

# Alliance for Innovation on Maternal and Child Health

## Expanding Access to Care for Maternal and Child Health Populations Pennsylvania

### 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, two physician leaders and the Executive Director of AAP's Pennsylvania Chapter. Physicians were asked questions about access, coverage and payment issues they or their patients encounter and were encouraged to share other successes or challenges they are facing. The interview highlights are documented below.

Pediatric Care Challenges	
Medicaid	<ul style="list-style-type: none"> <li>• Very low Medicaid payment rates for physicians</li> <li>• PA has 5 Medicaid managed care regions and each region has a different carrier</li> <li>• Difficult to meet increasing Medicaid mandates without payment increases</li> <li>• Some Medicaid managed care requires prior approvals creating an administrative burden for physician practices</li> </ul>
CYSHN	<ul style="list-style-type: none"> <li>• It is difficult to find adult providers to take care of adolescents with SHCN</li> <li>• Some private insurers do not cover all the necessary services for CYSHN</li> </ul>
Bright Futures	<ul style="list-style-type: none"> <li>• Many payers bundle payment for these services that don't cover the total costs/value of the services provided</li> <li>• Difficult to perform all of the expected services in one visit without adequate payment</li> </ul>
High Deductible Plans (HDHP)	<ul style="list-style-type: none"> <li>• Families are delaying needed services due to high out of pocket costs</li> <li>• Under HDHP plan, families go to urgent care for primary care as paying out of pocket there is cheaper than the unmet deductible</li> </ul>

Pediatric Care Successes	
Insurance Enrollment	<ul style="list-style-type: none"> <li>• State has a single online application process</li> <li>• AAP PA Chapter and family advocates meet quarterly to review issues related to application and enrollment</li> </ul>

Maternal Care Challenges	
Maternal Mental Health	<ul style="list-style-type: none"> <li>• Challenging to screen for maternal depression during well-child visits when performing all of the other Bright Futures recommendations</li> <li>• No payment for pediatricians for this screening</li> </ul>
Medicaid	<ul style="list-style-type: none"> <li>• New mothers report only having one post-partum visit before losing coverage</li> <li>• The state has seen a decrease in hospitals that provide delivery services resulting in a dramatic drop in the number of deliveries in Philadelphia</li> </ul>

Opportunities	
<ul style="list-style-type: none"> <li>• More access to mental health services, particularly to those that will accept Medicaid</li> <li>• A better / permanent structure to provide an overview of state programs for patients and families</li> <li>• Resources for pediatricians to navigate all the changes in healthcare, particularly administrative</li> </ul>	

**AIM Expanding Access to Care for Maternal and Child Health Populations  
Learning Collaborative Round 1 - Pennsylvania**

**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. 86 complete responses were received from patients/families in Pennsylvania. The three most common issues reported for access, coverage and payment are listed below:

<b>Access</b>	<ul style="list-style-type: none"> <li>• The wait time to get an appointment is too long (49%)</li> <li>• The recommended doctor or service is not available in my area (34%)</li> <li>• My provider does not or no longer accepts my insurance plan (21%)</li> </ul>
<b>Coverage</b>	<ul style="list-style-type: none"> <li>• A recommended service is not covered by my insurance plan (37%)</li> <li>• The recommended services are limited (36%)</li> <li>• A recommended provider / doctor is out of network (27%)</li> </ul>
<b>Payment</b>	<ul style="list-style-type: none"> <li>• My child’s health plan does not cover all the cost of care such as specific medications, therapy services, equipment, in-home services, etc (31%)</li> <li>• I quit work or cut back on my hours to care for my child (30%)</li> <li>• Out of pocket (deductibles / co-pays) costs are too high (20%)</li> </ul>

**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
  - *“Challenge getting psychiatrist to send evaluation to BHRS, BHRS provider not accepting the plan my child has, recommendations of psychiatrist were not appropriate according to BHRS, developmental pediatrician has long wait.”*
- **Lack of Specialists:** Many do not accept public plans, very long wait time for appoints, high co-pay, some not accepting new patients
  - *“There needs to be more availability among providers. There should not be a 1-2 year wait list for specialists.”*
  - *“We have to travel 2 ½ hours to see a specialist in-network.”*
- **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 special needs child require someone to care for and watch him at all times. I request for nursing services and the insurance company (Keystone First) keep denying the request for services. Even though I've told them that my child's life is in danger. I had to leave a very good paying job to work less hours with much less pay, to make sure my son is cared for appropriately.”*

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

## AIM Expanding Access to Care for Maternal and Child Health Populations Learning Collaborative Round 1 - Pennsylvania

- *“Had to have a fundraiser to pay for a \$23,000 power wheelchair insurance denied for our 4 year old son with leg paralysis from Spina Bifida and also lack of use of his right arm.”*
- *“My child’s therapies such as OT, PT, and speech are limited visits. He has been discharged from therapy due to insurance limits even though the doctors are recommending they continue.”*
- **Coordination of Care:** Little to no coordination of care for complex cases, benefits unclear
  - *“Insurance denials have delayed testing and possible results that could provide an effective treatment for my child.”*
  - *“Services were approved and then denied and had to be submitted 6 times before they stopped billing me personally. Co pays for some needed therapies were too high to continue. Hearing aids are needed but I cannot get them for him because at age 21 they will no longer be covered by insurance and he will have to stop using them after he became dependent on them. Therefore I have not gotten them.”*
- **Cost:** Unaffordable co-pays, do not qualify for assistance but cannot afford premiums and co-pays
  - *“My son’s prescription coverage thru Humana is very difficult with high co pays.”*

### **Conclusion:**

Parents in Pennsylvania 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.

**AIM Expanding Access to Care for Maternal and Child Health Populations  
Learning Collaborative Round 1 - Pennsylvania**

## **FAMILY STORIES**

---

### **Family Story #1**

#### **Health Care Systems for Children/Youth with Special Health Care Needs (CYSHCN) in Pennsylvania**

*Challenges Faced by Families: Interview with a Parent - 10/27/2015\**

Clarissa's experiences in raising her son Brett underscore the challenges of our healthcare systems to provide services and support for families of a child with autism based on their individual needs.

When Brett was about 18 months old his verbalization began regressing. His mom, Clarissa, brought this to the attention of the pediatrician who expressed concern about deafness and ordered a hearing evaluation. These tests came back normal. The pediatrician then referred Clarissa to Early Intervention (EI) and Brett began to receive Occupational (OT) and Speech Therapies.

When EI services ended at age 3, Clarissa sought ways to keep these therapy services available for Brett. She contacted Children's Hospital of Philadelphia (CHOP) but was told there was a 3-year wait list. Clarissa was successful in getting Brett enrolled in a program at a local university which provided opportunities for social skill development and recreation. It was from staff at this program that Clarissa learned that Brett was severely autistic.

Clarissa obtained medical assistance (Medicaid) as secondary coverage to her private insurance plan in order to address Brett's needs. Clarissa fought to get Therapeutic Staff Support (TSS) for Brett through the Medical Assistance Contracted Behavioral Health Managed Care Organization. Brett began receiving therapy services from a Behavioral Health Rehabilitation Service Provider twice a month. Clarissa experienced many frustrations with this provider. The provider never gave the family a treatment plan; there was no case management; there was continual staff turnover; and scheduling services was very problematic. Clarissa asked for information about support services, such as a peer group or play group for her son, but the provider could not help. Eventually the service provider concluded that their services were not needed by Brett.

Clarissa felt that Brett would benefit from private speech therapy but his primary care doctor would not recommend it.

Brett is now seven years old. He exhibits repetitive behaviors and is constantly moving. He often bites himself as a way of expressing emotion. Brett is potty trained but not for bowel movements. As a result he can become constipated and needs frequent enemas. Clarissa notes that while some of Brett's skills are well developed, others are not. He loves to memorize phrases and often repeats things. He is starting to memorize dances and enjoys searching YouTube for dance videos. Brett also likes playing with cell phones.

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

**AIM Expanding Access to Care for Maternal and Child Health Populations**  
**Learning Collaborative Round 1 - Pennsylvania**

Brett participates in an autism support classroom which unfortunately is not in his neighborhood school. There he receives speech, occupation, and Applied Behavior Analysis (ABA) therapy.

Clarissa loves her son and his “quirky-ness.” She is not looking for a cure. She just wants him to be ok. She notes, “It’s horrible to think that he may never have a friend.”

\* Names have been changed.

**AIM Expanding Access to Care for Maternal and Child Health Populations  
Learning Collaborative Round 1 - Pennsylvania**

**Family Story #2**

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

*Challenges Faced by Families: Interview with a Parent - 10/28/2015\**

Amy's story about her family of 5 children demonstrates the complexity of issues families face when seeking help for their children's medical concerns.

Amy and Ted are the parents of 5 boys, from 11 months old to 11 years old. Four of the children have medical concerns. They live in a rural area of Pennsylvania with two hospitals close by, but both lack the level of care needed for some of the asthma and allergy issues that her children have experienced. There are two higher-level hospitals, both an hour away.

Amy's oldest, Dan, has asthma, severe allergies, Attention Deficit Disorder (ADD), a learning disability, and can suffer from depression. Most of his treatments requiring hospital-level facilities have been provided at the regional level hospital, and while they have been "mostly satisfied" with their experience, in one instance her son's physical symptoms were dismissed as "in his head" and Amy chose to take him to a more specialized children's hospital where he was able to receive an accurate diagnosis.

The boys are covered by insurance through Ted's employer. In addition they are covered by a state medical assistance program, paid through the Health Insurance Premium Program (HIPPP) that covers medical expenses for children with special health care needs through fee-for-service rather than through a Medicaid Managed Care Organization. (This model has been determined to be more cost effective.) To be most cost effective for the family, they need to use providers who accept both the employer HMO insurance as well as Medical Assistance (PA term for Medicaid). This dual coverage is extremely valuable to the family, but the dual coverage can be confusing—to both parents and providers. One provider refused to see Dan even though they were a network provider within the HMO plan, because he also had the HIPPP coverage.

Amy is a very savvy mother who has learned through experience the signs and symptoms that indicate when her sons need emergency medical help. On occasion she has had to fight to get the care they need. In one instance she needed to convince her insurance company to cover costs for a hospital stay. Amy knew her child was going to need to be admitted; she'd done everything she could prior to admittance to treat her child's severe asthma attack. Similarly, she has had to persevere to have her children seen by providers with the right level of expertise as she has learned that this has made a significant difference in getting accurate—and even life-saving—diagnoses for problems.

Living in a rural area, combined with the needs of her family and schedules (Amy recently returned to school) has further complicated the health care options for her family. For example, Dan has had some appointments with an "awesome" behavioral therapist, but appointments were only available at times that his mother could not accommodate. Amy has sought support from other parents through allergy

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

## AIM Expanding Access to Care for Maternal and Child Health Populations Learning Collaborative Round 1 - Pennsylvania

support groups offered by the hospitals but the meetings occurred at times inconvenient for her family. A night time support group an hour away is impractical for the mother of 5 children.

Pennsylvania has excellent health care options and facilities to treat children with special health care needs—but access issues and lack of understanding of the complexity of the system make it a challenge for families like Amy's.

\* Names have been changed.

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