

Abstract

Accountable care organizations (ACOs) are groups of doctors, hospitals, and other health care providers who come together voluntarily to give coordinated, high quality care to patients with complex health needs. Children with disabilities have some of the most complex health needs and often experience poor health outcomes. In 2013, Partners for Kids (PFK), a pediatric ACO in Ohio, took on disabled children in 34 counties throughout the state who were classified as Aged/Blind/Disabled (ABD) to more effectively manage their care. Because pediatric ACOs are relatively new, there is currently little research available on them. Therefore, the purpose of this study was to learn how PFK prepared to take on the ABD population, what types of care coordination strategies were used to coordinate care, and the metrics put in place to evaluate success.

In-depth interviews were conducted with PFK stakeholders to understand their perspectives on caring for the ABD population. Results from these interviews suggest that an ACO like PFK prepares itself for taking on complex pediatric populations by addressing concerns from key stakeholders, such as caregivers who do not want their children receiving care coordination services. The ACO also works to build a strong infrastructure, such as putting together a team of care coordinators. Next, to coordinate care for patients with complex health needs, an ACO utilizes many different strategies related to staffing and technology. Staffing strategies include care coordinators identifying how they can best meet the unique health needs of each patient, and prioritizing communication to improve efficiency amongst staff and patients. Another care coordination strategy is to implement relevant forms of technology; for instance, the use of an electronic health record (EHR) allows the ACO to store patient information in a secure, centralized system to better coordinate their care. Lastly, an ACO relies on informal and formal feedback to evaluate success, using metrics related to health outcomes and cost.

Introduction

Problem statement

The passage of the Patient Protection and Affordable Care Act (ACA) in 2010 authorized the use of accountable care organizations (ACOs) to coordinate care for patients, particularly those with complex health needs.¹ An ACO is a network of doctors and hospitals that shares financial and medical responsibility for providing coordinate care to patients in hopes of limiting unnecessary spending.² By working together through an ACO, doctors, hospitals, and other health care providers can help reduce the fragmentation traditionally experienced by patients in fee-for-service systems, such as unnecessary tests and procedures.³ Further, ACOs are able to provide treatment to high-risk populations that were previously not covered under Medicaid managed care arrangements, since they are reimbursed for complex care management.⁴ ACOs share in any savings associated with better patient outcomes, but they also assume financial risks if these targets are not met.⁵ As a result, the goal is for ACOs to uniquely treat those with complex health needs, which will allow them to potentially improve the cost and quality of patient care.

Disabled children are among the most vulnerable populations ACOs seek to treat because they have a high risk of poor physical, psychological, and social health.⁶ Children's disabilities, also known as developmental disabilities, include health conditions such as autism spectrum disorder, cerebral palsy, and muscular dystrophy.⁷ Approximately 14 percent of children under the age of 18 in the United States have a developmental disability, which is an increase of more than 17 percent over the past decade.⁸ These children utilize a wider range of health services at a more frequent rate compared to children without disabilities. Yet, children with developmental disabilities experience greater barriers to accessing the health care system, and often face greater out-of-pocket health care costs and poorer health outcomes.⁹

In the state of Ohio alone, approximately 38,000 children are Medicaid-eligible under the Aged/Blind/Disabled (ABD) category based on their health status and family income. ABD children are typically 6 to 17 years of age, predominately male, and disproportionately African-American. Moreover, these children have involved care needs that lead to substantial medical expenses.¹⁰ The average monthly cost to Medicaid per ABD child is \$1,188, compared to \$205 for other Medicaid children. While ABD children represent 3.4 percent of Ohio Medicaid children, they account for 16.2 percent of all spending.¹¹

Research questions

This study used qualitative methods to identify stakeholder perspectives on care coordination before and after the adoption of the ACO model for children with disabilities. This study looked to answer the following questions:

- How does an ACO prepare itself for taking on complex populations?
- What types of care coordination strategies does an ACO use to help coordinate care for children with disabilities?
- By what metrics does an ACO evaluate its success treating patients with complex health needs?

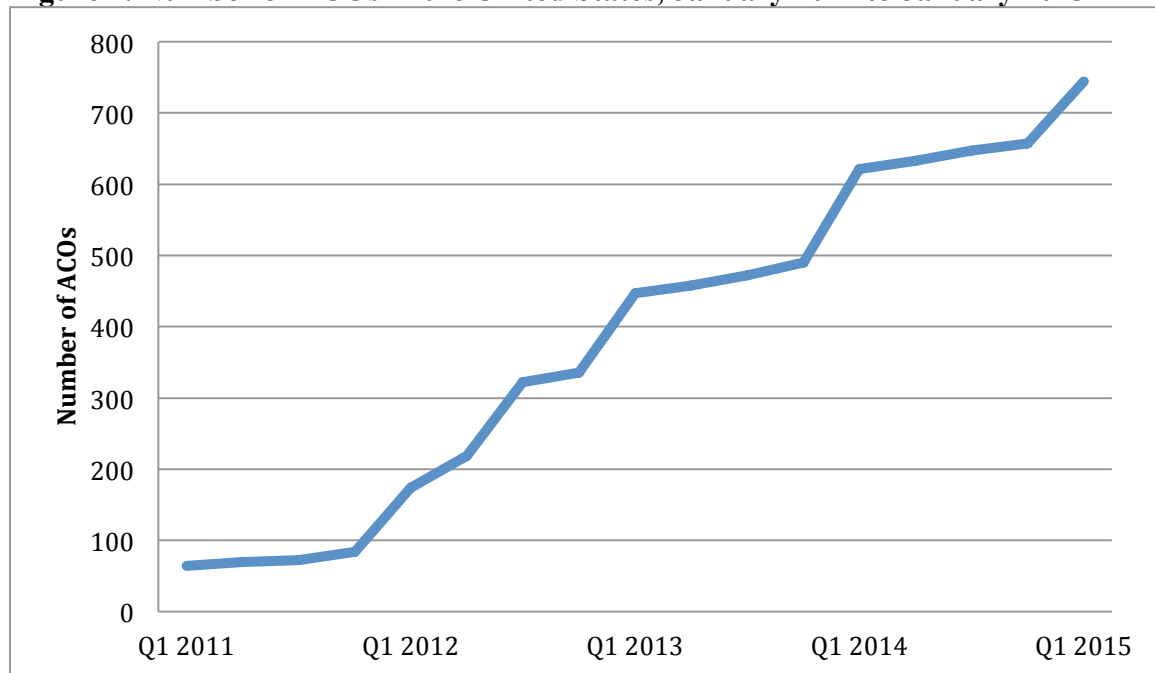
Background

Role of accountable care organizations

The goal of ACOs is to address shortcomings in the United States health care system to achieve the triple aim of improving the experience of care and health of populations, as well as reducing per capita costs of health care.¹² According to a study by Maxwell et al. in 2014, there are several ways ACOs seek to accomplish the goals of the triple aim. For instance, ACOs prioritize the transformation of health delivery systems through the creation of health homes and the management of high-cost cases. Specifically, these health homes involve multidisciplinary

teams and care coordination between health system sectors. Maxwell et al. have found that care coordination for high-cost patients allows ACOs to obtain an immediate positive return on investment while achieving improvements in quality and patient experience.¹³ Because of this potential for success, more than 740 organizations have become ACOs since 2011 (Figure 1).

Figure 1. Number of ACOs in the United States, January 2011 to January 2015



Source: Health Affairs, Muhlestein¹⁴

ACOs also need upfront capital to invest in resources, such as an information technology infrastructure with competencies to support governance, operations, and clinical goals and objectives.¹⁵ A national ACO survey conducted in 2013 showed that organizations need \$4 million of capital on average to start an ACO.¹⁶ Maxwell et al. have discussed how ACOs overcome this barrier through various strategies including grants, global capitation payments, and fundraising. Finally, ACOs focus on the social determinants of health through community partnerships. For instance, they partner with social services to address issues related to housing, food security, legal assistance, employment support, and health insurance enrollment assistance for patients.¹⁷

Therefore, it is important for an ACO to have the tools, data, and leadership necessary for coordinating and managing care for patients with complex health needs. In particular, family physicians and other primary care providers are considered to be the most important element in any ACO.¹⁸ According to Dr. Erica Brode, a family medicine doctor and assistant professor at the University of California San Francisco, primary care “should be the foundation of the ACO because primary care is the core function of any well-functioning delivery system.”¹⁹ Another key component of ACOs is the implementation of a quality measurement strategy.²⁰ Accountable care performance measures represent a relatively simple way of determining whether investments in health care actually result in improvements in health outcomes.²¹ Measurement processes and outcomes can help address population health and engage patients in making decisions and managing their care. Moreover, they can target safety and care coordination, as well as increase the likelihood of providing compassionate and appropriate end-of-life care.²² Such longitudinal approaches seek to use defined measures to capture patient-reported health outcomes.

In early 2015, the United States Department of Health and Human Services announced its goal to move 50 percent of Medicaid payments from fee-for-service to alternative payment models, including ACO-based arrangements, by the end of 2018.²³ Whereas traditional fee-for-service model bills and pays for each procedure, service, intervention, or medical device separately, ACOs are unique because they create incentives for efficiency by offering bonuses when providers keep costs down.²⁴ As Muhlestein discusses, state Medicaid programs have provided continued endorsement for ACOs, showing that there is strong support for this care delivery approach to continue. By January 2015, 132 different payers have entered into at least one accountable care contract, an increase of 26 percent from the year before. Further,

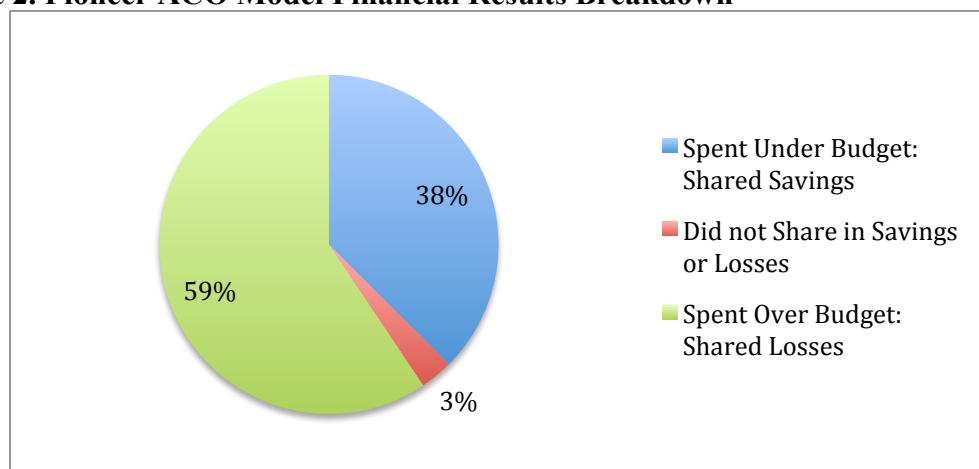
Muhlestein notes that ACOs now exist in all 50 states. Approximately 23.5 million Americans are currently being served by an ACO, of which more than six million are Medicare beneficiaries. Muhlestein predicts that approximately 70 million people will be covered by an ACO in 2020, and more than 150 million people, or approximately half the entire population, by 2025.²⁵

Early results

The Pioneer ACO Model consisted of ACOs who accepted the risk of losses—but also the potential for bonuses—based on how well hospitals and doctors could control Medicare spending and deliver quality care.²⁶ The Pioneer ACO model was designed for organizations with experience offering coordinated, patient-centered care, and operating in ACO-like arrangements. In 2011, 32 organizations had been selected by the Centers for Medicare and Medicaid Services (CMS) to determine the potential for ACO success.²⁷ In 2012, the Pioneer ACO Model included 669,135 Medicare beneficiaries and generated \$147 million in total program savings, exceeding the actuarial calculation of yearly total savings by \$60 million. Finally, the majority of Pioneer ACO Models outperformed Medicare fee-for-service models in all 15 quality metrics for which comparable data was available. By 2013, the Pioneer ACO Model improved performance in all dimensions of the triple aim.²⁸ Pham et al. found these organizations had a mean overall quality score of 84.0 percent in 2013 compared with 70.8 percent in 2012, and the mean performance score increased in six of seven patient/caregiver experience ratings.²⁹ While 12 of the organizations shared in savings, 19 did not share in savings or losses, and one shared in losses (Figure 2). To date, 13 of the initial enrollees have left the pioneer program due to the current design, as it inadequately supports efficient care delivery.³⁰

Nevertheless, preliminary results of the Pioneer ACO Model suggest that accountable care could potentially be an effective long-term solution for lowering health care costs.

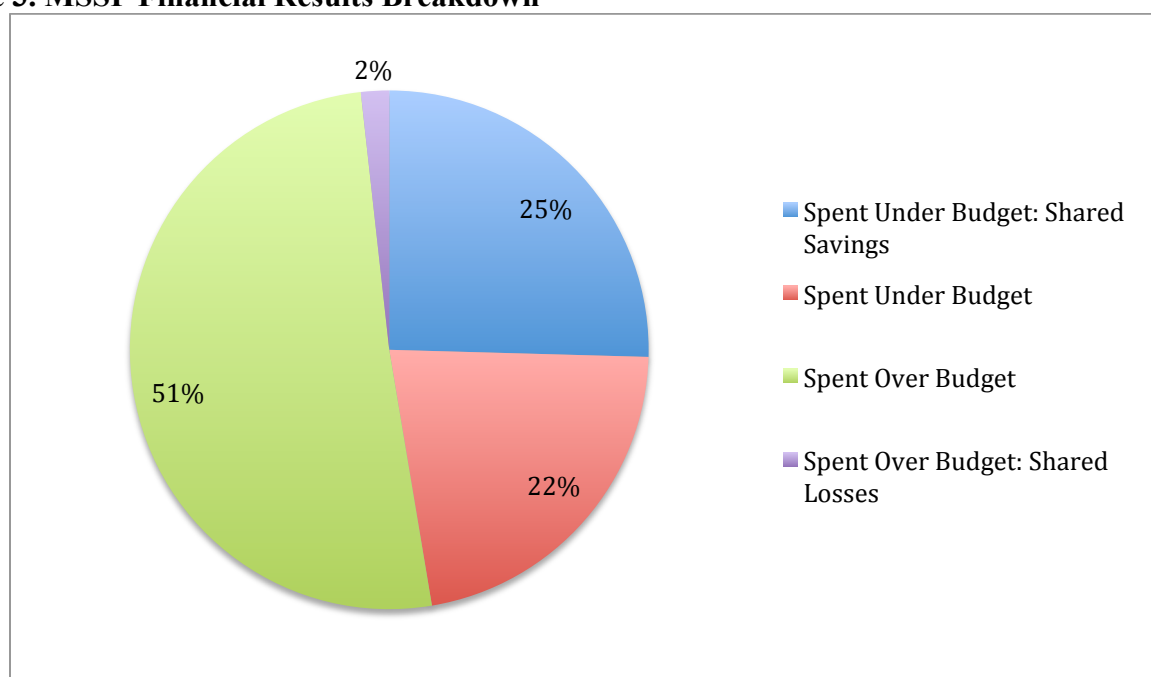
Figure 2. Pioneer ACO Model Financial Results Breakdown



Source: Health Affairs, Muhlestein and Petersen³¹

The Medicare Shared Savings Program (MSSP) is another ACO program that voluntarily contracts with Medicare to be responsible for the health outcomes and expenditures of a defined patient population. Compared to the Pioneer ACO Model, the MSSP has lower levels of savings and risk involved due to the difference in payment arrangements, beneficiary assignment, and benchmarks. There are more organizations in the MSSP compared to the Pioneer ACO Model, with more than 440 organizations supporting 5.3 million beneficiaries throughout the United States.³² Early results of the MSSP have been positive. Of the 114 ACOs that started in 2012, 54 kept costs below budget benchmarks and 29 of those saved more than two percent, thus qualifying for shared savings.³³ These 29 ACOs received \$126 million in savings and generated \$128 million in total CMS trust fund savings, while the other 60 MSSP ACOs experienced spending above their set benchmark (Figure 3).

Figure 3. MSSP Financial Results Breakdown



Source: Health Affairs, Muhlestein and Petersen³⁴

Care for children with disabilities

ACOs are increasingly seeking to provide care for children with developmental disabilities in order to deliver higher-quality care and spend health care dollars more wisely.³⁵ This model of care is particularly important for children with disabilities, because they typically have multiple chronic conditions and comorbidities such as cardiovascular disease or mental illness.³⁶ These children require a wide variety of services from specialty health providers, social service agencies, and their families or caregivers. Treating children with developmental disabilities is complex, and despite higher utilization of health services, unmet needs for health services for this population are high.³⁷ Children with disabilities often experience care marked by poor communication and coordination among health agencies, which hinders their ability to utilize health-related resources.³⁸ The ACO model has the potential to better coordinate the care this population typically experiences.

Methods

Case study

A case study approach was used, which is defined by Sharan Merriam as “an examination of specific phenomenon, such as a program, even event, a process, an institution, or a social group.”³⁹ This approach examined how one particular ACO took on a new patient population with complex health needs. This organization, Partners for Kids (PFK), is a leading pediatric ACO seeking to meet the needs of children with developmental disabilities. PFK is located in central and southeast Ohio and operates in 34 counties stretching from urban Columbus to rural Appalachia. Since opening in 1994, it has been the oldest and one of the largest exclusively pediatric ACOs in the United States. PFK was created to address rising costs and concerns about the quality of care delivered to low-income patients.⁴⁰ The ACO has approximately 760 physicians caring for children and adolescents, including primary care physicians, specialty care providers, and a sponsoring hospital, Nationwide Children’s Hospital. Participating physician practices have access to resources such as assistance with Medicaid and commercial managed care contracting, which leads to cost and time savings.⁴¹

According to a study by Kelleher et al., PFK has covered about 300,000 low-income children since 2008. Kelleher et al. found that PFK served 1,000,000 patient visits, cared for 21,000 admitted patients, and operated 68 facilities, including outpatient centers, urgent care, research, and primary care and specialty physician offices in 2013.⁴² In July 2013, all ABD children in Ohio were required to switch from a traditional fee-for-service plan to a managed care plan. This policy change moved approximately 8,000 Medicaid-eligible ABD children into PFK’s ACO.⁴³ Thus, outcomes data on PFK’s adoption of the ACO model relative to traditional fee-for-service were studied to compare the effectiveness of care coordination for disabled children.

Data source

Prior to this study, 24 face-to-face, semi-structured interviews were conducted with PFK stakeholders in the spring of 2014.⁴⁴ The goal of these interviews was to identify care coordination strategies for ABD children before and after the transition to the ACO model. PFK helped the study team identify participants for the interviews based on their care coordination experiences with ABD children. Four groups were sampled through the interviews: ACO leaders, care coordinators, clinicians, and payer representatives (Table 1). Each group provided a different perspective on coordination objectives and strategies. ACO leaders could speak to the desired outcomes of the ACO. Care coordinators and clinicians were able to talk about care coordination on a day-to-day basis. Representatives could discuss the motivations to delegate care coordination to the ACO and how it is monitored regularly. At least two researchers attended each interview to prompt for additional details and take notes. Each interview lasted about one hour and was digitally recorded then transcribed. The stakeholder interview guide can be found in appendix A.

Table 1. Key stakeholders interviewed

Participant Group	Example	Number of Interviews
ACO Leaders	Chief Financial Officer	9
Payer Representatives	Managed Care Insurer	8
Public Health Agency Personnel	Physician Administrator	3
ACO Care Coordinators	Social Worker	2
Clinicians	Doctor of Medicine	2

Data analysis

The author of this study created a codebook using the NVivo qualitative data management software to aid in organizing and analyzing data. To address the research questions for this study, the author used the constant comparative method to form, enhance, confirm, or

discount theories as a result of new data that emerges from the collected transcripts.⁴⁵ The goal of this method was to constantly compare data from the stakeholder interviews, specifically checking for patterns or variations. By using the constant comparative method, relationships were formed between themes and trends were explored within codes and sub-codes. To accomplish this, collected transcripts were continuously reviewed, and additional codes were created or expanded as more themes were identified. This method of analysis was inductive, as the author looked to examine data critically and draw new meaning from the data.⁴⁶ In sum, the constant comparative method allowed the author to understand perceptions surrounding the effectiveness of care coordination strategies.⁴⁷ The codes developed through this process represented interviewees' perspectives on the transition of ABD children from fee-for-service to the ACO model.^{48,49} The codebook was finalized with 16 codes and 12 sub codes (appendix B).

Ethical considerations

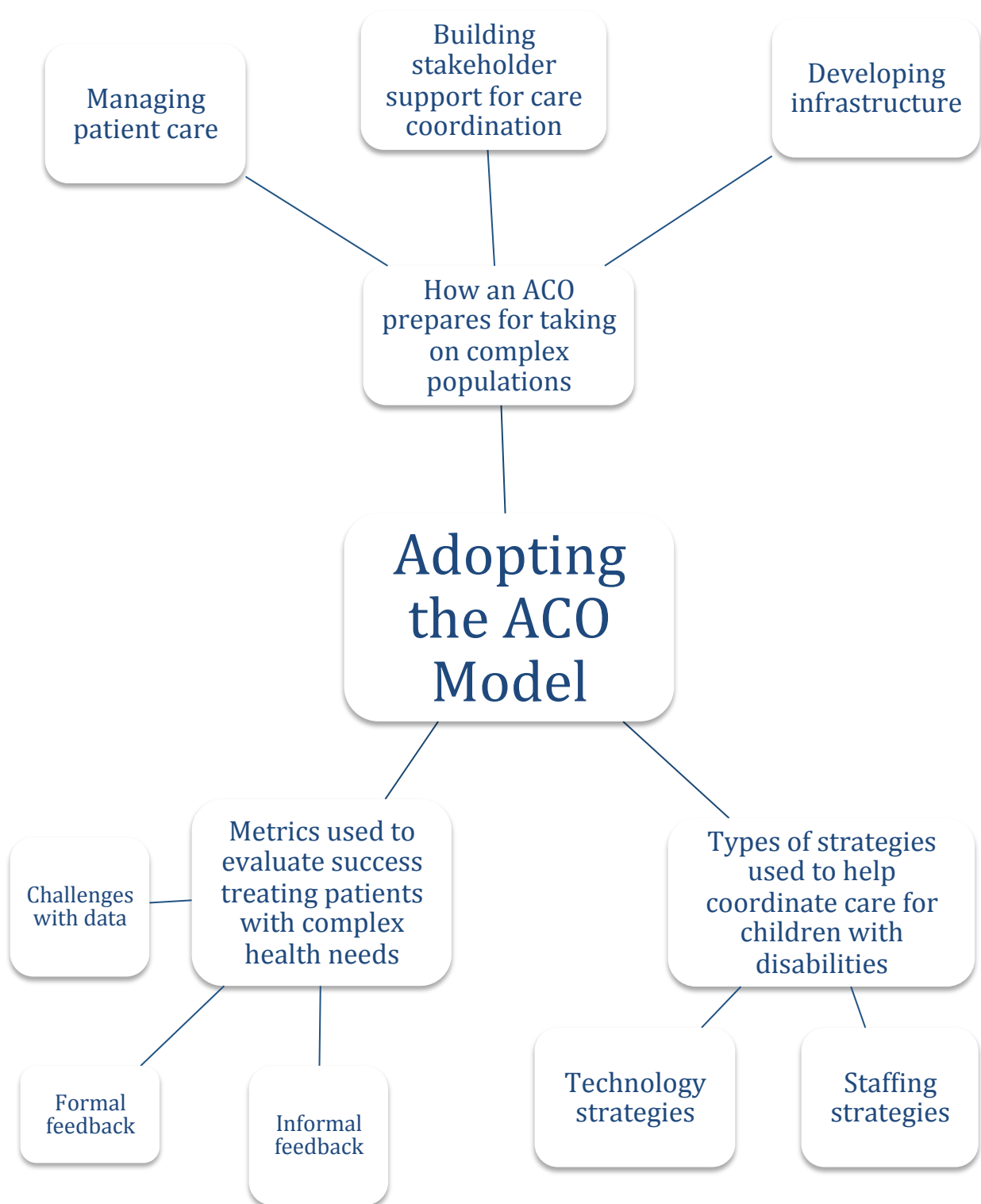
Institutional Review Board (IRB) approval was obtained through the University of North Carolina at Chapel Hill, Ohio State University, and Nationwide Children's Hospital for this study. When the initial interviews were conducted, participants were provided with an interview study information sheet. The principal investigator or study investigator reviewed the handout with the potential participant before starting the interview. The investigator answered any questions and obtained informed consent from the interviewee before continuing with the session. Once the participant gave verbal consent, the investigator proceeded with the interview using an IRB-approved interview guide. Interview participants were told they could decline to participate or be recorded. Further, they could refuse to answer a question or discontinue participation at any time. Although many interviewees were employees of the ACO, investigators emphasized that participation was completely voluntary and would not affect employment status.

There was little risk involved for participants. The primary risk was the loss of confidential data collected from the study. However, measures were put in place to minimize this potential risk. Stakeholder names were stripped from interviews. Study identification numbers, which did not link to any identifying databases, were kept to label records. Recordings and transcripts were stored on password-protected computers. Only the programmer and study investigators had access to the raw data.

Findings

This study found that when adopting the ACO model, PFK prepared to take on the ABD population by using its prior experiences managing complex populations, building stakeholder support for care coordination, and developing the infrastructure. Further, PFK used different staffing and technology strategies to help coordinate care for the ABD population. Finally, PFK implemented metrics to evaluate its success, including formal and informal feedback, and addressed challenges related to data analysis. In the following sections, it will be explained how PFK managed each of these dimensions of adopting the ACO model (Figure 4).

Figure 4. Concept Map of Key Findings.



Research question one: how an ACO prepares itself for taking on complex populations

Managing patient care

Due to PFK's history managing pediatric populations and those with complex health care needs, the organization already had a strong foundation in place when preparing to take on the ABD population. PFK managed complex populations for more than 20 years by engaging in full financial and clinical risk for Medicaid children aged zero to 18. By taking on this risk, PFK had received monthly payments for each child through Medicaid, and then had spent that money to cover all the costs of patient care regardless of how much was actually spent. PFK earned money if it provided care for less than the amount given from Medicaid; however, PFK lost money if it provided care for more than the amount given from Medicaid. This encouraged PFK to increasingly invest in strategies that would deliver more effective care to save the most amount of money. While PFK stakeholders stated they would have eventually been able to take on the ABD population, an ACO leader said the process would have taken much longer without its prior experiences with complex populations, particularly those related to the Health Care Innovation Award (HCIA).

Health Care Innovation Award

Prior to taking on the ABD population, PFK received the three-year HCIA through the Centers for Medicare and Medicaid Innovation (CMMI) in July 2012. This award was a \$13.1 million collaborative agreement between CMMI and PFK to implement strategies with the aims of reducing costs and improving health outcomes and population health. Through the HCIA, PFK worked to improve care for children with the most complex health needs, which is why it focused on those with feeding tubes and a neurological disease. Furthermore, PFK prioritized educating patients' caregivers on care management. For example, an ACO leader said they

realized caregivers were unaware of how to manage patients' feeding tubes, so an implemented intervention was educating caregivers on the proper use of feeding tubes. In particular, a project coordinator for the grant said, "We revised the education process for families, so when a new tube is placed, making sure all families have a front line of teaching at the Family Resource Center, as a more centralized repository for delivering this information." As a result of this intervention, ACO leaders said readmissions to the hospital due to improper feeding tube management decreased.

Process and outcome measures were then used to help PFK track the impact of interventions and adjust accordingly for the future. PFK used several process measures, such as the percentage of children enrolled in care coordination. This particular measure was put in place to determine how many children with feeding tubes had received coordinated care services. Outcome measures were also needed by PFK to understand how patients were affected by care coordination. The primary outcome measures looked at decreasing the number of in-patient days for children in the population and increasing the percentage of those who had weights between the 5th and 95th percentile. These outcome measures helped PFK understand the effect of care coordination on the overall health of patients. For instance, if there had actually been an increase in the number of in-patient hospitalization days, PFK would have potentially needed to devote more resources to expanding care coordination services. After reviewing both process and outcome measures, PFK focused on how patient treatment could be improved for the future. No specific examples were given as to how this was done.

The CMMI grant gave PFK the freedom to be experimental with the way it cared for patients; this helped prepare the ACO to later take on the ABD population. In particular, PFK used its experience with the CMMI grant to learn how to most effectively care for those with

complex health needs, such as ABD patients. To do this, an ACO leader noted that processes were revamped a lot more frequently. This leader said if a new process did not work, a different one could be tried, and then staff would “take that learning and apply it to the grander care coordination.” For instance, one process PFK tried was using the EHR to create management plans for families before their child was discharged from the hospital. Through this type of experimentation, an ACO leader said there were many positive outcomes for patients, like “a decrease in in-patient days that was pretty significant,” as well as overall improved health outcomes and reduced costs.

Building stakeholder support for care coordination

Caregivers

Before using care coordination to help manage the ABD population, PFK needed to respond to concerns from various stakeholders, including families, the state, payers, and providers. In particular, ACO leaders knew from previous experiences there would initially be some opposition from caregivers who did not want their children to receive care coordination services. One ACO leader said, “Families who have new onset of disease have been a little more receptive.” He then said, “I think the families who have been through all of this are a little less receptive, mainly because they’ve managed to this point, good or bad, but they’ve gotten through.” Additionally, families with a patient who had been in the health care system longer might have already been more knowledgeable about complex care services and felt comfortable navigating the system. To respond to caregivers, PFK listened to patients and their families by “finding out gaps in care” and seeing “what’s been asked, what’s been provided, and what still needs to be provided.” PFK assessed “with the family what their needs and wants are, then staff members worked with families to develop an action plan and connect them with necessary

resources. An example of such a resource was Healthcare Effectiveness Data and Information Set (HEDIS) alerts, a system that automatically generated a message when a patient was due for an appointment. This resource was beneficial for caregivers because they could more easily keep track of and schedule patient appointments. For instance, a care coordinator talked about “a family who wasn’t attending any of their visits who are now coming because they’ve been hooked up with the appropriate resources to do so.” Overall, engagement strategies with caregivers and patients were successful because PFK worked to best meet their needs.

State of Ohio

In addition to requiring Medicaid managed care, Ohio mandated care management plans for the top one percent of high cost patients from each health insurance plan’s population. The state believed PFK was well positioned to take on the ABD population; for instance, an ACO leader believed they had the ability to increase communication between providers and reduce duplication of services, which would have led to lower costs for the state. Three of the health insurance plans delegated the care coordination function to PFK formally, while two took on care coordination themselves. Medicaid managed care was prioritized by the state to help make costs more predictable. One ACO leader said, “It’s my impression that the state built into the transition a financial savings that they gave to the health plans, fewer premium dollars than they were spending on caring for those patients because of an assumption that, through the process of the health plans, these patients would be managed more effectively.” This predictability was beneficial because it allowed the state to better manage care for patients with complex health needs.

Payers

Over time, payers increasingly supported care coordination through PFK as they discovered the impact it could have on patients. PFK worked to gain support from payers, since delegating care management was a relatively new concept. Three of the plans were eager to delegate the care coordination function to PFK, while the other two were not. An ACO leader said the difference in responses was likely due to the payers' strategies, capabilities, and leverage in contracts. Additionally, because some payers were more mature in the market, they were "less compelled and motivated to pursue an outsourcing strategy," which made them more resistant to delegating care coordination functions to PFK. As a result, it was harder for PFK to engage with these payers. While a group of payer representatives said they were initially hesitant to delegate care coordination, they gradually became more motivated to work with PFK after realizing the potential to improve health outcomes and reduce costs.

ACO staff

PFK prepared to take on the ABD population by improving the relationship between providers and care coordinators. This was a necessary step because providers were not initially motivated to work with care coordinators. Care coordinators engaged with providers on behalf of patients, which added "another layer of people between the doctor and the patient," that providers generally did not like. One provider said care coordinator involvement meant there was "somebody else in addition to the doctor's usual staff that's asking for stuff." Thus, to get support from providers, PFK worked to educate and reeducate them on the role of care coordinators. For instance, the care coordinator role was clearly defined then communicated to providers. One provider said she had to ask questions like, "Should the clinic social worker be doing this?" or, "Should the clinic nurse be doing this?" to understand the responsibilities of the care coordinator. While there was confusion and frustration from providers regarding care

coordination after the transition, one provider said she saw positive changes over time, as trust was built between providers and care coordinators. It was important to engage with providers since they were primarily responsible for patient treatment plans, and the care coordinators could not work effectively without their support.

Communication from staff

An important part of building stakeholder support when preparing to take on the ABD population was implementing effective communication methods. One ACO leader said it was especially important for them to provide consistent communication to families. This ACO leader said parents were advocates for their kids, “so the more you can do on the front end to talk them through how [the transition] is going to work and lay it out specifically for them, I think then that only helps you do better on the other side when the [transition] actually takes place.” In short, when staff members communicated with caregivers, they were more likely to support and utilize care coordination services because there were fewer surprises throughout the process. To clearly communicate with these families, ACO leaders worked together to create “a list of principles that were going to be important as that transition was made.” These principles were customer member centric and culturally competent, and eventually became a series of twelve principles that served as “the hymnal from which every conversation was guided by.” None of the stakeholders provided examples of such principles during the conducted interviews.

Developing infrastructure

ACO staff

PFK developed a staffing model to help create a strong infrastructure. In particular, PFK used a triad model of social workers, nurses, and quality outreach coordinators to provide care coordination services for patients. Having a quality outreach coordinator on the team was

particularly important, as this person could support care coordination activities, such as making post discharge calls to follow up with families of patients after inpatient admissions. While PFK made an ongoing effort to hire enough care coordinators to reach patients, an ACO leader noted that financial resources were tight, and it was difficult “just finding enough social workers and nurses who are qualified to do care coordination.” A care coordinator said there was also a shortage because of issues related to recruitment. There were difficulties attracting new care coordinators, as it was a position “people don’t understand entirely yet.” Although the ACO eventually hired about 40 care coordinators, it was still not enough to adequately serve the population. According to many care coordinators, their workload was often too much to handle. PFK was aware of this problem, which is why one strategy was to assign care coordinators with “balanced caseloads,” giving them a range of higher to lower risk children. Receiving patients with a mix of care needs helped prevent care coordinators from having unmanageable amounts of work, which enabled them to provide appropriate levels of service.

Technology

Technology was an important aspect of creating a strong infrastructure prior to the transition. Therefore, PFK built modules from scratch in its EHR to make the system most relevant for the ABD population, as well as to enhance the capabilities of care coordinators. For example, a care coordinator said they were looking at building clinical guidelines and evidence-based practice resources into the EHR. As a result of these modules, one provider said they could “track data in a way that we would not otherwise be able to do.” Specifically, the EHR could provide an automatic flagging feature to highlight areas where providers and care coordinators needed to pay attention. Other features included patient identification, case-finding referrals, and sharing information across agencies. These were necessary for providing consistent and efficient

care for patients; for instance, a clinician did not have to order a test that had already been performed at another agency since he or she could access the information through the EHR. Moreover, anybody caring for a patient could use the EHR to check what other services he or she was receiving. One ACO leader said, “They can also see who the lead dietitian is, and the lead dietitian gets a six-month reminder to review the chart and make sure the feeding patterns have been updated, or whether the tube can come out or not.” While creating the EHR was initially “a little bit of a square peg in a round hole because that’s not what the [EHR] was designed to do,” making it relevant for the ABD population was a priority for PFK, so “we pushed through that and we’re very pleased with the results.”

Research question two: types of strategies used to help coordinate care for children with disabilities

Staffing strategies

Communication with providers

There were many staffing strategies used to help coordinate care for the ABD population. Specifically, a key strategy used by care coordinators was communicating with other staff members, particularly health care providers. Care coordinators facilitated communication between clinicians to ensure patients received the best possible care. One care coordinator talked about a situation where there was a problem with a patient, so “they got everybody on the phone—the medical staff from the payer’s office, the medical staff from the specialty department, and the primary care physician.” Through this open dialogue, they could come together to reach a solution for the patient, such as prescribing a new medication. Therefore, providers who were willing to communicate with care coordinators helped their patients receive a more comprehensive care plan.

Partnerships with schools

To help coordinate care for the ABD population, staff members continuously worked to identify areas where they could reach patients and their caregivers, such as providing services in convenient locations. One particular strategy was for staff members to build relationships with schools and “identify kids who need updated or modified equipment, and help push those through the system more effectively.” Through their work in the schools, care coordinators could “have a much better impact.” This ACO leader said a lot of work was done with the schools, and “we’ll continue that work.” A care coordinator said providing care through the schools was ideal because “you have a captive audience” and it was easy for caregivers. Because of the realized potential for reaching patients through the school system, PFK hired a full-time director for community wellness. This director’s goal was to work with the public school system to determine how PFK could meet the needs of the children. By partnering with schools, staff better coordinated patient care to meet their health needs. For instance, an ACO leader said they did this “including the care management teams and health care providers in [school board meetings] to ensure better communication.” There was no discussion from stakeholders regarding evidence of what had actually been done with schools; interviewees only talked about what they intended to do. Overall, this strategy seemed to promote care coordination, and it was well received by patients and their caregivers because of increased access to health services.

Tailoring care coordination services

A strategy employed by staff members was to coordinate care differently for each patient based on his or her situation. One care coordinator said, “Everything is kind of tailor-made, because it’s [based on] what the parents or patients want to work on.” Having unique services was important because each patient had a different health problem that needed to be prioritized. An example of this was looking at safety plans with caregivers to ensure their patients could be

fully cared for at all times, with the goal of reducing unnecessary hospital visits. A patient's care was also affected by how long he or she had been diagnosed with the disease. This measure was used because patients had varying responses to treatments based on the amount of time they had been in the hospital. For instance, when working with a patient who had recently been diagnosed, a care coordinator said, "You're talking about this unknown environment that's coming. They may not necessarily know all the connections they should have, and the care coordinator can help bring those to the table." Therefore, the strategies used by this care coordinator would have been adjusted to account for the patient's situation, such as providing more resources on available services at PFK. In short, when staff members worked to individually address each patient's health needs, they were able to provide better care coordination services.

Communication amongst ACO staff

When looking to coordinate care for the ABD population, PFK prioritized the development of communication strategies amongst staff members. An ACO leader said they focused on communication strategies "to align everybody who is involved in the care; most [patients] have specialty providers, primary care, and a lot of home nursing." For instance, care coordinators were able to communicate with each other by developing a "resource guide that allows all care coordinators to locate local services, whether it's an organization, a support group, or a charitable organization local to families." As staff members came across new resources, they shared it by adding to a shared drive file. This promoted collaboration and consistent communication amongst staff, since they were able to support each other and have access to the same materials.

There also needed to be communication strategies for staff members as they engaged with patients and caregivers. One particular strategy for staff related to scheduling meetings with

patients and their caregivers. An ACO leader said patients originally came to the hospital just to meet with their care coordinators, but PFK realized it made more sense to schedule these meetings when patients were already at the hospital for an appointment. Then, the care coordinator, patient, and doctor could all meet at the same time. This was easier than “playing telephone,” and it helped avoid miscommunication. A care coordinator said a strategy for maximizing meetings was attending a medical appointment and completing a home visit within the first three months of working with a patient. According to this care coordinator, visiting the home was beneficial because it provided “a well-rounded perspective,” and seeing a patient interact with his or her physicians “paints the whole picture.” This was also an effective strategy because it helped fulfill state requirements to “complete a specific number of face-to-face interventions.” After the first three months of working with a patient, it was more efficient for his or her care coordinator to primarily communicate through telephone calls because there was already an established relationship.

Technology strategies

Use of data

There were many data utilization strategies put in place by PFK to coordinate care for patients. An ACO leader said data was important for communicating between key stakeholders, including providers, patients, and caregivers. He said, “We’re in a much better position to [coordinate care] as a provider that’s at risk so that we have the data and we are able to implement our care coordination models.” Because PFK could track patient data, the ACO leader said, “We can physically meet the families when they’re in the clinics. We can have the conversation with the clinicians that are involved in it to identify issues to better coordinate the care. And it’s a pretty remarkable program. Most health plans would love to be able to sit there

and look into your [EHR].” Through the use of data, PFK could implement and share relevant care coordination strategies for its patients, such as easily facilitating conversations between caregivers and providers.

EHR system

PFK used its EHR system to coordinate care for patients. A care coordinator said the EHR was particularly beneficial coordinating care as staff members could better track patient information. She said the EHR allowed them to “read the notes from all doctors, look at all their testing, look at any x-ray they’ve had, and look at any work for all they’ve had. So it really helps a lot.” One ACO leader explained that the EHR was especially helpful for providing coordinated care by saying, “Being closer to the kids and closer to the providers and having all of that documented in the medical record so anybody who has access to the kid can know what’s going on in terms of care coordination can be a huge benefit.” This ACO leader said, “A clinician working with a kid can see when they’re getting care coordination and the care coordinator can easily populate and perform the functions they need using the [EHR] as their tool to record all of that.” Because the EHR could be used to keep track of patient information, a care coordinator said they could not have done their jobs well without the EHR.

Research question three: metrics used to evaluate success treating patients with complex health needs

Informal feedback

Health outcomes

PFK used several forms of evaluation to track care provided to the ABD population. Feedback from staff was often given informally and not officially documented, although it helped PFK understand general trends related to care coordination. First, PFK desired to improve patient outcomes through care coordination. An ACO leader said taking on the ABD population

“played out generally as we imagined,” and she felt like patients were healthier because they were treated through PFK. Another ACO leader said patients would have needed to be in the system for an extended period of time before outcomes would have been reflected in the data. Yet, she noted there had generally been a drop in utilization of unnecessary services and visits to the emergency department.

It was also important to consider indirect benefits of care coordination. In particular, one ACO leader said the data might not have reflected an overall change in patient outcomes, but care coordination could have still been beneficial. For example, even if utilization rates did not decrease long-term, families could have reported feeling “more in control of the condition, which is maybe the first step in getting to better utilization.” Such observations by stakeholders showed the importance of looking at informal feedback to learn how patients and their families were impacted by the services provided through PFK. Despite overall positive feedback, there were some negative outcomes as well. One ACO leader said, “We’re not 100 percent successful. Sometimes we still can’t achieve a great outcome for the families for whatever reason. The illness, refusing care, refusing assistance, whatever. Sometimes we don’t achieve a good outcome.” Because the ABD population had complex health needs, completely eliminating poor outcomes was not feasible, but informal metrics showed that PFK had the ability to improve patient health.

Costs

PFK also wanted to understand how the provision of coordinated care affected total costs. In particular, clinicians put in place several targets to evaluate their success in reducing costs. In the stakeholder interviews, specific targets were not mentioned. But, one clinician discussed how a clinical oversight committee was created that met every month. Through this committee,

clinicians held each other accountable meet the cost-related targets that mattered to PFK. Because PFK prioritized the reduction of health expenditures, an ACO leader said the ACO administration felt like “financially, we’re not taking a bath and we’re doing pretty well.” He said, “Now we know and we have our metrics, things look really pretty good in terms of decreasing the cost.” Overall, through such informal feedback, ACO stakeholders felt like care coordination led to a reduction in costs for the ABD population.

Payers

Payers also implemented different forms of evaluation to measure success for the ABD population. In particular, one payer representative said they used standard HEDIS measures monthly, such as effectiveness of care and experience of care, to evaluate patient care. When payers identified patients who had gaps in their care, they could communicate these findings to the providers. Moreover, payers followed what care managers were doing and their ability to close a case. This measure was important for showing the impact of care coordinators on patients. Payers also worked closely with PFK for evaluation purposes. One payer representative said they met with staff from PFK every month to check in because “they’re working on initiatives, we’re working on initiatives, and we want to be aligned and sharing ideas and best practices, a lot of really great dialogue on how to improve.” Because payers were engaged informally in the evaluation process, they had a better understanding of the success of care coordination services.

State

The state required PFK to provide informal feedback related to patient outcomes and cost. While the state eventually wanted to receive more formal feedback, informal evaluations allowed it to progressively track the status of PFK. For instance, according to an ACO leader, the

state wanted to know “contact was being made” with patients and “evaluations are being performed.” An ACO leader said the state was also interested in some particular metrics, like those related to asthma and pharmacy. Such metrics helped PFK know which areas to focus on in order to meet the expectations of the state. To informally share evaluations and metrics on patient outcomes and cost, ACO leaders met with state representatives once a year to discuss the status of PFK and the ABD population. Moreover, the state sent consultants to PFK to evaluate and provide feedback on key measures, such as the number of home visits made. Through the state’s involvement, PFK was held accountable to certain standards of care to ensure patients were positively affected by care coordination.

Formal feedback

In addition to informal evaluation and metrics, PFK started formally collecting data when it took on the ABD population to follow changes over time. An ACO leader said the goal of data collection was to “prove the impact of case management.” This was important for showing it would be beneficial to provide care coordination services long-term for patients with complex health needs. To start the data collection process, PFK hired a team of data analysts dedicated to studying care coordination. This type of data collection was necessary for PFK because the state required the tracking of certain measures. Specific metrics included emergency department visits, hospitalizations, and cost of care. According to an ACO leader, PFK also chose to evaluate “what kinds of conditions are most likely to be enrolled and what really have an impact.” Formal data collection was beneficial for PFK because it could better understand how to prepare for the future, such as adjusting services provided based on utilization trends.

Financial cost

One of the main indicators PFK used to evaluate success was the cost of care provided to ABD patients. One ACO leader said PFK looked at the total cost per member before and after care coordination. This was important for evaluating if care coordination had the ability to reduce long-term costs of care for patients with complex health needs. Another ACO leader said they worked hard to ensure data was representative of the entire ABD population and not skewed by a few high spenders. In short, PFK wanted the data to reflect the average cost of a typical patient.

Therefore, PFK created a database to track patients by their spending and utilization of health services. Thus, staff members could not only see overall trends in health expenditures, but they could also check for outliers in the data. An ACO leader said it was necessary to understand outliers in the data, because there could have been one patient who was really sick and needed significant amounts of health services, or “a bunch of kids we’re just not doing much of anything for.” After evaluating this data, PFK could act accordingly and implement different interventions to meet the needs of these patients and reduce costs in the future. A different ACO leader said, “I can see the overall spend is going down in general, except for the really high cost members who are outliers.” Unlike informal data, formal data did not show a significant improvement in cost for children being treated at PFK. But, by targeting high cost patients, PFK had the potential to decrease health expenditures long-term. However, many ACO leaders said the main goal of care coordination was not saving money; instead, they prioritized improving patient care and health outcomes.

Patient outcomes

Payers focused on improving quality measures for the ABD population to track changes in patients’ health outcomes. But, formal data did not show a strong benefit to providing care

coordination for the ABD population. One payer compared health outcomes of ABD patients treated at PFK to other ABD patients not treated at PFK; significant differences were not found between the two groups. This comparison showed that usage of the emergency department was about the same between the two groups, while inpatient admissions and readmissions were actually higher in the PFK region. While these results could have been meaningful long-term, the lack of improvement seen initially could have been due to insufficient access to data. Hence, data would have needed to be collected by payers for an extended period of time before fully understanding the differences between those who did and did not receive care coordination services.

Challenges with data

Patient variables

There were a couple obstacles faced by PFK as it collected data on the ABD population. One initial problem was the number of variables that affected what patients were included in data analyses performed by PFK. For instance, an ACO leader said there was confusion around how long a patient needed to have received care coordination services before being counted in the data. Additionally, there was uncertainty about how to document patients that had been referred by their doctor, health plan, or PFK because no formal system was in place. Another variable was determining when a patient could no longer be included in the data. In particular, an ACO leader said a patient could have been receiving care coordination services for an extended period of time, but if he or she failed to complete a face-to-face visit or if the sickness got significantly worse, PFK could no longer use that data. To address this problem, an ACO leader said they tried to define patients to avoid confusion around variables. PFK worked to “stratify into cohorts that make sense so you can identify broader trends that you can put interventions in place.”

While stratifying patients into cohorts helped reduce the problems with variables, the created cohorts could not always adequately define a patient, which made it difficult for PFK to accurately compare outcomes.

Data availability

Another significant challenge was the amount of time it took to formally collect data. PFK did not start caring for the ABD population until 2013, and it took up to a year to gather and analyze data. In particular, one ACO leader said there was a claims lag of about five months for these patients, so “we don’t have enough information yet to thoroughly evaluate our impact.” Even after claims data was received, PFK needed “to compare it to something and it’s hard to get that something to compare it to.” PFK did not have access to claims data outside its region, so this comparison was difficult to make. As one ACO leader said, “The controls are patients that aren’t in our population so getting our hands on that data and understanding it sufficiently to be able to make that comparison is just more work.” Once PFK had data for ABD patients and could make a comparison to non-ABD patients, it was still not enough to make conclusions about the success of care coordination, since demonstrating the results of care coordination would require years of data.

Future of data collection

While there were some implemented measures, PFK still needed to expand its ability to evaluate success in the future. In particular, PFK could have created additional measures to better track the ABD population. For instance, one ACO leader said PFK was working to hire another care coordination data analyst with the goal of “really digging deeper into the data and identifying some stronger measures and more thorough measurement on the program.” This ACO leader did not discuss specific measures. Another ACO leader said PFK was trying to

identify types of surveys that would measure quality of life, “because I think that would be the real critical measurement.” One way to do this would have been “adding PROMIS measures, especially activity related to daily living and pain scores.” The Patient-Reported Outcomes Measurement Information System (PROMIS) measures assessed many patient-reported outcome domains, including pain, fatigue, and emotional distress, and are based on common metrics that allow for comparisons across patient populations. This tool would have allowed PFK to evaluate what patients were able to do and how they felt. However, he added such measures would “require somebody to invest the money in a survey infrastructure, which we don’t have yet. As PFK continued to expand capacity for data collection, the ACO increasingly improved its ability to understand the costs and outcomes of patients.

Discussion

Conclusion of findings

This research aimed to answer three research questions regarding the provision of care for children with complex health needs:

How does an ACO prepare itself for taking on pediatric ABD populations?

To care for a population with complex health needs, there are many preparations an ACO must make. Since most people have little to no experience with care coordination, an ACO could address concerns from patients and their caregivers, ACO staff members, and payers. One particular way to do this would be clearly communicating with stakeholders, informing them of what to expect in the future. Furthermore, to build a strong infrastructure, an ACO could determine how many and what types of care coordinators would be needed to serve the incoming population. By addressing concerns from stakeholders and creating a strong infrastructure, an ACO would be more prepared to take on complex populations.

What types of care coordination strategies does an ACO use to help coordinate care for children with disabilities?

There are several staffing and technology-based strategies an ACO could consider when coordinating care for children with disabilities. When looking at staffing strategies, an ACO would initially need to hire a care coordination team to specifically work with the targeted population. The care coordinators would then want to explore how they could most effectively help patients, such as offering services in easily accessible locations. Because patients in this population would typically have unique health needs, it would be important for an ACO to provide tailored services, like creating a safety plan to educate each patient's caregiver. Finally, an ACO could focus on developing communication strategies for its staff members. These strategies could cover communication amongst staff to ensure consistency in information to increase efficiency. Moreover, an ACO could implement communication strategies for staff as they interact with patients to improve relationships. An ACO would also want to determine what forms of technology would be most beneficial to use for the population, such as the implementation of an EHR. Because care coordination is multi-faceted, having an EHR could allow a staff member to see all information about a patient in one place and provide care accordingly. Through the formation of care coordination strategies, specifically related to staff and technology, an ACO would be better prepared to care for patients.

By what metrics does an ACO evaluate its success?

Finally, an ACO could look at both informal and formal feedback when evaluating success. Both types of feedback could examine the impact of care coordination on health outcomes and cost. However, an ACO could understand the subsequent challenges of data collection. For example, several years could go by before having enough data to adequately

represent the population, making it difficult to track the effect of care coordination on patients. Once evaluation strategies have been set, an ACO could reflect on how it could continue to improve data collection processes. In particular, an ACO could implement additional metrics to gain a more holistic perspective of a patient's health, including those related to quality of life. Having informal and formal feedback would allow an ACO to track the targeted population over time, which would be beneficial for measuring the health outcomes and costs of patients.

Comparison to prior research

This research is consistent with previous evidence on ACOs. A 2016 study by Chien et al. found that pediatric ACOs primarily focused on reducing costs and improving patient outcomes, which was the same for PFK.⁵⁰ In 2016, Spatz et al. showed the importance of population-based measures used by pediatric ACOs to evaluate success. Similar to PFK's measures for the ABD population, metrics used by Spatz et al. generally showed no difference in outcomes for patients treated through the ACO, although only a limited amount of claims data was used.⁵¹ Further, a 2016 study by Christensen and Payne looked at claims data for a two-year period and saw no decrease in hospital readmissions for patients treated through an ACO.⁵² However, a 2015 study by Kelleher et al. looked at the historical cost of care for PFK and compared it to fee-for-service and managed care Medicaid cost histories. Kelleher et al. found a significant improvement in quality of care and reduction in the growth of costs for PFK compared to fee-for-service and managed care Medicaid.⁵³ These results suggest PFK could experience positive patient outcomes for the ABD population in the future.

Directions for future research

Because ACOs are relatively new, there is limited available research on the topic. Moreover, PFK's engagement with the ABD population would not necessarily be representative of the average ACO. Hence, further research could be done to recognize the experiences of a wide

range of organizations. In particular, it would be beneficial to examine how an ACO could take on a complex population without previously working with such patients. Another potential area of research would be studying patient data to understand if health outcomes and costs improve after patients had been in the ACO for an extended period of time. By having more comprehensive data available, an ACO thinking about the adoption of new, complex population could be better prepared.

Limitations

A limitation to this study would be the generalizability of the findings. Because this was a case study, data collected cannot necessarily be applied to other organizations. In particular, PFK had prior experience treating patients with complex health needs. Therefore, PFK had many advantages compared to a typical ACO when taking on the ABD population. While research on PFK could help inform other ACOs, some strategies presented might not be relevant or feasible for them. Another limitation would be interviewees potentially overstating the benefits of care coordination. Those who were interviewed could have consciously or unconsciously wanted to put themselves and PFK in a good light, which could have led them to focus more on the positive experiences and their successes.

Summary of paper

The purpose of this study was to identify stakeholder perspectives on care coordination for children with complex health needs before and after the adoption of the ACO model. The presented research discussed how ACOs could prepare to take on complex populations, provide care coordination, and measure success. ACOs looking to adopt such a population could learn from PFK's experiences treating ABD patients. Furthermore, additional research should be completed to supplement the findings of this paper. By considering the experiences of existing

ACOs including PFK, other organizations would have a greater ability to prepare for their own transitions.

Acknowledgements

This research would not have been possible without the support and guidance of Dr. Paula Song. The author would also like to recognize other members of the research team, Dr. Renee Ferrari and Dr. Mike Belden, for their help in the research process. Finally, the author would like to extend gratitude to Dr. Karl Umble and other honors thesis candidates for their encouragement and feedback.

Appendix A: Stakeholder Interview Guide

Supplies

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

Introduction and Background

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

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

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

Do you have any questions before we get started?

Introduction

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

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

The policy change

We want to talk about services and care coordination before and after the policy change, but

before we do that, let's first talk about the policy change itself.

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

[prompts]

- Why?
- What, if any, concerns did you have?
- What, if any, benefits did you anticipate from it?
- What is your opinion of the policy change now?

[prompts]

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

Before the policy change

Let's focus for a little while on the situation before the policy change, that is, before July 2013.

- What can you tell us generally about the provision of health services for this population prior to the policy change?

[prompts]

- ?

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

[prompts]

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

After the policy change

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

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

[prompts]

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

[prompts]

- Are any resources or programs dedicated to care coordination for the pediatric ABD population?
- [If yes: describe]
- [If no: why not]

- Are there other services or resources that patients and their caregivers use to help coordinate care?
 - [community? Social workers? Therapists? Family or friends? Others?]
- Are any additional coordination efforts or services planned or under consideration?

[for Care Coordinators and Providers] Your role in care coordination

Let's talk about your role in care coordination.

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

[prompts]

- *Examples?*
- How, if at all, has this changed since the conversion from the OLD PLAN to the NEW PLAN?
- How well informed do you feel you are about the care provided to your pediatric ABD patients by other doctors and healthcare providers?

[prompts]

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

[for Payors and ACO Administrators] Delegation and care coordination

Let's talk about how responsibilities are shared between the managed care plans and PFK.

- With respect to ABD pediatric patients, what responsibilities are retained by the managed care plan and what responsibilities are delegated to PFK?

[prompts]

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

Metrics and evaluation

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

- What evaluation efforts are in place?

[prompts]

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

Hospitalizations

Let's talk about care coordination and hospitalizations.

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

[prompts]

- *Examples?*

- How, if at all, has the move into managed care impacted these issues/concerns?
- What has been done or is currently being done to address these issues/concerns?
- How is care coordination managed during a hospitalization?

[prompts]

- How, if at all, has this changed since the conversion from the OLD PLAN to the NEW PLAN?
- What is the discharge process like? How are communications between inpatient and outpatient settings handled?

[prompts]

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

Overall assessment

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

[prompts]

- Is the ACO model better in some ways but not as good in others?
- Overall, what would you say is working best currently for the ABD pediatric population?

[prompts]

- ***Examples?***
- How, if at all, is this different since the conversion from the OLD PLAN to the NEW PLAN?
- Overall, what would you say is most in need of improvement for the ABD pediatric population?

[prompts]

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

[prompts]

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

Closing

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

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

Appendix B: Codebook

Code	Sub codes	Representative quote
Feelings about taking on new population		“We’re looking forward to having the aged, blind, and disabled population move into managed care because we felt we could take much better care of them than in the fee-for-service world, through care coordination.”
Comparison to other populations		“This population is so complex. [They need] to have the pediatric specialties in order to handle these kids properly. I mean, kids aren’t just small adults. They have their own nuance.”
Advocacy		“There were a lot of family advocates that were resisting moving the children into the managed care plans, so they delayed [implementation] until 2013.”
Characteristics of PFK	Formulary Care coordination resources Improved outcomes	“I think they can see the advantages of Partners for Kids being closer to the providers and closer to the patients—that we can be more impactful.”
Patient/caregiver satisfaction		“Every week we have our staff meetings, and people will share success stories where you hear about how the intervention that the care coordinator put into place has made a difference, or if it’s worked.”
History/background	CMMI grant	“[We wanted to put something together] that was more cohesive, and really follow the child from in-patient to out-patient, and across the continuum of care for a long period of time.”
Challenges (pre-implementation)		“We had a lot of challenges around trying to figure out a good way to document what we were doing, to insure that we were then able to report on what we were doing.”
Challenges (post-implementation)	Administration Access	“We have really, really struggled to get to our goal of [providing care coordination to] 85 percent [of the cohort]. And I kind of think by the end of the grant we need to get close to it.”
Choices of patient		“They can switch individual plans monthly, but they can only switch once from managed care Medicaid to fee-for-service.”
Characteristics of patient		“When I think about a family with a special needs child or a complex child, they’re likely going to live near where they have to get the kid services because they’re going to

		be at the doctor's office, at the clinic, at the hospital so often."
ACO staff	Shortage Care coordination	"Our resources are so tight. We're trying very hard to hire enough staff to do care coordination."
Family support		"I think the families who have new onset of disease, I think they've been a little more receptive."
Current status	Trainings Data collection Electronic health record Follow-up	"The more aligned all the policies are, the more remarkable the cultural shift in practice. So right now, we have 80 percent of our Medicaid kids in a capitated, value-based environment."
Future of ACO model		"There has been and will continue to be consolidation in the market as it relates to home care that the health plans require a more corporate approach and partner."
Foster care		"Everybody's looking forward to the foster kids next and other waiver kids, so I think everybody's learning that the sicker kids are, the more money can be saved."
Relationship with schools		"What we want to do is continue to identify those areas where there is a need—working with schools, for example, to identify kids who need updated or modified equipment, and help push those through the system more effectively."

References

- ¹ Gold, J. (2014, April 16). FAQ On ACOs: Accountable Care Organizations, Explained. Retrieved September 14, 2015, from <http://khn.org/news/aco-accountable-care-organization-faq/>
- ² Accountable Care Organizations (ACO). (2015, January 6). Retrieved September 11, 2015, from <https://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/ACO/index.html?redirect=/aco/>
- ³ Gold, J. (2014, April 16). FAQ On ACOs: Accountable Care Organizations, Explained. Retrieved September 14, 2015, from <http://khn.org/news/aco-accountable-care-organization-faq/>
- ⁴ Lewis, V., Larson, B., McClurg, A., Boswell, R., & Fisher, E. (2012). The Promise And Peril Of Accountable Care For Vulnerable Populations: A Framework For Overcoming Obstacles. *Health Affairs*, 8, 1777-1785.
- ⁵ American Hospital Association. *AHA Research Synthesis Report: Accountable Care Organization*. Chicago: American Hospital Association, 2010. 30 Sept. 2015.
- ⁶ Aday, L. (2001). *At risk in America the health and health care needs of vulnerable populations in the United States* (2nd ed.). San Francisco, California: Jossey-Bass.
- ⁷ Social Security Administration (2012). *SSI Annual Statistical Report* [Fact sheet]. Retrieved from http://www.ssa.gov/policy/docs/statcomps/ssi_asr/2012/ssi_asr12.pdf
- ⁸ Stockman, J. (2011). Trends in the Prevalence of Developmental Disabilities in US Children, 1997–2008. *Yearbook of Pediatrics*, 127(6), 89-90.
- ⁹ Simon, T., Berry, J., Feudtner, C., Stone, B., Sheng, X., Bratton, S., . . . Srivastava, R. (2010). Children With Complex Chronic Conditions in Inpatient Hospital Settings in the United States. *Pediatrics*, 126(4), 647-655. doi:10.1542

-
- ¹⁰ Health Policy Institute of Ohio, *Ohio Medicaid Basics 2011*. Columbus: Governor's Office of Health Transformation, 2011.
- ¹¹ Health Policy Institute of Ohio. (2013). *Ohio Medicaid Basics 2013*.
- ¹² Berwick, D., Nolan, T., & Whittington, J. (2008). The Triple Aim: Care, Health, And Cost. *Health Affairs*, 27(3), 759-769. doi:10.1377/hlthaff.27.3.759
- ¹³ Maxwell, J., Bailit, M., Tobey, R., & Barron, C. (2014, September 15). Early Observations Show Safety-Net ACOs Hold Promise To Achieve The Triple Aim And Promote Health Equity. Retrieved October 9, 2015.
- ¹⁴ Muhlestein, D. (2015, March 31). Growth And Dispersion Of Accountable Care Organizations In 2015. Retrieved October 2, 2015.
- ¹⁵ Maxwell, J., Bailit, M., Tobey, R., & Barron, C. (2014, September 15). Early Observations Show Safety-Net ACOs Hold Promise To Achieve The Triple Aim And Promote Health Equity. Retrieved October 9, 2015.
- ¹⁶ Gaus, Clif. *National ACO Survey*. Washington DC: National Association of ACOs, 2014.
- ¹⁷ Maxwell, J., Bailit, M., Tobey, R., & Barron, C. (2014, September 15). Early Observations Show Safety-Net ACOs Hold Promise To Achieve The Triple Aim And Promote Health Equity. Retrieved October 9, 2015.
- ¹⁸ Accountable Care Organizations. (n.d.). Retrieved October 6, 2015, from <http://www.aafp.org/practice-management/payment/acos.html>
- ¹⁹ Brode, E. (n.d.). *Primary Care in the ACO*. Lecture presented at Scholar Fellows in Graham Center, San Francisco.
- ²⁰ RTI International, *Accountable Care Organization 2015 Program Analysis Quality Performance Standards Narrative Measure Specifications*. Baltimore: Centers for Medicare and Medicaid Services, 2015. Print.
- ²¹ McClellan, M., McKethan, A., Lewis, J., Roski, ..., & Fisher, E. (2010). A National Strategy to put Accountable Care into Practice. *Health Affairs*, 29(5), 982-990. doi:10.1377/hlthaff.2010.0194
- ²² National Quality Forum, *Measurement Framework: Evaluating Efficiency Across Patient-Focused Episodes Of Care*. Washington DC: Robert Wood Johnson Foundation, 2009.
- ²³ US Department of Health & Human Services. (2015). Better, Smarter, Healthier: In historic announcement, HHS sets clear goals and timeline for shifting Medicare reimbursements from volume to value [Press release]. Retrieved from <http://www.hhs.gov/news/press/2015pres/01/20150126a.html>
- ²⁴ Gold, J. (2015, September 14). Accountable Care Organizations, Explained. Retrieved October 6, 2015, from <http://khn.org/news/aco-accountable-care-organization-faq/>
- ²⁵ Muhlestein, D. (2015, March 31). Growth And Dispersion Of Accountable Care Organizations In 2015. Retrieved October 2, 2015.
- ²⁶ Evans, M. (2014, November 04). Two more Pioneer ACOs exit as new CMS model emerges. Retrieved April 07, 2016, from <http://www.modernhealthcare.com/article/20151104/NEWS/151109941>
- ²⁷ Centers for Medicare and Medicaid Services. (2011). Pioneer Accountable Care Organization Model [Press Release]. Retrieved from <https://www.cms.gov/Newsroom/MediaReleaseDatabase/Fact-sheets/2011-Fact-sheets-items/2011-12-19.html>
- ²⁸ Lazerow, R. (2013, July 22). The results are in: How did the Pioneer ACOs do? Retrieved November 22, 2015, from <https://www.advisory.com/research/health-care-advisory-board/blogs/toward-accountable-payment/2013/07/pioneer-aco-model-early-results>
- ²⁹ Pham, H., Cohen, M., & Conway, P. (2014). The Pioneer Accountable Care Organization Model. *JAMA*, 312(16), 1635-1635. doi:10.1001/jama.2014.13109
- ³⁰ Toussaint, J., Krueger, D., Shortell, S., Milstein, A., & Cutler, D. (2015). ACO model should encourage efficient care delivery. *Healthcare*, 3(3), 150-152. doi:10.1016/j.hjdsi.2015.06.003
- ³¹ Muhlestein, D., & Petersen, M. (2014, March 30). ACO Results: What We Know So Far. Retrieved November 13, 2015, from <http://healthaffairs.org/blog/2014/05/30/aco-results-what-we-know-so-far/>
- ³² Behm, C. (2015). ACOs in Real Life: A Reflection on the Medicare Shared Savings Program. *The Journal of Medical Practice Management*, 312-315.
- ³³ Muhlestein, D., & Petersen, M. (2014, March 30). ACO Results: What We Know So Far. Retrieved November 13, 2015, from <http://healthaffairs.org/blog/2014/05/30/aco-results-what-we-know-so-far/>
- ³⁴ *Ibid.*
- ³⁵ *Ibid.*
- ³⁶ Connolly, J., Paradise, J. *People with Disabilities and Medicaid Managed Care: Key Issues to Consider*, Washington DC: The Henry J. Kaiser Family Foundation, 2012.

-
- ³⁷ Miller, J. E., Nugent, C. N., Gaboda, D., & Russell, L. B. (2013). Reasons for Unmet Need for Child and Family Health Services among Children with Special Health Care Needs with and without Medical Homes. *PLOS ONE*, 8(12). doi:10.1371/journal.pone.0082570
- ³⁸ Golden, S., & Nageswaran, S. (2012). Caregiver Voices: Coordinating Care for Children With Complex Chronic Conditions. *Clinical Pediatrics*, 51(8), 723-729. doi:10.1177/0009922812445920
- ³⁹ Merriam, S. B. (2015). *Qualitative research: A guide to design and implementation*.
- ⁴⁰ *Ibid.*
- ⁴¹ Partners for Kids. (n.d.). Retrieved October 2, 2015, from <http://www.nationwidechildrens.org/partners-for-kids>
- ⁴² Kelleher, K., Cooper, J., Deans, K., Carr, P., Brilli, R., Allen, S., & Gardner, W. (2015). Cost Saving and Quality of Care in a Pediatric Accountable Care Organization. *Pediatrics*. doi:10.1542/peds.2014-2725d
- ⁴³ (P. Song, personal communication, September 20, 2015).
- ⁴⁴ Mason, J. (2004). Semistructured Interview. *Encyclopedia of Social Science Research Methods*, 1021-1022. doi:10.4135/9781412950589
- ⁴⁵ Strauss, A., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, California: Sage Publications.
- ⁴⁶ Glaser, B. (1965). The Constant Comparative Method of Qualitative Analysis. *Social Problems*, 7(3), 436-445. doi:10.1023/A:1020909529486
- ⁴⁷ Glaser, B., & Strauss, A. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Chicago, Illinois: Aldine Pub.
- ⁴⁸ Miles, M., & Huberman, A. (1994). *Qualitative data analysis: An expanded sourcebook* (2nd ed.). Thousand Oaks, California: Sage Publications.
- ⁴⁹ Saldana, J. (2013). *The Coding Manual for Qualitative Researchers* (2nd ed.). Los Angeles, California: SAGE Publications.
- ⁵⁰ Chien, A. T., Schiavoni, K. H., Sprecher, E., Landon, B. E., Mcneil, B. J., Chernew, M. E., & Schuster, M. A. (2016). How Accountable Care Organizations Responded to Pediatric Incentives in the Alternative Quality Contract. *Academic Pediatrics*, 16(2), 200-207.
- ⁵¹ Spatz, E. S., Lipska, K. J., Dai, Y., Bao, H., Lin, Z., Parzynski, C. S., . . . Drye, E. E. (2016). Risk-standardized Acute Admission Rates Among Patients With Diabetes and Heart Failure as a Measure of Quality of Accountable Care Organizations. *Medical Care*.
- ⁵² Christensen, E. W., & Payne, N. R. (2016). Pediatric Inpatient Readmissions in an Accountable Care Organization. *The Journal of Pediatrics*, 170, 113-119.
- ⁵³ Kelleher, K. J., Cooper, J., Deans, K., Carr, P., Brilli, R. J., Allen, S., & Gardner, W. (2015). Cost Saving and Quality of Care in a Pediatric Accountable Care Organization. *Pediatrics*, 135(3).