

Alliance for Innovation on Maternal and Child Health

Expanding Access to Care for Maternal and Child Health Populations Kentucky

INTRODUCTION/BACKGROUND

As part of the Alliance for Innovation on Maternal and Child Health (AIM) program, the American Academy of Pediatrics (AAP) was tasked with gathering background information to better understand access to care and coverage issues from the patient/family and provider perspectives. This was accomplished through several different mechanisms: telephone interviews with pediatrician leaders, an online reporting form (survey) of patients/families, and telephone interviews with families to capture their stories; all taking place in September and October 2015. The intent of this information is to educate state teams about the challenges that patients/families and providers are experiencing, and to highlight potential opportunities. Below is a summary of the findings.

PHYSICIAN INTERVIEW FINDINGS

A phone interview was held between AAP staff, three pediatrician leaders and the AAP Executive Director of Kentucky. The goal of the interview was to obtain pediatrician insight into the health care financing environment in the state, including information about access, coverage, and payment for maternal and child health-related services. The interview highlights are documented below.

Pediatric Care Challenges	
Access in Rural Areas	<ul style="list-style-type: none"> • Few pediatricians in rural areas, GPs provide most services • Inadequate number of subspecialists • Lack of resources to follow-up on referrals
Behavioral Health	<ul style="list-style-type: none"> • Limited number of providers • Very long wait time for an appointment (6-9 months) • Primary care physicians managing behavioral and mental health services with limited resources and/or access to specialists
Medicaid	<ul style="list-style-type: none"> • Difficult for providers to navigate the state's 5 Medicaid managed care plans • Some subspecialists do not accept Medicaid
Telehealth	<ul style="list-style-type: none"> • Payers provide limited payment • Strict legal regulations (require hub-and-spoke model) • Most funded through Title V resulting in poor payment
Maternal Care Challenges	
Addiction	<ul style="list-style-type: none"> • Extreme rate of opioid addiction (25% of newborns are opioid exposed) • Neonatal abstinence syndrome is overwhelming NICUs and resulting in large number of CYSHCN • Smoking while pregnant is prevalent
Pediatric Care Successes	
Bright Futures	<ul style="list-style-type: none"> • Bright Futures Guidelines largely followed • Services are covered
Medicaid	<ul style="list-style-type: none"> • Over 95% of the population is insured due to Medicaid expansion • Re-enrollment is streamlined • Increased use of Navigators over the past 5 years
Maternal Care Successes	
Medicaid	<ul style="list-style-type: none"> • Medicaid expansion has increased postpartum insurance coverage
Opportunities	
<ul style="list-style-type: none"> • Increase access to: pediatric subspecialists, mental health services and telemedicine • Integrate mental health to provide seamless care using a home health model • More resources and support for social determinants of health 	

Family Voices conducted the family interviews and disseminated the online reporting tool in partnership with AAP under the AIM Grant supported by the Maternal and Child Health Bureau, Health Resources and Services Administration

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FAMILY SURVEY RESULTS

In an effort to gather data about the access, coverage and payment issues that patients and families experience at the community level, AAP partnered with Family Voices to create an online reporting form (ie. survey) in both English and Spanish. The online reporting form was disseminated through the state Family-to-Family Health Information Center via Family Voices, as well as via other AAP information dissemination mechanisms to families. 74 complete responses were received from patients/families in Kentucky. The three most common issues reported for access, coverage and payment are listed below:

Access	<ul style="list-style-type: none"> • None (42%) • The recommended doctor or service is not available in my area (39%) • The wait time to get an appointment is too long (35%)
Coverage	<ul style="list-style-type: none"> • A recommended service is not covered by my insurance plan (45%) • Recommended services were limited (40%) • A recommended doctor / provider is out-of-network (23%)
Payment	<ul style="list-style-type: none"> • My child’s health plan does not cover all the cost of care such as specific medications, therapy services, equipment, in-home services, etc (39%) • Out of pocket (deductibles / co-pays) costs are too high (27%) • I quit work or cut back on my hours to care for my child (25%)

Common Themes:

Several sections of the online reporting form invited participants to provide additional comments. Many respondents took the opportunity to offer information about their experience; and several recurring themes emerged:

- **Behavioral Health:** Poor access, poor coverage, little to no covered autism services, not enough providers, long wait time for appointments
 - *“There are very few psychiatrists and speech providers accepting patients. Most psychiatrists and many psychologists do not accept any insurance, they are all out of pocket and out of network.”*
 - *“My son's Family doctor is refilling his ADHD meds and other psychiatric meds.”*
- **Lack of Specialists:** Many do not accept public plans, very long wait time for appoints, high co-pay, some not accepting new patients
 - *“No doctors in this area that know much about autism, no one to diagnose autism, few therapist that are qualified to work with autistic kids, schools have very little training for working with autistic kids and not enough aides to support the kids.”*
 - *“The closest provider for neurology, braces, MRI and special needs ID/DD testing is over 1-2 hours away.”*
- **Inadequate Coverage:** Necessary services not covered or under-covered including DME, prescriptions, diapers for special needs children, music therapy, special needs strollers, PT, OT, home care
 - *“My son may use the approved number of seizure medicines before the insurance will allow us to fill the next prescription. We need therapy for one hour but only get approved for 30 minutes.”*
 - *“For DME Equipment it takes a very long time to get approval from the insurance sometimes we wait for up to 6months to get parts and them they get the wrong parts.”*
 - *“Private health insurance is self-funded, and does not cover therapies designed to help child with learning disabilities, ADHD, Autism, developmental delays. Even my three-year-old non-verbal child could not receive speech therapy under our family's insurance plan.”*

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- *“Needed therapies (e.g. speech therapy, occupational therapy) not covered by insurance.”*
- *“The need for respite care for special needs children is not being met. We have asked many agencies for over a year and cannot find a respite worker to help our family.”*
- Coordination of Care: Little to no coordination of care for complex cases, benefits unclear
 - *“Cancellation then re-approval, with same information caused her to be behind in immunizations. She has also missed about 3 months of Occupational and Speech therapy.”*
- Cost: Unaffordable co-pays, do not qualify for assistance but cannot afford premiums and co-pays, high premiums (especially for private payers)
 - *“Before our daughter had Medicaid our health insurance didn't cover a lot and we were near bankruptcy.”*
 -

Conclusion:

Parents in Kentucky and each of the other target states are encountering many of the same access, coverage and payment issues and are frustrated with the lack of available assistance. When children, especially children with special healthcare needs, are referred for specific services and parents are told the earlier they receive care the better the outcome will be, it can be incredibly frustrating to be unable to obtain the recommended care due to a lack of providers or unmanageable out of pocket costs. These themes are further illustrated in the attached family interviews.

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FAMILY STORIES

Family Story #1

Health Care Systems for Children/Youth with Special Health Care Needs (CYSHCN) in Kentucky

*Challenges Faced by Families: Interview with a Parent - 10/29/2015**

The story below illustrates the overwhelming bureaucratic issues that parents of children with complex medical needs can face.

Most of Brian's early life was spent in Georgia. He was born there 3 months early, delivered through an emergency caesarian section surgery. Due to lack of oxygen, Brian suffered brain damage and several other medical complications, including hydrocephalus, very poor vision (legally blind), and vocal pulmonary dysplasia, a chronic lung disease which required the use of a tracheostomy (trach) tube at various times when he was young. As a newborn, Brian was sick frequently. His mom, Bev, cared for him herself, but her confidence was undermined as doctors told her "you don't know what you are doing" and "it's all in your head" and "all you need to do is get him up and move him around." Bev couldn't see how this could be done with a trach tube. For the first 10 years of Brian's life, his family did not receive home nursing services. Brian was on Medicaid, but Bev did not know that she might have had nursing services to help care for him. Bev had three other small children at home.

When Brian was 9 years old, he contracted an adenovirus and was hospitalized. He was treated with Demerol, and when his breathing stopped for 45 minutes, he suffered severe brain injury. He spent 10 weeks at Children's Hospital and became dependent on a ventilator, feeding tube, breathing treatments, and multiple medications to treat seizures and other conditions. When he was discharged, Bev was told to "take him home on the ventilator and see how long he lives or take him home off the ventilator and let him die." A social worker, though, helped Bev get nursing services to help her care for her son at home. Bev pursued litigation against the hospital for medical errors and was given a court settlement which was put into an irrevocable trust.

When Brian was 18, Bev moved her family from Georgia to Kentucky. Prior to the move, Bev asked agencies in both states to identify what needed to be done to ensure his care after the move, but Kentucky officials indicated that nothing could be done until she actually lived in Kentucky. After the move, Bev contacted the state for home health care services, and was put in touch with the only service provider in her area. Bev was told that she herself had to be certified in CPR in order to receive services for Brian to live at home, and that this had to be done even before someone would come out to do an assessment. In Kentucky, providers are allowed to set their own policies, such as this one about CPR certification. Since this was the only provider in Bev's area, even though she was very experienced in caring for her son, she complied with this requirement and got the training and certification.

Bev requested that her son receive physical and occupation therapy and a larger wheelchair. State officials indicated they would need to send a therapist to her home to do an assessment, but that couldn't be scheduled until paper work was complete. She was told to apply for a Medicaid Model II waiver. That initial application

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process happened relatively quickly and in the meantime, Bev contacted a home health agency to line up nursing services and was told that there would be no problem providing services. However, after the initial application process, before someone is approved for any services, they have to go to the Department for Community Based Services to complete paperwork about their income and resources. Bev went to the state agency, waited for about 30 minutes, and then was told she couldn't be seen that day. The agency scheduled an appointment for three weeks later. She was told she also needed to apply for SSI for Brian. When Bev returned to the state office, she was given additional paper work to complete. However Bev did not understand what the papers were asking. The state official didn't explain the terms. When she returned to the office, the worker explained that the papers she had been given were for a provider to complete, not a parent. Bev was asked to complete paperwork to be sent to local banks to document that her son did not have any bank accounts.

Bev contacted the home health agency again – 8 weeks after her initial contact. She asked about getting nursing services, but this time was told that they had no nurses available. The agency indicated that they had been trying to hire more nurses, but to no avail. Bev believes this may be due to the low rate of pay offered under the Model II waiver.

Eventually it was determined that Bev could not get SSI for her son due to the fact that he has an irrevocable trust. While the trust pays for some of his needs, he would also benefit from SSI. If the trust is counted as income or a resource he will have to pay a patient liability fee to access services through the Medicaid Model II waiver.

Bev indicates that this experience of trying to get services for her son in a new state has been a confusing and a drawn-out nightmare. She worries about her son's future. "I'll be 53. I have disc problems in my lower back. I have difficulty walking. I don't have time to waste."

* Names have been changed.

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Family Story #2

Health Care Systems for Children/Youth with Special Health Care Needs (CYSHCN) in Kentucky

*Challenges Faced by Families: Interview with a Parent - 11/3/2015**

Carly's story exemplifies the shortfalls of our health system in meeting the needs of a family with a medically fragile child.

Carly's son Luke was born 6 weeks early. He was diagnosed with nemaline rod myopathy, a form of muscular dystrophy that can be severe in cases of infantile onset, as was Luke's situation. He spent 4 months in the neonatal intensive care unit (NICU) and was released with a tracheostomy (trach) tube and a feeding tube. Currently Luke is 7 months old and suffers from contractures all over his body, but the most critical concern has always been Luke's ability to breathe. His muscular dystrophy prevents him from expanding his lungs.

After release from the NICU, Luke had been home for about 2 months when he became sick. Carly took him to the pediatrician where blood work was taken. Carly anxiously waited for the results, calling the doctor's office several times. Eventually they told her that everything was fine. However, Carly was still concerned with her son's condition as she increasingly needed to suction his trach. She called the Health Department which had previously given Luke his vaccines. However, the Health Department wanted his medical records before seeing him and Carly was told by the pediatrician's office that would take a week to prepare. Desperate, Carly called a new pediatrician who advised Carly to take him by ambulance to the emergency room. By this time Luke's oxygen monitor was going off. At the hospital Luke was put on a ventilator and was there for 3 days.

Luke came home off the ventilator but within 2 days he again was not doing well. Carly took him to the new pediatrician who was very concerned. Carly was continually suctioning him. They called the ambulance and took him right to the hospital, where they realized that Luke would need to be put on a ventilator permanently. When Luke was ready to be released, he needed 8 to 16 hours of nursing services to maintain the ventilator. EPSDT would cover this, but only if Carly returned to work or school. This was out of the question since Carly had a very sick son.

Carly was told that in order for Luke to come home she would need to have an updated CPR training, something she had previously pursued when Luke was in the NICU. There was only one training scheduled for the remainder of the year and she needed to find someone to attend with her as a backup. Despite these challenges, Carly managed to get the training.

In the meantime, Carly began asking at the hospital for a nurse who could help her, but was not successful. Hospital staff discussed foster care with Carly but this made no sense. She was Luke's mother and could provide whatever a foster family could provide.

Eventually Carly was told she could place Luke in Home of the Innocents, a facility that provides care for medically fragile children. Luke remains at Home of the Innocents and they are helping Carly to apply for a Medicaid Model II waiver to provide in-home nursing services. Carly is waiting for this program to kick in, but she is concerned about finding a nurse needed for Luke's home care. There are only 3 agencies in her area that

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provide nursing services, and she has contacted each. One did not provide ventilator-trained nurses and another had no nurses available.

Carly visits her son every day, travelling over 40 miles each way. Luke lights up when his Mom enters his room. Carly wishes she could stay overnight with him, as she was able to do in the hospital, but this is against policy. Carly is drained and struggles to pay for basic expenses associated with this arrangement, like the food and gas costs of travelling to see Luke. Beyond everything else, Carly wants her son home for Christmas.

* Names have been changed.