

# **Improving Care Coordination for Children with Disabilities through an Accountable Care Organization**

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# Improving Care Coordination for Children with Disabilities through an Accountable Care Organization

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## STUDY PROTOCOL

Version 2

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## List of Acronyms

ABD	Aged, Blind, Disabled
ACO	Accountable Care Organization
	Center of Excellence on Quality of Care
COE4CCN	Measures for Children with Complex Needs
CSRL	Carolina Survey Research Lab
FECC	Family Experiences with Coordination of Care
NCH	Nationwide Children's Hospital
OSU	Ohio State University
PFK	Partners for Kids
SSI	Supplemental Security Income
UNC	University of North Carolina at Chapel Hill

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## Study Abstract

Children with disabilities have complex healthcare needs requiring multiple providers in multiple locations. The lack of coordinated care for this vulnerable population leads to poorer outcomes, higher costs, and increased stress and time demands for patients and their caregivers. Traditionally, under arrangements known as fee-for-service, there have been no financial incentives for providers to coordinate care; however, the Affordable Care Act is changing that. Accountable care organizations (ACOs) are groups of healthcare providers that organize in new ways to take responsibility for the care of a defined population. ACOs share in any savings associated with improved quality and efficiency of the care they provide. Although most ACOs currently do not cover children with disabilities, many are considering adding these to the populations they serve. Yet we know little about effectiveness of the care coordination strategies they employ on children with disabilities.

The goal of this research is to assess care coordination for and patient-centered outcomes of children with disabilities under an ACO as compared with traditional fee-for-service plans. We will use a recent policy change in Ohio that mandates children with disabilities move from traditional fee-for-service Medicaid plans into managed care arrangements such as ACOs. This mandate resulted in 8,000 disabled children automatically becoming part of the nation's largest pediatric ACO.

We will use multiple methods, including focus groups, interviews, a survey, medical record data, and Medicare claims, to compare patient experiences and care under the ACO with experiences and care under the previous fee-for-service model. What impact will this research have? Our research will inform ACOs about the relative benefits and challenges of coordinating care and improving the health outcomes of children with disabilities and will help those organizations determine whether or not they can adequately serve the needs of this population. In addition, the findings will provide patients and caregivers with valuable information that can help them make decisions when faced with an increasingly common scenario, for example: "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 are the problems that might occur?"

We will engage patients, their caregivers, and health system stakeholders throughout the research process. Patient advocates have been involved in the design of our study. A patient advisory panel comprised of caregivers and advocates of disabled children will guide our project by providing advice at quarterly meetings. In addition, we will collect data from more than 2,800 patient voices through direct study participation.

## Introduction

### Background

Disability is by definition a significant burden on health and functional status. Childhood disability places an additional, developmental burden on children, i.e., it makes it more difficult for them to do the important developmental work of childhood. For this reason, children's disabilities are sometimes referred to as developmental disabilities. Development disabilities span a wide range of health conditions but commonly include physical disabilities such as blindness, cerebral palsy, and spinal cord/ traumatic brain injuries and mental disabilities such as autism, mental health disorders and intellectual disabilities.[1,2] Approximately 14% of children 18 years and younger in the U.S. have a developmental disability, and the prevalence of developmental disabilities has increased by over 17% in the past decade.[3,4]

Disabled children are among the most vulnerable populations because having a disability creates a higher risk for poor physical, psychological and social health.[5] In addition to their primary disabling condition, children with disabilities are increasingly more likely to have multiple chronic conditions and comorbidities such as cardiovascular disease or mental illness.[6] For example, children with cerebral palsy commonly have intellectual disabilities, vision impairment, epilepsy or other secondary musculoskeletal conditions.[4,7] Consistent with the severity of the health condition, children with disabilities utilize health care services more frequently and intensively compared to children without disabilities [8]. They also face significant barriers to accessing health care, greater out-of-pocket health care costs and poorer health outcomes compared to children without disabilities.[9] Childhood disability is estimated to result in 66 million restricted activity days per year, 24 million days missed of school, 26 million physician contacts and 5 million hospital days annually.[10] Furthermore, the prevalence of developmental disability is higher among African Americans and children in low-income and single family households.[3,10]

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 serve as the main coordinator of care for children with disabilities, and the burden of care and coordination has implications for family welfare. Having a child with disabilities can have negative economic, health, and social consequences for families and caregivers. For example, the estimates of family costs of caring for a child with disability range from \$108 to \$8,742 per year and caregivers spend 4 to 84 hours per week coordinating care for their children.[11] Even low-income families with disabled children spend over \$500 annually.[12] Parental employment is also impacted by a child's disability. Only 1/3 of households with children with disabilities have both parents in the labor force compared to over 50% of all households without disabled children.[13] Maternal employment is particularly impacted by a child's disability.[14] Mothers of disabled children are less likely to work outside of the home. Those who do work report more hours of missed work due a child's disability, and mothers that quit their job due a child's disability are more likely to report a lower quality of life. [14–17] Having a child with a disability also indirectly impacts maternal employment through effects on maternal health.[18] Mothers of children with disabilities are more likely to report their health as poor or declining compared

to fathers, and are more likely to report greater levels of stress and poorer mental health. [19–22]

### **Accountable Care Organization Model of Care**

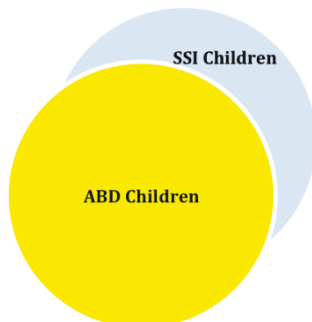
Emerging from the Affordable Care Act, Medicaid Accountable Care Organizations (ACOs) are being viewed by several states as a new model of health care delivery that offers significant opportunities to improve the quality and efficiency of care. ACOs are groups of providers that take responsibility for the care of a defined population and share in any savings associated with improved quality and efficiency of the care they provide.[23] 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.[24] Among other things, ACOs are expected to integrate high-risk populations, such as disabled children, that were previously excluded by Medicaid managed care arrangements to achieve the goals of higher quality care and improved efficiency through care coordination.[25–27] Unlike managed care arrangements, ACOs assume financial risk if they do not meet both cost and quality targets. Thus, the ACO model is designed to improve coordination of health services and, in turn, improve efficiency and outcomes through the presumption of financial risk. Failure to achieve these goals will not only result in financial losses to the ACO, but also increase the likelihood that ACOs will exit the market or exclude populations that they cannot effectively manage – the very populations who could benefit most from coordinated care. In contrast, traditional fee-for-service arrangements do not provide financial incentives for providers to coordinate care, so while disabled children 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. As a children’s hospital CEO and mother of a disabled child recently explained, “There is no other single person other than my husband who is really paying attention to how care is coordination for a kid like Katie.”[28] 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.[26,27] At the same time, the ACO model is being actively promoted by policy-makers in Ohio and elsewhere as a way to improve quality and lower costs in the state Medicaid programs [29–31]. This study will therefore fill 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 disabled children.

### **Ohio State Medicaid Policy Change**

Prior to July 2013, children with disabilities were eligible for traditional, fee-for-service Medicaid. In July 2013, all ABD children in Ohio were required to enroll in managed care. The policy change effectively moved approximately 8,000 Medicaid-eligible ABD children into the Partners for Kids (PFK) ACO. Partners for Kids (PFK) is owned by Nationwide Children’s Hospital, and assumes responsibility for approximately 300,000 Medicaid children in central and southeastern Ohio (34 of 88 counties).

## Study Population

### Defining the Study Population:



**Figure 1:SSI vs. ABD in Ohio**

The Social Security Administration (SSA) considers a child under age 18 disabled if the child 1) is not working at a job considered to be substantial work; 2) has a physical or mental condition that results in “marked and severe functional limitations”; and 3) the condition(s) has lasted or is expected to last at least 1 year or expected to result in death.[32] In most states, children who are Medicaid-eligible under the Aged/Blind/Disabled (ABD) category are the same children who qualify for Supplemental Security Income (SSI) under the SSA’s disabled definition. In Ohio and other “209b” states, the eligibility criteria for

Medicaid are more restrictive. In these states income-eligibility level for Medicaid may be set lower than that required for SSI eligibility, although it also allows for “spend down” to Medicaid monthly income eligibility by deducting medical expenses.[33] The result is that most, but not all, SSI children in Ohio also qualify for Medicaid under Ohio’s ABD definition (**Figure 1**).

**Because Medicaid eligibility is not automatic for all SSI children in Ohio, we refer to the disabled children population in this research proposal as “ABD children.”**

## Study Justification

There are approximately 1.3 million children in the United States who have physical or behavioral health conditions resulting in significant functional impairment [1]. In Ohio, there are approximately 38,000 ABD children.[34] They represent 3.4% of all Ohio Medicaid children, yet they account for 16.2% of all spending for Ohio Medicaid children ages 0-18.[34] The average monthly cost per ABD Medicaid child is \$1,188 compared to \$205 per month for all other Medicaid children.[34] The involved care needs of these ABD children, along with concerns about health plans’ provider network adequacy, experience, and willingness to serve this population, have been long considered great enough to exempt them from the managed care enrollment required of other Medicaid-eligible children and to leave them instead in the traditional fee-for-service system.[2] However, faced with increased pressure to improve care for beneficiaries with complex needs and address budgetary concerns, several states now mandate managed care enrollment and/or are investing in alternative models such as ACOs for the pediatric ABD population.[31] The significance of this study is that it compares the effectiveness of care coordination for disabled children under two models of health care delivery—fee-for-service and ACO.

## Projected Use of Study Results

- By health systems (including PFK specifically and others more generally) who want to understand the advantages and disadvantages of an ACO model for coordinating the care of children with disabilities and to plan more effective approaches to care for this population.

- By patients and families considering participating in an ACO—results offer them information for understanding the advantages and disadvantages as compared to a more traditional fee-for-service health plan.

## Study Design

### General Approach

The proposed study uses a recent policy change in Ohio as a natural experiment to assess outcomes and experiences of ABD children and their caregivers in an ACO model of care compared to their previous outcomes and experiences in a traditional fee-for-service model. Prior to the policy change, nearly all of the 38,000 Medicaid-eligible ABD children in Ohio were enrolled in a traditional fee-for-service plan. After the policy change went into effect in July 2013, all ABD children were required to enroll in managed care. In central and southeastern Ohio, the policy change effectively moved approximately 8,000 Medicaid-eligible ABD children into the *Partners for Kids* (PFK) ACO.

PFK is the nation's largest and oldest pediatric ACO focused solely on Medicaid-enrolled children. Established in 1994, PFK is a not-for-profit physician hospital organization jointly owned by Nationwide Children's Hospital in Columbus, Ohio and by a 750+ physician group comprised of primary care physicians, pediatricians, and specialists. In 2013, Nationwide Children's Hospital served 1,000,000 patient visits, 21,000 annual inpatient admissions and 68 facilities including outpatient centers, urgent care, research, and primary care and specialty physician offices. As an ACO, PFK currently provides both primary and specialty care to more than 300,000 Medicaid children enrolled in one of 5 Medicaid managed care plans operating in 34 counties (out of 88 total counties in Ohio) stretching from urban Columbus to rural Appalachia.

### Research Questions

The proposed study will address the following research questions:

- 1) Can an ACO implement a system of care coordination that improves upon what children with disabilities and families received before becoming part of an ACO?; and
- 2) What effects do these activities have on health care and outcomes?

### Hypothesis

Children with disabilities will have improved outcomes and experiences after becoming part of an ACO compared to their prior outcomes and experiences in a traditional fee-for-service model.

## Study Aims

### Aim 1

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

### Aim 2

Implement a novel caregiver and medical record abstraction tool designed to assess care coordination for children with special health care needs to evaluate the quality of care coordination provided by the ACO.

### Aim 3

Compare healthcare 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 health record data.

## Methods and Data Analysis

### Approach to Analysis: Mixed Methods

#### *Integrating the quantitative and qualitative analyses across aims*

A key strength of our research design is the ability to triangulate quantitative and qualitative approaches, thereby leveraging the strengths while minimizing the weaknesses of each.[35] This integration involves two approaches. First, findings from one Aim will be used to develop deeper insights from the other. For example, our analyses of the qualitative data, along with particular stories contained in that data set, may provide additional hypotheses to test using the quantitative data set and will be useful for developing explanations for the patterns we find in the quantitative analyses. Similarly, relationships observed among variables in the quantitative data analyses may be useful when inferring the extent to which findings from the qualitative analyses are likely to be generalizable.

Second, we will triangulate by merging the qualitative findings with the quantitative findings to develop a complete, well-substantiated analysis of the comparative effectiveness of care coordination under the fee-for-service and ACO models. Convergence in the results from the qualitative and quantitative analyses will provide stronger support for comparative effectiveness findings, while any divergences in the results of the analyses will be useful for tempering interpretations of findings and guiding subsequent research efforts. For example, our comparison of the quality of care under the two models will integrate patient perceptions of quality, as identified in the focus groups and interviews, with quantitative measures from the claims data, such as ED readmissions. Taken together, the findings from these multiple data sets will provide a complex, patient-centered understanding of how quality of care differs under the two models.

## Aim 1

We will conduct key informant interviews with ACO stakeholders (Sub-aim 1a), as well as focus groups with patients and caregivers and interviews with caregivers (Sub-aim 1b). **Table 1** provides an overview of Aim 1.

### Participants and Sample Size

**Table 1: Aim 1 Study Participants**

Data Collection	Participants	Interview Topics	Payment
<b>Sub-aim 1a</b> Interviews with ACO Stakeholders	<b>20 Stakeholders</b> <ul style="list-style-type: none"><li>• 5 ACO Leaders</li><li>• 5 ACO Care Coordinators</li><li>• 5 Clinicians</li><li>• 5 Payor Representatives</li></ul>	<ul style="list-style-type: none"><li>• Care coordination before &amp; after policy change</li><li>• Delegation</li><li>• Metrics and Evaluation</li><li>• Hospitalization/Discharge</li><li>• Overall Assessment</li></ul>	None
<b>Sub-aim 1b</b> Focus groups with Patients & Caregivers	<b>110 Individuals (across 10 focus groups)</b> <ul style="list-style-type: none"><li>• 2 Caregiver Groups: Physical disability, rural area</li><li>• 2 Caregiver Groups: Physical disability, urban area</li><li>• 2 Caregiver Groups: Mental disability, rural area</li><li>• 2 Caregiver Groups: Mental disability, urban area</li><li>• 2 Patient Groups: Teenagers</li></ul>	<ul style="list-style-type: none"><li>• Coordinating Care</li><li>• Accessing Needed Care</li><li>• Satisfaction and Quality</li><li>• Hospitalizations</li><li>• Additional Concerns</li><li>• Overall Assessment</li></ul>	\$50 gift card and light meal
<b>Sub-aim 1b</b> Caregiver Interviews	<b>30 Caregivers</b> <ul style="list-style-type: none"><li>• Dependent on findings from focus groups. Will entail a mix of rural and urban areas and physical and mental disabilities</li></ul>	<ul style="list-style-type: none"><li>• Coordinating Care</li><li>• Accessing Needed Care</li><li>• Satisfaction and Quality</li><li>• Hospitalizations</li><li>• Additional Concerns</li><li>• Overall Assessment</li></ul>	\$50 gift card
<b>Total</b>	<b>160 Stakeholders, Patients and Caregivers Study Participants</b>		

### Data Collection

*Sub-aim 1a: Interviews with ACO Stakeholders:* We will conduct key informant interviews with ACO stakeholders in order to identify care coordination strategies for ABD children before and after the policy change. We will sample purposively from four groups: ACO leaders, care coordinators, clinicians, and payor representatives. Each group will provide a different perspective on coordination objectives and strategies. ACO leaders can speak to the goals of the ACO. Care coordinators and clinicians can speak to the day-to-day practices of coordinating care. Payor representatives can speak to the motivations to delegate care coordination to the ACO and ongoing efforts to monitor this delegation. We will work with the ACO to identify and select key informants from each of the four stakeholder groups based on their knowledge about and experience with care coordination related decisions and practices for ABD children. At least two researchers will attend each in-person interview. The role of the researchers will be to prompt for additional details and to take notes. Each interview will last about one hour and will be digitally recorded and subsequently transcribed.

*Sub-aim 1b: Focus groups with patients and caregivers and interviews with caregivers:* We will conduct focus groups with patients and caregivers and interviews with caregivers in order to obtain their perceptions of the relative quality, value and experience of care and care

coordination under the two systems. We will recruit participants through the following means: 1) distribution of flyers throughout ACO provider sites and ACO care coordinators; 2) recruitment email sent through Patient Advisory Panel and Voice's For Ohio's Children listserv; and 3) snowball-sampling approaches to identify additional participants based on referrals from other participants. 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 since at least one year before the policy change;
2. Be no more than 18 years of age at the time of data collection; and
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.

These criteria ensure that participants will have had sufficient, relevant experience under both systems to be able to compare them. All recruitment materials will be developed by the research team in consultation with Patient Advisory Panel members and will be subjected to review by the Institutional Review Boards at UNC-Chapel Hill, The Ohio State University, and Nationwide Children's Hospital.

We will conduct a total of ten 1.5-hour focus groups, each with roughly 10-12 participants. Under guidance from members of our Patient Advisory Panel, we have developed a strategy that samples based on broad categories of disability and geographic location (**Table 1**). This approach will allow us to maximize the overall variation in our sample through inter-group diversity, while simultaneously ensuring focused, productive discussions within each group through intra-group similarity. While caregivers of ABD children are often the primary point of contact for coordination activities, we recognize that individuals with disabilities will have unique perspectives. Two focus groups with disabled teenagers will therefore be conducted to ensure these perspectives are incorporated. All focus group discussions will be guided by questions we have developed with input from our Patient Advisory Panel Members (**Appendix C**). One researcher will moderate these discussions, ensuring all participants have opportunities to share their thoughts, including those that differ from the majority. A second researcher will take notes. Focus group discussions will be recorded and transcribed.

*Interviews with Caregivers:* We will conduct 30 semi-structured interviews with caregivers of ABD children in order to gather in-depth, detailed accounts of their experiences with care coordination under both the fee-for-service and ACO models. Consistent with the logic of purposive sampling in qualitative studies, our goal is not to achieve statistical representation, but rather to ensure that our sample is comprised of richly informative cases.[35,36] We will therefore recruit those individuals who, by reason of their experiences, are most likely to provide useful insights for understanding the diverse challenges of coordinating care for ABD children and for evaluating the comparative effectiveness of the two models. Interviews will be guided by questions, refined with input from Patient Advisory Panel Members. One or two researchers will be involved in these interviews, prompting for additional details and to taking notes. Each interview will last about one hour and will be recorded and subsequently transcribed.

### ***Instruments***

We have developed interview guides for ACO stakeholder interviews, caregiver interviews and focus groups with patients and caregivers. The ACO stakeholder interview guides include questions around the following domains: Medicaid Policy change, Care Coordination, Metrics and Evaluations, Hospitalizations, Overall Assessment. The caregiver interviews and focus group interview guides current include questions around the following domains: Impact of Disability, Coordinating Care, Accessing Care, Satisfaction and Quality of Care. The caregiver and focus group interview guides will be vetted by our Patient Advisory Panel to make sure we are covering appropriate topics and utilizing clear and appropriate language in our interviews.

### ***Data Analysis***

We will use the same methods for analyzing all of the data gathered for Aim 1. Following standard qualitative coding techniques, we will code data segments within transcripts using labels that capture ideas contained in the data.[37,38] Related codes will then be grouped into themes that highlight common perceptions, ideas, or experiences across informants. We will follow an iterative approach to analysis that involves ongoing cycles of reading and coding transcripts, reviewing the literature, and discussing findings among the research team to identify themes. Throughout the process we will use the constant comparative method comparing data with data, data with codes, codes with codes, and codes with themes, in order to construct a detailed framework of perceptions regarding the effectiveness of care coordination strategies. [39,40] The research team will use the Atlas.ti software package (version 9.0) to facilitate the managing and coding of qualitative data. Our study investigators have used this approach in several previous studies.[41–44] Using all of the qualitative data (i.e., focus groups and ACO stakeholder and caregiver interviews), we will identify the advantages and disadvantages of each model and the situations under which each model is likely to be more or less effective based on patient and stakeholder perceptions of outcomes. We acknowledge that the retrospective nature of Aim 1 may affect recall. However, our intent will be to understand the perceptions of various stakeholder groups regarding care coordination under the two models, as well as, their experiences before, during and after the policy change. Under this aim we will investigate the extent to which participants perceive care coordination to have changed and their own assessments of the effects of any such changes.

### ***Aim 2***

In Aim 2, we will add to our qualitative assessment of care coordination and perceived changes in care coordination, using a newly developed quantitative care coordination measurement tool. This tool will measure experiences with and documentation of care coordination in the first year after the transition to the ACO. Data from this measurement will be used to describe the extent of care coordination, to assess whether measured care coordination is consistent with expectations identified in Aim 1, and to measure the relationships between care coordination and patient-centered utilization outcomes.

## Caregiver Survey

### *Participants & Sample Size*

Our study will implement the caregiver survey and the medical record abstraction tools in the PFK ABD population. Caregivers of all 8,080 newly enrolled ABD children will be invited to participate in the survey. We estimate that our methods will yield 2,750 caregiver survey respondents. The estimated 34% response rate considers a combination of those who are unreachable based on available contact information and those who are reached but who opt out of participation. This sample size will allow us to estimate performance on each survey-based care coordination indicator within a 95% confidence interval of  $\pm 1.5$  percentage points (conservatively assuming underlying performance of 50%). Confidence interval widths for age, gender, and urban/rural subpopulations will range from  $\pm 1.8$  to  $\pm 3.7$ . This sample size will allow us to identify a significant urban/rural difference ( $\alpha=0.05$ ) of 0.05 percentage points (i.e., 0.50 vs. 0.55) with a power of 0.83.

## Medical Record Abstraction

### *Participants & Sample Size*

We further estimate that 1,000 of those who complete the survey will consent to a review of their medical records that will allow data collection on medical record review based measures that can be linked to survey data and ultimately medical claims data. This consent rate is based on experience in current pilot work. This sample size will allow us to estimate performance on each medical record-based care coordination indicator within a 95% confidence interval of  $\pm 2.9$  percentage points (conservatively assuming underlying performance of 50%). Confidence interval widths for age, gender, and urban/rural subpopulations will range from  $\pm 3.6$  to 7.0. This sample size will allow us to identify a significant urban/rural difference ( $\alpha=0.05$ ) of 0.10 percentage points (i.e., 0.50 vs. 0.60) with a power of 0.89.

### *Analysis*

We will first calculate performance on each of the 31 care coordination measures using data from the FECC and the care coordination medical record review. We will stratify indicator performance by age group, urban/rural residence, and disabling diagnosis (physical vs. mental diagnosis). Where appropriate, performance in our sample will be compared with pilot data collected by COE4CCN. We will then link data from the FECC, the medical record review, and the PFK claims data, at the individual level, to assess the relationship between receipt of care coordination elements and selected outcomes. For example, this linked database will allow us to test the relationship between receipt of a useful and understandable discharge summary following an inpatient stay and 30 day readmission or the relationship between regular communication with a designated care coordinator and use of the emergency department. Specific quality/outcomes measures to be studied will be drawn from claims and EMR-based CHIPRA and HEDIS measures with input from our advisory panel. We expect limited missing data in the survey and medical record data due to our data collection methods. Missing data from the survey and the medical record review will be handled using the “available case

analysis approach” in which all cases with complete data for a selected analysis are included in that analysis.

The proposed analysis in Aim 2 will allow us to 1) quantitatively assess the quality and completeness of care coordination offered to ABD children upon roll-in to the ACO; 2) determine whether that quality and completeness is consistent across selected subpopulations; and 3) understand the relationships between elements of care coordination and patient-centered measures of quality and outcomes.

### Aim 3

In Aim 3, we will compare quality, utilization, and other patient-centered outcomes for ABD children before and after joining an ACO in Ohio using claims, survey and medical record data. Our comparative analysis includes both quantitative and qualitative measures identified through Aims 1 and 2. In addition, we will triangulate findings from our quantitative, qualitative and care coordination assessment analyses to provide a robust and multi-faceted analysis of the comparative effectiveness of care coordination under a fee-for-service system compared to an ACO model for children with disabilities.

**Data & Sample Size:** Our primary analytic data come from Ohio Medicaid administrative claims for years 2010-2016. This data captures service utilization, dates of service, diagnoses and expenditure data paid by Ohio Medicaid for the 8,080 ABD children attributed to the ACO. Claims data include 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.

Using the ABD eligibility identifier in the state Medicaid claims data, we will be able to identify the Medicaid beneficiary numbers and claims histories of the estimated 8,080 ABD children who automatically transitioned from fee-for-service to the ACO after the policy change, allowing for comparison of utilization and claims based quality measures prior to joining the ACO. For the subsets of this population who complete the survey and who consent for medical records review from Aim 2, these additional rich data sets will be merged with the claims data to test whether aspects of care coordination impact care, quality and utilization differences after the policy change.

We do not anticipate substantial missing data issues from the Ohio Medicaid claims database. While the claims data will have the traditional limitations of administrative data (i.e., the potential for under-coding of non- diagnoses, and the lack of information on reimbursed services), only paid claims will be used in the analysis. Thus, payment data and other fields such as patient id, date of service, procedure codes required for reimbursement will be well populated for each claim. This sample size is more than adequately powered; subgroup analyses described below will be conducted only when the subgroup size is large enough to have adequate power for the analyses.

**Outcomes Measures:** We will construct quality, utilization and other patient-centered outcomes measures for our comparative analyses. Our proposed measures, described below, draw on a review of the literature and existing recommendations by the Children’s Health Insurance Reauthorization Act (CHIPRA), the Healthcare Effectiveness Data and Information Set (HEDIS), and other quality-reporting metrics designed specifically for children and children with complex health care needs. Measures will be specified quarterly and annually as appropriate.

Administrative data-derived measures include items such as continuity of care, use of the emergency department, hospitalizations, and access to primary and specialty care, timely follow-up after initial prescriptions of ADHD medications or after psychiatric hospitalization.[45,46] We will incorporate recent methodological advances in operationalizing these measures from administrative data.[47] All study measures will be reviewed with our Patient Advisory Panel in order to prioritize the measures determined to be of greatest importance to our patient population. The Patient Advisory Panel may also propose and prioritize additional patient-centered outcome measures during the first two years of the project.

**Key treatment variable:** The key variable of interest is the enrollment in the ACO by children with disabilities. This “treatment” was assigned to children seen by one of the health care facilities within PFK’s 34-county service area in Ohio beginning in July 2013. Data from PFK-enrolled children prior to enrollment (July 2010 – June 2013) will serve as primary controls, adjusting for age and length of time on Medicaid. Children who were enrolled in Ohio Medicaid with ABD eligibility in other areas of the state will serve as additional potential controls using Medicaid claims data. We cannot use these children as primary controls due to important limitations in the data, namely the inability to attribute children to other ACOs outside the 34 county PFK region. PFK’s unique arrangement with the state allows us to clearly identify the ACO catchment area by county and thus we can clearly attribute these patients to PFK.

**Patient Characteristics:** Our analysis is conducted on a diverse population of children and adolescents. Their characteristics vary by age, gender, race, Latino ethnicity, SSI status, county of residence, diagnoses, procedures received, length of time on Medicaid and other patient characteristics as detailed in **Appendix F**. We will create baseline disease adjustment categories using the Chronic Illness and Disability Payment System, which was specifically designed for disabled Medicaid enrollees. [48]

**Methods:** Following the latest guidance on PCOR methods from the PCORI Methodology Report, we will define the analysis sample that represents the distribution of demographic and conditions among ABD children in Ohio from histories available in the administrative data.[49] We will use approaches appropriate to PCOR including mixed qualitative and quantitative methodologies in a quasi-experimental study design for this Aim.

*Quantitative Analysis:* Using the interrupted time series analysis for statistical models, we will estimate the effect of switching from FFS to ACO while controlling for secular trends. This method examines both the change in the average level of each outcome in the post period as

compared to the pre-ACO period, as well as changes in the trends in each outcome. For example, an interrupted time series analysis can determine whether access to outpatient visits with specialists increases or decreases after the children are enrolled in PFK as well as whether changes in the rate of access over time are greater or lower as compared with the pre-ACO period. Outcome models will be run separately on each outcome using generalized estimating equations with appropriate distributional assumptions for each type of outcome variable (e.g., binary, continuous). The key variables will be an indicator of the ACO enrollment period and its interaction with time trends.

While we believe this is the strongest study design for this Aim given the available data, the lack of a control group cannot rule out other explanations for differences in outcomes over time. Therefore, we will carefully consider alternative explanations to other trends with our Patient Advisory Panel and other key experts once we obtain preliminary analytic results. We will additionally examine the potential for controls from children in other regions of Ohio for a case/control analyses. Although ACO assignment was mandatory and assigned based only on region and thus may not suffer from self-selection bias, if we are able to incorporate data from children in other regions, we will carefully examine the baseline characteristics, utilization during the pre-treatment period and risk factors between ACO and other ABD children in Ohio to ensure balance in covariates. Incorporating control data from Medicaid claims for children in states other than Ohio is not plausible, given that these data are available with a three-year lag and thus post-period analysis would not be possible during our study period.

*Sub-group analysis:* Although our primary goal is to estimate the effect of ACO enrollment on vulnerable ABD children overall, we will also estimate the *heterogeneity of the ACO treatment effect* in populations defined by age, race/ethnicity, gender, care coordination metrics and diagnostic group to the extent allowable by sample size. The specific subgroups will be identified in advance collaboratively with our stakeholders. This sub- analysis will control for the health status and disease progress of a patient during the 6-year period.

We will also look at the impact of specific elements of care coordination provided on a sub-group of our population using information collected in our caregiver survey and medical record review. For example, as noted above, one of our potential outcomes variables is use of the emergency department. One potential research question is whether emergency department use is lower in children whose caregivers reported receipt of an understandable visit summary after their last outpatient visit.

## **Data Safety, Monitoring, and Handling**

### **Aim 1**

Interview data collected from participants will be identified only by an assigned participant ID number, not by name. The data confidentiality and informed consent process will be explained by the investigator prior to the start of the interview and before the recording begins.

Participants will have the option to not respond to any question and to not have their interviews recorded.

Similarly, for focus groups, participants will be identified only by number, not by name. The data confidentiality and informed consent process will be explained by the moderator prior to the start of the discussion, and before the recording begins. Participants will have the option to not respond to any question posed; if they do not wish to be recorded, they may elect to leave the discussion group.

Digital recordings and transcriptions of interview and focus group sessions, and any documents collected from ACO stakeholders will remain in the possession of the study investigators at all times and will be reviewed in seclusion. These will all be secured in a locked office at all times and stored on a password-protected computer. Upon completion of the study, all electronic and hard copy data will remain in password-protected files and reside with the principal investigator; these will be destroyed after five years.

Any forms and incentive receipt lists, which include patient names and study ID numbers, will be stored in locked file cabinets in a locked file room in a secure building

For both focus groups and interviews, participants' comments will never be quoted or reported in ways that disclose their identities. For medical record and Medicaid claims data, findings will only be reported in aggregate or summary form.

## **Aim 2**

Data from the telephone survey will be entered into an electronic database as it is collected. Once surveying is complete, a formatted and labeled SAS data file will be provided to the PI using a HIPAA compliant data transfer protocol. The data from the medical record abstraction will be directly entered into a Redcap database, which will also export data into a SAS format. Ultimately, linked survey, medical records, and claims data will be housed on a secured server at Nationwide Children's Hospital. Access to the data on the server will be limited to the project's investigators and programmer.

## **Aim 3**

NCH will provide UNC with de-identified data from the FECC survey, medical records, and medical claims.

### ***Handling Missing Data – PCORI Methodology Standards MD-1-5***

#### **Describe methods to prevent and monitor missing data (MD-1)**

The underlying population for this study is all children up to age 18 enrolled in the Partners for Kids (PFK) on May 30<sup>th</sup> 2015 who had been previously enrolled in fee-for-service (FFS) Medicaid and transitioned into PFK as a result of the ABD policy change. The primary analytic data comes from Ohio Medicaid administrative claims. Claims data have different missing data issues than do other primary or even secondary data sets on several dimensions. First, many of the fields are mandatory, which means fields such as procedure code and Medicaid eligibility status will

be 100% complete. Second, although claims data have the traditional limitations of any administrative data, including the lack of information of services paid fully out-of-pocket or financed through Medicare, only services provided through Medicaid will be used in the analysis, which will take a Medicaid/agency perspective. This means that services and expenditures will not aim to be a complete record, but those covered through the Medicaid program. We will clearly indicate the scope of analysis in publications. For the subsets of claims data merged with survey and medical records, we do not anticipate missing data problems for the same reasons above.

The estimated size of this population is 8,000. Because of the qualitative nature of Aim 1 we do not propose a missing data plan. The following assumptions have been made regarding rates of participation from this population for Aims 2 and 3:

#### *Aim 2 – Caregiver Survey*

We expect 34% percent of the eligible caregivers to complete the caregiver survey. This is based on assumptions from previous studies with this population regarding degree of incorrect addresses for the opt-out mailing, opt outs, missing/non-functional telephone numbers, and refusal when contacted.

- *Prevention of missingness*– We will use alternative sources of contact information (e.g. EHR records, internet look-up sites) for those families with missing telephone numbers.
- *Monitoring of missingness* – we will record and report the following statistics: % of invitation letters returned by the post office, % opting out, % bad telephone numbers that cannot be found after research, and % refusal by reached families. For each of these percentages, we will describe the lost respondents by gender, age, urban/rural residence, and diagnosis category using PFK data (note: race is not reliably available on the PFK data).

We expect 35% percent of those completing the telephone survey to consent to medical record abstraction.

- *Prevention of missingness* – The script requesting medical record access will clearly explain the reason for access and the processes for maintaining confidentiality.
- *Monitoring of missingness*– We will describe the lost respondents by gender, age, urban/rural residence, and diagnosis category using claims data. We will also test the relationship between perceptions of care coordination and consent to medical record abstraction using data from the telephone survey.

A consort-style diagram will be used to illustrate potential participant loss or refusal at each stage of the study **(MD-4)**.

#### *Aim 3 – Utilization Analysis*

Over 95% of the population will be included in claims data analysis looking at overall pre-/post-policy change utilization analysis. The primary risk of missingness for this analysis is failure of successful linking between the FFS (pre) and PFK (post) data. After acquisition of the data, we will first assess the data quality. Like the traditional Medicaid plan, PFK reimburses physicians

on the basis of services provided (fee-for-service), therefore we expect that the payment data and other fields such as patient id, date of service, and procedure codes required for reimbursement will be populated for each claim billed to Medicaid/PFK. The demographic files (e.g. gender, race) may also have missing data, which is anticipated to be proportionally small, based on the team's prior experience with claims.

- Prevention of missingness – We will investigate each non-match. When there is no matching Medicaid ID across the two databases, we will directly check the record to identify potential transposition or typographical errors. If no such error can be found, we will attempt to use probability matching using date of birth, zip code of residence, gender, and soundex last name to link records.
- Monitoring of missingness– We will calculate and report the final “no-match” rate between PFK and state FFS data.

### Statistical methods and sensitivity analysis to handle missing data (MD2, MD3, MD5)

#### *Aim 2 – Caregiver Survey*

Methods for statistical handling of missing responses on the Family Experiences of Care Coordination survey are documented in the survey's scoring guide. We will use these methods to assure that our results are consistent with those being generated in other implementations of the survey. Missing data will not be imputed, however, we will use sensitivity analysis to estimate the effect of differential non-response by age, gender, urban/rural residence, and diagnosis category. We do not hypothesize differential missingness.

#### *Aim 3 - Utilization Analysis*

The pre-/post-policy change utilization analysis will be performed on all individuals where we are able to link FFS and PFK claims. We expect a low non-link rate. However, to estimate the impact of the missing data, we will conduct sensitivity analysis by testing change in setting-specific utilization if all the unlinked cases were at the 90<sup>th</sup> percentile of their age/gender/diagnosis category group and if all unlinked cases were at the 10<sup>th</sup> percentile of their age/gender/diagnosis category group.

For time invariant missing variables in the FFS or PFK data, such as gender or race, we will carry the last observation forward, assuming gender and race is unchanged for each individual. In the rare case of substantial amount of other types of missing data in the claims, we will employ Multiple Imputation (MI) methods to generate imputations for the missing values, from predicted probabilities estimated based on the complete data (observed and missing data).

## Procedures

### **Aim 1**

In all aspects of Aim 1, we will use purposive sampling, attempting to get a mix of participants and to maximize the diversity of our sample in terms of perspectives that we expect to be

relevant to the coordination of care for children with disabilities. For interviews with ACO stakeholders, we will sample purposively from four groups: ACO leaders, care coordinators, clinicians, and payor representatives. Each group will provide a different perspective on coordination objectives and strategies. For focus groups with youths and caregivers and interviews with caregivers, we will sample based on broad categories of condition and geographic location (rural v. urban). This approach will allow us to maximize the overall variation in our sample through inter-group diversity, while simultaneously ensuring focused, productive discussions within each group through intra-group similarity. Finally, for the interviews with Caregivers, we intend to select 30 parents, as this number provides a large enough sample to gather a rich mix of different stories and experiences in rural and urban settings and from parents of children with different types of disabilities.

To be eligible to participate in ACO stakeholder interviews, participants must be involved with the ACO as either an ACO leader, a care coordinator or clinician, or as a representative of a payor organization (i.e., insurer). To be eligible to participate in focus groups or caregiver interviews, 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 (i.e., Medicaid disability status) since at least one year before the policy change;
2. be no more than 18 years of age at the time of data collection; and
3. have been, at the time of the policy change, at least 14 years of age for youth focus groups or 2 years of age for caregiver focus groups and interviews.

Children under the age of 15 will be excluded on the grounds that they may not be able to recall with sufficient detail their experiences under the previous Fee-for-service system. These criteria ensure that participants will have had sufficient, relevant experience under both systems to be able to compare them.

Our recruitment strategies vary by sub-aim. For sub-aim 1a (Interviews with ACO Stakeholders) we will work with the ACO to identify and select key informants from each of the four stakeholder groups based on their knowledge about and experience with care coordination related decisions and practices for ABD children. Research staff already have relationships with key leaders at the Partners For Kids ACO. Researchers will use these individuals both as participants and also to identify other key stakeholders within the Partners For Kids organization and at the payor organizations with which Partners For Kids deals. The researchers will send information about the study along with an invitation to participate to these individuals via email. ACO stakeholders will not be compensated for participation.

For sub-aim 1b (Focus groups with youths and caregivers and interviews with caregivers) we will recruit participants through the following means:

1. distribution of flyers throughout ACO provider sites and by ACO care coordinators who will distribute flyers to all of their patients/caregivers with whom they interact during the study period;
2. recruitment email sent through Voice's For Ohio's Children listserv; and

3. snowball-sampling approaches to identify additional participants based on referrals from other participants.

Caregivers and patients (i.e., youths) who participate in focus groups will receive a \$50 gift card and light meal for participation. Caregivers who participate in interviews will receive a \$50 gift card. Compensation will not be pro-rated. If participants choose to discontinue participation once the interview or focus group has started, they will still be compensated the full amount.

Participants in the ACO stakeholder key informant interviews, caregiver interviews, and caregiver or youth focus groups will be provided a fact sheet with details about the study at the start of the interview. All participants will be told that they may decline to participate, decline to be recorded, refuse to answer any question, or discontinue participation at any time. While many of the ACO key informants will be employees of the ACO, we will emphasize that their participation is completely voluntary and will in no way affect their employment with the ACO or Nationwide Children's Hospital. Focus group participants and caregiver interviewees may be patients (or parents of patients) of providers associated with the organization being studied; thus, we will emphasize that their participation is completely voluntary and in no way will affect their ability to obtain care, their relationship with Partners For Kids, Nationwide Children's Hospital or their interaction with their doctor(s). The PI or study investigator will review the fact sheet with participants, ask for and address any questions they may have, and then request verbal informed consent/assent in all cases EXCEPT for the youth focus groups, in which case written consent will be requested. If the participant provides consent/assent, then the study investigator will proceed with the interview or focus group using the interview or focus group guide. Additionally, in the case of teenagers participating in the youth focus groups, we will obtain written informed assent from the teenager participant.

All interviews and focus groups will follow the list of questions and topics in the respective guides prepared by research staff with consultation from the patient advisory panel. The interviews and focus groups are semi-structured in the sense that additional, follow-up questions will be asked to probe comments made by participants. Interviews with ACO stakeholders and with caregivers will last about 1 hour. Focus groups will last about one and one half hours. All interviews and focus groups will be digitally recorded and subsequently transcribed.

#### STEPS – Youth Focus Groups (see IRB)

1. Post flyers, send recruitment email (list document names)
2. Youth call 888-218-1040 number or send email to [caregiverinterview@nationwidechildrens.org](mailto:caregiverinterview@nationwidechildrens.org) – can leave a confidential message (write out confidential message)
3. Ascertain eligibility (form name: )obtain verbal assent during telephone recruitment
4. In lieu of signed parental permission, we will provide study information to parents over the phone and gain parental consent for participation and receiving a gift card. . Specifically, when the youth call about the study, we will ask to speak to a parent and describe the study to the parent. If the parent approves of the youth's participation, we

will continue with enrolling the youth into the study. If the parent does not wish for the youth to participate, we will thank the parent for his/her time and conclude the call.

5. If a parent is not available over the phone, we will ask the youth for an address and mail a fact sheet to the parent prior to the focus group. The fact sheet has clear information about whom to call should the parent not want their child to participate. The youth will need to have the parent call back or come with the youth to the focus group to obtain verbal or signed parental permission
6. Mail or email directions to the youth.
7. ARRIVING AT FOCUS GROUP. Signage will be placed to guide participants to the proper location. At the focus group we will provide the participants with an additional copy of the fact sheet and then written assent when the focus group convenes.

#### STEPS – Parent/Caregiver Focus Groups (see IRB)

1. Caregivers call 888-218-1040 number or send email to [caregiverinterview@nationwidechildrens.org](mailto:caregiverinterview@nationwidechildrens.org)– can leave a confidential message (write out confidential message)
2. Ascertain eligibility (form name: ) obtain verbal consent during telephone recruitment
3. Mail or email directions to the caregiver.
4. ARRIVING AT FOCUS GROUP. Signage will be placed to guide participants to the proper location. At the focus group we will provide the participants with an additional copy of the fact sheet and then written assent when the focus group convenes.

#### STEPS – Parent/Caregiver Interviews (see IRB)

1. Post flyers, send recruitment email
2. Caregivers call 888-218-1040 number or send email to [caregiverinterview@nationwidechildrens.org](mailto:caregiverinterview@nationwidechildrens.org)– can leave a confidential message (write out confidential message)
3. Ascertain eligibility (form name: ) obtain verbal assent during telephone recruitment
4. Mail or email directions to the participant.
5. ARRIVING AT INTERVIEW. Signage will be placed to guide participants to the proper location. At the interview provide participants with an additional copy of the fact sheet.

We will use the same methods for analyzing all of the data gathered for Aim 1. Following standard qualitative coding techniques, we will code data segments within transcripts using labels that capture ideas contained in the data. Related codes will then be grouped into themes that highlight common perceptions, ideas, or experiences across informants. We will follow an iterative approach to analysis that involves ongoing cycles of reading and coding transcripts, reviewing the literature, and discussing findings among the research team to identify themes. Throughout the process we will use the constant comparative method comparing data with data, data with codes, codes with codes, and codes with themes, in order to construct a detailed framework of perceptions regarding the effectiveness of care coordination strategies.

The research team will use the Atlas.ti software package (version 9.0) to facilitate the managing and coding of qualitative data. Our study investigators have used this approach in several previous studies. Using all of the qualitative data (i.e., focus groups and ACO stakeholder and caregiver interviews), we will identify the advantages and disadvantages of each model and the situations under which each model is likely to be more or less effective based on patient and stakeholder perceptions of outcomes. We acknowledge that the retrospective nature of Aim 1 may affect recall. However, our intent will be to understand the perceptions of various stakeholder groups regarding care coordination under the two models, as well as, their experiences before, during and after the policy change. Under this aim we will investigate the extent to which participants perceive care coordination to have changed and their own assessments of the effects of any such changes.

Interview data collected from ACO stakeholder participants will be identified only by position title, not by name. Similarly, for interviews and focus groups with caregivers and youths, participants will be identified only by number, not by name. Participants' comments will not be quoted in such a way as to disclose their identity. All data will be reported either in aggregate, summary, or individually de-identified form.

## Aim 2

### *Caregiver Survey Methodology*

The FECC will be administered by the Carolina Survey Research Lab (CSRL) at the University of North Carolina at Chapel Hill. Survey steps are outlined below:

- The ACO (PFK) mails letters to potentially eligible enrollees describing the study and offering them the option of opting out of the sampling frame. Contact information for those who do not opt out will be sent to CSRL for survey contact.
- CSRL will send letters to all non-opt out families. The letter will include thanks for willingness to participate, telephone survey logistics, and a web address that can be used to complete the survey on their own. We expect up to five percent of respondents to use the web-based survey.
- Trained interviewers will make up to 10 telephone attempts for each caregiver who does not complete the online survey. When telephone numbers are found to be non-functional, research staff will make reasonable efforts to find working numbers through use of Lexus-Nexus and through working with PFK staff with access to electronic medical record (EMR) information that may offer updated contact information.
- Surveys will be conducted using a computer-assisted telephone interviewing (CATI) system with interviewer performance monitored through review of randomly selected taped interviews.
- Prior to the close of the interview, the interviewer will request verbal consent for a review of care coordination documentation in their medical records and for linking of their survey responses to medical record and claims data.
- All individuals who complete the interview will be mailed a \$20 gift card in appreciation of their participation.

## Key Decisions

- We will keep the survey wording the same because it has been field tested and underwent cognitive development testing.
  - It is not necessary to allow for N/A (for e.g. 5E – needing equipment, in all the piloted work this was never an issue).
  - Refusals or don't know – they may not be read, but interviewer can fill it in. If subject says they don't know, record in notes and leave unanswered or say respondent refused. For programming purposes, refuse/don't know is a (non-read) option. Email-based surveys can allow blanks (in fact are mandated to allow).
- Web survey
  - We will pilot the web survey.
    - CSRL will do in-house.
    - We will also pilot with Patient Advisory Panel prior to April 6<sup>th</sup> patient advisory panel meeting.
  - We will work on web survey first to make sure it is available for pilot testing, and then focus on the phone survey.
  - CSRL will mail the follow-up letter to non-opt-out families with a web link and code. Participants will have one month to answer. After the month, CSRL will discontinue access to the web and then will know which part of the sample remaining to be called.
- Eligibility/Survey Administration
  - NCH will provide a summary of demographic data on opt-outs.
  - Families with more than 2 eligible patients – ask about the patient (i.e. child) for whom the interviewer is calling only.
  - Interviewer will ascertain which caregiver is the one who obtains health care/ the most involved in going to health care visits with the child and interview this person.
  - At end of survey, interviewer will confirm to whom the check should be mailed and confirm mailing address – participant can choose any person to send check to.
  - We will add 'Yes I agree, No I don't agree' for consent box at the end of survey – this will serve as documentation that interviewer obtained verbal consent.
- Reporting
  - CSRL will provide weekly reports on calls that will include such information as: bad numbers, number called, number ineligible, those we haven't screened, screened but declined, and completed, and medical record consents. May also include how long the interview has taken and profiling.

## Timeframe

March 1      UNC provide CSRL with all IRB-approved materials, including consent

	materials, screener, and the survey in both English and Spanish.
March 27	CSRL send web-based survey link for pilot testing with the patient advisory panel.
March 27-April 5	Patient advisory panel members pilot the web-based survey.
April 6	Quarterly Advisory Panel Meeting – investigators solicit PAP input including such things as need for more instructions, navigation issues, using the interface (do links work, etc.), is survey user-friendly.
April 10	UNC provide feedback about the web-based survey to CSRL
May 1	PFK mail out opt-out letters.
May 31	Preliminary demographics due to PCORI (prepared by NCH).
June 9	End of 40-day period.
June 23	NCH send eligible sample to CSRL.
July 1	Begin web survey. CSRL send follow-up letters to eligible sample with code and web address.
July 31	End date for web survey.
August 1	Begin telephone survey.
October 31	End date for telephone survey.
Nov 30	CSRL send final dataset to UNC.

### ***Medical Record Review***

Based on our pilot work, we expect that 1,000 caregivers who complete the phone survey will also provide consent for abstraction of their medical records for MR based care coordination measures. Data for Medical record-based care coordination measures will be collected primarily through review of the Epic EMR at Nationwide Children’s Hospital (NCH) conducted by an experienced, trained NCH abstractor using a field-tested data abstraction tool. The integrated EMR at NCH allows review of NCH inpatient visits and primary and specialty care services provided by physicians in the NCH system. We estimate 50% of ABD children enrolled in PFK were seen in the NCH system in the past year. If a participant lists a main provider outside of the NCH system, a copy of the relevant medical records will be requested from that provider for review. The first 20 records will be re-reviewed by a second abstractor for quality control and training.

### ***Aim 3***

#### **Assumptions**

- PFK data and claims data are housed on servers at NCH.

- NCH has permission from PFK to use data.
- NCH has permission from the state to use data.
- NCH will provide a limited de-identified dataset at the person-month level.
- Data will be provided in SAS and STATA format.
- Data will be available for download from a secure server using a double-password system.
- Deena, Marisa, Wendy, Paula, and the NCH programmer will have access to the data.

#### Steps for Data Preparation and Access

1. Wendy and Marisa will develop a programming guide for the programmer.
2. NCH Programmer links PFK and state data (EHR data, claims data) to study data (caregiver data) and strips identifiers.
3. NCH Programmer creates an analytic file.
4. NCH Programmer runs frequencies.
5. NCH Programmer makes de-identified dataset available in both SAS and Stata formats.
6. NCH will notify team that data are available for download.
7. MD/WX/PS will log on to server using double-password system (VPN-like system).
8. MD/WX/PS will download and house data on secure site at UNC & OSU.

### Dissemination Plan

The Patient Advisory Panel will assist us in developing our final dissemination plan. The patient-centered quality of the research will ensure that the findings disseminated to policy-makers and providers also emphasize patients and caregivers, alerting them to the importance of these groups in their decision-making going forward. The results of our research might be disseminated through various stakeholder groups, including families of disabled children, child disability advocacy groups, state Medicaid agencies, policy makers and ACO and health system leaders. In addition to the dissemination activities included in our proposal, the results of this research could be disseminated through stakeholder newsletters, webinars, websites, patient or community conferences, news media outlets and issue briefs. Target stakeholder meetings and conferences will include the AcademyHealth Annual Research Meeting and National Health Policy Conference and the Pediatric Academic Societies/Ambulatory Pediatrics Association Complex Care Special Interest group meeting, Target journal for publication will include *Health Affairs* and *Pediatrics*.

The results of this research have real potential to be implemented in other settings, namely in other ACOs. In the wake of the Affordable Care Act, ACOs are developing across the country. Medicare ACOs have largely dominated the ACO market, however, there is increasing interest and growth in Medicaid and pediatric ACOs. Our research involves one of the most highly regarded pediatric ACOs in the country and pediatric ACOs across the state of Ohio and elsewhere are likely to look to results from our research to help guide their care coordination efforts for ABD children.

## **Collaborating Organizations, Personnel, Project Roles**

### **University of North Carolina at Chapel Hill**

Paula Song, Ph.D, Associate Professor, will serve as Principal Investigator. As such she will lead the project's efforts and assumes overall responsibility for completing project milestones according to the PCORI contract.

Marisa Domino, Ph.D., Professor, will serve as Co-Investigator with primary responsibility for Aim 3. She will work together with Dr. Xu of OSU to conduct quantitative comparative analyses using survey, medical record, and claims data. She will also contribute to the quantitative analyses under Aim 2 and the cross-aim analyses under Aim 3.

Renée Ferrari, Ph.D, Research Associate, will serve as Project Manager. She will assume responsibility for day to day management of tasks and operations associated with the study, including IRB submission, study protocol development, reporting, and ensuring that project milestones are met and on time. Dr. Ferrari will also participate in data analysis.

### **Ohio State University**

Brian Hilligoss, Ph.D., Assistant Professor, will be Principal Investigator of The Ohio State University subcontract and a Co-Investigator on the overall study. He will lead the OSU team and assume responsibility for assuring that all staff are performing the required tasks and that all reports are submitted in a timely manner. He will serve as the primary link between the OSU team and the project PI. He will lead the qualitative data collection and analyses under Aim 1 and assist in the cross-aim analyses under Aim 3. He will hire and supervise a student employee who will handle functional tasks relating to the focus groups and other tasks as needed.

Sandra Tanenbaum, Ph.D., Professor, will be a Co-Investigator on the overall study. She will serve as the primary liaison between the overall study research team and the Patient Advisory Panel. In addition, she will contribute to the qualitative data collection and analyses under Aim 1 and the cross-aim analyses under Aim 3.

Wendy Yi Xu, Ph.D., Assistant Professor, will be a Co-Investigator on the overall study. She will conduct quantitative comparative analyses under Aim 3. She will also contribute to the quantitative analyses under Aim 2 and the cross-aim analyses under Aim 3.

A to be named hourly OSU student will be hired to assist with the focus group onsite logistics and to perform other functions as directed by the Principal Investigator.

### **NCH/PFK**

Deena Chisolm, Ph.D., Nationwide Children's Hospital and Partners for Kids will have overall responsibility for activities associated with Aim 2. For recruitment, NCM/PFK responsibilities include identifying the eligible population within their patient population, mailing opt-out letters to the eligible persons notifying them about the study, and providing the Carolina Survey

Research Lab (CSRL) with contact information for persons who did not opt-out of the study. NCM/PFK is responsible for providing de-identified medical record data to the study team for analysis. Dr. Chisolm at NCM will also participate in other study activities of data analysis, manuscript development, and study dissemination.

Madhurima Sarkar, Ph.D., Research Associate, will serve as Project Manager at NCH/PFK for activities associated Aim 2. She will be responsible for IRB maintenance, project documentation, timeline management, and other administrative activities.

Karen Leonhart, B.S, Senior Research Associate/Medical Record Abstractor will conduct the care coordination record reviews (medical record abstraction) using the NCH electronic medical record system.

To Be Named, Programmer/Analyst, who will be responsible for data management and analysis for Aims 2 and 3.

Gary Norwitz, MD, Associate Medical Director for Utilization Management at Nationwide Children's Hospital, will provide physician perspectives on care coordination-related project design, implementation, and analysis.

Joshua Nowack, MHA, Manager of Care Coordination at Partners for Kids, will serve as the liaison between the grant team and Partners for Kids. That role will include assistance with scheduling interviews for Aim 1 and coordinating data sharing issues.

### **Patient Advisory Panel – Voices for Ohio's Children**

Sandy Oxley, Chief Executive Officer, Voices for Ohio's Children (Voices), will serve as co-investigator with primary responsibility for leading the Patient Advisory Panel.

Thomas Scheid, MA, Health Policy Consultant, Voices for Ohio's Children in Columbus, Ohio will serve as co-investigator with primary responsibility for leading the Patient Advisory Panel.

Ms. Oxley and Mr. Scheid will identify and invite representatives to the patient advisory panel. They will host quarterly Patient Advisory Panel meetings. Ms. Oxley and Mr. Scheid will also assist in communicating information about focus groups, caregiver interviews and surveys by distributing recruitment information through their email listserv. They will assist with dissemination efforts by inviting study investigators to present study findings at their annual conference and highlighting study results in Voices newsletters and related publications.

Patient Advisory Panel Members – see complete list in Attachment A.

### **Seattle Children's Research Institute**

Dr. Mangione-Smith, Ph.D, developed the caregiver survey that will be implemented as part of Aim 2, and as such she will provide expertise on the survey administration, analysis, and

interpretation. Dr. Mangione-Smith will also participate in manuscript development and study dissemination activities.

### **Carolina Survey Research Lab**

Robert Agans, Ph. D, Clinical Associate Professor and Co-Director of the CSRL, assumes overall responsibility for the caregiver survey administration. Dr. Agans will oversee the survey methodology, participate in determining the sampling frame.

Anna Hoffmeyer, B.A., Operations Manager of CSRL, will be responsible for the caregiver survey administration and training and oversight of telephone interviewers.

To Be Named, Telephone Interviewers will conduct the caregiver telephone survey.

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## Attachments

ATTACHMENT A

**PCORI: Improving Care Coordination for Children with Disabilities Through an Accountable Care Organization**

**Principal Investigator: Paula H. Song, Ph.D.  
The University of North Carolina at Chapel Hill**

**Patient Advisory Panel Members**

**Updated: January 5, 2015**

The Patient Advisory Panel consists of parent/caregivers of ABD children and/or individuals who have professional expertise as advocates for ABD children. The Patient Advisory Panel will be led by three study investigators: Sandy Oxley, Tom Scheid and Sandra Tanenbaum.

<b><u>Member Name</u></b>	<b><u>Qualifications</u></b>
Sandy Oxley	Study Investigator CEO, Voices for Ohio's Children
Thomas Scheid	Study Investigator Health Policy Consultant, Voices for Ohio's Children
Sandra Tanenbaum, PhD	Study Investigator The Ohio State University
Maria Beckstedt	Parent/Caregiver
Geoffrey Collver	Policy and Communications Director, Disability Rights Ohio
Patty Dovell	Project Coordinator, Family Voices for Ohio
Becky Fusco	Parent/Caregiver
Earnestine Hargett	Senior Disability Rights Advocate, Disability Rights Ohio
Stacy Isenbarg	Parent/Caregiver
Angi Lee*	Government Relations for Easter Seals of Ohio
Peggy Martin	Parent/Caregiver
Marla Root	Parent/Caregiver of ABD Child Public Policy Chair & Board Member, Autism Society of Ohio
Candace Knight	Director of Programs and Services, Easter Seals Central and Southeast Ohio

\*Ms. Lee will serve as an observer of the Patient Advisory Panel.

## ATTACHMENT B

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

All are on 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 nonmissing for a dependent item to be scored

If items are 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 nonmissing for a multi-item indicator to be scored.

MP=Main Provider

Indicator ID	Indicator Description	Eligible	Survey Item	Scoring notes
<b>CARE COORDINATION SERVICES</b>				
<b>CC2</b>	Caregivers should report that their child has a designated care coordinator.	Q2=1 (Child visited more than one doctor's office or used more than one kind of health care service in last 12 months)	Q3 (Someone in MP's office helped manage child's care or treatment from different doctors/providers)	
<b>CC3</b>	Caregivers who report that their child has a designated care coordinator (as identified in CC2) should report that they know how to access their care coordinator.	Q2=1 (Child visited more than one doctor's office or used more than one kind of health care service in last 12 months), Q3=1 (Someone in MP's office helped manage child's care or treatment from different doctors/providers)	Q6 (Knew how to contact person who helped manage child's care when you needed help or had a question)	
<b>CC5</b>	Caregivers who report having a designated care coordinator (as identified in CC2) and who require community services should also report that their care coordinator helped their child to obtain needed community services in the last year.	Q2=1 (Child visited more than one doctor's office or used more than one kind of health care service in last 12 months), Q3=1 (Someone in MP's office 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)	Q16(Person in MP's office who helped manage child's care helped get community services)	

<b>CC7</b>	Caregivers who report having a care coordinator (as identified in CC2) 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.	Q2=1 (Child visited more than one doctor's office or used more than one kind of health care service in last 12 months), Q3=1 (Someone in MP's office helped manage child's care or treatment from different doctors/providers)	Q7 (In last 3 mos, person contacted you w/o you getting in touch w/them first)
<b>CC8</b>	Caregivers of children with complex needs who report having a care coordinator and who report that their care coordinator has contacted them in the last 3 months should also report that their care coordinator asked them about the following:	Q2=1 (Child visited more than one doctor's office or used more than one kind of health care service in last 12 months), Q3=1 (Someone in MP's office 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)	Mean of CC8a and CC8b
<b>CC8a</b>	Caregiver concerns	Q9 (Care coordinator asked about caregiver concerns)	
<b>CC8b</b>	Health changes of the child	Q10 (Care coordinator asked about health changes of child)	
<b>CC8c</b>	Caregivers who report the following: having a designated care coordinator, having a copy of a written shared care plan for their child, and having been contacted by their care coordinator in the last 3 months should also report that their care coordinator asked them about the following: Progress towards goals documented in the patient's shared care plan	Q2=1 (Child visited more than one doctor's office or used more than one kind of health care service in last 12 months), Q3=1 (Someone in MP's office 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	Q31 (In last 12 mos, has MP or anyone from MP's office talked w/you about progress child was making toward goals written in shared care plan)  If Q31=3 (Child's shared care plan does not have written goals), score as No

		touch w/them first), Q29=1 (MP created shared care plan for child), Q30=1 (Caregiver has copy of child's shared care plan)		
<b>CC9</b>	Caregivers who report their child was referred to see a specialist in the last 12 months and who report having a care coordinator for their child should also report that the care coordinator contacted them to confirm they were able to get an appointment with the specialist	Q2=1 (Child visited more than one doctor's office or used more than one kind of health care service in last 12 months), Q3=1 (Someone in MP's office helped manage child's care or treatment from different doctors/providers), Q13=1 (MP told you child needed to see specialist during last 12 mos)	Q14 (Person in MP's office who helped manage child's care contacted you to make sure child got appointment to see specialist)	If Q14=3 (Did not get help managing child's care), score as No
<b>CC10</b>	Caregivers who report having a care coordinator should also report that their care coordinator:	Q2=1 (Child visited more than one doctor's office or used more than one kind of health care service in last 12 months), Q3=1 (Someone in MP's office helped manage child's care or treatment from different doctors/providers)	Q5 (In last 12 mos, person in MP's office who helped manage child's care...)	Give partial credit (No=0, Yes Somewhat=50, Yes Definitely=100), take mean of CC10a-c
CC10a	Was knowledgeable about their	Q5a, Q5b		Mean of rescaled Q5a and Q5b

CC10b	child's health			
CC10c	Supported the caregiver Advocated for the needs of the child	Q5d, Q5e	Q5c	Mean of rescaled Q5d and Q5e
<b>MH8</b>	Caregivers or patients who self-identify as having a preference for conducting medical visits in a language other than English should have access to a professional medical interpreter (live or telephonic) at all visits for which an interpreter is needed.	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 visit to MP some, most, or all visits)	Q45 (How often was professional interpreter available when needed)	Partial credit: rescale Q45 to 0-100 Q45=1 (Never): 0 points, Q45=2 (Sometimes): 100/3 points, Q45=3 (Usually): 100*2/3 points, Q45=4 (Always): 100 points
<b>MESSAGING</b>				
<b>IE2</b>	Caregivers/patients 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:	Q17=1 (received written visit summary in last 12 mos)	Q18 (How often did written visit summaries include...)	Give partial credit (Never=0, Sometimes=50, Always=100), take mean of IE2a-f
IE2a	Current problem list		Q18a	
IE2b	Current medication list	Q18b (Rx), Q18c (OTC)		Mean of rescaled Q18b and Q18c
IE2c	Drug allergies		Q18d (list of "child's allergies", not drug allergies specifically)	
IE2d	Specialists involved in the child's care		Q18e	
IE2e	Planned follow-up		Q18f	
IE2f	What to do for problems related to the		Q18g	

outpatient visit

<b>IE3</b>	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:	Q17=1 (received written visit summary in last 12 mos)	Give partial credit (Never=0, Sometimes=50, Always=100), take mean of IE3a and IE3c
IE3a	Was easy to understand	Q19	
IE3c	Was useful	Q20	
<b>IE4</b>	Caregivers should report having been invited to join in hospital rounds during their child's last hospitalization	Q21=1 (child had overnight hospital stay in last 12 mos)	Q25 (Last time child was in hospital, invited to take part in hospital rounds)
<b>IE5</b>	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:	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)	Q23 (Did written hospital stay summary include...) Mean of IE5a-f
IE5a	Problem list at time of discharge	Q23a	
IE5b	Medication list at time of discharge	Q23b (Rx), Q23c (OTC)	Mean of rescaled Q23b and Q23c
IE2c	Drug allergies	Q18d (list of "child's allergies", not drug allergies specifically)	
IE2d	Specialists involved in the child's care	Q18e	
IE2e	Planned follow-up	Q18f	
IE2f	What to do for problems related to the outpatient visit	Q18g	

<b>IE3</b>	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:	Q17=1 (received written visit summary in last 12 mos)	Give partial credit (Never=0, Sometimes=50, Always=100), take mean of IE3a and IE3c
IE3a	Was easy to understand	Q19	
IE3c	Was useful	Q20	
<b>IE4</b>	Caregivers should report having been invited to join in hospital rounds during their child's last hospitalization	Q21=1 (child had overnight hospital stay in last 12 mos)	Q25 (Last time child was in hospital, invited to take part in hospital rounds)
<b>IE5</b>	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:	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)	Q23 (Did written hospital stay summary include...) Mean of IE5a-f
IE5a	Problem list at time of discharge	Q23a	
IE5b	Medication list at time of discharge	Q23b (Rx), Q23c (OTC)	Mean of rescaled Q23b and Q23c
IE5c	Drug allergies		Q23d (list of "child's allergies", not drug allergies specifically)
IE5d	Specialists involved in the child's care during the hospitalization		Q23e
IE5e	Planned follow-up		Q23f
IE5f	What to do for problems related to the hospitalization		Q23g
<b>IE6</b>	Caregivers who received a written summary of their child's hospitalization at discharge (as	Q21=1 (child had overnight hospital stay in last 12 mos), Q22=1 (Last time child was in	Q24 (Hospital stay summary easy to understand)

described in indicator IE5) should report that the information contained in the visit summary was easy to understand

hospital, got written hospital stay summary at discharge)

<b>MH3a</b>	Caregivers should report having access to an electronic health record 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)	If Q26=1 (Yes): 100 points If Q26=2 or 3 (No or Don't Know): 0 points
<b>MH3b</b>	Caregivers who report having access to an electronic health record should also report that it includes the following health information:	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)		Do not score the N/A's; If no immunizations (meds), do not score MH3b1 (MH3b2); If didn't look at med list, do not score MH3b2 Take mean of MH3b1 and MH3b2
MH3b1	Immunization record	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)	Q27 (In last 12 mos, MP's web site or app had list of immunizations child has received)	If Q27=3 (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
MH3b2	List of child's medications	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)	Q28 (In last 12 mos, MP's web site or app had list of child's meds)	If Q28=3 (no meds in last 12 mos): do not score MH3b2 If Q28=1 (Yes): 100 points for MH3b2 If Q28=2 or 4 (No or Don't Know): 0 points for MH3b2

<b>MH6</b>	Caregivers who report their child's condition causes difficulty learning, understanding, or paying attention in class should also report that one of their child's health care providers (i.e., primary care physician, specialist physician, care coordinator, NP, nurse, social worker, etc) communicated with school staff at least once a year about the educational impacts of the child's condition.	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)	Q37 (In last 12 mos, someone from MP's office contacted staff at child's school to make sure they understood how child's condition affected ability to learn, understand, or pay attention)	If Q37=1 (Yes): 100 points If Q37=2 or 3 (No or Don't Know): 0 points
<b>PROTOCOLS/PLANS</b>				
<b>SCP2</b>	Caregivers should report that their child's primary care provider created a shared care plan for their child.	All caregivers of children with medical complexity	Q29 (MP created shared care plan for child)	Q29=1 (Yes): 100 points Q29=2 (No): 0 points
<b>SCP4</b>	Caregivers of children (age 15 years or older) should report that their child's main provider created a written transition plan for their child.	Q33=1 (Child age 15 or older)	Q34 (MP created transition plan for child)	Q34=1 (Yes): 100 points Q34=2 or 3 (No or Don't Know): 0 points
<b>SCP6</b>	Caregivers should report that their child's main provider created an emergency care plan for their child.	All caregivers of children with medical complexity	Q32 (MP created emergency care plan for child)	Q32=1 (Yes): 100 points Q32=2 (No): 0 points

