices.\textsuperscript{18,19}

We followed an iterative approach to analysis that involved ongoing cycles of reading and coding transcripts, reviewing the literature, and discussing findings among the research team. Throughout the process we used the constant comparative method, comparing data with data, codes with codes, and transcripts with transcripts in order to compare perceptions of and experiences with care and care coordination under fee-for-service with perceptions and experiences under the ACO. Disagreements over interpretations were resolved through discussion and consensus. All transcripts were coded using NVivo 11\footnote{http://www.qsrinternational.com/nvivo/free-nvivo-resources/getting-started/nvivo-11-for-windows}, a qualitative data analysis software application.\textsuperscript{20}

Throughout the coding and interpretation stages of analysis, we used analyst triangulation (ie, having multiple researchers analyze data)\textsuperscript{21} as well as member checking (ie, obtaining patient and stakeholder input on results interpretation) via our PAP to improve the rigor of the analyses.

\textbf{Aim 1 Changes to the Original Study Protocol}

We originally planned to conduct 10 focus groups with caregivers stratified by geography and disability type and 2 youth focus groups. Our PAP agreed with stratifying by geography but advised us that stratifying participants by disability type (physical compared with mental) was not realistic because many children in this population have multiple diagnoses that cross the physical and mental disability spectrum and caregivers do not necessarily identify their child by whether they have a physical or mental disability. In response to PAP advice, we stratified solely by geography (urban vs rural).

We also reduced the overall number of focus group participants. We realized that a focus group size of 10 participants as originally planned was too large for the study population, as they often have complex stories that require more time per person. Therefore, we aimed for a focus group size of 6 to 8 participants. We originally planned to hold 2 youth focus groups but
held only 1; in addition to difficulties recruiting youth, the 1 group we held was not informative as the youth were not knowledgeable about care coordination.

To maximize recruitment, we added a question to the caregiver survey asking respondents whether they would be interested in being contacted to participate in a focus group or interview.

Aim 2 Methods

Aim 2: To evaluate the quality of care coordination provided by the ACO, implement a novel caregiver and medical record abstraction tool designed to assess care coordination for children with disabilities.

Aim 2 Study Overview and Design

We used the Family Experiences with Care Coordination (FECC) survey to assess caregiver experiences with care coordination. We also used medical record abstraction to evaluate the communication loop between the child’s primary care provider (PCP) and specialist referral. These methods were selected to quantify the experiences of care coordination explored qualitatively in aim 1, using a larger sample size than could be included in focus groups and interviews and to determine whether medical record documentation of care would reflect and align with self-reported experiences. The survey was conducted in both English and Spanish to capture the potentially unique experiences of Spanish-speaking caregivers.

Aim 2 Participants

Our source population was identified using administrative data from the ACO. Inclusion criteria for the survey population were as follows: (1) children aged 3 to 18 years at the time of interview; (2) newly enrolled in the ACO as of July 1, 2013 as part of the policy change that moved ABD-eligible Medicaid enrollees to managed care; (3) 12 months of continuous Medicaid coverage before the sample being drawn from the ACO’s administrative eligibility files in February 2015; (4) caregiver ability to complete the survey in English or Spanish; (5) caregiver at
least 18 years of age; and (6) caregiver resident in the 34-county ACO region for at least 1 year before the survey date. A subset of the survey participants consented to abstraction of their EMRs.

Each household of a potentially eligible child received a letter informing them of their eligibility for the study. Caregivers could choose to opt out of further communication, complete the survey online, or agree to be contacted by phone to complete the survey.

Aim 2 Interventions and Comparators or Controls

Not applicable.

Aim 2 Study Outcomes

Measures

The FECC questionnaire\(^2^\) (Appendix G, caregiver survey; Appendix H, measure specifications) was used to assess and measure caregiver perceptions of care coordination. We selected the FECC because of its rigorous development process and use as part of the Pediatric Quality Measurement Program Core Set\(^2^\) funded by the Agency for Healthcare Research and Quality. Caregivers were asked if their child had a care coordinator and, if so, were asked regarding the specific elements received from their care coordinator. Three items (shared care plan, comprehensive written visit summary, and access to medical interpreter) were asked of all caregivers whether they received care coordination services or not.

We used the Pediatric Medical Complexity Algorithm (PMCA)\(^2^\) to classify disabled children’s degree of medical complexity based on 3 years of Medicaid claims data. Children were classified as either complex chronic (eg, cystic fibrosis), noncomplex chronic (eg, asthma), or nonchronic (eg, ear infection). These values were further dichotomized for analyses as complex chronic or other. We note that the nonchronic classification included children who did not have a medical visit for a chronic condition in the 3 years preceding the index visit. This group represented children with a disability-eligible chronic condition who could not be grouped into a higher level of complexity using the PMCA methodology. It can be hypothesized
that such children had conditions that were relatively stable or were not amenable to care (eg, blindness).

**Outcomes.** The primary outcome was care coordination, defined as a caregiver reporting that their child had a designated care coordinator. Secondary outcomes were defined as follows:

- **Care services/planning/communication/confirmation:** Caregivers of children with complex needs who report having a care coordinator for their child should also report that the care coordinator assists them with specialty service referrals by ensuring that the appointment with the specialty service provider occurs.

- **Coordinator knowledge/skills:** Caregivers of children with complex needs who report having a care coordinator should also report that their care coordinator (1) was knowledgeable about their child's health; (2) supported the caregiver; and (3) advocated for the needs of the child.

- **Medical interpreter services/accessibility:** Caregivers of children with complex needs or children with complex needs who self-identify as having a preference for conducting medical visits in a language other than English should have access at all visits to a professional medical interpreter (in person or by telephone).

- **Main/specialty provider communication:** The EMR should contain communication or shared notes between the main provider and specialists.

**Aim 2 Study Setting**

Participants accessed the caregiver survey via the web on their computer, phone, or tablet. Once web access closed, surveys were conducted via phone by trained interviewers calling from a survey research lab and utilizing phone lists supplied by the ACO.
Aim 2 Time Frame for the Study

Recruitment occurred in June 2015. The web survey was accessible for 4 weeks, spanning mid-July to mid-August 2015. The phone survey began in mid-August 2015 and concluded in March 2016.

Aim 2 Data Collection and Sources

After the respondent provided electronic consent, they were able to complete the survey. They could decline simply by not consenting. Respondents who consented answered basic demographic questions in addition to FECC survey questions. All potential participants who did not complete the electronic survey by the deadline provided in the letter were forwarded to our telephone survey vendor for further outreach.

For EMR abstraction, we first attempted to identify each consenting patient’s “main provider” and then determined if that provider was part of the ACO’s primary physician network. For those with a primary-network main provider, we reviewed all EMR data in the 12 months preceding the survey completion to determine if a referral was made from the main provider to a specialty provider. If a referral was made, we then looked for evidence documenting communication between the main provider and the primary- or nonprimary-network specialty provider and back from the specialty provider to the main provider. EMR data were collected and managed using Research Electronic Data Capture (REDCap) tools hosted at Nationwide Children’s Hospital.

Aim 2 Analytical and Statistical Approaches

First, we quantified experiences of care coordination indicators calculated from the FECC questionnaire and the care coordination medical record review. We stratified FECC indicator performance by subpopulations defined by age group, urban/rural residence, medical complexity, caregiver education, and number of children in the home with disabilities. We then linked these indicators with the ACO’s claims data at the individual patient level to assess the relationship between receipt of care coordination elements measured by the FECC survey (eg, access to a care coordinator) and selected outcomes (eg, patient satisfaction). Due to our data
collection methods, we had limited missing data in the survey and limited missing EMR data. We handled the missing data using the “available case analysis approach” in which all cases with complete data for a selected analysis were included.

**Aim 2 Changes to the Original Study Protocol**

1. Eligibility criteria were modified to allow additional flexibility for inclusion of caregivers of children who had moved between ABD and non-ABD eligibility category but remained within the ACO’s Medicaid population.

2. Our proposed sample size was 2750 and we achieved a sample size of 2062. Although the sample size was slightly lower than expected, we retained the power to test our hypotheses. The primary reason for the lower than projected number of surveys was the lack of valid contact information in the ACO administrative data source. Our proposed sample size for medical record review was 1000. We exceeded our goal in number of respondents consenting to allow their records to be reviewed (N = 1608).

3. Our original proposal stated that the FECC included 31 indicators. The FECC development continued after our submission and the number of validated indicators was reduced to 20, of which 8 were endorsed by the National Quality Forum (NQF) in 2016. These 8 became the focus of our analyses. We also added caregiver satisfaction with experiences of care coordination, a stand-alone item in the FECC survey. The measure reduction was the result of validation research and measure review that found the excluded measures had limited clinical relevance or could not be reliably collected. Although the breadth of measures that we could test was reduced, we felt, with the support of our PAP, that using measures not deemed valid or acceptable would be inappropriate. Some nuance and detail were lost in exchange for validity. Additional research is needed to create a broader data set of care coordination for future research.

4. Due to unforeseen challenges in accessing out-of-system medical records, we could only conduct full EMR review for children whose “main provider” was in the ACO’s primary clinical network. Of the 1608 medical records reviewed, 583 qualified for full review and
abstraction. We also note that, ultimately, the EMR-based indicators were not successfully validated by the survey developers, so they are reported for information only.

Aim 3 Methods

**Aim 3:** Compare health care quality, utilization, and other patient-centered outcomes for children with disabilities before and after joining the ACO and the impact of care coordination on these outcomes using data collected in aims 1 and 2, along with claims and EMR data.

**Aim 3 Study Overview and Design**

We used Ohio Medicaid claims data to examine differences in patterns of health care services use by ABD-eligible children before and after enrolling in an ACO, compared with similar children who enrolled in non-ACO managed care plans or other waiver-based programs. This study design, often referred to as a difference-in-differences (DID) analysis, or a pre-post/case-control design, is one of the strongest study designs for observational data, using a contemporaneous control group to reduce the threats to validity from other policy changes or changes in the scientific evidence base that might have occurred disproportionately during the ACO implementation period. On the date the ACO was implemented in 1 region of Ohio, Medicaid-covered children with disabilities statewide were switched from fee-for-service coverage into managed care plans. Children in the intervention counties (ie, the 34 counties in central and southeastern Ohio for which the ACO is contractually responsible), therefore, were simultaneously switched into capitated managed care plans, which contracted with an ACO to pass on the risk of capitation and engage in care coordination. The remaining counties in Ohio serve as the controls. Our sample included children under age 18 enrolled in Ohio Medicaid at any point between August 2011 and June 2016. The intervention group (n = 17 356) was defined as those with at least 1 month enrolled under ABD eligibility who resided in one of the 34 counties (central/southeast region) where all pediatric Medicaid enrollees are subcapitated to an ACO, measured monthly. The control group (n = 47 206) comprised children with at least 1 month of enrollment under ABD eligibility who resided in one of the other 54 counties in the state (west and northeast regions). In both groups, all children enrolled under ABD as of July 1, 2013, moved from fee-for-service to ACO (intervention) or other managed care (control). The
DID study design, therefore, isolated the effect of the ACO on top of the switch to capitated managed care plans. In addition, we used person-level fixed effects to control for any time-invariant differences that might have occurred between ACO and non-ACO enrollees, possibly due to regional differences.

**Aim 3 Participants**

Aim 3 included no active participants, as it was limited to secondary data analysis. The data analyzed represented Ohio Medicaid-enrolled children who met the criteria for the ABD enrollment category for at least 1 month in our study period (see Aim 3 Study Setting for more detail). As of July 1, 2013, all children enrolled under ABD moved from fee-for-service to managed care. All subsequent ABD enrollees were also enrolled under managed care. Managed care enrollment was limited to 5 plans that were selected to contract with the state through a competitive bid process. All plans enrolled members statewide. There were no “regional” plans. In the first month of the “roll in,” the largest plan covered 50.9% of the ABD population and the smallest plan covered 3.6%. The data use agreement for use of claims data between the state Medicaid agency and our research team did not allow any comparative analyses of demographics or other heterogeneity across plans.

In 34 counties in central and southeastern Ohio, all 5 plans subcapitated their entire pediatric population to our studied ACO. In these counties, the plans retained responsibility for marketing, eligibility, bill payment, and other administrative functions related to these enrollees, but carved out the risk for utilization.

**Aim 3 Interventions and Comparators or Controls**

Our sample included children under age 18 enrolled in Ohio Medicaid at any point between August 2011 and June 2016. The intervention group ($n = 17,356$) was defined as those with at least 1 month enrolled under ABD eligibility who resided in one of the 34 counties (central/southeast region) where all pediatric Medicaid enrollees are subcapitated to an ACO, measured monthly. The control group ($n = 47,206$) comprised children with at least 1 month of enrollment under ABD eligibility who resided in one of the other 54 counties in the state (west
and northeast regions). In both groups, all children enrolled under ABD as of July 1, 2013, moved from fee-for-service to ACO (intervention) or other managed care (control).

**Aim 3 Study Outcomes**

We measured the effect of the ACO on multiple annual health care utilization outcomes related to preventive health, behavioral health, hospitalizations, home health, and medication use.

**Aim 3 Study Setting**

The non-ACO children received the standard Medicaid managed care package, which included inpatient, outpatient, physician, Early and Periodic Screening, Diagnostic and Treatment (EPSDT), prescription drugs, behavioral health, dental, vision, and other core services, all of which are covered under the capitation agreement. They also received value-added services that could vary by plan and included 24/7 nurse hotlines, health education materials, care management, transportation benefits, incentives, and other benefits (see Appendix I). None of the plans operated as integrated delivery systems and each plan had to cover services offered by any Medicaid provider in the state on a fee-for-service basis. Although there was some use of bundled payment, few bundled payments applied to the pediatric population. Narrow networks were not permitted.

ACO-enrolled children received all the standard and extended benefits associated with their chosen managed care plan. In this aspect, benefits for children in the intervention group and control group did not differ. Care within the ACO was differentiated by an active approach to pediatric-specific quality improvement projects, disease- and process-specific learning networks, and financial incentive programs that were open to Medicaid-serving pediatric providers in the designated region. The ACO worked within the same strictures of the plans including payment of fee-for-service claims from any Ohio Medicaid provider; however, over 1000 providers participated in and were eligible to receive performance-based incentives associated with a project or network. The ACO also provided pediatric-focused care coordination beyond the standard care coordination offered by the child’s managed care plan.
Aim 3 Time Frame for the Study

Claims data analysis utilized data from July 2011 to June 2016. Data for most outcomes were collapsed to state fiscal years 2012 to 2016. For other outcomes, such as hospital readmission rates, we used episode-based observations.

Aim 3 Data Collection and Sources

Our primary analytic data come from Ohio Medicaid administrative claims for fiscal years 2012 to 2016. These data captured service utilization, dates of service, diagnoses, and expenditure data paid by Ohio Medicaid for the 17,356 children with disabilities attributed (or “assigned”) to the ACO and an additional 47,026 controls, thus reflecting a Medicaid perspective. Claims data included encounter data on patient-level services provided through the ACO as well as those directly reimbursed through Medicaid, including all mental health services paid by Ohio Medicaid. Race in the Medicaid administrative data is collected at enrollment by county Medicaid case managers or through self-report during e-enrollment through HealthCare.gov (https://www.healthcare.gov/).

Aim 3 Analytical and Statistical Approaches

Using person-level fixed effects for most outcomes, we ran DID regressions on annual measures of use. Using the ABD eligibility identifier in the state Medicaid claims data, we identified the Medicaid beneficiary numbers and claims histories of the 17,356 children in the ACO “intervention” group and the 47,026 non-ACO controls. We did not have any missing data issues with the Ohio Medicaid claims database. We controlled for the number of months of Medicaid enrollment during each annual observation in order to retain the 27.1% of annual observations with less than 12 months of coverage.

This sample size was more than adequately powered; subgroup analyses were conducted only when the subgroup size was large enough to have adequate power for the analyses. We conducted subgroup analyses by rural areas, behavioral health diagnoses, intellectual or developmental disorder (IDD) diagnoses, and complex chronic conditions. The
models were refitted to each subgroup with no test of interactions. We hypothesize the following for the subgroup analyses:

- **Rural areas:** Given the shortage of providers in rural areas, we hypothesize that the ACO will have a smaller effect on utilization measures in rural than urban populations.

- **Behavioral health diagnoses:** Although children with behavioral health diagnoses are generally more underserved than children without these diagnoses, it is not generally a focal area for ACOs; therefore we hypothesize that the ACO will have a similar effect among children with behavioral health conditions than children without these conditions (null hypothesis).

- **IDD diagnoses:** Although children with IDD diagnoses are generally more underserved than children without these diagnoses, it is not generally a focal area for ACOs; therefore we hypothesize that the ACO will have a similar effect among children with intellectual or developmental disorders than children without these conditions (null hypothesis).

- **Complex chronic conditions:** Because there is often greater room for improvement in patterns of care by children with complex chronic conditions, we hypothesize that there will be a larger ACO effect in this population.

To determine whether there was a substantially different effect during the first year after ACO implementation, we conducted sensitivity analyses by running models with annual ACO indicators rather than the aggregated effect. We found very little difference in ACO effects across years for most covariates; thus only the aggregated results are reported.

**Aim 3 Changes to the Original Study Protocol**

1. In our original study design, we did not think we could access data on non-ACO controls, and therefore had proposed a pre-post study design. However, as part of the data use agreement, we were provided access to these data and were able to incorporate data on similar children who were in other regions of the state and not enrolled in an ACO as a contemporaneous control group. This addition substantially strengthened the study design for the aim 3 analyses, and simultaneously altered the interpretation of the comparison,
from a pre-post comparison to a pre-post/case-control comparison, allowing us to isolate differences likely due to the ACO from other differences that were implemented during the same period.

2. We have both added and dropped some measures based on stakeholder feedback or practical reasons. Our PAP suggested we monitor a number of other patient-centered outcomes, such as access to home health services and to physical, occupational, and speech therapy. We excluded several proposed outcomes due to the lack of a reliable coding algorithm in the data, including urgent care center visits, and visits to behavioral health specialists as well as other specialists. We dropped the latter set of variables because we discovered that the provider specialty indicator was unreliable.

3. We originally proposed using multiple imputation or last-observation-carried-forward in the case of substantial amounts of missing data on gender or race. We had no cases of missing gender, and only 4% of the study participants were coded as missing race. We were able to retain these individuals in the analysis, as race does not appear as a covariate, but is absorbed into the individual fixed effects, which control for all observed and unobserved time invariant differences between the ACO and comparison group.
RESULTS

The following section presents the results of our study organized by the study aims.

Aim 1

*Use qualitative methods to identify stakeholder perspectives on care coordination before and after the transition from Medicaid fee-for-service to the ACO model of care for children with disabilities.*

**Aim 1 Overview of Participant Flow**

Participant flows for ACO stakeholder interviews, caregiver interviews, and caregiver focus groups are depicted in Figures 1, 2, and 3, respectively.
Stakeholders from ACO, insurance payers, departments of health, and other organizations who have knowledge of/experience with care coordination for children with disabilities before and after the 2013 policy change.

Recruitment & Participation

Contacted for Participation (n=36)

Total Excluded (n=12)
- Unable to be reached (n=3)
- Declined, no reason given (n=8)
- Declined, perspective represented by other participants (n=1)

Recruited (n=24)

Interviewed (n=24)

Analysis

Analysed (n=24)
Figure 2. Caregiver focus groups participant flow

Eligibility Assessment

Assessed for Eligibility
(n=87)

Eligibility Criteria: English-speaking caregivers of children with disabilities whose child: resided continuously in the ACO region during the study period; was continuously enrolled in Medicaid and had ABD status since at least one year before the policy change; was no more than 18 years of age at the time of data collection; and was at least 2 years of age at the time of the policy change.

Recruited (n=53)

Total Excluded (n=34)
- Ineligible (child age, child deceased, geographic location, did not qualify as ABD, remained in Medicaid Fee for Service via waiver (n=19)
- Declined (not interested, no transportation) (n=15)

Recruitment and Participation

No show (n=20)

Participated in Focus Groups (n=33)

Analysis

Analyzed (n=33)
Aim 1 Analysis

All focus groups and interviews were digitally recorded, transcribed verbatim, and then coded using NVivo 11. Multiple analysts coded initial transcripts independently, compared their work, and resolved differences to improve the dependability of the coding process.\textsuperscript{18,19} Researchers independently read through transcripts and coded content, comparing comments
about experiences under fee-for-service with comments about experiences under the ACO to identify patterns.\textsuperscript{21}

\textbf{Aim 1 Results}

\textit{ACO Stakeholder Interview Results.} Our analysis of ACO stakeholder interviews revealed 3 key themes related to how the policy change impacted their approach to care coordination for children with disabilities (Table 2). The themes were (1) care management responsibilities, (2) approach to care coordination, and (3) approach to caregiver engagement. Table 3 displays participant quotes that illustrate the theme.

\begin{table}[h]
\centering
\begin{tabular}{|l|l|}
\hline
\textbf{Before the policy change} & \textbf{After the policy change} \\
\hline
Had no formal care management duties; these resided with managed care plans. & Created formal delegated care coordination agreements with most managed care plans. \\
\hline
Had no systematic approach to care coordination & Created interprofessional care coordination teams to serve medically complex and ABD children. \\
\hline
Provided medical care to most ABD children, but without any financial risk & Assumed financial risk for ABD population; began systematic engagement of caregivers. \\
\hline
\end{tabular}
\caption{ACO Experiences With Care Coordination Before and After the Policy Change}
\end{table}

Abbreviations: ABD, Medicaid category of Aged, Blind, and Disabled; ACO, accountable care organization.
Table 3. Themes and Representative Quotes From ACO Stakeholder Interviews

<table>
<thead>
<tr>
<th>Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Theme 1: Care management responsibilities</strong></td>
</tr>
<tr>
<td>“[A health insurance company] has come to us—we offered to do a demonstration for them to show them how we do care coordination. They liked what they saw, and they've actually changed their minds about delegating to us and would like to do that after all...I think they can see the advantages of [the ACO] being closer to the providers and closer to the patients, that we can be more impactful.” ACO Stakeholder No. 001</td>
</tr>
<tr>
<td>“Prior to the policy change, again, I don’t know how we would have been able to provide care coordination for any or all of those kids. What it does is transitions things from caring for kids who make it through our doors to really caring for our population. So usually you know, in a traditional sense we would only be able to identify kids that need, if they show up to our clinic because they've had a problem or a referral or whatever, and we know that the referral rate completion is very, very low, so it's really the kids who don't show up to our offices that we need to be most concerned about as the kids who are showing up in the ED [emergency department] multiple times, or who are being admitted multiple times. Or perhaps who the plans are identifying through, you know, high cost of other services...So the delegated care coordination through the health plans has allowed us to, I think, better reach all of those different kids. And then once we reach them, you know, wrap a system of care around them.” ACO Stakeholder No. 008</td>
</tr>
<tr>
<td>“When it comes to delegating [care coordination] to [the ACO], again, I just think that our being closer to the kids and closer to the providers and having all of that documented in the medical record so that anybody who has access to the kid can know what's going on in terms of care coordination can be a huge benefit.” ACO Stakeholder No. 001</td>
</tr>
<tr>
<td>“The biggest advantage [of payers delegating care coordination to the ACO] is [that the care coordinators are] able to be here [at the ACO] when the kids come, whether it's just a routine appointment, whether it's an urgent appointment where we have to get in because something is really wrong, or because they're having surgery or they need to be admitted. So that's a major, major deal. Especially when it comes to trying to build that relationship and the rapport with the family, you're able to be there with them when they're going through these things. It really gives them a sense that you're here, you care, and you're here to help their child. So to me, that's the biggest thing of them all, is that: the touch, being able to touch your people.” ACO Stakeholder No. 005</td>
</tr>
<tr>
<td><strong>Theme 2: Approach to care coordination</strong></td>
</tr>
<tr>
<td>“[For care coordination services we found it best to use] the team of 3: the RN, social worker and unlicensed support staff [outreach coordinator] ... So tons of recruiting and hiring. And I still have, I think, 17 empty positions ... [It's a] huge amount of investment in staff. The staffing ratio is 1 to 25 for a high-risk case management so ... if you have this many who will fall in the high risk, you divide by 25, that's how many people you need to bring in and so it's a lot.” ACO Stakeholder No. 004</td>
</tr>
<tr>
<td>“So there's a single point of contact assigned. So let's say patient Sally is assigned to nurse Robin, so to Sally it's just Robin. She talks with Robin all the time, but Robin will pull in the social worker and the quality outreach coordinator as needed. So Sally and Robin are talking and they're talking about how she needs, oh, social work, food, and transportation issues. Now Robin and social worker so-and-so always work together. But the patient doesn't know any different. Come in and talk with you about...” ACO Stakeholder No. 004</td>
</tr>
</tbody>
</table>
### Themes

that. Or same thing. Next time I visit I'm going to send, you know, Amanda out, one of our quality outreach coordinators come out and meet with you instead of me coming...That single point of contact kind of directs traffic for [the team].” *ACO Stakeholder No. 004*

“At a basic level the idea is to assess with the family what their needs and wants are. Find out gaps in care ... sort of what’s been asked, what’s been provided, what still needs to be provided. Find that third bucket. And then work with the family to develop an action plan based on their prioritized goals. Help them achieve that by providing them resources. A lot of the times we don’t have the money or the resources directly, but we can figure out who can help them get their resources. And when we can’t that opens up the door to a question, which is to say we have a population of people who need something that isn’t available in the community, what do we do now?...The idea is that everyone, regardless of your payer, your classification, ABD, CFS [Child and Family Services], gets the same sort of baseline care coordination.” *ACO Stakeholder No. 009*

### Theme 3: Approach to caregiver engagement

“So we measure ... every step of the way so referral, assessment, care plan completion, which is synonymous with what we call you enrolled. To be enrolled you have to have said ‘yes,’ consented and completed your assessment and agreed on a set of goals that we’re gonna work to. Then you’re enrolled. That can take up to 90 days sometimes. You might have had 3 months of intervention before you get to that point. And then all the way to closure and sometimes reopening back to the beginning ... so we track all those data points.” *ACO Stakeholder No. 004*

“So we spent a lot of time on enrollment, and in that, we had to do our health risk assessment and care plan and so on. And so as time went on, we noticed the things that we should probably be adding to the health risk assessment, ’cause we didn’t think it was thorough enough or didn’t get into enough detail ... [Specifically] more disease-specific questions ... So we developed a list of questions for, like, asthma, for behavioral health issues, for seizures, for diabetes, the big diagnoses. So we got more disease-specific questions, and I think really kind of expanding and getting more—what am I trying to say? ... Getting questions that’d hone in on what the specific issues are and what are the priority issues for the guardian/parent. If the kid was old enough to verbalize themselves what they wanted to do, if they wanted to do anything, get their input too. So we were able to kinda prioritize goals. And in this whole effort, we worked mainly on what the family thinks are the most important thing.” *ACO Stakeholder No. 005*

“We have quality outreach coordinators, and they make the first outreach calls, and they explain the program to them. So it’s a totally voluntary, totally free—some families would like it, some families are not interested. [The interested families like it because] ... they have someone that they can rely on that they can call if they have a question, that there’s someone there that can—like I say, go to those doctors’ appointments with them. They don’t understand, you can help intervene and you can talk to them afterwards. Say, ‘This is what I feel like happened at the doctor’s visit, is this what you think happened?’ And it gives them someone to talk to.” *ACO Stakeholder No. 006*

Abbreviation: ACO, accountable care organization.
ACO Stakeholder Theme 1—Care management responsibilities: Ohio policy required that formal care-management plans be in place for the highest-risk managed care beneficiaries, including Medicaid-eligible children with disabilities. Before the policy change, the managed care companies retained all care management duties, effectively limiting the ACO’s ability to manage health outcomes of many children in its region.

After the policy change, the ACO and 3 of the 5 managed care companies entered into formal agreements that delegated care management duties to the ACO. These agreements made it possible for the ACO to set up a care coordination program that would actively reach out to caregivers and families, help manage their care processes, and address many of their needs.

ACO Stakeholder Theme 2—Approach to care coordination: Before the policy change, some care coordination was provided by individual provider offices and Nationwide Children’s Hospital clinics; however, there was no centrally organized staff of care coordinators and no systematic approach to coordinating care for any ACO population.

After the policy change, the ACO developed a centrally located care coordination program. By 2015 the ACO had hired 30 care coordinators and assembled them into teams of 3, including 1 nurse, 1 social worker, and 1 outreach coordinator who assisted the nurse and social worker with clerical and patient outreach support. Each team managed a panel of 25 to 50 patients. Between July 2013 and June 2016, the ACO enrolled 3072 children in care coordination, 422 of them from the newly acquired ABD population. The ACO identified these children using multiple metrics. Initially, they enrolled children identified as “high-risk” by each health plan’s proprietary risk-stratification methodology. To this group, the ACO added children with multiple ED visits and/or hospitalizations, those who had accrued more than $25 000 in charges within 6 months, discharged patients identified by the inpatient care team as needing care coordination, patients referred to care coordination by providers, and self-referrals.

ACO Stakeholder Theme 3—Approach to caregiver engagement: Before the policy change, Nationwide Children's Hospital and affiliated providers were, in fact, already providing
care to most of the ABD children in the ACO region. However, the ACO was not financially at risk for these children. ACO informants reported little in the way of systematic engagement of caregivers of ABD children under fee-for-service.

After the policy change, as the ACO assumed financial risk for the ABD population, efforts were focused on engaging the families and caregivers of this population. Care coordinators performed regular outreach through phone and in-person interactions, including making periodic home visits and attending clinical appointments to facilitate communication with providers. These outreach efforts were aimed at building relationships with caregivers and helping them address barriers that might prevent ABD children from benefiting from care.

**Caregiver Focus Group and Interview Results.** Most caregivers in our sample could recall having received the letter from the State notifying them of the planned move into the ACO, and most were aware that a managed care company had assumed oversight of their child’s Medicaid coverage. Our analysis of the focus groups and interviews with caregivers revealed 4 themes related to how the policy change did or did not impact their experiences with care and care coordination (Table 4). Table 5 includes participant quotes that reflect the themes.

**Table 4. Caregiver Experiences With Care Coordination Before and After the Policy Change**

<table>
<thead>
<tr>
<th>Before the policy change</th>
<th>After the policy change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver experienced self as primary care coordinator for child’s care</td>
<td>Caregiver still experienced self as primary care coordinator for child’s care</td>
</tr>
<tr>
<td>Little experience with formal care coordination; some coordination obtained through county or community organizations</td>
<td>Little utilization of ACO care coordination; mixed experiences with it; some would like it.</td>
</tr>
<tr>
<td>Child’s disability had considerable impact on caregivers and households</td>
<td>Child’s disability continued to have considerable impact on caregivers and households</td>
</tr>
<tr>
<td></td>
<td>Caregivers experienced changes in coverage of certain services (e.g., home health, prescription drug).</td>
</tr>
</tbody>
</table>

Abbreviation: ACO, accountable care organization.
Table 5. Themes and Representative Quotes From Caregiver Focus Groups and Interviews

<table>
<thead>
<tr>
<th>Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Theme 1: Primary care coordinator</strong></td>
</tr>
<tr>
<td>“Basically [I’m] just trying to keep it all organized and scheduling and appointments and just listening to the advice of the professionals that he works with and doing my own research and asking questions. Just kind of organizing it all, mostly ... he’s got, like, a bunch of people that he works with and stuff and just seems like I’m always on the phone or scheduling appointments or talking to someone, or, you know, like giving a status update.” Family caregiver No. 101, urban focus group</td>
</tr>
<tr>
<td>“I think it’s all on me when it came down to that [coordinating appointments]. It was just schedule them; remember that you scheduled them; now get to them. I was so happy when they started the text reminders. Yes, I was so happy, ‘cause even if I took my little minute to check my calendar, I’d get so wrapped into something else that it’s like ‘Oh, I gotta get going.’ And then once a car became an issue, not having, it really became an issue; ’cause now I gotta put another hour or two before actually getting to the appointment and the schedule.” Family caregiver No. 142, urban interview</td>
</tr>
<tr>
<td>Interviewer: “So when you had the therapists, the pediatrician, the [hospital’s] doctors you said they were very good about communicating. Was there anyone who coordinated the very services you needed?” Interviewee: “Me. Yeah, definitely me.” Family caregiver No. 161, rural interview</td>
</tr>
<tr>
<td><strong>Theme 2: Formal care coordination</strong></td>
</tr>
<tr>
<td>“They’ve been a big help [ACO care coordinators]. I mean, they always call me and check up on us, you know what I mean, if we ever need anything, uniforms, school. Always, they’ll give me those resources ... food, clothes, you know, school equipment. I mean, pretty much any resource. Any kind of help that you’re looking for, I mean, if it’s for rent, utilities, something like that, they always have some form of resource. And they just call periodically. That’s why I like it. They’ll just call out the blue periodically to see how she’s doing and to ask if I’m okay, if I need anything. And, you know, I like it for the simple fact, you know, these are people—they on top of it, man. They always calling and checking on me, but I try not to—if I don’t need anything, I tell them no, I’m fine right now. But if I ever needed something, they jump right on it, send all that stuff out to my house, as far as information on where to go.” Family caregiver No. 160, urban interview</td>
</tr>
<tr>
<td>“He was right around, a little bit, 3, probably, when I started the care coordination. They never really helped with anything, though, to be honest. ... I mean, they would send me stuff that’ll ask me like, ‘Is there anything you’re interested in or that you wanna know?’ and then sometimes mail me stuff for tutoring or stuff for day camps or something like that, but not really—they didn't help much. Pretty much was easier for me to just do it myself ’cause it seemed like going through them was more of a hassle, so, doing it myself was easier.” Family caregiver No. 141, urban interview</td>
</tr>
<tr>
<td><strong>Theme 3: Impact of disabilities</strong></td>
</tr>
</tbody>
</table>
| “It’d be nice to have a coordinator to make sure everything’s in order, or if it's time for a checkup or something ’cause with both of them, there’s a lot I do forget. Until I'm just, like, ‘Your glasses are ...
Themes

broken. When's the last time you had a checkup?’ You know? It'd be nice to have little reminders or things like that.” *Family caregiver No. 141, urban interview*

“It’s hard to have a job. She does weird things. I can’t leave her at home alone very long because she does, like, weird things. Like dying her hair with Kool-Aid. Just sporadic. She’ll get a thought in her head, look it up on YouTube and go and do it. She’s caught 2 microwaves on fire. So she’s not home alone ever ... when she was younger I would take her to my mom and my mom would watch her. But it got to be too much [for her mom to handle her daughter].” *Family caregiver No. 158, rural interview*

“His condition has—I mean, it impacted me greatly. I had to deal with the emotional stuff of him being diagnosed, and the fear for him, and then trying to get him in to as many intervention services as possible trying to figure out what worked. Having to quit school and having to wait to be able to go back when he was older and I was able to. It basically made me a hermit for 5 years because I couldn’t leave the house. I really couldn’t be around anyone because no one really could watch him for very long because they couldn't control him.” *Family caregiver No. 151, rural interview*

“[Child’s name] was my first child, she was born with an extreme amount of medical needs, way more than I was ever ready for. Like my husband at the time wasn’t in for that, didn’t want in for all the care that came with it, so we ended up splitting up and getting divorced.” *Family caregiver No. 151, rural interview*

“Before the change [from fee-for-service Medicaid to ACO], there was—I could get a nurse to come in and help me out with [my grandson], help him manage his medications and stuff, just help in general with getting—taking—getting us to the grocery stores and getting what he needed and I could probably go and find a job, one that would pay—where I could pay a bill or something. After that, it just looked like everything went downhill. Everything. It was like, ‘Oh, you can have this but not for that long,’ or, ‘You can do this but it'll have to be the generic whatever.’ Kind of just messed us up a little bit. You know, I think the old way was the best way.” *Family caregiver No. 144, urban interview*

Theme 4: Covered services

“The only issue I had, it was with [my nephew] and trying to get him back on a med that he started when he got with me. With his first insurance, they covered it no problem; now with that change, it was like he needed so much prior authorizations just to get, and he was through [health insurance company] I believe, and that system is a little still iffy with me. But he's in definite need of medications, and they won't try, it's like pulling needles to try and start, or get, or approve a medication for him. So now we’ve just been without meds, and he’s hit or miss in trouble all the time. But the stuff that they would approve wasn’t working.” *Family caregiver No. 142, urban interview*

“I think if he had the regular Medicaid card now I could get the testing I needed. It seemed to cover more of what he needed. Whereas now you have to get everything preauthorized or have referrals or you have a list of things you can and can't do.” *Family caregiver No. 157, rural interview*

Abbreviation: ACO, accountable care organization.
**Caregiver Theme 1—Primary care coordinator:** The first theme revealed an area in which participants perceived no change as a result of the move into the ACO. Caregivers perceived themselves as the primary coordinators of their children’s care. This was true even in cases of caregivers who acknowledged having received help from formal care coordinators or their provider’s office.

**Caregiver Theme 2—Formal care coordination:** Some caregivers reported receiving formal care coordination services through county boards or other community organizations both before and after the policy change; however, none reported formal care coordination services from a provider before the change. Very few caregivers in our sample reported receiving formal care coordination services under the ACO since the move into the ACO. Those who had received these services reported a mix of experiences. Some told stories of positive impacts, while others asserted that they had not found the formal coordination services helpful. Some caregivers in our sample reported that they felt they would benefit from some level of formal care coordination services, including help setting up appointments and reminders about attending them. We also identified 4 themes related to caregiver engagement, or lack thereof, with care coordination services. These included factors related to (1) availability or caregiver awareness of care coordination services, (2) alignment of services with family needs, (3) the logistical ease or difficulty of participation in care coordination programs, and (4) timing of services relative to the child’s and caregiver’s changing circumstances. Table 6 includes participant quotes that illustrate each of these subthemes.
Table 6. Subthemes and Representative Quotes From Caregiver Focus Groups and Interviews

<table>
<thead>
<tr>
<th>Engagement status</th>
<th>Theme</th>
<th>Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>Availability of care coordination</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| Not engaged in care coordination | Not available | *Interviewer:* “Do you feel like it would be helpful if there were ... a professional person helping you organize these appointments?”  
*Interviewee 1:* “That’d be great, yeah.”  
*Interviewee 2:* “Of course they’d probably end up with a 100+ person caseload.” *Caregivers in rural focus group* |
<p>| Alignment with needs | | |
| Engaged in care coordination | Aligned with needs | “If you’ve gotta go out to different hospitals in Lexington for something that they’re sending you to, they coordinate it all with your appointments. ... You do it all at the same time. So I only have to go 3 hours away once.” <em>Caregiver in rural focus group</em> |
| Engaged in care coordination | Aligned with needs | “Just kind of gives you resources, which is kind of helpful because they tell you like there's—like I say for instance I need some food, they give me a food pantry ... I was so concerned about [my child] talking to herself ... so she got me hooked up to a psychologist through the county, so had her tested there.” <em>Urban caregiver</em> |
| Engaged in care coordination | Aligned with needs, partially | “The [care coordinator] helps us out a little bit. I mean pretty much I try and juggle it all myself. If I need help getting something I can call her and usually she can steer me in the right direction.” <em>Rural caregiver</em> |
| Engaged in care coordination | Not aligned with needs | “They’re not doing anything ... they’re asking for an update on the kid ... But they’re not giving me any input. They’re not telling me: ‘Well, you should do this,’ or, ‘You should call this doctor.’” <em>Caregiver from rural focus group</em> |
| Not engaged in care coordination (would not want care coordination) | Not aligned with needs | “I don’t remember anyone [offering to coordinate care] and I think it's easier for me to do it because he's my only child.” <em>Rural caregiver</em> |
| Not engaged in care coordination (exited care coordination) | Not aligned with needs | “She would tell me, you know, if I ever needed anything, if I needed an appointment set up or this or that, you know, just give her a call... ... [once] she called and got me in and it was a totally wrong day and time and I had to reschedule anyway.” <em>Rural caregiver</em> |</p>
<table>
<thead>
<tr>
<th>Engagement status</th>
<th>Theme</th>
<th>Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not engaged in care coordination (refused care coordination)</td>
<td>Not aligned with needs</td>
<td>“[Care coordinators] wanna talk about his asthma, and he hasn’t had asthma symptoms since he was like 12. So I keep telling them, ‘No. I don’t need help with his medications. I don’t need help with coordinating doctor’s appointments. I just need help with services.’ But they can’t help me with that.” Caregiver from urban focus group</td>
</tr>
</tbody>
</table>

**Ease or difficulty of engagement**

<table>
<thead>
<tr>
<th>Engagement status</th>
<th>Theme</th>
<th>Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>Engaged in care coordination</td>
<td>Easy to engage, met at appointments</td>
<td>“They’ll look up when my son has an appointment at [the hospital] and they’ll call and say ‘Can I meet you at his speech group’ ... they’ll just meet me when he’s at another appointment and talk to me while I’m sitting in the waiting room.” Caregiver from urban focus group</td>
</tr>
<tr>
<td>Engaged in care coordination</td>
<td>Easy to engage, met at appointments</td>
<td>“[The care coordinator] would come out and she would go with me to some of the doctor appointments if I understand why [my child] was getting evaluated again ... she would go with me to the [individual education plan] meetings ... then she would just call and check on us.” Rural caregiver</td>
</tr>
<tr>
<td>Engaged in care coordination (nearly refused services)</td>
<td>Difficult to engage, long enrollment call</td>
<td>“I didn’t know what [the care coordination program] was. They kept calling me and telling me it would take a half hour on the phone and I’d be in the grocery store or something. And you know how sometimes the insurance company calls and you’re doing—they just want a survey and you’re like, no way, I don’t have time to sit here and tell you all this stuff.” Caregiver from urban focus group</td>
</tr>
<tr>
<td>Not engaged in care coordination (never enrolled)</td>
<td>Difficult to engage, unable to reach on the phone</td>
<td>“[A woman from the ACO] asked if I still wanted services or not because they were closing. I said, ‘Well I thought I was waiting for her to get occupational therapy for [my child], and calling me back to let me know that she got it.’ I didn’t get that call. She’s like ‘Well, she made it seem like she couldn't get in touch with you.’” Urban caregiver</td>
</tr>
<tr>
<td>Not engaged in care coordination (never enrolled)</td>
<td>Difficult to engage, could not make meeting</td>
<td>“A few months ago it ended because we couldn’t make an appointment that she wanted to have to do like an in-home or an in-person visit, I couldn’t schedule something with her that would work out for both of us.” Rural caregiver</td>
</tr>
<tr>
<td>Engagement status</td>
<td>Theme</td>
<td>Quote</td>
</tr>
<tr>
<td>-------------------</td>
<td>-------</td>
<td>-------</td>
</tr>
<tr>
<td><strong>Timing of care coordination</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Engaged in care coordination</td>
<td>Good timing, needed extra help</td>
<td>“The last year and some change is when I got full custody of my kids, so pretty much, like I said, I’m doing everything ... it’s been hard because with her condition, I can’t—you know [work full time].” <em>Urban caregiver</em></td>
</tr>
<tr>
<td>Engaged in care coordination</td>
<td>Good timing, needed extra help</td>
<td>“They had helped another family in the same situation I was in. Desperate for help, and got their hours taken away because of the HMO ... I had my hours back probably within a couple of months.... I’m so sick. I had no hair. I mean, I was really struggling.” <em>Urban caregiver</em></td>
</tr>
<tr>
<td>Not engaged in care coordination (refused)</td>
<td>Poor timing, unable to work with care coordinator</td>
<td>“Well, I need to schedule [appointments] because I know what I have to work around. If you have 2 deaths [in the family], and you know you gotta travel for this one and travel for that one, and you make the appointment, then they’re not gonna work around what I have to do.” <em>Urban caregiver</em></td>
</tr>
<tr>
<td>Not engaged in care coordination (refused)</td>
<td>Poor timing, not ready for care coordination</td>
<td>“That was kinda when I was in that thought process of ‘They’re saying my kid has this, but do I really deserve these services’ type. I was still trying to process.” <em>Rural caregiver</em></td>
</tr>
<tr>
<td>Not engaged in care coordination (would refuse if offered)</td>
<td>Poor timing, no longer needs care coordination</td>
<td>“At this point in the game, I’ve been doing it for so long that it would be weird for me to have someone help me. But when I think about when she first got sick, of being a young mom ... and having to learn all that stuff ... it’d have been nice in the very beginning when we were at [the] hospital all the time.” <em>Caregiver in a rural focus group</em></td>
</tr>
<tr>
<td>Not engaged in care coordination (was dropped from program)</td>
<td>Poor timing, care coordinator not available when needed</td>
<td>“When we found out that he had the cognitive delay, I ... got him on with a case worker ... she helped us kind of get some things for the house that he needed. And then, after that, we didn’t need her anymore ... and then I needed something and I tried to call, and they said, ‘[The child is] no longer [enrolled] with us.’” <em>Caregiver in an urban focus group</em></td>
</tr>
</tbody>
</table>
**Caregiver Theme 3—Impact of disabilities:** Another factor unchanged by the move from fee-for-service into the ACO was that the disabilities had considerable impact, not only on the children themselves, but also on the caregivers and others in the household. For example, caregivers reported that they got divorced, lost jobs, or felt they couldn’t find suitable work as a result of the demands of their child’s disability. They also partly attributed other stresses in the home, such as fighting among siblings, to situations created or exacerbated by the disabilities. No caregiver reported experiencing any change in such situations as a result of the move into the ACO.

**Caregiver Theme 4—Covered services:** One type of change that caregivers reported experiencing, and which they attributed to the policy change, was changes in covered services. Most commonly, caregivers reported experiencing reductions in the number of hours of home health services their child was allowed, changes to prescription formularies, and lost access to trusted providers. Caregivers reported increased stresses and challenges as a result of reduced home health support. Some relayed stories in which home health hours were restored to pre-managed care levels. These stories usually involved the advocacy of ACO care coordinators or providers. Some caregivers experienced frustrations when medications that had been providing benefit to their children were no longer covered. Similarly, others reported that providers they had known and trusted were no longer available to them. Typically, these stories pointed to the fact that there were multiple managed care companies insuring patients in the ACO. Whereas under fee-for-service, patients could access any provider who accepted Medicaid, under the managed care ACO arrangement, patients could only access those providers who had agreements with their managed care plan.

Although the overall goal of the caregiver focus groups and interviews was to assess caregiver perception of care coordination before and after the transition to the ACO model of care, we found that participants had relatively little to say about care coordination and its provision by the ACO. Rather, many spoke at length about other difficulties they faced in caring for their children. Data analysis identified a theme of scarce resources, further classifiable as
scarcity of family support, financial support, and health services under managed care; and resource constraints on other public agencies and programs from which families might benefit.

Aim 2

To evaluate the quality of care coordination provided by the ACO, implement a novel caregiver and medical record abstraction tool designed to assess care coordination for children with disabilities.

Aim 2 Overview of Participant Flow

Caregiver survey and medical record abstraction participant flow charts are depicted in Figures 4 and 5, respectively.
Caregivers of children with disabilities. Caregiver child must have: resided continuously in the region served by the ACO; been continuously enrolled in Medicaid and had ABD status since at least one year before the policy change; be no more than 18 years of age at the time of data collection; and have been, at the time of the policy change, at least 2 years of age. (n=6,548)

Assessed for Eligibility (n=3,575)

Assessed for Eligibility Web Survey (n=336)

Assessed for Eligibility Phone Survey (n=3,239)

Participated in Web Survey (n=336)

Participated in Phone Survey (n=1760)

Completed Web Survey (n=333)

Completed Phone Survey (n=1,729)

Total Completed Surveys (n=2,062)

Excluded (n=1) • Invalid data

Analyzed (n=2,061)

Did not complete survey (n=3)

Did not complete survey (n=31)

Total Excluded (n=2,973)
• Opted out (n=31)
• Unable to reach (undeliverable mail, did not answer phone)  (n=2,942)

Total Excluded (n=1,479)
• Ineligible (caregiver language or age, child age)  (n=60)
• Declined (not interested, no reason given, reason missing)  (n=1,419)
Figure 5. Medical record abstraction flow

Excluded:
No record in the NCH EMR system during the study period because:
- a) no visits to NCH main provider during study period;
- b) no referrals from a community main provider to NCH during the study period; or
- c) main provider could not be determined from information provided in the phone survey (n=852)

EMR\textsuperscript{†} Reviews (n=1,435)

EMR Abstractions (n=583)

Web surveys with consent for medical record abstraction (n=210)
Respondents who consented to medical record abstraction (n=1,608)
Phone surveys with consent for medical record abstraction (n=1,398)

Excluded: No NCH* Medical Record Number (n=173)

Excluded:
- No referrals made by NCH main provider, therefore no care coordination to document
- Either an NCH main provider or a referring main provider was included in the NCH EMR
- Both an NCH main provider and a referring provider were included in the NCH EMR

Abstraction Complete (n=279)
One-sided communication review Abstraction Complete (n=103)
Two-sided communication review Abstraction Complete (n=201)

*Nationwide Children’s Hospital
†Electronic Medical Record
Aim 2 Analyses

We ran descriptive statistics for child and caregiver characteristics and for overall frequencies of each FECC measure endorsed by the NQF. Bivariate associations between demographic characteristics and FECC quality measures including satisfaction were tested using the chi-square test. Associations were also examined by demographic characteristics. Because we made multiple comparisons in the analyses, $P$ values $< 0.01$ were considered statistically significant. We fit a logistic regression model with caregiver satisfaction as the dependent variable and entered all FECC care coordination items in the model to determine which specific FECC items might be driving the association between care coordination quality and caregiver satisfaction. Significance was set at $P < 0.05$ for this analysis. Our intent was to adjust this model for all demographic variables found to be significantly associated with satisfaction in bivariate analysis; however, no demographic variables met the threshold for significance (data not shown). Bivariate correlations between FECC measures and utilization outcomes and between FECC measures and EMR review–based care coordination measures were also assessed using the chi-square test.

Aim 2 Results

The final sample size for this analysis is 2061, as we discarded 1 survey response because we could not confirm eligibility. After exclusions, the total survey response rate was 59% (2061/3515). Table 7 presents the demographic and clinical characteristics of children (Table 7a) and their caregivers (Table 7b) who participated in the survey.
### Table 7a. Demographics and Clinical Characteristics of Children

<table>
<thead>
<tr>
<th>Child characteristics</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male sex</td>
<td>1337</td>
<td>65</td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>1139</td>
<td>55</td>
</tr>
<tr>
<td>Black</td>
<td>617</td>
<td>30</td>
</tr>
<tr>
<td>Other</td>
<td>298</td>
<td>14</td>
</tr>
<tr>
<td>Hispanic ethnicity</td>
<td>120</td>
<td>6</td>
</tr>
<tr>
<td>Age group (years)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2-5</td>
<td>208</td>
<td>10</td>
</tr>
<tr>
<td>6-12</td>
<td>971</td>
<td>47</td>
</tr>
<tr>
<td>13-19</td>
<td>882</td>
<td>43</td>
</tr>
<tr>
<td>Urban residence</td>
<td>1473</td>
<td>71</td>
</tr>
<tr>
<td>PMCA categorization</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nonchronic</td>
<td>110</td>
<td>5</td>
</tr>
<tr>
<td>Noncomplex chronic</td>
<td>574</td>
<td>28</td>
</tr>
<tr>
<td>Complex chronic</td>
<td>1373</td>
<td>67</td>
</tr>
<tr>
<td>CDPS diagnoses from April 2015 to March 2016</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cancer</td>
<td>21</td>
<td>1</td>
</tr>
<tr>
<td>Cardiovascular</td>
<td>195</td>
<td>9</td>
</tr>
<tr>
<td>Cerebrovascular</td>
<td>24</td>
<td>1</td>
</tr>
<tr>
<td>Developmental disability</td>
<td>442</td>
<td>21</td>
</tr>
<tr>
<td>Diabetes</td>
<td>28</td>
<td>1</td>
</tr>
<tr>
<td>Gastrointestinal</td>
<td>177</td>
<td>9</td>
</tr>
<tr>
<td>Hematological</td>
<td>45</td>
<td>2</td>
</tr>
<tr>
<td>Infectious disease</td>
<td>24</td>
<td>1%</td>
</tr>
<tr>
<td>Metabolic</td>
<td>319</td>
<td>15%</td>
</tr>
<tr>
<td>Child health condition characteristics</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nervous system</td>
<td>313</td>
<td>15%</td>
</tr>
<tr>
<td>Psychiatric</td>
<td>1138</td>
<td>55%</td>
</tr>
<tr>
<td>Pulmonary</td>
<td>521</td>
<td>25%</td>
</tr>
<tr>
<td>Renal</td>
<td>207</td>
<td>10%</td>
</tr>
<tr>
<td>Skeletal/connective</td>
<td>296</td>
<td>14%</td>
</tr>
<tr>
<td>Skin</td>
<td>115</td>
<td>6%</td>
</tr>
</tbody>
</table>

Abbreviations: CDPS, Chronic Illness and Disability Payment System; PMCA, Pediatric Medical Complexity Algorithm.
### Table 7b. Demographics and Clinical Characteristics of Caregivers

<table>
<thead>
<tr>
<th>Caregiver characteristics</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female sex</td>
<td>1908</td>
<td>93</td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>1265</td>
<td>61</td>
</tr>
<tr>
<td>Black</td>
<td>628</td>
<td>30</td>
</tr>
<tr>
<td>Other</td>
<td>162</td>
<td>8</td>
</tr>
<tr>
<td>Hispanic ethnicity</td>
<td>76</td>
<td>4</td>
</tr>
<tr>
<td>Age group (years)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-24</td>
<td>42</td>
<td>2</td>
</tr>
<tr>
<td>25-34</td>
<td>656</td>
<td>32</td>
</tr>
<tr>
<td>35-44</td>
<td>825</td>
<td>40</td>
</tr>
<tr>
<td>45-54</td>
<td>336</td>
<td>16</td>
</tr>
<tr>
<td>Caregiver characteristics</td>
<td></td>
<td></td>
</tr>
<tr>
<td>≥55</td>
<td>198</td>
<td>10</td>
</tr>
<tr>
<td>Education level</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than high school</td>
<td>417</td>
<td>20</td>
</tr>
<tr>
<td>High school graduate or GED</td>
<td>753</td>
<td>37</td>
</tr>
<tr>
<td>Some college, college graduate, or more</td>
<td>890</td>
<td>43</td>
</tr>
<tr>
<td>No. of children in household</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>386</td>
<td>19</td>
</tr>
<tr>
<td>2</td>
<td>573</td>
<td>28</td>
</tr>
<tr>
<td>≥3</td>
<td>1102</td>
<td>53</td>
</tr>
<tr>
<td>No. of children in household with disabilities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>1227</td>
<td>60</td>
</tr>
<tr>
<td>2</td>
<td>563</td>
<td>27</td>
</tr>
<tr>
<td>≥3</td>
<td>264</td>
<td>13</td>
</tr>
</tbody>
</table>
Access to a care coordinator: Of the 1201 individuals who reported seeing > 1 medical provider during the 12 months before the survey, 864 (72%) indicated they had someone help coordinate their child’s care (Table 8).

Care coordination activities: Of the 4 FECC indicators assessing care coordinator functions, “confirmed appointment with a specialist” was reported most often (80%), followed by “helped obtain needed community services” (71%). Caregivers were less likely to report that their care coordinators “asked about concerns and health changes” (60%) or were “knowledgeable, supportive, and advocated for patient needs” (40%).

Communication and documentation: Of the 3 communication and documentation indicators of care coordination, 70% of those who needed a medical interpreter had access to one. Caregivers were less likely to report that they received a “written visit summary” containing all necessary elements (42%) or that their “PCP [primary care provider] created a shared care plan” (49%).

Table 8. Survey Respondents Answering “Yes” to the FECC Quality Measures Examined

<table>
<thead>
<tr>
<th>FECC quality measures</th>
<th>No. Eligible</th>
<th>No. Meta</th>
<th>% Meta</th>
</tr>
</thead>
<tbody>
<tr>
<td>Access to a CC</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FECC-1: Child has a CC</td>
<td>1201</td>
<td>864</td>
<td>71.9</td>
</tr>
<tr>
<td>Care coordination activities</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FECC-3: CC helped obtain needed community services</td>
<td>455</td>
<td>324</td>
<td>71.2</td>
</tr>
<tr>
<td>FECC-5: CC asked about concerns and health changes</td>
<td>435</td>
<td>261</td>
<td>60.0</td>
</tr>
<tr>
<td>FECC-7: CC confirmed appointment with specialist</td>
<td>504</td>
<td>404</td>
<td>80.2</td>
</tr>
<tr>
<td>FECC-8: CC was knowledgeable, supportive, and advocated for needs</td>
<td>852</td>
<td>345</td>
<td>40.5</td>
</tr>
<tr>
<td>Communication and documentation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FECC-9: Written visit summary contains all elements</td>
<td>1259</td>
<td>523</td>
<td>41.5</td>
</tr>
<tr>
<td>FECC-15: Access to medical interpreter when needed</td>
<td>37</td>
<td>26</td>
<td>70.3</td>
</tr>
<tr>
<td>FECC-16: Primary care provider created a shared care plan</td>
<td>1983</td>
<td>965</td>
<td>48.7</td>
</tr>
</tbody>
</table>

Abbreviation: CC, care coordinator; FECC, Family Experiences with Care Coordination.

aRefers to a score = 100 on the FECC indicator.
Demographic predictors of FECC measures: Caregivers of younger children were more likely to have knowledgeable/supportive/advocating care coordinators, and caregivers of black children were more likely to have received comprehensive written visit summaries and shared care plans. Caregivers of medically complex children were more likely to report having more knowledgeable/supportive/advocating care coordinators and shared care plans (Table 9).

Demographic analysis of FECC measures (caregiver/household characteristics): Living in a rural county was associated with the largest number of care coordination items (Table 10). Caregivers living in rural areas were reported as less likely to receive help obtaining needed community services, less likely to receive comprehensive written visit summaries, and less likely to have shared care plans. Lower caregiver education was associated with higher likelihood of having a shared care plan. There was no association among number of children with disabilities in the household and any care coordination measure.
Table 9. Bivariate Associations Between FECC Quality Measures and Child Demographic and Clinical Characteristics

<table>
<thead>
<tr>
<th>FECC quality measures</th>
<th>Age</th>
<th>Race</th>
<th>PMCA complex chronic</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2-5</td>
<td>6-12</td>
<td>13-19</td>
</tr>
<tr>
<td></td>
<td>n</td>
<td>%</td>
<td>n</td>
</tr>
<tr>
<td>1: Child has a CC</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes (score=100)</td>
<td>96</td>
<td>71</td>
<td>464</td>
</tr>
<tr>
<td>No (score = 0)</td>
<td>39</td>
<td>29</td>
<td>156</td>
</tr>
<tr>
<td>3: CC helped obtain</td>
<td>0.53</td>
<td></td>
<td></td>
</tr>
<tr>
<td>needed community services</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes (score = 100)</td>
<td>33</td>
<td>67</td>
<td>170</td>
</tr>
<tr>
<td>No (score = 0)</td>
<td>16</td>
<td>33</td>
<td>73</td>
</tr>
<tr>
<td>5: CC asked about</td>
<td>0.72</td>
<td></td>
<td></td>
</tr>
<tr>
<td>concerns and health</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>changes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes (score = 100)</td>
<td>37</td>
<td>65</td>
<td>141</td>
</tr>
<tr>
<td>No (score &lt;100)</td>
<td>20</td>
<td>35</td>
<td>97</td>
</tr>
<tr>
<td>7: CC confirmed</td>
<td>0.53</td>
<td></td>
<td></td>
</tr>
<tr>
<td>appointment with</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>specialist</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes (score = 100)</td>
<td>53</td>
<td>85</td>
<td>214</td>
</tr>
<tr>
<td>No (score = 0)</td>
<td>9</td>
<td>15</td>
<td>56</td>
</tr>
<tr>
<td>FECC quality measures</td>
<td>Age</td>
<td>Race</td>
<td>PMCA complex chronic</td>
</tr>
<tr>
<td>-----------------------</td>
<td>-----</td>
<td>------</td>
<td>----------------------</td>
</tr>
<tr>
<td></td>
<td>2-5</td>
<td>6-12</td>
<td>13-19</td>
</tr>
<tr>
<td>8: CC knowledgeable, supportive, and advocated for needs</td>
<td>n</td>
<td>%</td>
<td>n</td>
</tr>
<tr>
<td>Yes (score = 100)</td>
<td>55</td>
<td>57</td>
<td>177</td>
</tr>
<tr>
<td>No (score &lt; 100)</td>
<td>41</td>
<td>43</td>
<td>278</td>
</tr>
<tr>
<td>15: Access to medical interpreter when needed</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes (score = 100)</td>
<td>6</td>
<td>86</td>
<td>12</td>
</tr>
<tr>
<td>No (score &lt; 100)</td>
<td>1</td>
<td>14</td>
<td>8</td>
</tr>
<tr>
<td>9: Written visit summary contains all elements</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes (score = 100)</td>
<td>57</td>
<td>42</td>
<td>256</td>
</tr>
<tr>
<td>No (score &lt;100)</td>
<td>79</td>
<td>58</td>
<td>359</td>
</tr>
<tr>
<td>16: PCP created a shared care plan</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes (score= = 100)</td>
<td>96</td>
<td>47</td>
<td>45</td>
</tr>
<tr>
<td>No (score= = 0)</td>
<td>7</td>
<td>53</td>
<td>8</td>
</tr>
</tbody>
</table>

Abbreviations: CC, care coordinator; FECC, Family Experiences with Care Coordination; PCP, primary care provider; PMCA, Pediatric Medical Complexity Algorithm.

<sup>a</sup> Fisher exact P value reported.
<table>
<thead>
<tr>
<th>FECC quality measures</th>
<th>Urban county (vs rural)</th>
<th>Education beyond high school</th>
<th>No. of children with disabilities in home</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>No</td>
<td>χ²</td>
</tr>
<tr>
<td>1: Child has a CC</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes (score = 100)</td>
<td>624</td>
<td>240</td>
<td>0.08</td>
</tr>
<tr>
<td>No (score = 0)</td>
<td>226</td>
<td>111</td>
<td>0.08</td>
</tr>
<tr>
<td>3: CC helped obtain needed community services</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes (score = 100)</td>
<td>251</td>
<td>168</td>
<td>0.002</td>
</tr>
<tr>
<td>No (score = 0)</td>
<td>83</td>
<td>82</td>
<td>0.002</td>
</tr>
<tr>
<td>5: CC asked about concerns and health changes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes (score = 100)</td>
<td>190</td>
<td>124</td>
<td>0.83</td>
</tr>
<tr>
<td>No (score &lt;100)</td>
<td>125</td>
<td>79</td>
<td>0.83</td>
</tr>
<tr>
<td>7: CC confirmed appointment with specialist</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes (score = 100)</td>
<td>287</td>
<td>207</td>
<td>0.43</td>
</tr>
<tr>
<td>No (score = 0)</td>
<td>75</td>
<td>62</td>
<td>0.43</td>
</tr>
<tr>
<td>8: CC knowledgeable, supportive, and advocated for needs</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes (score = 100)</td>
<td>249</td>
<td>168</td>
<td>1.00</td>
</tr>
<tr>
<td>No (score &lt;100)</td>
<td>366</td>
<td>260</td>
<td>1.00</td>
</tr>
<tr>
<td>FECC quality measures</td>
<td>Urban county (vs rural)</td>
<td>Education beyond high school</td>
<td>No. of children with disabilities in home</td>
</tr>
<tr>
<td>-----------------------</td>
<td>-------------------------</td>
<td>-----------------------------</td>
<td>------------------------------------------</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td>No</td>
<td>χ²</td>
</tr>
<tr>
<td>15: Access to medical interpreter when needed</td>
<td></td>
<td></td>
<td>1.00&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td>Yes (score = 100)</td>
<td>25</td>
<td>69</td>
<td>1</td>
</tr>
<tr>
<td>No (score &lt;100)</td>
<td>11</td>
<td>31</td>
<td>0</td>
</tr>
<tr>
<td>9: Written visit summary contains all elements</td>
<td></td>
<td></td>
<td>0.0004</td>
</tr>
<tr>
<td>Yes (score = 100)</td>
<td>412</td>
<td>44</td>
<td>111</td>
</tr>
<tr>
<td>No (score &lt;100)</td>
<td>514</td>
<td>56</td>
<td>222</td>
</tr>
<tr>
<td>16: PCP created a shared care plan</td>
<td></td>
<td></td>
<td>0.001</td>
</tr>
<tr>
<td>Yes (score = 100)</td>
<td>727</td>
<td>51</td>
<td>238</td>
</tr>
<tr>
<td>No (score = 0)</td>
<td>696</td>
<td>49</td>
<td>322</td>
</tr>
</tbody>
</table>

Abbreviations: CC, care coordinator; FECC, Family Experiences with Care Coordination; PCP, primary care provider.

<sup>a</sup>Fisher exact P value reported.
Caregiver satisfaction with care coordination: Caregivers who were very satisfied with their care coordination were more likely to report that they had a care coordinator who (1) helped them get needed community services; (2) asked about their child’s health changes and concerns; (3) confirmed appointments with specialists; and (4) was knowledgeable, supportive, and advocated for their child’s needs (Table 11).

Table 11. FECC Quality Measures and Caregiver Satisfaction

<table>
<thead>
<tr>
<th>FECC quality measures</th>
<th>Very satisfied</th>
<th>χ²</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td></td>
<td>n</td>
<td>%</td>
<td>n</td>
</tr>
<tr>
<td>3: CC helped obtain needed community services</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes (score = 100)</td>
<td>249</td>
<td>76</td>
<td>75</td>
</tr>
<tr>
<td>No (score = 0)</td>
<td>77</td>
<td>24</td>
<td>54</td>
</tr>
<tr>
<td>5: CC asked about concerns and health changes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes (score = 100)</td>
<td>233</td>
<td>67</td>
<td>28</td>
</tr>
<tr>
<td>No (score &lt;100)</td>
<td>116</td>
<td>33</td>
<td>58</td>
</tr>
<tr>
<td>7: CC confirmed appointment with specialist</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes (score = 100)</td>
<td>333</td>
<td>86</td>
<td>71</td>
</tr>
<tr>
<td>No (score = 0)</td>
<td>56</td>
<td>14</td>
<td>44</td>
</tr>
<tr>
<td>8: CC knowledgeable, supportive, and advocated for needs</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes (score = 100)</td>
<td>316</td>
<td>50</td>
<td>29</td>
</tr>
<tr>
<td>No (score &lt;100)</td>
<td>315</td>
<td>50</td>
<td>192</td>
</tr>
</tbody>
</table>

Abbreviations: CC, care coordinator; FECC, Family Experiences with Care Coordination.

Correlations among these indicators were modest (Table 12). This limited amount of collinearity allowed us to consider the relative impact of the indicators, controlling for the presence of one another.
Table 12. Correlations Among FECC Variables Associated With Care Coordination Satisfaction

<table>
<thead>
<tr>
<th>FECC measures</th>
<th>FECC-3</th>
<th>FECC-5</th>
<th>FECC-7</th>
<th>FECC-8</th>
</tr>
</thead>
<tbody>
<tr>
<td>FECC-3</td>
<td>1.0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FECC-5</td>
<td>0.100</td>
<td>1.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>FECC-7</td>
<td>0.234&lt;sup&gt;a&lt;/sup&gt;</td>
<td>0.154&lt;sup&gt;b&lt;/sup&gt;</td>
<td>1.0</td>
<td></td>
</tr>
<tr>
<td>FECC-8</td>
<td>0.224&lt;sup&gt;a&lt;/sup&gt;</td>
<td>0.299&lt;sup&gt;a&lt;/sup&gt;</td>
<td>0.259&lt;sup&gt;a&lt;/sup&gt;</td>
<td>1.0</td>
</tr>
</tbody>
</table>

Abbreviation: FECC, Family Experiences with Care Coordination.
<sup>a</sup>P < 0.01.
<sup>b</sup>P < 0.05.

Logistic regression results (Table 13) indicated that of the 4 care coordination FECC quality measures included, 2 items were significant predictors of satisfaction in the adjusted model controlling for all 4 items. Caregivers whose care coordinator asked them about their child’s health changes and concerns and caregivers who reported their care coordinator was knowledgeable, supportive, and advocated for their child had significantly higher odds of being very satisfied.

Table 13. Logistic Regression Key Driver Analysis for Predicting Caregiver Satisfaction With Care Coordination

<table>
<thead>
<tr>
<th>FECC measures</th>
<th>Odds ratio</th>
<th>95% CI</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>FECC-3: Help with needed community services</td>
<td>1.41</td>
<td>0.46-4.32</td>
<td>0.55</td>
</tr>
<tr>
<td>FECC-5: Asked about concerns and health changes</td>
<td>2.97</td>
<td>1.09-8.09</td>
<td>0.03</td>
</tr>
<tr>
<td>FECC-7: Confirmed specialist appointment</td>
<td>2.25</td>
<td>0.67-7.52</td>
<td>0.19</td>
</tr>
<tr>
<td>FECC-8: Knowledgeable, supportive, and advocated for child’s needs</td>
<td>6.49</td>
<td>2.01-20.99</td>
<td>0.002</td>
</tr>
</tbody>
</table>

Abbreviation: FECC, Family Experiences with Care Coordination.

**FECC measures and utilization:** FECC survey measures were not consistently correlated with measures of utilization. We tested the association between FECC measures, which had a look-back period of “past 12 months,” and claims-based utilization in the same period and found the following correlations:
• **FECC-7:** Confirmed specialist appointment was positively associated with PCP visits (mean visits, 6.7 vs 5.4, $P = 0.01$)

• **FECC-8:** Knowledgeable, supportive, and advocated for child’s needs was positively associated with PCP visits (mean visits, 7.0 vs 5.4, $P < 0.01$)

• **FECC-16:** PCP created a shared care plan was positively associated with mental health visits (mean visits 9.9 vs 8.5, $p = 0.01$)

• **FECC-1:** Had a care coordinator was marginally associated with mental health visits (mean visits, 11.2 vs 9.1, $P = 0.04$). There were no significant relationships for emergency department (ED) visits; physical, occupational, or speech language therapy (PT/OT/SLT) visits; or well-child visits.

**Medical record–based care coordination measures:** There were no significant bivariate relationships between any medical record–based indicator and any survey-based indicator. Children residing in rural counties were more likely to have documentation of comprehensive previsit communication from the main provider to the specialist (42.1% vs 14.6%, $P < 0.01$) but less likely to have documentation of timely postvisit communication from the specialist (22.2% vs 78.9%, $P < 0.01$). Teens were most likely to have documentation of comprehensive postvisit communication between providers, with documentation in 79% of reviews compared with 49% in those ages 6 to 12 years and 44% in those under age 6 years ($P = 0.01$). No other demographic relationships were significant.

**Aim 3**

*Compare health care quality, utilization, and other patient-centered outcomes for children with disabilities before and after joining the ACO and the impact of care coordination on these outcomes using data collected in aims 1 and 2, along with claims and EMR data.*

Using Medicaid claims data, we compared patterns of quality and utilization outcomes for children with disabilities before and after joining the ACO compared with similar children who were not in an ACO.
Aim 3 Overview of Participant Flow

Not applicable.

Aim 3 Analyses

We used a DID regression analysis on annual measures of health services use using person-level fixed effects to control for selection bias on time-invariant variables. In addition to the pooled analysis, stratified analyses were conducted for children with diagnoses of behavioral health issues (ie, mental health and/or substance use), developmental disabilities, or pulmonary conditions during the year. Subsample analyses were also conducted among children who had “complex chronic” conditions defined by the PMCA. Stratified analyses were also conducted based on rural and urban residency.

We constructed annual binary measures for the outcomes of well-child visits, PCP visits, ED visits, any hospitalizations, any hospitalizations due to mental health conditions, use of medications, and home health visits. We constructed discharge/event-level measures for outpatient follow-up visits, hospital readmissions within 30 days, and follow-up after initial use of attention-deficit/hyperactivity disorder (ADHD) medications.

Aim 3 Results

We identified 64,383 children who were enrolled in Medicaid’s ABD program during the study period, including 17,356 who were in the region that implemented the ACO model of care. Observations include children who had ≤12 months of enrollment during each fiscal year of observation (29.3% of the ACO observations and 26.4% of the control observations for an average of 27.1% of all observations; the percentage with 11 to 12 months of enrollment was 88.1% and 89.3%, respectively). Demographics are depicted in Table 14.
Table 14. Demographic Characteristics of ACO Sample Compared With Controls

<table>
<thead>
<tr>
<th>Demographics</th>
<th>ACO sample mean (n = 17,356)</th>
<th>Control sample mean (n = 47,026)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>34.0%</td>
<td>34.5%</td>
</tr>
<tr>
<td>Age</td>
<td>12.3 years</td>
<td>12.7 years</td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td>29.4%</td>
<td>46.0%</td>
</tr>
<tr>
<td>Native American</td>
<td>0.2%</td>
<td>0.1%</td>
</tr>
<tr>
<td>Asian/Pacific Islander</td>
<td>0.008%</td>
<td>0.4%</td>
</tr>
<tr>
<td>Native Hawaiian</td>
<td>~0%</td>
<td>0.1%</td>
</tr>
<tr>
<td>White (referent)</td>
<td>65.1%</td>
<td>50.0%</td>
</tr>
<tr>
<td>Race unknown</td>
<td>4.5%</td>
<td>4.3%</td>
</tr>
</tbody>
</table>

Abbreviation: ACO, accountable care organization.

*Difference between ACO and control sample mean is statistically significant at \( P < 0.05 \).

Table 15 presents descriptive statistics on the outcomes used in our analysis. Outcomes were measured on an annual basis, except hospital follow-up measures and follow-up after ADHD prescriptions, which were based on discharges and ADHD prescription use, respectively. Significant differences emerged from the DID analyses (Table 16). Although we found no difference in well-child visits among young children (age 6 and under) after the implementation of the ACO, we did observe a greater probability of adolescents receiving a well-child visit in the ACO; the average marginal effect reflects a 5.1-percentage point–higher rate of well-child visits in the ACO region compared with the other regions of the state. This reflects a 14% relative increase in the rate of well-child visits among adolescents in contrast with the control group mean (5.1/37.5% = 14%; Table 15). No differences were observed in the broader measure of access to primary care visits, which was relatively high in both groups.
Table 15. Annual Descriptive Statistics on Health Services Use in the ACO Sample Compared With Controls

<table>
<thead>
<tr>
<th>Outcome</th>
<th>ACO sample mean, % (n = 49 358)</th>
<th>Control sample mean, % (n = 142 579)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Primary care</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Any well-child visit, age ≤6 years</td>
<td>56.7</td>
<td>58.7</td>
</tr>
<tr>
<td>Any well-child visit, age ≥12 years</td>
<td>33.7</td>
<td>37.5</td>
</tr>
<tr>
<td>Any PCP</td>
<td>77.1</td>
<td>72.3</td>
</tr>
<tr>
<td><strong>Immediate care use</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Any ED</td>
<td>34.5</td>
<td>40.0</td>
</tr>
<tr>
<td><strong>Inpatient use</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Any hospitalization</td>
<td>7.1&lt;sup&gt;a&lt;/sup&gt;</td>
<td>8.6</td>
</tr>
<tr>
<td>Follow-up after hospitalization in 7 days&lt;sup&gt;b&lt;/sup&gt;</td>
<td>34.8&lt;sup&gt;a&lt;/sup&gt;</td>
<td>29.8</td>
</tr>
<tr>
<td>Follow-up after hospitalization in 30 days&lt;sup&gt;b&lt;/sup&gt;</td>
<td>69.5&lt;sup&gt;a&lt;/sup&gt;</td>
<td>61.5</td>
</tr>
<tr>
<td>Readmission within 30 days&lt;sup&gt;b&lt;/sup&gt;</td>
<td>20.8&lt;sup&gt;a&lt;/sup&gt;</td>
<td>19.4</td>
</tr>
<tr>
<td><strong>Mental health</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Any mental health specialty procedure</td>
<td>39.9</td>
<td>39.9</td>
</tr>
<tr>
<td>Any mental health hospitalization</td>
<td>1.5</td>
<td>2.3</td>
</tr>
<tr>
<td>Follow-up after mental health hospitalization in 7 days&lt;sup&gt;c&lt;/sup&gt;</td>
<td>16.6</td>
<td>15.0</td>
</tr>
<tr>
<td>Follow-up after mental health hospitalization in 30 days&lt;sup&gt;c&lt;/sup&gt;</td>
<td>40.6</td>
<td>37.6</td>
</tr>
<tr>
<td><strong>Medication use and adherence</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Any antidepressant</td>
<td>11.9</td>
<td>11.6</td>
</tr>
<tr>
<td>Any anticonvulsant</td>
<td>13.9</td>
<td>11.1</td>
</tr>
<tr>
<td>Any antianxiety</td>
<td>5.8</td>
<td>4.8</td>
</tr>
<tr>
<td>Any antipsychotic</td>
<td>14.2</td>
<td>14.3</td>
</tr>
<tr>
<td>Any asthma medication</td>
<td>13.9</td>
<td>13.6</td>
</tr>
<tr>
<td>Any ADHD medication</td>
<td>26.8</td>
<td>28.0</td>
</tr>
<tr>
<td>Follow-up after ADHD prescription in 30 days</td>
<td>26.3</td>
<td>23.5</td>
</tr>
</tbody>
</table>
## Outcome

<table>
<thead>
<tr>
<th>Outcome</th>
<th>ACO sample mean, % (n = 49 358)</th>
<th>Control sample mean, % (n = 142 579)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home health</td>
<td>21.5&lt;sup&gt;a&lt;/sup&gt;</td>
<td>17.1</td>
</tr>
<tr>
<td>Home-based PT/OT/SLT</td>
<td>0.2</td>
<td>0.2</td>
</tr>
<tr>
<td>Office-based PT/OT/SLT</td>
<td>35.2</td>
<td>34.9</td>
</tr>
</tbody>
</table>

Abbreviations: ACO, accountable care organization; ADHD, attention-deficit/hyperactivity disorder; ED, emergency department; PCP, primary care provider; PT/OT/SLT, physical therapy, occupational therapy, and speech language therapy.

<sup>a</sup>Difference between ACO and control sample mean is statistically significant at $P < 0.05$.

<sup>b</sup>Sample size for ACO sample is 5738 and control group is 18 227 based on discharges.

<sup>c</sup>Sample size for ACO sample is 4025 and control group is 13 394.
### Table 16. ACO Marginal Effects on Health Services Use\(^a\)

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Observations</th>
<th>Coefficient</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Primary care</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Any well-child visit, age ≤6 years</td>
<td>34 341</td>
<td>-0.0064</td>
<td>-0.0467</td>
</tr>
<tr>
<td>Any well-child visit, age ≥12 years(^b)</td>
<td>97 145</td>
<td>0.0506</td>
<td>0.0290</td>
</tr>
<tr>
<td>Any PCP</td>
<td>191 937</td>
<td>-0.0005</td>
<td>-0.0109</td>
</tr>
<tr>
<td><strong>Immediate care use</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Any ED(^b)</td>
<td>191 937</td>
<td>0.0162</td>
<td>0.0036</td>
</tr>
<tr>
<td><strong>Inpatient use</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Any hospitalization</td>
<td>191 937</td>
<td>0.0037</td>
<td>-0.0028</td>
</tr>
<tr>
<td>Follow-up after hospitalization in 7 days</td>
<td>42 570</td>
<td>0.0151</td>
<td>-0.0129</td>
</tr>
<tr>
<td>Follow-up after hospitalization in 30 days</td>
<td>42 570</td>
<td>-0.0066</td>
<td>-0.0328</td>
</tr>
<tr>
<td>Readmission within 30 days</td>
<td>42 570</td>
<td>-0.0153</td>
<td>-0.0421</td>
</tr>
<tr>
<td>Hospital days</td>
<td>191 937</td>
<td>-0.0207</td>
<td>-0.3205</td>
</tr>
<tr>
<td><strong>Mental health</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Any mental health specialty procedure(^b)</td>
<td>191 937</td>
<td>-0.0207</td>
<td>-0.0318</td>
</tr>
<tr>
<td>Any mental health hospitalization</td>
<td>5786</td>
<td>0.0006</td>
<td>-0.0031</td>
</tr>
<tr>
<td>Follow-up after mental health hospitalization in 7 days(^c)</td>
<td>5786</td>
<td>-0.0347</td>
<td>-0.094</td>
</tr>
<tr>
<td>Follow-up after MH hospitalization in 30 days(^c)</td>
<td>5786</td>
<td>0.0207</td>
<td>-0.0572</td>
</tr>
<tr>
<td><strong>Medication use and adherence</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Any antidepressant(^b)</td>
<td>191 937</td>
<td>0.0072</td>
<td>0.001</td>
</tr>
<tr>
<td>Any anticonvulsant(^b)</td>
<td>191 937</td>
<td>0.0058</td>
<td>0.0009</td>
</tr>
<tr>
<td>Any antianxiety(^b)</td>
<td>191 937</td>
<td>0.0054</td>
<td>0.0001</td>
</tr>
<tr>
<td>Any antipsychotic</td>
<td>191 937</td>
<td>-0.0039</td>
<td>-0.0095</td>
</tr>
<tr>
<td>Any asthma medication</td>
<td>191 937</td>
<td>0.0026</td>
<td>-0.0036</td>
</tr>
<tr>
<td>Any ADHD medication(^b)</td>
<td>191 937</td>
<td>-0.0110</td>
<td>-0.0178</td>
</tr>
<tr>
<td>Follow-up after ADHD prescription in 30 days(^b)</td>
<td>17 419</td>
<td>0.0715</td>
<td>0.0411</td>
</tr>
<tr>
<td>Outcome</td>
<td>Observations</td>
<td>Coefficient</td>
<td>95% CI</td>
</tr>
<tr>
<td>------------------------------------</td>
<td>--------------</td>
<td>-------------</td>
<td>---------</td>
</tr>
<tr>
<td>Home health(^b)</td>
<td>191,937</td>
<td>−0.0450</td>
<td>−0.0531</td>
</tr>
<tr>
<td>Home-based PT/OT/SLT(^b)</td>
<td>191,937</td>
<td>0.0019</td>
<td>0.0008</td>
</tr>
<tr>
<td>Office-based PT/OT/SLT</td>
<td>191,937</td>
<td>0.0002</td>
<td>−0.0092</td>
</tr>
</tbody>
</table>

Abbreviations: ACO, accountable care organization; ADHD, attention-deficit/hyperactivity disorder; ED, emergency department; PCP, primary care provider; PT/OT/SLT, physical therapy, occupational therapy, and speech language therapy.

\(^a\)Marginal effects are outcomes in the ACO compared with the non-ACO after the policy change.

\(^b\)The reported marginal effect is statistically significant at \(P < 0.05\).

We observed a modest increase of 1.6 percentage points in the use of ED visits in the ACO region, over a control group ED utilization rate of 40%. In contrast, we observed no difference in any of the measures of hospital utilization or of follow-up to outpatient providers after a hospitalization. The implementation of the ACO also did not significantly change the number of hospital days per year.

After the implementation of the ACO, we observed a decline in the use of visits for specialty mental health procedures paid for by general Medicaid revenues. We estimated greater rates of access to 3 of the 6 classes of medications by ACO enrollees: antidepressants, anticonvulsants, and antianxiety medications. These 3 classes were the least used of the 6 classes examined in the control participants (Table 15). We observed a decline in the use of ADHD medication in the ACO group compared with the non-ACO managed care controls. The remaining 2 categories (antipsychotics and asthma rescue medications) showed no differences in the probability of use between the ACO group and non-ACO managed care group. We did find that ACO implementation substantially increased the probability of follow-up after an initial ADHD medication by 2.0 percentage points.

Finally, we estimated that there was a large, proportionate decline in access to Medicaid-paid home health services after ACO implementation, in contrast to trends in the comparison group. The size of this effect was a 4.5-percentage point decrease in use of home health services, which was a 26% relative decline over the rate in the non-ACO population. We observed an increase of 0.2% points in the probability of having \(\geq 1\) PT/OT/SLT services.
delivered in the home, which was modest in absolute value, but represented a relatively large increase of almost 100%. There was no statistically significant change in the use of office-based PT/OT/SLT services.

Our subgroup analyses were generally similar to the findings from the main analytic model (Table 17), although a few differences were notable. We found that the increase in well-child visits for adolescents did not seem to occur in rural children in the ACO but did occur in children with either behavioral health diagnoses or complex conditions. The effect size was smaller and not statistically significant in adolescents with IDD. While we found no change in overall PCP use in the full sample, we did observe that children with either behavioral health or IDD diagnoses had lower rates of access to primary care than did otherwise similar children not in the ACO. We also saw no difference in the use of inpatient services in the general population but did see a reduction in the use of hospital care in rural ACO enrollees. There were some small differences in the use of medications, in terms of magnitude or significance, but all effects were similarly small, and many lost significance in subgroup analyses. Finally, the reduction in the use of home health services in the ACO was larger in magnitude in subgroups with behavioral health, IDD, or complex conditions.
Table 17. ACO Marginal Effects on Health Services Use in Subsamples Based on Region and Diagnostic Groups

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Marginal effect in full sample</th>
<th>Marginal effect in rural sample</th>
<th>Marginal effect in sample with behavioral health diagnoses</th>
<th>Marginal effect in sample with IDD diagnoses</th>
<th>Marginal effect in sample with complex conditions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Primary care</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Any well-child visit, age ≤6 years</td>
<td>−0.0064</td>
<td>−0.0023</td>
<td>−0.0073</td>
<td>−0.0712</td>
<td>−0.0051</td>
</tr>
<tr>
<td>Any well-child visit, age ≥12 years</td>
<td>0.0506&lt;sup&gt;a&lt;/sup&gt;</td>
<td>0.0037</td>
<td>0.0591&lt;sup&gt;a&lt;/sup&gt;</td>
<td>0.0324</td>
<td>0.0487&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td>Any PCP</td>
<td>−0.0005</td>
<td>0.0154</td>
<td>−0.0179&lt;sup&gt;a&lt;/sup&gt;</td>
<td>−0.0256&lt;sup&gt;a&lt;/sup&gt;</td>
<td>−0.0003</td>
</tr>
<tr>
<td><strong>Immediate care use</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Any ED</td>
<td>0.0163&lt;sup&gt;a&lt;/sup&gt;</td>
<td>−0.0036</td>
<td>0.0241&lt;sup&gt;a&lt;/sup&gt;</td>
<td>0.0266</td>
<td>0.0204&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td><strong>Inpatient use</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Any hospitalization</td>
<td>0.0037</td>
<td>0.0005</td>
<td></td>
<td></td>
<td>0.0073</td>
</tr>
<tr>
<td>Hospital days</td>
<td>1.503</td>
<td>0.88</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Mental health</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Any mental health specialty procedure</td>
<td>−0.0207&lt;sup&gt;a&lt;/sup&gt;</td>
<td>0.0188</td>
<td>−0.0372&lt;sup&gt;a&lt;/sup&gt;</td>
<td>0.0068</td>
<td>−0.0229&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td>Any mental health hospitalization</td>
<td>0.0006</td>
<td>−0.0113&lt;sup&gt;a&lt;/sup&gt;</td>
<td></td>
<td></td>
<td>−0.0005</td>
</tr>
<tr>
<td><strong>Medication use and adherence</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Any antidepressant</td>
<td>0.0072&lt;sup&gt;a&lt;/sup&gt;</td>
<td>0.0005</td>
<td>0.0122</td>
<td></td>
<td>0.0069</td>
</tr>
<tr>
<td>Any anticonvulsant</td>
<td>0.0058&lt;sup&gt;a&lt;/sup&gt;</td>
<td>−0.0209&lt;sup&gt;a&lt;/sup&gt;</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Any antianxiety</td>
<td>0.0054&lt;sup&gt;a&lt;/sup&gt;</td>
<td>0.0088</td>
<td>0.0086</td>
<td></td>
<td>0.0047</td>
</tr>
<tr>
<td>Outcome</td>
<td>Marginal effect in full sample</td>
<td>Marginal effect in rural sample</td>
<td>Marginal effect in sample with behavioral health diagnoses</td>
<td>Marginal effect in sample with IDD diagnoses</td>
<td>Marginal effect in sample with complex conditions</td>
</tr>
<tr>
<td>----------------------------------------</td>
<td>-------------------------------</td>
<td>-------------------------------</td>
<td>----------------------------------------------------------</td>
<td>----------------------------------------------</td>
<td>--------------------------------------------------</td>
</tr>
<tr>
<td>Any antipsychotic</td>
<td>−0.0039</td>
<td>−0.0099</td>
<td>−0.0072</td>
<td>−0.0054</td>
<td>−0.0005</td>
</tr>
<tr>
<td>Any asthma medication</td>
<td>0.0026</td>
<td>0.0002</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Any ADHD medication</td>
<td>−0.0110&lt;sup&gt;a&lt;/sup&gt;</td>
<td>−0.0065</td>
<td>−0.0124</td>
<td>−0.0093</td>
<td>−0.0138&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home health</td>
<td>−0.0450&lt;sup&gt;a&lt;/sup&gt;</td>
<td>−0.0039</td>
<td>−0.0640&lt;sup&gt;a&lt;/sup&gt;</td>
<td>−0.0463&lt;sup&gt;a&lt;/sup&gt;</td>
<td>−0.0459&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td>Home-based PT/OT/SLT</td>
<td>0.0019&lt;sup&gt;a&lt;/sup&gt;</td>
<td>−0.0005</td>
<td>0.0003</td>
<td>0.0030</td>
<td>0.0028&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td>Office-based PT/OT/SLT</td>
<td>0.0002</td>
<td>−0.0781&lt;sup&gt;a&lt;/sup&gt;</td>
<td>0.0024</td>
<td>−0.0187</td>
<td>0.0063</td>
</tr>
</tbody>
</table>

Abbreviations: ACO, accountable care organization; ADHD, attention-deficit/hyperactivity disorder; ED, emergency department; IDD, intellectual or developmental disorder; PCP, primary care provider; PT/OT/SLT, physical therapy, occupational therapy, and speech language therapy.

<sup>a</sup>The reported marginal effect is statistically significant at \( P < 0.05 \).
DISCUSSION

Context for Study Results

Aim 1: Qualitative Focus Groups and Interviews With Stakeholders and Caregivers

ACO leaders reported how the policy change impacted their approach to care coordination for children with disabilities in 3 key ways. First, they developed formal delegated care coordination agreements with managed care plans. Second, they developed a systematic approach to care coordination by creating interprofessional care coordination teams to serve medically complex children, including those with disabilities. Finally, they assumed full financial risk for the medical care needs of this population and began systematic engagement of caregivers. These findings suggest that the policy change did, in fact, increase the ACO’s attention to care coordination.

Caregivers viewed themselves as primary coordinators of their children’s care; this was true even of caregivers who received formal care coordination either through the ACO or other providers and agencies. The prevailing assumption among policy makers and providers is that if care coordination services are offered, caregivers will take advantage of them. Emerging literature suggests that this is not always the case.\(^{25}\) Consistent with this literature, we found variation in the level of caregivers’ engagement in care coordination services based on the limited availability of care coordination services, poor alignment of coordination service with the caregiver’s and child’s needs, logistical challenges related to engagement, and poor timing of service offerings with caregiver and child needs. For example, some caregivers discussed how care coordinators made it easier for them to engage by meeting them during medical appointments; however, other caregivers cited logistical difficulties with scheduling the half-hour phone meeting needed to complete the care coordination enrollment call. Similarly, caregivers reported several ways that ongoing care circumstances changed and affected their care coordination needs, such as new diagnoses, emerging needs as the children develop, and changes in social or family situations, such as parent divorce or illness. Although some
caregivers experiencing these changes welcomed care coordination services, others found this timing suboptimal for their situation.

Being part of an ACO did not change the considerable impact of their children’s disability on caregivers’ lives (eg, stressors on relationships, jobs, health). Ample evidence demonstrates that having a child with disabilities can have negative economic, health, and social consequences for families and caregivers. Although it is not expected that enrollment in an ACO would fundamentally change the experience of raising a child with a disability, ACOs are designed to make care for that child more accessible and better coordinated and potentially to act as a support system for the caregiver vis-à-vis the child’s health care needs. As such, participation in an ACO might be expected to reduce caregiver stress. However, our findings did not support such a hypothesis. Our analysis identified a theme of scarce resources, unrelated to being part of the ACO, including scarcity of family support, financial support, benefits available under managed care plans, and resource constraints on other agencies and programs from which families might benefit.

Our results from aim 1 provide greater insight on caregiver perspectives about care coordination that will help inform ACO leaders, health care providers, and policy makers as they develop or enhance care coordination programs. Simply offering care coordination services will not be enough for this population, given the complex social and medical needs these caregivers and their children often face. Together, the findings suggest that to successfully impact outcomes for complex, high-need populations, such as children with disabilities, provider-based care coordination services will need to be highly adaptable to the needs of individual patients and their caregivers, as well as supportive of needs that extend well beyond traditional medical care. Understanding these needs can inform ACO decisions about whether and how to engage the forces and institutions that bear on the health and health status of children with disabilities. For example, ACOs may develop formal partnerships with community organizations or local government agencies to address the nonmedical needs of children with disabilities and potentially develop financial incentives or alternative payment structures for meeting particular desired outcomes for this population.
**Aim 2: Caregiver Survey to Assess Care Coordination**

About half of surveyed caregivers reported that their child saw >1 medical provider during the 12 months before the survey, which was administered from 2015 to 2016. Of those, 72% indicated that someone helped to coordinate their child’s care. The most often-reported care coordinator activities were confirming appointments with a specialist (80%) followed by “helped obtain needed community services” (71%). Logistic regression analyses predicting caregiver satisfaction indicated 2 items were significant: care coordinators asking about the child’s health changes/concerns, and care coordinators who were knowledgeable, supportive, and advocated for children (OR, 2.97; 95% CI, 1.09-8.09; \( P = 0.03 \); OR, 6.49; 95% CI, 2.01-20.99; \( P = 0.002 \), respectively). We found positive correlations between measures of care coordination and utilization. Specifically, caregivers who reported their care coordinators confirmed appointments with specialists or who were knowledgeable and supportive were positively associated with primary care visits. This might be because the care coordinators helped reinforce the importance of ongoing relationships with PCPs and “closed the loop” with referrals to specialists. Having access to a care coordinator and having a provider who created shared care plans was positively associated with mental health visits. There was no significant relationship between care coordination measures and ED visits; physical, speech, or occupational therapy visits; or well-child visits.

Our findings suggest that having a care coordinator who asked about the child’s health changes/concerns and was knowledgeable, supportive, and advocated for the child were the most important drivers of caregiver satisfaction. These findings support previous research that shows care coordination is associated with increased caregiver satisfaction in their child’s overall health care, fewer problems obtaining specialty referrals, reduced ED visits, and positive health outcomes for the child.\(^{29-31}\) Having high-quality care coordination improves the lives of both children and caregivers and may provide families with an ally while navigating the health care system. Few differences were found when comparing demographic/clinical characteristics of caregivers and children who either met or did not meet the FECC quality measures. Caregivers of younger children were more likely to report their care coordinator was knowledgeable, supportive, and advocated for their child’s needs. It may be that caregivers of
younger children have more interaction with their care coordinator because well-child visits occur more frequently with younger children than with older children. Caregivers of children with complex chronic conditions were more likely to report that their care coordinator was knowledgeable and that their PCP created a shared care plan for their child. These findings seem reasonable as medically complex chronic children are more likely to see multiple providers, and having frequent contact with the care coordinator may be helpful in establishing and maintaining care. The finding of higher rates of shared care planning and comprehensive visit summaries in black children was unexpected given documentation of racial disparities in unmet needs of care and coordination in black children with disabilities.\textsuperscript{32-34} These findings merit additional studies.

The results from aim 2 provide useful insight for key decision makers such as ACOs, policy makers, or other groups interested in evaluating and designing care coordination programs. Results from the survey suggest that children with disabilities have varying medical needs and thus care coordination needs. For example, approximately half of our survey respondents reported their child saw $>1$ medical provider over the past 12 months. Presumably, children who see fewer medical providers require fewer care coordination services. Decision makers can use this result to motivate the development of methods to identify those children who may benefit most from care coordination. Decision makers can also use the results of this study to inform the design of care coordination services by focusing on the elements of care coordination services that are positively correlated with caregiver/patient satisfaction and outcomes.

**Aim 3: Medicaid Claims Analysis to Compare Health Service Use for Children in the ACO Compared With Similar Children Not in the ACO**

Our findings suggest that being part of the ACO had a sizable impact on increased preventive services, particularly for adolescents when compared with similar children in non-ACO capitated managed care plans. Although primary care visits were similar between the 2 groups, access to primary care for children both in the ACO and non-ACO regions is relatively high, suggesting that access to primary care may not be problematic for this population and
thus not a focus of the ACOs’ efforts. While many payers tend to focus on reducing ED use, we found a modest increase in ED use for children in the ACO compared with similar children in non-ACO capitated managed care. Although studies on Medicaid-serving pediatric ACOs are limited, a recent analysis found similar increases in ED visits among children receiving Medicaid in an ACO compared with those not in an ACO in Minnesota.\textsuperscript{35} Our quantitative analysis cannot disentangle why there was an increase in ED visits, nor were there any indications in our qualitative analysis that might explain this pattern. It is possible that modest increases in ED visits for children in the ACO could indicate greater or more appropriate access to emergency services.

Our results show that the ACO had a higher rate of providing antidepressants and anxiolytic medications among children with disabilities compared with other capitated managed care plans. As child and adolescent depression and anxiety are substantially underdetected and undertreated in the United States,\textsuperscript{36} particularly among children with disabilities, this finding may reflect specific efforts by ACO providers to screen and detect mental health disorders. The increase in the use of antidepressants and antianxiety medications may also explain the increase in use of anticonvulsants. Members of our PAP reported their children were often prescribed anticonvulsants alongside antidepressants because of increased risk of seizures associated with some antidepressants.\textsuperscript{37,38} Moreover, our findings of a significant improvement in ADHD medication follow-ups may reflect the efforts of the ACO to implement the care coordination and disease management services to higher-risk patients.

Finally, our analysis revealed lower access to nontherapy home health use among children in the ACO compared with similar children in non-ACO capitated managed care plans. Home health services are determined by the managed care plans’ benefit design, not the ACO. Our analysis cannot explain why we might observe children in the ACO having lower access to home health services, and the existing literature is scant on home health utilization by children with disabilities. A possible explanation for this finding is that it may reflect a change in the supply of home health providers in the ACO region during the ACO implementation period. Alternatively, we cannot rule out that this difference may reflect a change in billing practices by
ACO providers compared with other managed care providers. Regardless, our qualitative analysis suggests that this particular health service is very important to patients and their caregivers.

Our results provide insights to ACOs, policy makers, and caregivers of children with disabilities on the degree of impact that being part of an ACO may have on health service utilization by children with disabilities. For example, it is unlikely that ABD-eligible children in ACOs will experience a reduction in ED visits and may possibly see an increase in these visits within the first 2 to 3 years of joining the ACO. ACO leaders, therefore, should not necessarily anticipate a reduction in health care costs attributable to ED reduction for this population. It may be that longer attribution in the ACO may be necessary to affect ED use, primary care, or other services. However, other dimensions of utilization, such as medication use, may be observable in the near-term after joining the ACO. Given the importance of home health services cited by caregivers in our study, ACOs, policy makers, managed care companies, and other decision makers may want to focus on improving access to home health services. Caregivers and advocates of children with disabilities may want to engage with ACO leaders, managed care plans, and policy makers to improve access to home health services. In general, our results do not indicate that being part of an ACO has a negative impact on quality of care for children with disabilities, and in some areas, such as access to medications, it may improve quality. Our findings are consistent with a previous study of this ACO that evaluated the impact on quality for its broader population.

Generalizability of the Findings

Our study is based on a specific population involving 1 large ACO in 1 state, following implementation of statewide capitated Medicaid coverage, which may limit the generalizability of our findings. In addition, children with disabilities became part of the ACO because of enrollment in Medicaid managed care plans in 1 region of the state. However, our study adds to the limited literature on pediatric ACOs and provides a basis on which future studies can build.
Implementation of Study Results

The results of this research have potential to be implemented in other settings, namely in other ACOs. Value-based payment design continues to gain momentum and new ACOs are developing across the country. Although Medicare ACOs have largely dominated the ACO market, there is increasing interest and growth in Medicaid and pediatric ACOs. As of 2017, 10 states have sponsored Medicaid ACOs (ie, Oregon, Utah, Colorado, Minnesota, Maine, Vermont, Massachusetts, Rhode Island, New Jersey, and New York). These states could use our results to help better predict what to expect with respect to utilization changes, or factors to consider when developing care coordination programs for this population.

Subpopulation Considerations

We conducted subsample analyses to test whether our results were similar in specific subpopulations based on region and diagnoses. Specifically, stratified analyses were performed based on urban/rural residency and various clinical diagnostic categories. We also conducted subsample analyses on children who had complex chronic conditions based on the PMCA. Our results were largely similar to our main analysis; however, some differences emerged. Access to primary care was reduced only for children with behavioral health or IDD diagnoses after ACO implementation, whereas reductions in psychiatric hospitalizations only occurred in rural areas. Finally, home health reductions were particularly acute among children with behavioral health, IDD, or complex conditions, compared with the full sample of children with disabilities. Although our results do not provide information as to why some utilization differences were more acute in specific subpopulations, these are vulnerable populations to which policy makers and plan administrators may want to pay more attention in order to limit access barriers.

Study Limitations

Our study has several important limitations. The qualitative data were self-reported and, in part, retrospective. Participants were asked to compare the present and recent past with a previous period, before July 2013. This retrospectivity is especially pertinent to the reported changes in service availability under managed care. A second limitation is that despite
enlisting both urban and rural participants, the research was conducted only in the central and southeastern part of 1 state, Ohio. In addition, our qualitative approach did not allow us to ensure representativeness; however, we were purposeful in our sampling to ensure we included the perspectives of both urban and rural family caregivers. To ensure this, we consulted with our PAP to determine which urban and rural counties we should target, resulting in focus groups and interviews across 7 counties in different areas of central and southeastern Ohio, including the Appalachian region. Although our caregiver survey was offered in Spanish, the focus groups and interviews were conducted only in English. It is possible that we did not capture the unique perspective of Spanish-speaking caregivers; however, only approximately 1% of caregivers took the survey in Spanish, suggesting that only a small proportion of our sample was excluded from participating in focus groups and interviews. The generalizability of the findings to Medicaid ACO states (listed previously) is also limited by the fact that the state of Ohio has not adopted a Medicaid ACO program; rather, the ACO featured in this research is a sui generis Medicaid-serving ACO. We were not always able to clearly discern which care coordination program each family participated in, and so could not comment on types of programs, or programmatic structures; thus we could only report broad caregiver perceptions and responses. Despite these limitations, this study provides insight into factors that may shape patient engagement with care coordination services.

In our survey analysis, only 41% of confirmed eligible respondents completed the survey, and caregivers who responded to the survey may not be representative of all caregivers who receive care coordination for their child. Although respondents were demographically similar to the sample frame, those with strongly held positive or negative opinions might have been more likely to agree to participate. We also lacked a variable to distinguish potential variation between web and phone respondents; however, the response rates were similar between the 2 data collection methods. We also cannot attribute the perceptions of care coordination to any specific source. Care coordination may be provided through physician’s offices, the child’s ACO or managed care plan, the county developmental disability board, or a combination of these and other sources. We cannot, therefore, make any statements about specific care coordination models. Another limitation concerns the survey responses, which are
based on self-report and caregiver perceptions. The caregiver’s perspective of the child having a care coordinator or receiving any care coordination services may not align with actual services received. In addition, for the key-driver regression analysis the sample used was small (n = 147), as complete responses to all 4 FECC quality measures were needed to conduct the analysis; this could affect the findings’ validity. In determining the child’s PMCA classification, we used health care visits available in the Medicaid claims data. Information on care received outside of Medicaid-approved providers was not included in our database, leading to possible misclassification.

Finally, our claims analysis has a few limitations. First, if any other factors disproportionately occurred in ACO-enrolled children in the post period as compared with controls, then the DID analysis is at risk of attributing their effect to the implementation of the ACO. Second, claims data do not contain complete information on all conditions experienced by insured populations, but rather those diagnoses noted by providers in billing data. In addition, it does not capture services that were not reimbursed by Ohio Medicaid (eg, paid entirely out-of-pocket). We employed quality and utilization algorithms that were designed for administrative claims data (eg, HEDIS [Healthcare Effectiveness Data and Information Set] measures) and we are likely to provide conservative identification of service utilization. We also triangulated the findings of aim 3 with the findings from interviews and focus groups in aims 1 and 2 for comparative analysis. Some outcomes could not be included due to lack of reliable coding algorithms, such as urgent care use, behavioral health specialists, and other specialists, and thus we were unable to assess how being in the ACO might have impacted utilization of these services. Another limitation of our study is the relatively short study period post ACO-implementation. It may be that investments in health care services made by the ACO in its early years won’t pay off in terms of utilization differences for several years postimplementation. Despite these limitations, our study is the first to provide insights into how a Medicaid-funded ACO impacted a population of pediatric patients that have high demands for medical resources.
Future Research

Future research should focus on the impact of ACOs on children’s health and outcomes. Vulnerable populations, such as children with disabilities or youth in foster care, are of particular concern due to their medical and social needs. Although the results of our study are informative, they are focused on 1 ACO in 1 state and more research involving more ACOs across various geographic regions is needed. Further, ACOs serving Medicaid-eligible children with disabilities and other low-income populations should acknowledge the limits of what health care innovation can achieve and seek out opportunities to ally themselves with broader anti-poverty efforts—at the community level, through the state Medicaid program, or as part of a higher-level effort to reduce American inequality. Future research should focus on the ways in which innovative health care organizations such as ACOs do or do not succeed in reducing the scarcities that undermine health.
CONCLUSIONS

Caregivers did not perceive that becoming part of an ACO increased their access to care coordination services. Many of the needs for caregivers applied more to social services than to medical services. The biggest impact noted was the change in benefits associated with the change from fee-for-service to Medicaid managed care. When caregivers were offered care coordination services, factors related to availability, alignment, ease or difficulty of engagement, and timing were found to be associated with caregiver engagement or disengagement.

Just over half of caregivers reported seeing > 1 medical provider in the past 12 months, which suggests not all children with disabilities “need” care coordination services. Of those who did see multiple providers, most reported having someone help coordinate their care though not necessarily through formal care coordination services offered through the ACO. Care coordinators who asked about the child’s health changes/concerns and were knowledgeable, supportive, and advocated for the child were the most important drivers of caregiver satisfaction.

Overall, being part of an ACO, in addition to the switch to capitated managed care, did not appear to have any negative impacts on quality as indicated by health services use. Being part of the ACO did not decrease emergency department visits or increase primary care visits over the level experienced by similar children who switched to managed care plans statewide. There was some evidence of increased preventative services through adolescent well-child visits in the ACO region. Children in the ACO also had increased access to antidepressants, anticonvulsants, and antianxiety medication and decreased use of ADHD medication over similar children in capitated managed care plans. Home health services, which were noted as a great concern during our focus groups and interviews, declined for those in the ACO vs those in the comparison group.
REFERENCES


ACKNOWLEDGMENTS

The authors wish to thank all the families, as well as Partners for Kids and Nationwide Children’s Hospital, for participating in this study. In addition we would like to thank the members of our patient advisory panel for their active participation and insightful feedback; Charles Micha Belden for assisting with the study’s implementation; Anna Hoffmeyer, Tim Egan, and Robert Agans from the Carolina Survey Research Lab for assistance with survey administration; Emily Alexy, Laura Chavez, Millie Harris, and Yuri Sebastio of Nationwide Children’s Hospital for input on analysis and interpretation; Arielle Sheftall for quantitative data analysis and manuscript development; and Abby Hoffman for qualitative data analysis and manuscript development. Management of medical record abstraction data was supported in part by Clinical and Translational Science Award grant number UL1TR0010.
APPENDICES

Appendix A. Patient Advisory Panel Members

**Patient Advisory Panel**

The Patient Advisory Panel consists of parent caregivers of children with disabilities and/or individuals who have professional expertise as advocates for children with disabilities, led by co-investigator Thomas Scheid.

**Members and Former Members**

Thomas Scheid, co-investigator, Health Policy Consultant, Voices for Ohio’s Children

Maria Beckstedt, Parent Caregiver

Patty Dovell, Parent Caregiver

Rachel Eakins, Parent Caregiver

Becky Fusco, Parent Caregiver

Peggy Martin, Parent Caregiver

Stacy Murphy (formerly Isenbarg), Parent Caregiver

Marla Root, Parent Caregiver

Melissa Ropp, Parent Caregiver

Geoffrey Collver, Policy and Communications Director, Disability Rights Ohio

Earnestine Hargett, Senior Disability Rights Advocate, Disability Rights Ohio

Candace Knight, Director of Programs and Services, Easter Seals Central and Southeast Ohio

Kristy Emch-Roby, Chief Operating Officer, Easter Seals Central and Southeast Ohio

Melissa Kimmel, Chief Operating Officer, Easter Seals Central and Southeast Ohio
Sandy Oxley, Chief, Maternal, Child and Family Health, Ohio Department of Health

Angie Lee, Observer, Easter Seals Central and Southeast Ohio

Note: Easter Seals had one representative attend the PAP meetings at any given point in time during the project.
Appendix B. Detailed Patient and Stakeholder Engagement

The Patient Advisory Panel (PAP) consisted of 12 members, including seven family caregivers of patients (i.e., parents of children with disabilities) and five representatives of statewide advocacy or state health organizations working with this population. Two of the caregivers and three of the stakeholder agency representatives had worked together previously as part of an advisory group to the state Medicaid agency on communicating with families when the Medicaid agency implemented the policy change to serve this population through managed care rather than on traditional fee-for-service. They were therefore very familiar with the challenges and opportunities with moving this population into managed care following the policy change. Voices for Ohio’s Children, a patient advocacy organization, had chaired this earlier advisory group.

In expanding that original advisory group, we aimed to maintain a strong patient voice that would be representative of the various disability groups affected and that had experience receiving services through fee-for-service, managed care, and an ACO. We included caregivers whose children were at different age groups and who needed different types of medical services and care coordination. We recruited via letters and personal phone calls to statewide and county organizations that serve families of children with disabilities and parent advisory groups operated by the ACO. Potential PAP members were sent materials to describe the project and the role/expectations of the PAP; they received a personal follow-up interview to answer their questions and determine their interest and suitability. The interview process helped us identify PAP members who understood the patient engagement process, really wanted to be part of it, and felt empowered to speak up and share their views.

Keeping the PAP members engaged throughout the project was accomplished primarily through providing consistent and visible feedback to the PAP members on their participation. At every meeting, the research team made sure to close the loop on the PAP’s input. PAP members really appreciated knowing exactly what the researchers heard in the conversation, how they thought it could be reflected in the project work plan or in project communications, and exactly how input was going to be used. PAP members talked about how this made them...
feel like they were really respected as “experts” and that their opinions mattered. Running these meetings like a business also made them feel like they were being taken seriously. When a topic generated a lot of discussion, the research team would adjust the agenda on the fly to allow more time for PAP discussion and recommendations. And, because patient stakeholders felt that they were being taken seriously and their input was having an impact on the research, they were very engaged in discussions during the meeting and put time and thought into preparing for the meetings.

Although we had a very motivated and committed group of patient stakeholders, we had to replace two of them mid-way through the project due to unplanned demands on their time as the needs of their families changed. We had anticipated a possible need to replace some members of the PAP during the project and were prepared to go back through the same process as we followed for the initial recruitment, including one-on-one time to bring new members up to speed on the project. In retrospect, it would have gone more smoothly if we had initially over-recruited and had one or two potential patient stakeholders to immediately go to following a vacancy.

Our PAP members were meaningfully involved in the project from the initial stages of proposal development through the implementation process. The final framing of the research questions and study design was based on suggestions from stakeholders, that what was needed was a more informative comparative analysis to evaluate how children were affected before and after the policy change in addition to comparing experiences and outcomes for this population in ACO vs non-ACO settings. The PAP also suggested that the analysis needed to be stratified by risk and severity, recognizing the different levels and types of care coordination needs among the broad group of children with special health care needs.

The research involved conducting various types of interviews and focus groups and the PAP provided specific recommendations on family-friendly wording and ways to approach families to increase their willingness to participate and helped recruit possible participants. They provided insights on preliminary results from a family perspective on how such factors as a lack of services in non-urban areas, and unwillingness to disrupt existing sources of care
coordination services, could affect family perceptions on care coordination. As preliminary research results became available and were shared at the last three quarterly meetings of the PAP, there was specific discussion on what was being learned from the research that would be of most interest to families and possible strategies for getting the information to them. The PAP was asked to respond to three basic questions: what they found interesting about the findings; ways they thought the researchers could share the findings, and audiences they thought would be interested in learning about the findings. The PAP recommended specific organizations who might be approached to disseminate information on the project as they are trusted sources of information for families of children with special health care needs. These quarterly meetings of the PAP were the primary means for soliciting input and engagement, so we made sure to get information out to members the week before meetings, so they knew what materials were going to be discussed and what kinds of questions the research team had for them to discuss. We put a priority on members attending each meeting in-person so we could have face-to-face discussions. Those who missed meetings received a follow-up phone call to review the discussion highlights and to ask for any input. Members of the Patient Advisory Panel participated in the Voices for Ohio’s Children Conference on a panel discussion to share their experiences with being engaged in this research project. This activity generated interest by the research team to potentially develop a manuscript to share our experience with patients/stakeholders about engagement in research. Finally, ACO stakeholders (including leadership, care coordinators, and clinicians) were invited to several PAP meetings and gave thoughtful, insightful feedback on preliminary results.
Appendix C. Project Timeline

Project Time Line – 3 Year Study

- Year 1 (9/2014-8/2015)
  - ACO Stakeholder Interviews
  - Patient/Caregiver Focus Groups
  - Quarterly Patient Advisory Panel Meetings*

- Year 2 (9/2015-8/2016)
  - Caregiver Interviews
  - Caregiver Surveys / Medical Record Abstraction
  - Quarterly Patient Advisory Panel Meetings

- Year 3 (9/2016-8/2017)
  - Medicaid Claims Analysis
  - Interview, Survey and Claims Integration & Analysis
  - Quarterly Patient Advisory Panel Meetings

- Dissemination of Study Results

* Approximately 10 hours per year; Compensation $75/hour; Led by Voices for Ohio’s Children & Ohio State University
Appendix D. Recruitment Materials

Recruitment Email: ACO Stakeholder

Dear [Stakeholder]:

[Insert Name] referred me to you as someone who might be interested in participating in an interview about health care coordination for children with disabilities as part of a research study I am conducting with partners at Ohio State University and Nationwide Children’s Hospital.

The Patient-Centered Outcomes Research Institute (PCORI) funded this research project to enhance our understanding about care coordination before and after the transition from fee-for-service to the accountable care organization (ACO) model of care for children with disabilities. The research we are conducting will provide PCORI with usable, evidence-based information about care coordination under the ACO model. We are interested in learning from stakeholders such as yourself about perspectives and experiences with care coordination before and after the transition. Our study has been approved by the Institutional Review Boards at the University of North Carolina at Chapel Hill and Ohio State University.

Approximately 30 individuals will participate in the interviews, including ACO leadership, care coordinators, clinicians, and payor representatives. Topics we will cover in the interview include:

- Care coordination before and after the policy change
- Delegation
- Metrics and evaluation
- Hospitalization and discharge
- Overall assessment

I hope you will consider participating in our study. Please feel free to contact me with any questions at the phone number or email address listed below. Thank you for your consideration, and I look forward to hearing from you.
Sincerely,

Paula Song, PhD
Principal Investigator
Associate Professor, Health Policy and Management
The University of North Carolina at Chapel Hill
Cecil G. Sheps Center for Health Services Research
725 Martin Luther King, Jr. Blvd
Chapel Hill, NC 27599
Phone: (919) 966-8778
Fax: (919) 966-5764
Email: psong@unc.edu
Recruitment Email: Patient Advisory Panel/Voices for Ohio’s Children –

Focus Groups

Dear [Member of Patient Advisory Panel] [Representative of Voices for Ohio’s Children],

I’m writing to request your help in recruiting participants to a research study that I am conducting together with researchers at The Ohio State University and Nationwide Children’s Hospital. The purpose of the research is to enhance our understanding about care coordination for children with disabilities. Our study has been approved by the Institutional Review Boards at the University of North Carolina at Chapel Hill and Ohio State University. The study is funded by the Patient-Centered Outcomes Research Institute (PCORI). Information about PCORI can be found at http://www.pcori.org/. Specific information about our project can be found at http://www.pcori.org/research-results/2014/improving-care-coordination-children-disabilities-through-accountable-care.

We plan to conduct focus groups with eligible teens and parents/family caregivers about their experiences with their health care providers and with care coordination. Participants will receive a $50 gift card for their time.

I’ve attached flyers with more information. If you would, please distribute the attached flyers to persons and/or groups who might be interested in our study by [DATE] as the focus groups will be conducted [TIME PERIOD].

Please feel free to contact me with any questions at the phone number or email address listed below.

Thank you for supporting this important research!

Sincerely,

Paula H. Song, PhD
Principal Investigator
Recruitment Email: Patient Advisory Panel/Voices for Ohio’s Children – Interviews

Dear [Member of Patient Advisory Panel] [Representative of Voices for Ohio’s Children],

I’m writing to request your help in recruiting participants to a research study that I am conducting together with researchers at The Ohio State University and Nationwide Children’s Hospital. The purpose of the research is to enhance our understanding about care coordination for children with disabilities. Our study has been approved by the Institutional Review Boards at the University of North Carolina at Chapel Hill and Ohio State University. The study is funded by the Patient-Centered Outcomes Research Institute (PCORI). Information about PCORI can be found at http://www.pcori.org/. Specific information about our project can be found at http://www.pcori.org/research-results/2014/improving-care-coordination-children-disabilities-through-accountable-care.

We plan to conduct interviews with eligible parents/family caregivers of children with disabilities about their experiences with their child’s health care providers and with care coordination. Participants will receive a $50 gift card for their time.

I’ve attached flyers with more information. If you would, please distribute the attached flyers to persons and/or groups who might be interested in our study by [DATE] as the interviews will be conducted [TIME PERIOD].

Please feel free to contact me with any questions at the phone number or email address listed below.

Thank you for supporting this important research!

Sincerely,

Paula H. Song, PhD
Principal Investigator
Associate Professor, Health Policy and Management
Parent/ Family Caregiver

Focus Group

Are you a parent or family member who provides care to a child between 3 and 18 years old?

Do you live in central or southeastern Ohio?

Does your child receive Medicaid due to a disability?

If so, you may be eligible to participate in a focus group as part of a research study and tell us about your child’s experiences with his or her health care providers and Nationwide Children’s Hospital.

In a focus group, there are no right or wrong answers. We just want to know what you think!

Please respond by June 19th, 2015

Focus Groups will be held June 23-27th in Columbus, Cambridge & Athens

- You will receive a $50 gift card for participation.
- Light refreshments will be provided.
- There is no cost to you for participating.
- Any feedback provided during the focus group will be confidential.
- Your decision to participate will not affect your or your child’s medical care or relationship with Nationwide Children’s Hospital.
For more information, please call toll-free 1-888-218-1040 or email

PCORI_focusgroup@nationwidechildrens.org

This study is being conducted by the University of North Carolina at Chapel Hill, Ohio State University, and Nationwide Children’s Hospital, and is funded by the Patient-Centered Outcomes Research Institute (PCORI).

Dr. Paula Song is the study principal investigator and can be reached at 919-966-8778.
Youth Patient Focus Group

Are you 15-18 years old? Do you live in central or southeastern Ohio? Do you receive Medicaid due to a disability?

If so, you may be eligible to participate in a focus group as part of a research study and tell us about your experiences with your health care providers and Nationwide Children’s Hospital.

In a focus group, there are no right or wrong answers. We just want to know what you think!

Please respond by June 19th, 2015

Youth Focus Groups will be held June 25th in Athens & June 26th in Columbus

• You will receive a $50 gift card for participation.
• Light refreshments will be provided.
• There is no cost to you for participating.
• Any feedback provided during the focus group will be confidential.
• Your decision to participate will not affect your medical care or relationship with Nationwide Children’s Hospital.

For more information, please call toll-free 1-888-218-1040 or email PCORI_youthfocusgroup@nationwidechildrens.org
This study is being conducted by the University of North Carolina at Chapel Hill, Ohio State University, and Nationwide Children’s Hospital, and is funded by the Patient-Centered Outcomes Research Institute (PCORI).

Dr. Paula Song is the study principal investigator and can be reached at 919-966-8778.
Parent/ Family Caregiver

Interviews

Are you a parent or family member who provides care to a child between 3 and 18 years old? Do you live in central or southeastern Ohio? Does your child receive Medicaid due to a disability?

If so, you may be eligible to participate in an interview as part of a research study and tell us about your child’s experiences with his or her health care providers and Nationwide Children’s Hospital.

In this interview, there are no right or wrong answers. We just want to know what you think!

Please respond by [DATE] to be considered for participation in an interview.

- You will receive a $50 gift card for participation.
- There is no cost to you for participating.
- Any feedback provided during the interview will be confidential.
- Your decision to participate will not affect your or your child’s medical care or relationship with Nationwide Children’s Hospital.

If you are interested or would like more information,
please contact the study coordinator toll free at 1-888-218-1040, or via email at caregiverinterview@nationwidechildrens.org.

If you have questions, you may also call the research study principal investigator, Paula Song, at 919-966-8778.

This research is being conducted by researchers at the University of North Carolina at Chapel Hill, Ohio State University, and Nationwide Children’s Hospital, and is funded by the Patient-Centered Outcomes Research Institute (PCORI).
Appendix E. Interview and Focus Group Guides

Interview Guide for ACO Stakeholders

Improving Care Coordination for Children with Disabilities Through an Accountable Care Organization

Supplies:
1. Consent forms (2 copies per participant)
2. Digital recorders, extra batteries

INTRODUCTION AND BACKGROUND

First, THANK YOU for agreeing to participate in this research project. We are researchers from the University of North Carolina at Chapel Hill and The Ohio State University in Columbus, Ohio. [Introduce researchers by name.] As you may know, we are studying how care is coordinated for children with disabilities. In particular, we are comparing coordination of care for the pediatric ABD population in central and southeast Ohio before and after the recent policy change that moved this population into managed care. This research is part of a study funded by the Patient Centered Outcomes Research Institute.

You have been identified to participate in this research because of your role as a(n) [administrator/provider/payor] who is knowledgeable about the transition of the pediatric ABD population in this region into Partners For Kids and of efforts to coordinate the care of this population before and after this policy change. We have scheduled the next hour to learn more about these matters from you.

We are going to be talking a lot about managing and coordinating health care, so it might help to explain that we are interested in learning what we can about both the formal, official means, as well as, the informal and unofficial means by which care is coordinated. Throughout the interview we’ll ask you to compare and contrast situations before and after the July 2013 policy change.

Do you have any questions before we get started?
**INTRODUCTION**

First, for context, we’d like to learn a little about you.

- What are your title, role and responsibilities at [organization]?
- What was your role and responsibilities with respect to implementing the policy change and moving the pediatric ABD population into managed care?

**THE POLICY CHANGE**

We want to talk about services and care coordination before and after the policy change, but before we do that, let’s first talk about the policy change itself.

- What is your understanding of the rationale for the policy change? What prompted it?
- What was your opinion of the policy change before it went into effect? Did you see it as a good thing? Bad thing? Mixed?

[prompts]

- Why?
- What, if any, concerns did you have?
- What, if any, benefits did you anticipate from it?

- What is your opinion of the policy change now?

[prompts]

- Why?
- What, if any, concerns do you have going forward?
- What, if any, benefits did you anticipate going forward?

**BEFORE THE POLICY CHANGE**

Let’s focus for a little while on the situation before the policy change, that is, before July 2013.
• What can you tell us generally about the provision of health services for this population prior to the policy change?

[prompts]

– ?

• What can you tell us more specifically about the coordination of care for this population prior to the policy change?

[prompts]

– Were any resources or programs dedicated to care coordination for the pediatric ABD population?
– [If yes: describe]
– [If no: why not]
– Were there other services or resources that patients and their caregivers used to help coordinate care?
  ▪ [Community? Social workers? Therapists? Family or friends? Others?]

**AFTER THE POLICY CHANGE**

Let’s focus now on the situation since the policy went into effect, that is, since July 2013.

• What can you tell us generally about the provision of health services for this population since the policy change?

[prompts]

– Any changes in what services are available or covered for this population?
• What can you tell us more specifically about the coordination of care for this population since the policy change?

[prompts]

– Are any resources or programs dedicated to care coordination for the pediatric ABD population?
Are there other services or resources that patients and their caregivers use to help coordinate care?
- [community? Social workers? Therapists? Family or friends? Others?]

Are any additional coordination efforts or services planned or under consideration?

[for Care Coordinators and Providers] YOUR ROLE IN CARE COORDINATION

Let’s talk about your role in care coordination.

- What, if any, role do you play in helping to coordinate care for your ABD pediatric patients?

[prompts]

- Examples?
- How, if at all, has this changed since the conversion from the OLD PLAN to the NEW PLAN?

- How well informed do you feel you are about the care provided to your pediatric ABD patients by other doctors and healthcare providers?

[prompts]

- Examples?
- Do you have access to these patients’ complete medical records electronically? If so, could you talk about how you see this impacting your practice?
- How, if at all, has this changed since the conversion from the OLD PLAN to the NEW PLAN?

[for Payors and ACO Administrators] DELEGATION AND CARE COORDINATION

Let’s talk about how responsibilities are shared between the managed care plans and PFK.
With respect to ABD pediatric patients, what responsibilities are retained by the managed care plan and what responsibilities are delegated to PFK?

- [prompts]
- **Examples**?
- Coordination of care in particular?
- How did this change since the conversion from the OLD PLAN to the NEW PLAN?
- In your opinion, how is this arrangement working out?

**METRICS AND EVALUATION**

Let’s talk now about efforts to measure and evaluate the costs and quality of care in general and any care coordination efforts in particular.

- What evaluation efforts are in place?
  
  [prompts]
  
  - What metrics do you use?
  - How did you decide on these metrics?
  - Was there any patient or caregiver involvement in determining these metrics?
  - How, if at all, has this changed since the conversion from the OLD PLAN to the NEW PLAN?
  - Do you have any results of evaluations you can share with us?

**HOSPITALIZATIONS**

Let’s talk about care coordination and hospitalizations.

- What are the big issues or concerns for this population in terms of hospitalizations?

  [prompts]
  
  - **Examples**?
  - How, if at all, has the move into managed care impacted these issues/concerns?
  - What has been done or is currently being done to address these issues/concerns?

- How is care coordination managed during a hospitalization?
[prompts]

– How, if at all, has this changed since the conversion from the OLD PLAN to the NEW PLAN?

• What is the discharge process like? How are communications between inpatient and outpatient settings handled?

[prompts]

– How, if at all, has this changed since the conversion from the OLD PLAN to the NEW PLAN?

**OVERALL ASSESSMENT**

• In your opinion, is an ACO model, such as PFK, better positioned to coordinate care for the pediatric ABD population than the previous fee-for-service model or perhaps some other model? Why?

[prompts]

– Is the ACO model better in some ways but not as good in others?

• Overall, what would you say is working best currently for the ABD pediatric population?

[prompts]

– *Examples?*

– How, if at all, is this different since the conversion from the OLD PLAN to the NEW PLAN?

• Overall, what would you say is most in need of improvement for the ABD pediatric population?

[prompts]

– *Examples?*
– How, if at all, is this different since the conversion from the OLD PLAN to the NEW PLAN?

• Overall, how would you compare care coordination under the OLD PLAN with care coordination under the NEW PLAN?

[prompts]

– What, if anything, has gotten better?
– What, if anything, has gotten worse?

CLOSING

• Is there anything else you’d like to share? Anything else we should know that we haven’t asked about?

    Thank you for your time and participation. Your comments were extremely helpful.
Focus Group Guide for Patients & Caregivers

Improving Care Coordination for Children with Disabilities Through an Accountable Care Organization

**Supplies:**

1. Consent forms (2 copies per participant)
2. Participant list and sign in sheet
3. Demographic questionnaire
4. Gift cards for participant payment
5. Markers, signs, pens and paper
6. Digital recorders, extra batteries
7. Refreshments

**INTRODUCTION AND BACKGROUND**

First, THANK YOU for agreeing to participate in this research project. We are researchers from the University of North Carolina at Chapel Hill and The Ohio State University in Columbus, Ohio. [Introduce researchers by name.] We are here to learn from you about the experiences you have had with health care for [yourself/your child]. As you may know, we are studying the care needs and experiences of children with disabilities and their caregivers. This research is part of a study funded by the Patient Centered Outcomes Research Institute.

You have been identified to participate in this group because as a [person/parent of a child] with a disability, you know better than anyone what’s involved with obtaining and coordinating needed services. We have scheduled the next hour and a half to discuss [your/your child’s] care needs and how well the health care system coordinates the various services you require, as well as your own role in coordinating those services.

We are going to be talking a lot today about coordinating health care, so it might help to explain what we mean. When people receive health care services from multiple doctors, therapists and other providers, there is usually a lot of work involved in making all of that care fit together in a way that benefits the individual. For example, we are interested in hearing...
about your experiences finding health care providers, scheduling appointments, resolving problems that arise with services received, dealing with duplicated care, facilitating conversations between health care providers, or any number of other activities that you or someone else acting on your behalf has had to do to make the different services that [you/your child] receive fit together. In short, we want to learn more about how you ensure that [you/your child] gets the care that [you/they] need in a timely manner.

As you may know, in July 2013, the state of Ohio made some changes to the way that health care services for ABD children are managed. We’re interested in knowing whether you have noticed any changes as a result in terms of the care [you/your child] receives or the way that care is coordinated. So, when I ask you to talk about these changes, I’ll ask about care under the Old System, that is before July 2013 vs care under the New System, that is since July 2013. You may also know this New System as “managed care” (e.g. CareSource, Molina, Paramount, Buckeye Health, or United Healthcare). Do you have any questions about this?

**INTRODUCTIONS**

Before we begin, please take a moment to write down all of the people you can think of, including yourself, who play a role in coordinating the care [you/your child] receives. Also, write down some examples of what each of these people do. We won’t be collecting these notes. They are meant to get you thinking about the topic and to serve as a memory aid that you can refer to as we continue to talk. [Allow time to write down these notes.]

Now, to get going, let’s have each of you introduce yourself and briefly describe [your/your child’s] health care needs. Since our time is limited, please just give us a quick overview of your situation. There will be more opportunities to tell us stories in greater detail a little later.

**COORDINATING CARE**

Let’s talk about coordinating the care [you/your child] receives from multiple doctors and other health care providers. You can use the notes you’ve jotted down.
Let’s start with a general question about what care coordination means to you. In your opinion: if [your/your child’s] care were well coordinated, what would that look like?

What is your role in coordinating [your/your child’s] care?

[prompts]

• Example?
• How easy or difficult is it for you to coordinate [your/your child’s] care?
• How, if at all, has this changed since the conversion from the OLD SYSTEM to the NEW SYSTEM?

Who else helps manage or coordinate care for [you/your child]? And how?

[prompts]

• Pediatrician?
• Nurse?
• Care coordinators or case managers?
• Social workers?
• Therapists?
• Family or friends?
• Others?
• Examples?
• How, if at all, has this changed since the conversion from the OLD SYSTEM to the NEW SYSTEM?

What, if any, resources in your community are helpful for coordinating care? And how?

[prompts]

• Support groups?
• Help Me Grow; Home Visiting; BCMH; School System; PCP; ADAMH; County Board of Developmental Disabilities

• **Examples?**

• How, if at all, has this changed since the conversion from the OLD SYSTEM to the NEW SYSTEM?

If you have a designated care coordinator, how well informed is that person about [your/his or her] health conditions?

[prompts]

• **Examples?**

• Do they have access to [your/your child’s] complete medical record electronically?

• Do they only review your child’s chart once per year?

What else, if anything, do you need or want in terms of coordinating your child’s care? What additional help or resources would improve [your/your child’s] outcomes and experiences?

How well informed are [your/your child’s] other doctors and healthcare providers about [your/his or her] health conditions?

[prompts]

• **Examples?**

• Do they have access to [your/your child’s] complete medical record electronically?

• How, if at all, has this changed since the conversion from the OLD SYSTEM to the NEW SYSTEM?

**ACCESSING NEEDED CARE**

How easy is it to get the care [you/your child] needs? What is easy? What is difficult?

[prompts]
• Getting necessary appointments?
• Timeliness—not having to wait?
• How, if at all, has this changed since the conversion from the OLD SYSTEM to the NEW SYSTEM?

Think about a time when you had difficulty accessing needed care. What did you do?
[prompts]

• Did anyone else help you? How?
• Was this under the OLD SYSTEM or the NEW SYSTEM?

**SATISFACTION AND QUALITY OF CARE**

How satisfied are you with the quality of care [you/your child] receive(s)?
[prompts]

• [care coordination example? Example(s) beyond coordination?]
• Would you give a specific example of something you have been particularly satisfied with?
• Would you give a specific example of something you have been particularly dissatisfied with?
• How, if at all, has this changed since the conversion from the OLD SYSTEM to the NEW SYSTEM?

**HOSPITALIZATIONS**

I’d like to hear about your experiences with hospitals, for those of you [who have/whose child has] been hospitalized.

What was the experience like? And was this under the OLD SYSTEM or the NEW SYSTEM?
[prompts]

• **Examples** under both systems?

What was the discharge process like? Did the hospital communicate and coordinate well with your doctor or other healthcare providers?
ADDITIONAL CONCERNS

What other concerns do you have or what other challenges do you face with respect to coordinating [your/your child’s] care?

[prompts]

• School?
  – Childcare?
  – Transportation?
  – Social services?
  – Medications?
  – Transition to adulthood?

OVERALL ASSESSMENT

Overall, what would you say is the biggest challenge in terms of the coordination of care for [you/your child]? In other words, what is most in need of improvement?

[prompts]

• Examples?

• How, if at all, has this changed since the conversion from the OLD SYSTEM to the NEW SYSTEM?

Overall, what would you say is the best aspect of the coordination of care for [you/your child]? In other words, what is working best?

[prompts]

• Examples?
• How, if at all, has this changed since the conversion from the OLD SYSTEM to the NEW SYSTEM?

Overall, how would you compare care coordination under the OLD SYSTEM with care coordination under the NEW SYSTEM?

[prompts]

• What, if anything, has gotten better?
• What, if anything, has gotten worse?

**CLOSING**

Is there anything else you’d like to share? Anything else we should know that we haven’t asked about?

Thank you for your time and participation. Your comments were extremely helpful.
Interview Guide for Caregivers

Improving Care Coordination for Children with Disabilities Through an Accountable Care Organization

**Supplies:**
1. Consent forms (2 copies per participant)
2. Participant payment
3. Digital recorders, extra batteries

**INTRODUCTION AND BACKGROUND**

First, THANK YOU for agreeing to participate in this research project. We are researchers from the University of North Carolina at Chapel Hill and The Ohio State University in Columbus, Ohio. [Introduce researchers by name.] We are here to learn from you about the experiences you have had with health care for your child. As you may know, we are studying the care needs and experiences of children with disabilities and their caregivers. This research is part of a study funded by the Patient Centered Outcomes Research Institute.

You have been identified to participate in this research because as a parent of a child with a disability, you know better than anyone what’s involved with obtaining and coordinating needed services. We have scheduled the next hour to discuss your child’s care needs and how well the health care system coordinates the various services you require, as well as your own role in coordinating those services.

We are going to be talking a lot today about coordinating health care, so it might help to explain what we mean. When people receive health care services from multiple doctors, therapists and other providers, there is usually a lot of work involved in making all of that care fit together in a way that benefits the individual. For example, we are interested in hearing about your experiences finding health care providers, scheduling appointments, resolving problems that arise with services received, dealing with duplicated care, facilitating conversations between health care providers, or any number of other activities that you or someone else acting on your behalf has had to do to make the different services that your child...
receives fit together. In short, we want to learn more about how you ensure that your child gets the care that s/he needs in a timely manner.

As you may know, in July 2013, the state of Ohio made some changes to the way that health care services for ABD children are managed. We’re interested in knowing whether you have noticed any changes as a result in terms of the care your child receives or the way that care is coordinated. So, when I ask you to talk about these changes, I’ll ask about care under the Old System, that is before July 2013 vs care under the New System, that is since July 2013. You may also know this New System as “managed care” (e.g. CareSource, Molina, Paramount, Buckeye Health, or United Healthcare). Do you have any questions about this?

YOU AND YOUR FAMILY

For context, it would be helpful if you tell me a little about yourself, your child and your family situation in general.

• To start, please tell me a little about yourself.

[prompts]

– Work outside the home?

• Tell me a little about your family?

[prompts]

– Spouse or partner (including employment)?
– Children?
– Others who live with you or are an integral part of your daily life?

• Tell me about your child?

[prompts]

– Age?
– Condition(s)?
– How long?
– How (if at all) has his/her condition(s) changed over time?
**IMPACT OF THE DISABILITY**

I’d like to understand what impact you see the disability having on your child, on your family and on you.

- On your child?
  
  [prompts]
  
  – Daily activities?
  – School (if school age)?
  – Other impacts?

- On your family and household routines?
  
  [prompts]
  
  – Spouse/partner?
  – Other children?
  – Household routines?

- On you?
  
  [prompts]
  
  – Health?
  – Other impacts?

**COORDINATING CARE**

Now, let’s talk about managing and coordinating the care your child receives from multiple doctors and other health care providers.

- Let’s start with a general question about what care coordination means to you. In your opinion, if your child’s care were well coordinated, what would that look like?
- What is your role in coordinating your child’s care?
  
  [prompts]
– **Example?**
– How easy or difficult is it for you to coordinate your child’s care? Why?
– How, if at all, has this changed since the conversion from the OLD PLAN to the NEW PLAN?

• Who else helps manage or coordinate care for your child? And how?

[prompts]

– Pediatrician?
– Nurse?
– Care coordinators or case managers?
– Social workers?
– Therapists?
– Family or friends?
– Others?
– **Examples?**
– How, if at all, has this changed since the conversion from the OLD PLAN to the NEW PLAN?

• What, if any, resources in your community are helpful for managing and coordinating care? And how?

[prompts]

– Support groups?
– Help Me Grow; Home Visiting; BCMH; School System; PCP; ADAMH; County Board of Developmental Disabilities
– **Examples?**
– How, if at all, has this changed since the conversion from the OLD PLAN to the NEW PLAN?

• Do you have a designated care coordinator?
• If so:
– How well informed is that person about your child’s health conditions?
  [prompts]
    o *Examples*?
    o Do they have access to your child’s complete medical record electronically?
    o Do they only review your child’s chart once per year?

– How helpful is that person and why?
  [prompts]
    o *Examples*?

• What else, if anything, do you need or want in terms of coordinating your child’s care?
  What additional help or resources would improve [your/your child’s] outcomes and experiences?

• How well informed are your child’s other doctors and healthcare providers about his or her health conditions?
  [prompts]
    – *Examples*?
    – Do they have access to your child’s complete medical record electronically? If so, could you talk about how you see this impacting the care your child receives?
    – How, if at all, has this changed since the conversion from the OLD PLAN to the NEW PLAN?

ACCESSING NEEDED CARE

• How easy is it to get the care your child needs? What is easy? What is difficult?
  [prompts]
    – Getting necessary appointments?
    – Timeliness—not having to wait?
    – *Examples*?
How, if at all, has this changed since the conversion from the OLD PLAN to the NEW PLAN?

Think about a time when you had difficulty accessing needed care for your child. What did you do?

[prompts]

Did anyone else help you? How?

Was this under the OLD PLAN or the NEW PLAN?

### SATISFACTION AND QUALITY OF CARE

How satisfied are you with the quality of care your child receive(s)?

[prompts]

[care coordination example? Example(s) beyond coordination?]

[example(s) of something you have been particularly satisfied with?]

Would you give a specific example of something you have been particularly dissatisfied with?

How, if at all, has this changed since the conversion from the OLD PLAN to the NEW PLAN?

### HOSPITALIZATIONS

If your child has ever been hospitalized, I’d like to hear about that experience.

What was the experience like? And was this under the OLD PLAN or the NEW PLAN?

[prompts]

Examples under both plans?

What was the discharge process like? Did the hospital communicate and coordinate well with your doctor or other healthcare providers?

[prompts]
- *Examples* under both plans?

**ADDITIONAL CONCERNS**

- What other concerns do you have or what other challenges do you face with respect to managing and coordinating your child’s care?

[prompts]

- School?
- Childcare?
- Transportation?
- Social services?
- Medications?
- Transition to adulthood?

**OVERALL ASSESSMENT**

- Overall, what would you say is the biggest challenge in terms of the coordination of care for your child? In other words, what is most in need of improvement?

[prompts]

- *Examples*?
  - How, if at all, has this changed since the conversion from the OLD PLAN to the NEW PLAN?

- Overall, what would you say is the best aspect of the coordination of care for your child? In other words, what is working best?

[prompts]

- *Examples*?
  - How, if at all, has this changed since the conversion from the OLD PLAN to the NEW PLAN?
• Overall, how would you compare care coordination under the OLD PLAN with care
  coordination under the NEW PLAN?

[prompts]

  – What, if anything, has gotten better?
  – What, if anything, has gotten worse?

CLOSING

• Is there anything else you’d like to share? Anything else we should know that we haven’t
  asked about?

  Thank you for your time and participation. Your comments were extremely helpful.
## Appendix F. Qualitative Data Codebook

### PCORI Project Focus Group Coding Dictionary 1.2

<table>
<thead>
<tr>
<th>Codes</th>
<th>Abbreviation</th>
<th>Definitions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal Background</td>
<td></td>
<td>Focus group participant's personal or professional background</td>
</tr>
<tr>
<td>Description of ABD Child</td>
<td></td>
<td>Statements about the child's health condition(s), history.</td>
</tr>
<tr>
<td>Specific Health Condition</td>
<td></td>
<td>Asthma, Autism, Brain disorders, etc.</td>
</tr>
<tr>
<td>Description of Family</td>
<td></td>
<td>Description of parents, other family members, including siblings, friends. Statements about family life.</td>
</tr>
<tr>
<td>Transition to adulthood</td>
<td></td>
<td>Statements about challenges of ABD child's transition to adulthood.</td>
</tr>
<tr>
<td>Support Groups</td>
<td></td>
<td>Statements about formal or informal support groups, social activities for children with disabilities. Also include</td>
</tr>
</tbody>
</table>

**Notes:**
- Typically will occur at beginning of interview in response to specific question.
- Specific question. Perhaps add subcode for "Parenting challenges."
<table>
<thead>
<tr>
<th>Codes</th>
<th>Abbreviation</th>
<th>Definitions</th>
<th>Examples and key words</th>
<th>Likely to be coded with or near...</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social Support</td>
<td></td>
<td>participation in support groups by parents or caregivers.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other Organizations</td>
<td></td>
<td>Includes statements about social support, but does not include support groups. Includes social support from family, extended family, friends, etc.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospitalizations</td>
<td></td>
<td>Statements about specific organizations that provide helpful resources for children. Statements about how resources provided by specific organizations have changed since policy change.</td>
<td>Easter Seals, Kiwanis, Head Start, Help Me Grow; Home Visiting; BCMH; School System; PCP; ADAMH; County Board of Developmental Disabilities other specific organizations that help kids/caregivers.</td>
<td></td>
<td>Specific question</td>
</tr>
<tr>
<td>Codes</td>
<td>Abbreviation</td>
<td>Definitions</td>
<td>Examples and key words</td>
<td>Likely to be coded with or near…</td>
<td>Notes</td>
</tr>
<tr>
<td>-------------</td>
<td>--------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------------------</td>
<td>----------------------------------</td>
<td>----------------------------</td>
</tr>
<tr>
<td>hospitalizations, or the discharge and follow up processes</td>
<td>Critical Event</td>
<td>Statements about events, frequently about a specific health care provider, that had a significant impact on child. Statements about someone or some activity (even if it's a repeated activity and not an isolated event) that the participant perceives as critical/crucial in some way (positively or negatively) for their/the child’s experience.</td>
<td>Therapist or counselor loses certification job, or relocates.</td>
<td>Actions when difficulty with access</td>
<td></td>
</tr>
<tr>
<td>Health Plans</td>
<td></td>
<td>Statements about specific health plans</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Care Outside Ohio</td>
<td></td>
<td>Statements about receiving care for child outside of Ohio.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IEPs</td>
<td></td>
<td>Statements about Individual Education Plans</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Opinion of Policy Before Change</td>
<td></td>
<td>Focus group participant’s opinion of the policy change before it took effect</td>
<td></td>
<td></td>
<td>Specific question</td>
</tr>
<tr>
<td>Opinion of Policy Now</td>
<td></td>
<td>Focus group participant's opinion of the policy change now, after it has taken effect</td>
<td></td>
<td></td>
<td>Specific question</td>
</tr>
<tr>
<td>Codes</td>
<td>Abbreviation</td>
<td>Definitions</td>
<td>Examples and key words</td>
<td>Likely to be coded with or near...</td>
<td>Notes</td>
</tr>
<tr>
<td>--------------------------------------------</td>
<td>--------------</td>
<td>-----------------------------------------------------------------------------</td>
<td>------------------------</td>
<td>------------------------------------</td>
<td>----------------------------------------------------------------------</td>
</tr>
<tr>
<td>Services Before Policy Change</td>
<td></td>
<td>Statements about the provision or availability of health services for this population prior to the policy change</td>
<td></td>
<td></td>
<td>Specific question</td>
</tr>
<tr>
<td>Care Coordination Before Policy Change</td>
<td></td>
<td>Statements about how care was coordinated for this population prior to the policy change. Do not include statements about satisfaction or dissatisfaction with care coordination.</td>
<td></td>
<td>Non-ACO Care Coordination Services (35)</td>
<td>Specific question</td>
</tr>
<tr>
<td>Services After Policy Change</td>
<td></td>
<td>Statements about the provision of health services for this population since the policy went into effect. May include statements that assert nothing has changed.</td>
<td></td>
<td></td>
<td>Specific question</td>
</tr>
<tr>
<td>Care Coordination After Policy Change</td>
<td></td>
<td>Statements about how the coordination of care for this population has or has not changed since the policy went into effect. Do not include statements about satisfaction or dissatisfaction with care coordination.</td>
<td></td>
<td></td>
<td>Specific question. Do NOT double code with ACO Care Coordination Activities (34) unless the statement provides specific details about what care</td>
</tr>
<tr>
<td>Codes</td>
<td>Abbreviation</td>
<td>Definitions</td>
<td>Examples and key words</td>
<td>Likely to be coded with or near…</td>
<td>Notes</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>--------------</td>
<td>-----------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------------------</td>
<td>---------------------------------</td>
<td>--------------------------------</td>
</tr>
<tr>
<td>Role in Care Coordination</td>
<td></td>
<td>Statements about the role the informant plays in coordinating care</td>
<td></td>
<td></td>
<td>coadators actually do.</td>
</tr>
<tr>
<td>Care Coordination Referral and Eligibility</td>
<td></td>
<td>Statements about eligibility requirements for ACO care coordination, as well as alternate ways of being referred into care coordination services and how these different referral mechanisms might impact engagement</td>
<td>Provider or self-referral. Trigger lists. Top 1-2%.</td>
<td></td>
<td>Specific question.</td>
</tr>
<tr>
<td>ACO Care Coordination Activities</td>
<td></td>
<td>Statements about what ACO care coordinators actually do (or don't do) in coordinating care</td>
<td></td>
<td></td>
<td>ACO Care Coordination Team</td>
</tr>
<tr>
<td>Non-ACO Care Coordination Services</td>
<td></td>
<td>Statements or descriptions of care coordination services, formal or informal, that may be utilized by this population beyond the care coordination services provided by ACO</td>
<td>BCMH care coordination; public health nurses; other hospital care coordinators; care/case managers at the plans. Family members, friends.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Codes</td>
<td>Abbreviation</td>
<td>Definitions</td>
<td>Examples and key words</td>
<td>Likely to be coded with or near...</td>
<td>Notes</td>
</tr>
<tr>
<td>----------------------------</td>
<td>--------------</td>
<td>----------------------------------------------------------------------------</td>
<td>---------------------------------------------------------------------------------------</td>
<td>----------------------------------</td>
<td>----------------------------------------------------------------------</td>
</tr>
<tr>
<td>Satisfaction with Care coordination</td>
<td></td>
<td>Statements about satisfaction associated with care coordination or quality of care.</td>
<td></td>
<td></td>
<td>Specific question. May overlap with High Quality Care Coordination</td>
</tr>
<tr>
<td>Dissatisfaction with Care coordination</td>
<td></td>
<td>Statements about dissatisfaction associated with care coordination or quality of care.</td>
<td></td>
<td></td>
<td>Specific question</td>
</tr>
<tr>
<td>Care Coordinator</td>
<td></td>
<td>Statements about Care Coordinators, how well informed they are about child's health condition.</td>
<td>Access to complete EMR. Frequency they review chart/medical record. Has this changed since policy change?</td>
<td></td>
<td>Specific question</td>
</tr>
<tr>
<td>High-quality Care Coordination</td>
<td></td>
<td>Informant's opinions regarding what it would look like if child's care was well coordinated.</td>
<td></td>
<td></td>
<td>Specific question</td>
</tr>
<tr>
<td>Who Helps Coordinate Care</td>
<td></td>
<td>Statements about other professionals, family, or friends who help with care coordination.</td>
<td>Pediatrician, Nurse, Care Coordinator, Case Manager, Social Worker, Therapists, Family, Friends</td>
<td></td>
<td>Specific question</td>
</tr>
<tr>
<td>Codes</td>
<td>Abbreviation</td>
<td>Definitions</td>
<td>Examples and key words</td>
<td>Likely to be coded with or near…</td>
<td>Notes</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>--------------</td>
<td>-----------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------------------</td>
<td>----------------------------------</td>
<td>--------------------------------------------</td>
</tr>
<tr>
<td>Other Care Coordination Concerns</td>
<td></td>
<td>Statements about other concerns related to coordinating child’s care.</td>
<td>Concerns that are not School, Child Care, Transportation, Social Services, Medications, Transition to Adulthood</td>
<td></td>
<td>Specific question</td>
</tr>
<tr>
<td>Overall Assessment</td>
<td></td>
<td>Statements comparing different models: ACO’s ACO with managed care or FFS, or managed care with FFS</td>
<td></td>
<td></td>
<td>Specific question</td>
</tr>
<tr>
<td>What’s Working Well</td>
<td></td>
<td>Responses to the question: &quot;Overall, what would you say is working best currently for the ABD pediatric population?&quot;</td>
<td></td>
<td></td>
<td>Specific question</td>
</tr>
<tr>
<td>What Needs Improvement</td>
<td></td>
<td>Responses to the question: &quot;Overall, what would you say is most in need of improvement for the ABD pediatric population&quot;</td>
<td></td>
<td></td>
<td>Specific question</td>
</tr>
<tr>
<td>Transition</td>
<td></td>
<td>Discussions about processes, procedures, behaviors, practices and even internal policies aimed at preparing for or coping with the transition of the ABD population into managed care. Can include statements about</td>
<td>Do NOT code with opinion codes (8 and 9) UNLESS the statement includes information</td>
<td></td>
<td>Specific question</td>
</tr>
<tr>
<td>Codes</td>
<td>Abbreviation</td>
<td>Definitions</td>
<td>Examples and key words</td>
<td>Likely to be coded with or near...</td>
<td>Notes</td>
</tr>
<tr>
<td>---------------</td>
<td>--------------</td>
<td>-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>------------------------</td>
<td>-----------------------------------</td>
<td>----------------------------------------------------------------------</td>
</tr>
<tr>
<td>providers</td>
<td></td>
<td>advising patients to opt out, about fears or concerns of patients, providers or advocates about the impact of the change, as well as, actions taken to address these concerns, including the state delaying implementation.</td>
<td></td>
<td></td>
<td>about the opinions/actions/concerns of stakeholders other than the interviewee.</td>
</tr>
<tr>
<td>ACO Identity</td>
<td></td>
<td>Statements about patients' (un)awareness of ACO, including about practices used to identify ACO with Nationwide Children’s Hospital or the health plan when interacting (e.g., phone calls) with patients</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home Health Care</td>
<td></td>
<td>Statements about home health care services, including access, availability, costs, utilization, etc.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Durable Medical Equipment</td>
<td></td>
<td>Statements about physical equipment patients need, including difficulties (or lack of difficulties) obtaining it, using it, paying for it, etc.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prior Authorization</td>
<td></td>
<td>Statements about requirements for prior authorizations before services may be obtained, including how these</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Codes</td>
<td>Abbreviation</td>
<td>Definitions</td>
<td>Examples and key words</td>
<td>Likely to be coded with or near...</td>
<td>Notes</td>
</tr>
<tr>
<td>-------</td>
<td>--------------</td>
<td>-------------</td>
<td>-----------------------</td>
<td>-----------------------------------</td>
<td>-------</td>
</tr>
<tr>
<td></td>
<td></td>
<td>requirements are viewed by patients, caregivers and providers and impacts</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Waiver</td>
<td></td>
<td>Statements explaining policies around waivers--who gets them and under what conditions, as well as, statements about how waivers work, changes to waiver policies or use, etc.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Schools</td>
<td></td>
<td>Statements about the role of schools and school programs for this population (public and private). Include the role of teachers, integration and mainstreaming children with disabilities with other children.</td>
<td>IEPs; Colerain, School of Bright Promise/ Spectrum Center</td>
<td></td>
<td></td>
</tr>
<tr>
<td>School Health Services</td>
<td></td>
<td>Statements about health services received at schools. Include statements about occupational therapy, physical therapy, speech-language pathology, etc received at schools.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ABD Population Characteristics</td>
<td></td>
<td>Descriptions of the pediatric ABD population that provide information about the size of the population, a definition of the population, including who is or is</td>
<td>Other Populations; Care Coordination Referral and Eligibility</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Codes</td>
<td>Abbreviation</td>
<td>Definitions</td>
<td>Examples and key words</td>
<td>Likely to be coded with or near...</td>
<td>Notes</td>
</tr>
<tr>
<td>-------</td>
<td>--------------</td>
<td>-------------</td>
<td>-----------------------</td>
<td>-------------------------------</td>
<td>-------</td>
</tr>
<tr>
<td>Geography</td>
<td></td>
<td>Statements that are explicitly about physical locations or geographical regions. Statements about how service availability or patient or provider experiences may vary depending on geographic location, such as contrasting the Columbus-Franklin County area with rural areas. May include statements that contrast geographical regions of the state beyond ACO's area of responsibility.</td>
<td>Rural, Urban, Appalachia, Franklin County, [some other] County, Toledo, Cincinnati, Cleveland</td>
<td>Availability of Services</td>
<td></td>
</tr>
<tr>
<td>Costs</td>
<td></td>
<td>Statements about managing costs of the ABD population. May include statements about costs and efficiency concerns as drivers for the policy change or other stakeholder actions</td>
<td>Costs of care, capitation, managing risk, per member per month (PMPM)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Healthcare Providers</td>
<td></td>
<td>Statements about specific healthcare providers, how well informed they are about child's health condition.</td>
<td>Access to complete EMR. Frequency they review chart/medical</td>
<td></td>
<td>Specific question</td>
</tr>
</tbody>
</table>
## PCORI Project Focus Group Coding Dictionary 1.2

<table>
<thead>
<tr>
<th>Codes</th>
<th>Abbreviation</th>
<th>Definitions</th>
<th>Examples and key words</th>
<th>Likely to be coded with or near...</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ease of Access</td>
<td></td>
<td>Statements about how easy it is to get care the child needs. Is it easy or difficult?</td>
<td>Appointments, timeliness. Has this changed since policy change?</td>
<td></td>
<td>Specific question</td>
</tr>
<tr>
<td>Actions when difficulty with access</td>
<td></td>
<td>Examples about what informant did when there was difficulty with access. Did someone else help?</td>
<td>Has this changed since policy change?</td>
<td></td>
<td>Specific question</td>
</tr>
<tr>
<td>Medical Services</td>
<td></td>
<td>Statements about patient needs related to medical issues. Statements about the availability of medical services, including statements that make comparisons with other services. Statements about how medical issues are handled by policy, providers, caregivers.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Behavioral and Mental Health Services</td>
<td></td>
<td>Statements about patient needs or issues related to behavioral and mental health services. Statements about the availability of behavioral and mental health services, including statements</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Codes</td>
<td>Abbreviation</td>
<td>Definitions</td>
<td>Examples and key words</td>
<td>Likely to be coded with or near…</td>
<td>Notes</td>
</tr>
<tr>
<td>-------------</td>
<td>--------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>------------------------</td>
<td>----------------------------------</td>
<td>-------</td>
</tr>
<tr>
<td>Transportation</td>
<td></td>
<td>Statements about patient needs related to transportation issues. Statements about the availability of transportation services, including statements that make comparisons with other services. Statements about how transportation issues are handled by policy, providers, caregivers.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child Care</td>
<td></td>
<td>Statements about patient needs related to childcare issues. Statements about the availability of childcare, including statements that make comparisons with other services. Statements about how childcare issues are handled by policy, providers, caregivers, including carve-outs.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Therapeutic Services</td>
<td></td>
<td>Statements about occupational therapy, physical therapy,</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Codes</td>
<td>Abbreviation</td>
<td>Definitions</td>
<td>Examples and key words</td>
<td>Likely to be coded with or near…</td>
<td>Notes</td>
</tr>
<tr>
<td>-------</td>
<td>--------------</td>
<td>-------------</td>
<td>------------------------</td>
<td>---------------------------------</td>
<td>-------</td>
</tr>
<tr>
<td>speech-language pathology services. Include these services that are provided in schools. Statements about how these services are handled by policy, providers, caregivers.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medications</td>
<td></td>
<td>Statements about medication needs, or changes in availability of medications.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other Services</td>
<td></td>
<td>Statements about services that are not included in medical services, mental/behavioral health, or therapeutic services. Include statements where it is not clear what service the caregiver is describing.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chit-chat</td>
<td>Chit-Chat</td>
<td>Apply to quotes that are purely conversational and do not include any substantive discussion of research, e.g. &quot;how are you?&quot; weather, etc. USE THIS CODE SPARINGLY.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not sure what code?</td>
<td>Z-HOLD</td>
<td>Apply to quotes that do not clearly fit any of the codes noted above; review with research team</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix G. Family Experiences With Coordination of Care (FECC) Survey

The FECC initial design included a caregiver survey, assessing experiences with care coordinators and their services and an associated medical record review, assessing communication between primary care providers and specialists. It was developed in a large, multi-site study of caregivers of children with medical complexity and validated against existing Consumer Assessment of Healthcare Providers and Systems (CAHPS) quality measures. Its development began with a set of 39 proposed quality measures, based on an extensive literature review, which an expert panel reduced to 31 for further development. A final set of 20 items was validated and submitted to the National Quality Forum (NQF) for review. Ultimately, eight measures were endorsed by the NQF as reflecting sound science, being useful to providers and patients, and having the potential to make a difference in improving quality.

CARE COORDINATION SURVEY

8/12/15

1. Your child’s main provider is the doctor, physician assistant, nurse or other health care provider who knows the most about your child’s health, and who is in charge of your child’s care overall.

1A. OPEN TEXT (100 CHARACTERS) What is the name of your child’s main provider?

1B. EMPTY The questions in this survey will refer to [FILL 1A.] as “your child’s main provider.” Please think of that person as you answer the questions.

2-INTRO EMPTY This first set of questions are about the people who help you manage care, treatment and services for your child.

2. 0=NO (GO TO 17-INTRO) 1=YES (GO TO 3A) 8 = DON’T KNOW (GO TO 3A) In the last 12 months, did your child visit more than one doctor’s office or use more than one kind of health care service, such as physical or speech therapy, or community service, such as home health care or transportation services?
<table>
<thead>
<tr>
<th>9 = REFUSED (GO TO 3A)</th>
<th>IF NEEDED: Other examples of community services are early intervention programs, respite care, and parent or caregiver support services.</th>
</tr>
</thead>
<tbody>
<tr>
<td>3A.</td>
<td>Did anyone in the main provider’s office help you to manage your child’s care or treatment from these different doctors or care providers?</td>
</tr>
<tr>
<td>3B.</td>
<td>Did anyone else outside of [1A]’s office help you to manage your child’s care or treatment from these different doctors or care providers?</td>
</tr>
<tr>
<td>3C.</td>
<td>Who was it that helped you? If more than one person helped you, we want to know the person who helped you most often in the last 12 months.</td>
</tr>
<tr>
<td>4.</td>
<td>Who in the main provider’s office helped you? If more than one person helped you, we want to know the person who helped you most often in the last 12 months.</td>
</tr>
</tbody>
</table>
### In the last 12 months, did the person who helped you with managing your child’s care know the important information about your child’s health and care needs? Would you say:

- **5a.**
  - 1 = Yes, definitely
  - 2 = Yes, somewhat
  - 3 = No
  - 8 = DON’T KNOW
  - 9 = REFUSED

### In the last 12 months, did the person who helped you with managing your child’s care seem informed and up-to-date about the care your child got from other providers? Would you say:

- **5b.**
  - 1 = Yes, definitely
  - 2 = Yes, somewhat
  - 3 = No
  - 8 = DON’T KNOW
  - 9 = REFUSED

### In the last 12 months, did the person who helped you with managing your child’s care support your decisions about what is best for your child’s health and treatment?

- **5c.**
  - 1 = Yes, definitely
  - 2 = Yes, somewhat
  - 3 = No
  - 8 = DON’T KNOW
  - 9 = REFUSED

### In the last 12 months, did the person who helped you with managing your child’s care help you to get appointments to visit other providers?

- **5d**
  - 1 = Yes, definitely
  - 2 = Yes, somewhat
  - 3 = No
  - 8 = DON’T KNOW
  - 9 = REFUSED
| 5e | 1 = Yes, definitely  
2 = Yes, somewhat  
3 = No  
8 = DON'T KNOW  
9 = REFUSED | In the last 12 months, did the person who helped you with managing your child’s care help you to get special medical equipment your child needed like a special bed, wheelchair, or feeding tube supplies? |
| 6. | 0=NO  
1=YES  
8 = DON'T KNOW  
9 = REFUSED | In the last 12 months, did you know how to contact the person who helped you with managing your child’s care when you needed help or had a question? |
| 7. | 0=NO (GO TO 11.)  
1=YES  
8 = DON'T KNOW  
9 = REFUSED | In the last 3 months, did this person contact you without you getting in touch with them first? |
| 8. | CHOOSE ALL  
1. During a visit to the main provider’s office?  
2. By telephone?  
3. By email?  
4. By mail?  
5. Some other way?  
8 = DON'T KNOW  
9 = REFUSED | How did he or she contact you? Please tell me all the ways you were contacted. Was it: |
| 9. | 1. Never  
2. Sometimes  
3. Usually  
4. Always  
8= DON’T KNOW  
9 = REFUSED | In the last 3 months, when the person who helped you with managing your child’s care contacted you, how often did he or she ask if you had any concerns about your child’s health or treatment? |
| 10. | 1. Never  
2. Sometimes  
3. Usually  
4. Always  
8= DON’T KNOW  
9 = REFUSED | In the last 3 months, when the person who helped you with managing your child’s care contacted you, how often did he or she ask if your child’s health had changed in any way? |
| 11. | 1. Never  
2. Sometimes  
3. Usually  
4. Always  
8= DON’T KNOW | Overall, how often did you get the help you needed to manage your child’s care or treatment from different doctors or care providers in the last 12 months? |
<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>12.</td>
<td>Overall, how satisfied or dissatisfied were you with the help you received in managing your child’s care or treatment in the last 12 months?</td>
<td>9 = REFUSED</td>
</tr>
<tr>
<td>13-INTRO</td>
<td>The next few questions ask about your experiences with getting care for your child from specialists.</td>
<td></td>
</tr>
<tr>
<td>13.</td>
<td>Specialists are doctors like surgeons, heart doctors, allergy doctors, mental health doctors, and other doctors who specialize in one area of health care. During the last 12 months, did the main provider tell you that your child needed to see a specialist?</td>
<td>0=NO (GO TO 15-INTRO) 1=YES 8 = DON’T KNOW 9 = REFUSED</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14.</td>
<td>Did the person who helped you with managing your child’s care contact you to make sure your child got an appointment to see a specialist?</td>
<td>0=NO (GO TO 15-INTRO) 1=YES (GO TO 15-INTRO) 8 = DON’T KNOW 9 = REFUSED</td>
</tr>
<tr>
<td>15-INTRO</td>
<td>The next few questions ask about your experiences with getting community services for you or your child.</td>
<td></td>
</tr>
<tr>
<td>15.</td>
<td>Community services are services to help maintain your and your child’s health and well-being, which may or may not be ordered by one of your child’s doctors. This can include things like home health care, early intervention programs, respite care, help with transportation, and parent or caregiver support services. In the last 12 months, did you or your child need or use community services?</td>
<td>0=NO (GO TO 17-INTRO) 1=YES 8 = DON’T KNOW 9 = REFUSED</td>
</tr>
<tr>
<td>16.</td>
<td>Did the person who helped you with managing your child’s care help you to get the community services you or your child needed?</td>
<td>0=NO 1=YES 8 = DON’T KNOW 9 = REFUSED</td>
</tr>
<tr>
<td>17-Intro</td>
<td>The next set of questions asks about different ways in which you might get information about the care your child is receiving. We are interested in summaries you might have received after visiting the main provider’s office or after your child was in the hospital.</td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td></td>
</tr>
</tbody>
</table>
| 17. | 0=NO (GO TO 21)  
1=YES  
8 = DON’T KNOW  
9 = REFUSED  
A written visit summary sums up what happened during your child’s visit to a health care provider. A written visit summary can be available on paper, on a web site, through an app, or sent by email. In the last 12 months, did anyone at the main provider’s office give you a written visit summary after your child’s visits? |
| 18a. | 1. Never  
2. Sometimes  
3. Always  
8 = DON’T KNOW  
9 = REFUSED  
How often did the written visit summaries you got from the main provider’s office include a list of your child’s health problems at the time of the visit? |
| 18b. | 1. Never  
2. Sometimes  
3. Always  
8 = DON’T KNOW  
9 = REFUSED  
How often did the written visit summaries you got from the main provider’s office include an up-to-date list of all the prescription medicines your child is taking? |
| 18c. | 1. Never  
2. Sometimes  
3. Always  
8 = DON’T KNOW  
9 = REFUSED  
How often did the written visit summaries you got from the main provider’s office include an up-to-date list of all the over the counter medicines your child is taking? |
| 18d. | 1. Never  
2. Sometimes  
3. Always  
8 = DON’T KNOW  
9 = REFUSED  
How often did the written visit summaries you got from the main provider’s office include a list of your child’s allergies? |
| 18e. | 1. Never  
2. Sometimes  
3. Always  
8 = DON’T KNOW  
9 = REFUSED  
How often did the written visit summaries you got from the main provider’s office include the names of all the specialist doctors who help care for your child? |
<p>| | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
</table>
| **18f.** | 1. Never  
2. Sometimes  
3. Always  
8 = DON'T KNOW  
9 = REFUSED | How often did the written visit summaries you got from the main provider’s office include the plan for follow-up care for your child after the visit? |   |
| **18g.** | 1. Never  
2. Sometimes  
3. Always  
8 = DON'T KNOW  
9 = REFUSED | How often did the written visit summaries you got from the main provider’s office include what to do if your child had a problem after the visit? |   |
| **19.** | 1. Never  
2. Sometimes  
3. Always  
8 = DON'T KNOW  
9 = REFUSED | In the last 12 months, how often was the written visit summary you got from the main provider’s office easy to understand? |   |
| **20.** | 1. Never  
2. Sometimes  
3. Always  
8 = DON'T KNOW  
9 = REFUSED | In the last 12 months, how often was the written visit summary you got from the main provider’s office useful to you and your family? |   |
| **21.** | 0=NO (GO TO 26-INTRO)  
1=YES  
8 = DON'T KNOW  
9 = REFUSED | Has your child had an overnight hospital stay in the last 12 months? |   |
| **22.** | 0=NO (GO TO 25)  
1=YES  
8 = DON'T KNOW  
9 = REFUSED | A written hospital stay summary sums up all that happened during your child’s hospital stay. A written hospital stay summary can be available on paper, on a web site, through an app, or sent by email. The last time your child was in the hospital, did your child’s doctor, nurse, or other hospital staff give you a written hospital stay summary on the day your child left the hospital? |   |
| **23a.** | 0=NO  
1=YES  
8 = DON'T KNOW  
9 = REFUSED | Did the written hospital stay summary you got include a list of the health problems your child had when he or she left the hospital? |   |
23b. 0=NO  
1=YES  
8= DON’T KNOW  
9= REFUSED
Did the written hospital stay summary you got include a list of all the prescription medicines your child was taking when he or she left the hospital?

23c. 0=NO  
1=YES  
8= DON’T KNOW  
9= REFUSED
Did the written hospital stay summary you got include a list of all the over the counter medicines your child was taking when he or she left the hospital?

23d. 0=NO  
1=YES  
8= DON’T KNOW  
9= REFUSED
Did the written hospital stay summary you got include a list of your child’s allergies?

23e. 0=NO  
1=YES  
8= DON’T KNOW  
9= REFUSED
Did the written hospital stay summary you got include the names of all the specialist doctors who helped care for your child during the hospital stay?

23f. 0=NO  
1=YES  
8= DON’T KNOW  
9= REFUSED
Did the written hospital stay summary you got include what the planned follow-up care was for your child after the hospital stay?

23g. 0=NO  
1=YES  
8= DON’T KNOW  
9= REFUSED
Did the written hospital stay summary you got include who to call if your child had problems after the hospital stay?

24. 1. Yes, definitely  
2. Yes, somewhat  
3. No  
8= DON’T KNOW  
9= REFUSED
Was the information in the written hospital stay summary you got easy to understand?

25. 0=NO  
1=YES  
8= DON’T KNOW  
9= REFUSED
Hospital rounds are the daily visits the health care team makes to patients in the hospital to check up on how they are doing and how well the treatment is working, and what the plan for the day will be. Nurses, doctors, medical students and other health care providers may join hospital rounds to discuss the plan for the day for every patient. The last time your child was in the hospital, did any of your child’s doctors or
<table>
<thead>
<tr>
<th>Question</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>26-Intro</strong></td>
<td>In addition to information you may get after a visit or a hospital stay, some providers make information available through a web site or an app. We are interested in your experiences with this way of getting information about your child’s health and health care.</td>
</tr>
<tr>
<td><strong>26.</strong></td>
<td>In the last 12 months, did the main provider’s office have a web site or app you could use between visits to look up information about your child’s visits and health care? Would you say:</td>
</tr>
<tr>
<td>0=No (GO TO 29-INTRO)</td>
<td></td>
</tr>
<tr>
<td>1=Yes</td>
<td></td>
</tr>
<tr>
<td>2= Or are you not sure if the main provider’s office has a web site or app? (GO TO 29-INTRO)</td>
<td></td>
</tr>
<tr>
<td>9 = REFUSED</td>
<td></td>
</tr>
<tr>
<td><strong>27.</strong></td>
<td>In the last 12 months, did the main provider’s web site or app have a list of the shots or immunizations your child has received? Would you say:</td>
</tr>
<tr>
<td>0=No</td>
<td></td>
</tr>
<tr>
<td>1=Yes</td>
<td></td>
</tr>
<tr>
<td>2= Or your child did not get any shots or immunizations in the last 12 months?</td>
<td></td>
</tr>
<tr>
<td>8 = DON’T KNOW</td>
<td></td>
</tr>
<tr>
<td>9 = REFUSED</td>
<td></td>
</tr>
<tr>
<td><strong>28.</strong></td>
<td>In the last 12 months, did the main provider’s web site or app have a list of your child’s medications? Would you say:</td>
</tr>
<tr>
<td>0=No</td>
<td></td>
</tr>
<tr>
<td>1=Yes</td>
<td></td>
</tr>
<tr>
<td>2= Or your child did not take any medications in the last 12 months?</td>
<td></td>
</tr>
<tr>
<td>8 = DON’T KNOW</td>
<td></td>
</tr>
<tr>
<td>9 = REFUSED</td>
<td></td>
</tr>
<tr>
<td><strong>29-Intro</strong></td>
<td>The next set of questions asks about three different types of written care plans the main provider may have created for your child: shared care plans, emergency care plans, and transition care plans. We are interested in your experiences, if any, with these different types of plans.</td>
</tr>
</tbody>
</table>
29. 0=NO (GO TO 32-INTRO) 1=YES 8 = DON'T KNOW 9 = REFUSED
A shared care plan is a written document that contains information about your child’s active health problems, medicines he or she is taking, special considerations that all people caring for your child should know, goals for your child’s health, growth and development, and steps to take to reach those goals. Has the main provider created a **shared care plan** for your child?

30. 0=NO (GO TO 32-INTRO) 1=YES 8 = DON'T KNOW 9 = REFUSED
Do you have a copy of your child’s shared care plan?

31. 0= No 1= Yes 2= Or are there no goals written in your child’s shared care plan? 8 = DON'T KNOW 9 = REFUSED
In the last 12 months, has the main provider or anyone from the main provider’s office talked with you about the progress your child was making toward the goals written in his or her shared care plan? Would you say:

32-Intro
An emergency care plan is a written document that contains important information about your child’s health, treatment and medications. It also includes special considerations that all people caring for your child should know, for example, how your child lets you know he or she is in pain, or how to communicate with your child if he or she can’t hear or speak. Families often bring the emergency care plan when they take a child to an emergency room or urgent care clinic.

32. 0=NO 1=YES 8 = DON'T KNOW 9 = REFUSED
Has the main provider created an emergency care plan for your child?

33-INTRO
If your child is at least 15 years old, we are interested in your experiences with making plans for your child’s care when he or she
becomes an adult. This is sometimes called a transition plan.

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>33.</td>
<td>0=NO (GO TO 35-INTRO) 1=YES 8 = DON’T KNOW 9 = REFUSED</td>
<td>Is your child age 15 or older?</td>
</tr>
<tr>
<td>34.</td>
<td>0=NO 1=YES 8 = DON’T KNOW 9 = REFUSED</td>
<td>Has the main provider created a written transition plan that summarizes how your child’s care will change and how it will stay the same when he or she becomes an adult?</td>
</tr>
<tr>
<td>35-Intro</td>
<td></td>
<td>The next set of questions asks about your child’s experiences in school.</td>
</tr>
<tr>
<td>35.</td>
<td>0=NO (GO TO 38-INTRO) 1=YES 8 = DON’T KNOW 9 = REFUSED</td>
<td>In the last 12 months, did your child attend school?</td>
</tr>
<tr>
<td>36.</td>
<td>0=NO (GO TO 38-INTRO) 1=YES 8 = DON’T KNOW 9 = REFUSED</td>
<td>Because of his or her health condition does your child have any difficulty learning, understanding, or paying attention in class?</td>
</tr>
<tr>
<td>37.</td>
<td>0=NO 1=YES 8 = DON’T KNOW 9 = REFUSED</td>
<td>In the last 12 months, did anyone from the main provider’s office contact staff at your child’s school to make sure they understood how your child’s health condition affected his or her ability to learn, understand or pay attention in class?</td>
</tr>
<tr>
<td>38-Intro</td>
<td></td>
<td>This last set of questions is about you and your child. This information will help us to describe the caregivers and children who take part in this study.</td>
</tr>
<tr>
<td>39.</td>
<td>0=NO (GO TO 46) 1=YES 8 = DON’T KNOW</td>
<td>Do you speak a language other than English at home?</td>
</tr>
<tr>
<td></td>
<td>9 = REFUSED</td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>-------------</td>
<td>-----------------------------------------------------------------</td>
</tr>
</tbody>
</table>
| 40. | 1. SPANISH  
2. SOME OTHER LANGUAGE  
8 = DON'T KNOW  
9 = REFUSED | What is the language you speak at home? |
| 41. | 1. ENGLISH (GO TO 46)  
2. ANOTHER LANGUAGE  
8 = DON'T KNOW  
9 = REFUSED | Do you prefer to talk with your child's doctors and care providers in English or in another language? |
| 42. | 0=NO  
1=YES  
8 = DON'T KNOW  
9 = REFUSED | In the last 12 months, did the main provider speak to you in the language you prefer? |
| 43. | 0=NO  
1=YES  
8 = DON'T KNOW  
9 = REFUSED | In the last 12 months, did anyone in the main provider's office speak to you in the language you prefer? |
| 44. | 1. No visits (GO TO #46)  
2. Some visits  
3. Most visits  
4. All visits  
8 = DON'T KNOW  
9 = REFUSED | A medical interpreter is a professional who helps you talk with doctors and other providers who do not speak your language. The interpreter can do this over the phone or in-person. In the last 12 months, how often did you need an interpreter during a visit to the main provider? |
| 45. | 1. Never  
2. Sometimes  
3. Usually  
4. Always  
8 = DON'T KNOW  
9 = REFUSED | When you needed a professional interpreter during a visit to the main provider, how often was an interpreter available? |
| 46. | 1. YES, HISPANIC OR LATINO  
2. NO, NOT HISPANIC OR LATINO  
8 = DON'T KNOW  
9 = REFUSED | Is this child of Hispanic or Latino origin or descent? |
| 47. | **What is this child’s race? Please choose one or more from this list:**
1. White  
2. Black or African American  
3. Asian  
4. Native Hawaiian or Other Pacific Islander  
5. American Indian or Alaska Native  
6. Other  
8 = DON'T KNOW  
9 = REFUSED | 47a. | **Counting all children living in the household, including this child as well as any adult children, how many children live in the household?**
1. ONLY ONE (GO TO 48)  
2. 2 (GO TO 47B)  
3. 3 (GO TO 47B)  
4. 4 OR MORE (GO TO 47B)  
8 = DON'T KNOW (GO TO 48)  
9 = REFUSED (GO TO 48) | 47b. | **And how many of these [IF 47A=1,2, OR 3, FILL WITH 47A, OTHERWISE LEAVE BLANK] children have special health care needs?**
**IF R ASKS FOR DEFINITION OF ‘SPECIAL NEEDS’: There’s no definition provided. The researchers are interested in the answer you think is most appropriate.**
**IN: INCLUDE CHILD WHO IS FOCUS OF THIS SURVEY** | 48. | **What is your age?** | 48a. | **Are you . . .**
18 to 24?  
25 to 34?  
35 to 44?  
45 to 54?  
55 to 64?  
65 to 74?  
75 or OLDER? | **IN: OKAY TO STOP READING ONCE YOU GET A RESPONSE**
**TRIGGER ALERT IF RESPONSE IS GREATER THAN THE TOTAL # OF CHILDREN REPORTED IN 47a**
<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
<th>Description</th>
</tr>
</thead>
</table>
| 49.      | 1. MALE  
2. FEMALE  
8 = DON'T KNOW  
9 = REFUSED | I’m required to ask, are you male or female? |
| 50.      | 1. YES, HISPANIC OR LATINO  
2. NO, NOT HISPANIC OR LATINO  
8 = DON'T KNOW  
9 = REFUSED | Are you of Hispanic or Latino origin or descent? |
| 51.      | 1. White  
2. Black or African American  
3. Asian  
4. Native Hawaiian or Other Pacific Islander  
5. American Indian or Alaska Native  
6. Other  
8 = DON'T KNOW  
9 = REFUSED | What is your race? Please choose one or more from this list. |
| 52.      | 1. 8th grade or less  
2. Some high school, but did not graduate  
3. High school graduate or GED  
4. Some college or 2-year degree  
5. 4-year college graduate  
6. More than 4-year college degree  
8 = DON'T KNOW  
9 = REFUSED | What is the highest grade or level of school that you have completed? |

THANKS

EMPTY

That’s the end of the survey. To thank you for your time, we’d like to get your name and address so we can send you your $20 check. I just need to verify your mailing address.
| CHK_ADDR[IF DO_SURVEY=1] | 1-7, REF  
1=NAME IS WRONG  
2=STREET ADDRESS (1ST LINE) IS WRONG  
3=STREET ADDRESS (2ND LINE) IS WRONG  
4=CITY IS WRONG  
5=STATE IS WRONG  
6=ZIP CODE IS WRONG  
7=INFORMATION ON RECORD IS CORRECT  
9=R REFUSES ADDRESS VERIFICATION AND/OR DOESN'T WANT CHECK (GO TO REF_CHECK) | Should we still send that to:  
[FILL PRELOAD DATA: FIRST & LAST NAME ADDRESS (1ST LINE) ADDRESS (2ND LINE) CITY, STATE & ZIP]  
INTERVIEWER: CHECK ALL PARTS OF NAME OR ADDRESS THAT NEED CORRECTING (OR CHECK "INFORMATION ON RECORD IS CORRECT" IF NO CORRECTIONS ARE NECESSARY) |
| UPD_NAME[IF CHK_ADDR=1] | OPEN TEXT [100 CHAR] | ENTER CORRECT NAME |
| UPD_ADDR[IF CHK_ADDR=2] | OPEN TEXT [100 CHAR] | ENTER CORRECT STREET ADDRESS (1ST LINE) |
| UPD_ADDR2[IF CHK_ADDR=3] | OPEN TEXT [50 CHAR] | ENTER CORRECT STREET ADDRESS (2ND LINE) |
| UPD_STATE[IF CHK_ADDR=5] | DROP-DOWN LIST OF STATES | ENTER CORRECT STATE |
| VERIFY| 1=OK (GO TO REC_CHK) | Let me read this back to you to verify that I've entered everything correctly: [FILL: CONF_NAME CONF_ADDR CONF_ADDR2 CONF_CITY CONF_STATE CONF_ZIP] READ BACK TO MAKE SURE CONTACT INFORMATION IS 100% CORRECT AND COMPLETE. IF ANY CORRECTIONS ARE NEEDED, BACK UP TO THE APPROPRIATE SCREEN. |
| REC_CHK | EMPTY | Your check should be mailed within 4 to 6 weeks. |
| REF_CHECK | EMPTY | In that case we won't send you your thank you gift. However, I can give you a toll-free number to call, if you decide later that you would like to claim your $20 check. Would you like to write that down? The number is 1-866-829-0911. You'll also need your ID number, which is #######. |
| WHY_HIPAA | 0=NO (GO TO FOCUS_INTEREST) 1=YES (GO TO HIPAA) 8 = DON’T KNOW 9 = REFUSED | Thank you for participating in this survey. As part of our research on improving health care coordination for children with disabilities, we plan to gather additional information from medical records and billing data. We will use medical records to learn about referrals your primary doctor makes to other doctors and about how those doctors communicate with each other. Billing data will help us understand when and how the patient is using

IF RELATIONSHIP = 1 OR 6, GO TO WHY_HIPAA
IF RELATIONSHIP = 2,3,4,5,7,8 OR 9 GO TO FOCUS_INTEREST

IF RELATIONSHIP = 1 OR 6, GO TO WHY_HIPAA
IF RELATIONSHIP = 2,3,4,5,7,8 OR 9 GO TO FOCUS_INTEREST
healthcare services. This survey information will be linked with the medical record and billing data and will be de-identified, meaning your child’s name will not be associated with the data. All information will be kept confidential, shared only among the study team, and protected according to strict data security guidelines. Do you give permission for us to gather information from your child’s medical record?

<table>
<thead>
<tr>
<th>HIPAA</th>
<th>0=NO (GO TO FOCUS_INTEREST) 1=YES 8 = DON’T KNOW 9 = REFUSED</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>This is a permission called a “HIPAA authorization.” It is required by the “Health Insurance Portability and Accountability Act of 1996” (known as “HIPAA”) in order for us to get information from your medical records or health insurance records to use in this research study.</td>
</tr>
</tbody>
</table>

1. If you give your consent to this HIPAA authorization form, you are giving your permission for the following people or groups to give the researchers certain information about you (described below):
   Any health care providers or health care professionals or health plans that have provided health services, treatment, or payment for you such as physicians, clinics, hospitals, home health agencies, diagnostics centers, laboratories, treatment or surgical centers.

2. If you sign this form, this is the health information about you that the people or groups listed in #1 may give to the researchers to use in this research study:
   Any information in your medical records that relates to your participation in this research. These records might include information about mental health, drug or alcohol use, HIV/AIDS or other communicable diseases, or genetic testing. Other information includes referrals your primary doctor makes to other doctors and about how those doctors communicate with each other; services listed in billing data that
<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>will help us understand when and how the patient is using healthcare services.</td>
</tr>
<tr>
<td>2.</td>
<td>The HIPAA protections that apply to your medical records will not apply to your information when it is in the research study records. Your information in the research study records may also be shared with, used by or seen by collaborating researchers, the sponsor of the research study, the sponsor’s representatives, and certain employees of the university or government agencies (like the FDA) if needed to oversee the research study. HIPAA rules do not usually apply to those people or groups. If any of these people or groups reviews your research record, they may also need to review portions of your original medical record relevant to the situation. The informed consent document describes the procedures in this research study that will be used to protect your personal information. You can also ask the researchers any questions about what they will do with your personal information and how they will protect your personal information in this research study. For this particular study, information will be linked with the medical record and billing data and will be de-identified, meaning your child’s name will not be associated with the data. All information will be kept confidential, shared only among the study team, and protected according to strict data security guidelines.</td>
</tr>
<tr>
<td>3.</td>
<td>If this research study creates medical information about you that will go into your medical record, you may not be able to see the research study information in your medical record until the entire research study is over. NOTE: This study will not create medical record information about you or your child.</td>
</tr>
<tr>
<td>4.</td>
<td>If you want to participate in this research study, you must sign this HIPAA authorization form to allow the people or groups listed in #1 on this form to give access to the information about you that is listed in #2. If you do not want to sign this</td>
</tr>
</tbody>
</table>
HIPAA authorization form, you cannot participate in this research study. However, not signing the authorization form will not change your right to treatment, payment, enrollment or eligibility for medical services outside of this research study.

6. This HIPAA authorization will not stop unless you stop it in writing.
7. You have the right to stop this HIPAA authorization at any time. You must do that in writing. You may give your written stop of this HIPAA authorization directly to Principal Investigator or researcher or you may mail it to the department mailing address listed at the top of this form, or you may give it to one of the researchers in this study and tell the researcher to send it to any person or group the researcher has given a copy of this HIPAA authorization. Stopping this HIPAA authorization will not stop information sharing that has already happened.

Do we have your permission to access your child’s medical record for the purposes of this study?

<table>
<thead>
<tr>
<th>FOCUS_INTEREST</th>
<th>0=NO (GO TO END) 1=YES 8 = DON’T KNOW 9 = REFUSED</th>
<th>Thank you for participation in the survey. We also wanted to let you know that later this year researchers may be holding focus groups and one-on-one interviews with family caregivers of children with disabilities in your area. Each session would last 60-90 minutes and participants would receive a $50 gift card in recognition of their time. Would you like to be contacted in the future about participating in a focus group or caregiver interview?</th>
</tr>
</thead>
<tbody>
<tr>
<td>FOCUS_PREF</td>
<td>1=PHONE (GO TO PRIM#) 2=EMAIL (GO TO EMAIL)</td>
<td>Would you prefer to be contacted about these sessions by phone or by email?</td>
</tr>
<tr>
<td>PRIM#</td>
<td>ENTER PHONE</td>
<td>What is the best number to reach you?</td>
</tr>
<tr>
<td>ADDL_NUMS</td>
<td>0 = NO 1 = YES 8 = DON’T KNOW 9 = REFUSED</td>
<td>Are there any other numbers we should try?</td>
</tr>
<tr>
<td>EMAIL</td>
<td>OPEN TEXT (50 CHARACTERS)</td>
<td>What is that email address?</td>
</tr>
<tr>
<td>--------</td>
<td>---------------------------</td>
<td>-----------------------------</td>
</tr>
<tr>
<td>END</td>
<td>EMPTY</td>
<td>That’s the end of the survey. IF CHK_ADDR=1-7: Your $20 check should be mailed to you within 4 to 6 weeks. Thank you. Goodbye.</td>
</tr>
</tbody>
</table>
Appendix H. Family Experiences With Coordination of Care Measure Specifications

**Detailed Measure Specifications and Scoring for FECC Caregiver Survey Indicators**

- All are on a 0-100 scale, where higher is better. Survey response items should be coded to reflect that. For dichotomous items, “no” = 0 and “yes” = 100.
- More specific instructions are included where applicable in Scoring Notes.
- All screener items must be non-missing for a dependent item to be scored.
- If items are a part of a yes/no checklist, if at least one item is answered, impute “no” for skipped items in mailed surveys or “don’t know” for telephone surveys (but not for items that telephone respondents refused to answer). Otherwise, all component items must be non-missing for a multi-item indicator to be scored.

**MP=Main Provider**

<table>
<thead>
<tr>
<th>Indicator ID</th>
<th>Indicator Description</th>
<th>Items used for Eligibility</th>
<th>Items used in Scoring</th>
<th>Scoring Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>CARE COORDINATION SERVICES</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FECC-1</td>
<td>Caregivers of children with medical complexity should report that their child has a designated care coordinator.</td>
<td>Q2=1 (Child visited more than one doctor’s office or used more than one kind of health care service in last 12 months)</td>
<td>Q3a or Q3b (Someone helped manage child’s care or treatment from different doctors/providers.)</td>
<td>Q3a or 3b = 1 (yes) = 100 Q3a and 3b = 2 (no) = 0</td>
</tr>
<tr>
<td>FECC-2</td>
<td>Caregivers of children with medical complexity who report that their child has a designated care coordinator (as identified in FECC-1) should</td>
<td>Q2=1 (Child visited more than one doctor’s office or used more than one kind of health care service in last 12 months) Q3a = 1 or Q3b = 1 (Someone helped manage child’s care or</td>
<td>Q6 (Knew how to contact person who helped manage child’s care when you needed help or had a question)</td>
<td>Q6 = 1 (yes) = 100 Q6 = 2 (no) = 0</td>
</tr>
<tr>
<td>Indicator ID</td>
<td>Indicator Description</td>
<td>Items used for Eligibility</td>
<td>Items used in Scoring</td>
<td>Scoring Notes</td>
</tr>
<tr>
<td>--------------</td>
<td>-----------------------</td>
<td>----------------------------</td>
<td>-----------------------</td>
<td>---------------</td>
</tr>
<tr>
<td>FECC-3</td>
<td>Caregivers of children with medical complexity who report having a designated care coordinator (as identified in FECC-1) and who require community services should also report that their care coordinator helped their child to obtain needed community services in the last year.</td>
<td>Q2=1 (Child visited more than one doctor’s office or used more than one kind of health care service in last 12 months) Q3a = 1 or Q3b = 1 (Someone helped manage child’s care or treatment from different doctors/providers) Q15=1 (Caregiver or child needed or used community services in last 12 mos)</td>
<td>Q16 (Person who helped manage child’s care helped get community services)</td>
<td>Q16 = 1 (yes) = 100 Q16 = 2 (no) = 0</td>
</tr>
<tr>
<td>FECC-4</td>
<td>Caregivers of children with medical complexity who report that their child has a designated care coordinator (as identified in FECC-1) should also report that their care coordinator has contacted them (via face-to-face contact, telephone, email, or written correspondence) or attempted to contact them at least once in the last 3 months.</td>
<td>Q2=1 (Child visited more than one doctor’s office or used more than one kind of health care service in last 12 months) Q3a = 1 or Q3b = 1 (Someone in helped manage child’s care or treatment from different doctors/providers)</td>
<td>Q7 (In last 3 mos, person contacted caregiver w/o caregiver getting in touch w/them first)</td>
<td>Q7 = 1 (yes) = 100 Q7 = 2 (no) = 0</td>
</tr>
<tr>
<td>FECC-5</td>
<td>Caregivers of children with medical complexity who report that their child has a designated care coordinator (as identified in FECC-1) should</td>
<td>Q2=1 (Child visited more than one doctor’s office or used more than one kind of health care service in last 12 months)</td>
<td></td>
<td>Partial credit: Rescale Q9 to 0-100: Q9 =1 (Never): 0 pts, Q9 =2 (Sometimes): 33 pts,</td>
</tr>
<tr>
<td>Indicator ID</td>
<td>Indicator Description</td>
<td>Items used for Eligibility</td>
<td>Items used in Scoring</td>
<td>Scoring Notes</td>
</tr>
<tr>
<td>--------------</td>
<td>----------------------</td>
<td>----------------------------</td>
<td>-----------------------</td>
<td>---------------</td>
</tr>
<tr>
<td></td>
<td>also report that the care coordinator has contacted them in the last 3 months and asked them about the following:</td>
<td>Q3a = 1 or Q3b = 1 (Someone helped manage child’s care or treatment from different doctors/providers) Q7=1 (In last 3 mos, care coordinator contacted you w/o you getting in touch w/them first)</td>
<td>Q9 =3 (Usually): 66 pts, Q9 =4 (Always): 100 pts Rescale Q10 to 0-100: Q10 =1 (Never): 0 pts, Q10 =2 (Sometimes): 33 pts, Q10 =3 (Usually): 66 pts, Q10 =4 (Always): 100 pts</td>
<td></td>
</tr>
<tr>
<td></td>
<td>FECC-5a) Caregiver concerns</td>
<td>Q9 = Care coordinator asked about caregiver concerns</td>
<td>FECC-5: Mean of Q9 and Q10</td>
<td></td>
</tr>
<tr>
<td></td>
<td>FECC-5b) Health changes of the child</td>
<td>Q10 = Care coordinator asked about health changes of child</td>
<td></td>
<td></td>
</tr>
<tr>
<td>FECC-6</td>
<td>Caregivers of children with medical complexity who report having a copy of a written shared care plan for their child, should also report that either their main provider (MP) or someone in the main provider’s office asked them about progress towards goals documented in the child's shared care plan</td>
<td>Q29=1 (MP created shared care plan for child), Q30=1 (Caregiver has copy of child’s shared care plan) Q31 (In last 12 mos, MP or another person in MP’s office talked with caregiver about progress child was making toward goals written in shared care plan)</td>
<td>Q31 = 1 (yes) = 100 Q31 = 2 (no) = 0 If Q31=3 (Child’s shared care plan does not have written goals), score = 0</td>
<td></td>
</tr>
<tr>
<td>FECC-7</td>
<td>Caregivers of children with medical complexity who report that their child has a designated care coordinator (as</td>
<td>Q2=1 (Child visited more than one doctor’s office or used more than one kind of health care service in last 12 months) Q14 (Person in who helped manage child’s care contacted you to make sure</td>
<td>Q14 = 1 (yes) = 100 Q14 = 2 (no) = 0</td>
<td></td>
</tr>
<tr>
<td>Indicator ID</td>
<td>Indicator Description</td>
<td>Items used for Eligibility</td>
<td>Items used in Scoring</td>
<td>Scoring Notes</td>
</tr>
<tr>
<td>--------------</td>
<td>----------------------</td>
<td>---------------------------</td>
<td>----------------------</td>
<td>---------------</td>
</tr>
<tr>
<td></td>
<td>identified in FECC-1) and who report their child was referred to see a specialist in the last 12 months, should also report that the care coordinator contacted them to confirm they were able to get an appointment with the specialist</td>
<td>Q3a = 1 or Q3b = 1 (Someone helped manage child’s care or treatment from different doctors/providers) Q13=1 (main provider told caregiver child needed to see specialist during last 12 mos)</td>
<td>child got appointment to see specialist</td>
<td>If Q14=3 (Did not get help managing child’s care), score = 0</td>
</tr>
<tr>
<td>FECC-8</td>
<td>Caregivers of children with medical complexity who report that their child has a designated care coordinator (as identified in FECC-1) should also report that their care coordinator:</td>
<td>Q2 = 1 (Child visited more than one doctor’s office or used more than one kind of health care service in last 12 months) Q3a = 1 or Q3b = 1 (Someone helped manage child’s care or treatment from different doctors/providers)</td>
<td>Q5 (In last 12 mos, person who helped manage child’s care...)</td>
<td>Partial credit for Q5a-e: Yes Definitely = 100 Yes Somewhat=50 No = 0 If “Not applicable” (Q5d and Q5e only) = don’t score</td>
</tr>
<tr>
<td>FECC-8a</td>
<td>FECC-8a) Was knowledgeable about their child’s health</td>
<td>Q5a, Q5b</td>
<td>FECC-8a: Mean of rescaled Q5a and Q5b</td>
<td></td>
</tr>
<tr>
<td>FECC-8b</td>
<td>FECC-8b) Supported the caregiver</td>
<td>Q5c</td>
<td>FECC-8b: Mean of rescaled Q5c</td>
<td></td>
</tr>
<tr>
<td>FECC-8c</td>
<td>FECC-8c) Advocated for the needs of the child</td>
<td>Q5d, Q5e</td>
<td>FECC-8c: Mean of rescaled Q5d and Q5e (only score if applicable)</td>
<td></td>
</tr>
<tr>
<td>FECC-15</td>
<td>Caregivers of children with medical complexity who self-identify as having a preference for conducting medical visits in a language other than English should have access to a</td>
<td>Q39=1 (Speak language other than English at home), Q41=2 (Prefer to talk w/child’s doctors in language other than English), Q44=2, 3, or 4 (Needed professional interpreter during</td>
<td>Q45 (How often was professional interpreter available when needed)</td>
<td>FECC-8 Measure Score: Take mean of FECC-8a-c Partial credit: rescale Q45 to 0-100: Q45=1 (Never): 0 pts, Q45=2 (Sometimes): 33</td>
</tr>
<tr>
<td>Indicator ID</td>
<td>Indicator Description</td>
<td>Items used for Eligibility</td>
<td>Items used in Scoring</td>
<td>Scoring Notes</td>
</tr>
<tr>
<td>-------------</td>
<td>----------------------</td>
<td>---------------------------</td>
<td>-----------------------</td>
<td>---------------</td>
</tr>
<tr>
<td></td>
<td>professional medical interpreter (live or telephonic) at all visits for which an interpreter is needed.</td>
<td>visit to MP some, most, or all visits)</td>
<td></td>
<td>pts, Q45=3 (Usually): 66 pts, Q45=4 (Always): 100 pts</td>
</tr>
<tr>
<td>MESSAGING</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FECC-9</td>
<td>Caregivers of children with medical complexity who report receiving a written visit summary during the last 12 months from their child’s MP’s office should report that it contained the following elements:</td>
<td>All caregivers of children with medical complexity Q17=1 (received written visit summary in last 12 mos)</td>
<td>Q18 (How often did written visit summaries include...)</td>
<td>Partial credit for Q18a-g: Always = 100 Sometimes =50 Never = 0</td>
</tr>
<tr>
<td>FECC-9a) Current problem list</td>
<td></td>
<td>Q18a</td>
<td></td>
<td></td>
</tr>
<tr>
<td>FECC-9b) Current medication list</td>
<td></td>
<td>Q18b (Rx), Q18c (OTC)</td>
<td>FECC-9b) Mean of rescaled Q18b and Q18c</td>
<td></td>
</tr>
<tr>
<td>FECC-9c) Drug allergies</td>
<td></td>
<td>Q18d (list of “child’s allergies”, not drug allergies specifically)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>FECC-9d) Specialists involved in the child’s care</td>
<td></td>
<td>Q18e</td>
<td></td>
<td></td>
</tr>
<tr>
<td>FECC-9e) Planned follow-up</td>
<td></td>
<td>Q18f</td>
<td></td>
<td></td>
</tr>
<tr>
<td>FECC-9f) What to do for problems related to the outpatient visit</td>
<td></td>
<td>Q18g</td>
<td>FECC-9 Measure Score: Take mean of FECC-9a-f</td>
<td></td>
</tr>
<tr>
<td>Indicator ID</td>
<td>Indicator Description</td>
<td>Items used for Eligibility</td>
<td>Items used in Scoring</td>
<td>Scoring Notes</td>
</tr>
<tr>
<td>-------------</td>
<td>-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------------------------</td>
<td>-----------------------</td>
<td>----------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>FECC-10</td>
<td>Caregivers/patients who reported ever receiving a visit summary in the last 12 months from their child’s MP’s office (as identified in IE2) should report that the summary:</td>
<td>Q17=1 (received written visit summary in last 12 mos)</td>
<td></td>
<td>Partial credit for Q19 and Q20:</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Always = 100</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Sometimes=50</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Never = 0</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>FECC-10 Measure Score:</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Take mean of FECC-10a and FECC-10b</td>
</tr>
<tr>
<td></td>
<td>FECC-10a) Was easy to understand</td>
<td>Q19</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>FECC-10b) Was useful</td>
<td>Q20</td>
<td></td>
<td></td>
</tr>
<tr>
<td>FECC-11</td>
<td>Caregivers of children with medical complexity should report having been invited to join in hospital rounds during their child’s last hospitalization</td>
<td>Q21=1 (child had overnight hospital stay in last 12 mos)</td>
<td>Q25</td>
<td>Q25 = 1 (yes) = 100</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Q25 = 2 (no) = 0</td>
</tr>
<tr>
<td>FECC-12</td>
<td>Caregivers/patients should report receiving a written visit summary of their child’s last hospitalization at the time of discharge, and they should report the summary contained the following elements:</td>
<td>Q21=1 (child had overnight hospital stay in last 12 mos), Q22=1 (Last time child was in</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>hospital, got written hospital stay summary at discharge)</td>
<td>Q23</td>
<td>Impute “no” for missing values if any responses are provided to Q23a - g</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Q23a-g = 1(yes) = 100</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Q23a-g = 2 (no) = 0</td>
</tr>
<tr>
<td></td>
<td>FECC-12a) Problem list at time of discharge</td>
<td>Q23a</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>FECC12b) Medication list at time of discharge</td>
<td>Q23b (Rx), Q23c (OTC)</td>
<td></td>
<td>FECC-12b: Mean of rescaled Q23b and Q23c</td>
</tr>
<tr>
<td>Indicator ID</td>
<td>Indicator Description</td>
<td>Items used for Eligibility</td>
<td>Items used in Scoring</td>
<td>Scoring Notes</td>
</tr>
<tr>
<td>-------------</td>
<td>----------------------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>FECC-12c</td>
<td>Drug allergies</td>
<td>Q23d (list of “child’s allergies”, not drug allergies specifically)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>FECC-12d</td>
<td>Specialists involved in the child’s care during the hospitalization</td>
<td>Q23e</td>
<td></td>
<td></td>
</tr>
<tr>
<td>FECC-12e</td>
<td>Planned follow-up</td>
<td>Q23f</td>
<td></td>
<td></td>
</tr>
<tr>
<td>FECC-12f</td>
<td>Who to call for problems related to the hospitalization</td>
<td>Q23g</td>
<td></td>
<td>FECC-12 Measure Score: Take mean of FECC-12a-f</td>
</tr>
</tbody>
</table>
| FECC-13     | Caregivers of children with medical complexity who receive a written summary of their child’s hospitalization at discharge (as described in indicator FECC-12) should report that the information contained in the visit summary was easy to understand | Q21=1 (child had overnight hospital stay in last 12 mos), Q22=1 (Last time child was in hospital, got written hospital stay summary at discharge) | Q24 (Hospital stay summary easy to understand)                                          | Q24 = 1 (Yes, definitely) = 100  
Q24 = 2 (Yes, somewhat) = 50  
Q24 = 3 (no) = 0                                                                                       |
| FECC-19     | Caregivers of children with medical complexity should report having access to an EMR to look up information about their child’s visits and health care. | All caregivers of children with medical complexity                                        | Q26 (In last 12 mos, MP’s office had web site or app caregiver could use between visits to look up information about child’s visits and care) | Q26=1 (Yes) = 100  
Q26=2 or 3 (no or don’t know) = 0                                                                   |
<p>| FECC-20     | Caregivers of children with medical complexity who report having access to an EMR should | Q26=1 (In last 12 mos, MP’s office had web site or app caregiver could use between          |                                                                                        |                                                                                                        |</p>
<table>
<thead>
<tr>
<th>Indicator ID</th>
<th>Indicator Description</th>
<th>Items used for Eligibility</th>
<th>Items used in Scoring</th>
<th>Scoring Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>also report that it includes the following health information: visits to look up information about child’s visits and care</td>
<td>Q26=1 (In last 12 mos, MP’s office had web site or app caregiver could use between visits to look up information about child’s visits and care)</td>
<td>Q27 (In last 12 mos, MP’s web site or app had list of immunizations child has received)</td>
<td>FECC-20a: If Q27=3 or 4 (no immunizations in last 12 mos): do not score If Q27=1 (Yes): 100 points If Q27=2 or 4 (No or Don’t Know): 0 points FECC-20b:</td>
</tr>
<tr>
<td>FECC-20a) Immunization record</td>
<td>Q26=1 (In last 12 mos, MP’s office had web site or app caregiver could use between visits to look up information about child’s visits and care)</td>
<td>Q28 (In last 12 mos, MP’s web site or app had list of child’s meds)</td>
<td>If Q28=3 (no meds in last 12 mos): do not score Q28=1 (Yes): 100 points If Q28=2 or 4 (No or Don’t Know): 0 points FECC-20 Measure Score: Take mean of FECC-20a and FECC-20b</td>
<td></td>
</tr>
<tr>
<td>FECC-20b) List of child’s medications</td>
<td>Q26=1 (In last 12 mos, MP’s office had web site or app caregiver could use between visits to look up information about child’s visits and care)</td>
<td>Q35=1 (Child attended school in last 12 mos) Q36=1 (Because of health condition child has difficulty learning, understanding, or paying attention in class)</td>
<td>Q37 (In last 12 mos, someone from MP’s office contacted school staff at child’s school to make sure they understood how child’s condition affected ability to learn, understand, or pay attention)</td>
<td>Q37=1 (Yes) = 100 Q37=2 or 3 (no or don’t know) = 0 points</td>
</tr>
<tr>
<td>FECC-14</td>
<td>Caregivers of children with medical complexity who report their child’s condition causes difficulty learning, understanding, or paying attention in class should also report that someone from the MP’s office communicated with school staff at least once a year about the educational impacts of the child’s condition.</td>
<td>Q35=1 (Child attended school in last 12 mos) Q36=1 (Because of health condition child has difficulty learning, understanding, or paying attention in class)</td>
<td>Q37 (In last 12 mos, someone from MP’s office contacted school staff at child’s school to make sure they understood how child’s condition affected ability to learn, understand, or pay attention)</td>
<td>Q37=1 (Yes) = 100 Q37=2 or 3 (no or don’t know) = 0 points</td>
</tr>
<tr>
<td>Indicator ID</td>
<td>Indicator Description</td>
<td>Items used for Eligibility</td>
<td>Items used in Scoring</td>
<td>Scoring Notes</td>
</tr>
<tr>
<td>--------------</td>
<td>----------------------</td>
<td>----------------------------</td>
<td>-----------------------</td>
<td>---------------</td>
</tr>
<tr>
<td><strong>FECC-16</strong></td>
<td>Caregivers of children with medical complexity should report that their child’s primary care provider created a shared care plan for their child.</td>
<td>All caregivers of children with medical complexity</td>
<td>Q29 (MP created shared care plan for child)</td>
<td>Q29=1 (Yes) = 100 Q29=2 (No) = 0</td>
</tr>
<tr>
<td><strong>FECC-18</strong></td>
<td>Caregivers of children with medical complexity who are age 15 years or older should report that their child’s main provider created a written transition plan for their child.</td>
<td>Q33=1 (Child age 15 or older)</td>
<td>Q34 (MP created transition plan for child)</td>
<td>Q34=1 (Yes) = 100 Q34=2 or 3 (no or don’t know) = 0 pts</td>
</tr>
<tr>
<td><strong>FECC-17</strong></td>
<td>Caregivers of children with medical complexity should report that their child’s main provider created an emergency care plan for their child.</td>
<td>All caregivers of children with medical complexity</td>
<td>Q32 (MP created emergency care plan for child)</td>
<td>Q32=1 (Yes) = 100 pts Q32=2 (No) = 0 pts</td>
</tr>
</tbody>
</table>
Appendix I. Ohio Medicaid Managed Care Benefits Package

Medicaid Managed Care Benefit Package

Ohio’s Medicaid Managed Care Program covers primary and acute care services mandated by the federal government as well as optional services Ohio has elected to provide. Some services are limited by the number of visits per year or the setting in which they can be provided.

Ohio Medicaid Managed Care Covered Benefits

The following includes but is not limited to a general list of the benefits covered by Medicaid MCPs:

- Inpatient hospital services
- Outpatient hospital services (including those provided by rural health clinics & federally qualified health centers)
- Physician services
- Laboratory and x-ray services
- Screening, diagnosis, and treatment services for children under age 21, under Healthchek (EPSDT)
- Immunizations
- Family planning services and supplies
- Home health and private duty nursing services
- Podiatry
- Chiropractic services
- Physical, occupational, developmental, and speech therapy services
- Nurse-midwife, certified family nurse practitioner, and certified pediatric nurse practitioner services
- Prescription drugs
- Ambulance and ambulette services
- Dental services
- Durable medical equipment and medical supplies
• Vision care services, including eyeglasses
• Nursing facility services (limited to short-term rehabilitative stays for certain population groups)
• Hospice care
• Behavioral health services
• Respite services for eligible children receiving Supplemental Security Income (SSI)
• Value-Added Services

MCPs add value for their members by providing services not normally offered in the traditional Medicaid fee-for-service program. Some of these services include the following:

• care management to help members coordinate care and ensure they are getting the care they need
• access to a toll-free 24/7 nurse hotline for medical advice
• on-line searchable provider directory
• member handbook
• grievance resolution system
• access to a toll-free member services hotline
• preventive care reminders
• health education materials & activities
• expanded benefits including additional transportation options, and other incentives (varies among MCPs)
• extended office hours (varies among MCPs)

Source:
http://medicaid.ohio.gov/Portals/0/Providers/ProviderTypes/Managed%20Care/ManagedCareBenefitPackage.pdf
Disclaimer:
The [views, statements, opinions] presented in this report are solely the responsibility of the author(s) and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute® (PCORI®), its Board of Governors or Methodology Committee.

Acknowledgment:
Research reported in this report was funded through a Patient-Centered Outcomes Research Institute® (PCORI®) Award (#IHS-1310-07863). Further information available at: https://www.pcori.org/research-results/2014/use-healthcare-services-among-children-disabilities-enrolled-accountable-care