

# Alliance for Innovation on Maternal and Child Health

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

### Rhode Island

#### 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 and three pediatrician leaders from Rhode Island. 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	
Behavioral Health	<ul style="list-style-type: none"> <li>Families unable to access child psychiatrists</li> <li>Very high out-of-pocket costs for these services (esp. private coverage)</li> <li>High rate of hospitalization for mental health; more should be done outpatient</li> </ul>
Payment Reform	<ul style="list-style-type: none"> <li>Little emphasis on pediatrics due to payer perception of limited return on investment for pediatricians and low payment</li> <li>Emphasis on movement to PCMH and ICD-10 Implementation; afraid pediatrics is being forgotten</li> <li>Physicians are receiving low payment and patients have high copays/deductibles</li> <li>Patients are delaying/refusing care due to high deductibles/copays</li> </ul>
Bright Futures	<ul style="list-style-type: none"> <li>Insurers are not paying for multiple screens on the same day leading pediatricians to avoid some screens or requiring a second appointment</li> </ul>
Foster Care	<ul style="list-style-type: none"> <li>Foster children often don't have or lose their medical home when transitioned</li> <li>Lack of care coordination and exchange of medical information</li> <li>Significant behavioral health needs</li> </ul>

Pediatric Care Successes	
Bright Futures	<ul style="list-style-type: none"> <li>Children receiving most services</li> </ul>

Maternal Care Challenges	
Maternal Mental Health	<ul style="list-style-type: none"> <li>Lack of coverage for screening for postpartum depression by pediatricians</li> <li>Uncertainty as to where to refer a mother if she is at risk for depression; perception that pediatricians are not aware of available community resources</li> </ul>

Opportunities	
<ul style="list-style-type: none"> <li>Increase the BF recommended visits to a total of 12 from age 0-3 years rather to cover the extra visit many parents request in the first month</li> <li>Need a behavioral and mental health system that is easily navigable by families and providers</li> <li>Promote better and ongoing communication between OB/GYNs and pediatricians</li> </ul>	

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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. 42 complete responses were received from patients/families in Rhode Island. 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 (60%)</li> <li>• My provider does not accept or no longer accepts my insurance plan (38%)</li> <li>• The recommended doctor or service is not available in my area (30%)</li> </ul>
<b>Coverage</b>	<ul style="list-style-type: none"> <li>• A recommended service is not covered by my insurance plan (64%)</li> <li>• A recommended doctor / provider is out-of-network (44%)</li> <li>• Previously authorized or covered services were denied (36%)</li> </ul>
<b>Payment</b>	<ul style="list-style-type: none"> <li>• Out of pocket (deductibles / co-pays) costs are too high (66%)</li> <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 (61%)</li> <li>• I quit work or cut back on my hours to care for my child (45%)</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
  - *"Referrals and access to treatment for behavioral health issues are a nightmare."*
  - *"My private insurance won't provide my autistic child with any home based services or any services for behaviors."*
- **Lack of Specialists:** Many do not accept public plans, very long wait time for appoints, high co-pay, some not accepting new patients
  - *"It took months to find an orthodontist that was both wheelchair accessible and accepted his state dental plan."*
- **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
  - *"Quality pull ups / diapers are not available since Medicaid changed the rules."*
  - *"The cheap and poor quality diapers my child now receives are junk. She leaks through them every time she goes to the bathroom. It's ridiculous."*

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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- Coordination of Care: Little to no coordination of care for complex cases, benefits unclear
  - *“My child has a rare genetic disorder. It has been a nightmare navigating the health insurance piece!! 17 years’ worth of bad experiences.”*
- Cost: Unaffordable co-pays, do not qualify for assistance but cannot afford premiums and co-pays, high premiums (especially for private payers)
  - *“Our deductible is too high, and copays to high. My child needs counseling twice a week with a co-pay of 40.00 each visit, which we can't afford.”*
  - *“Families who have insurance through their employers find that although individual insurance may be affordable, family plans through these companies can be very expensive with the high out of pocket and premium expenses (sometimes up to 25% of the households annual income).”*

### **Conclusion:**

Parents in Rhode Island 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**

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### **Family Story #1**

**Health Care Systems for Children/Youth with Special Health Care Needs (CYSHCN) in Rhode Island**  
*Challenges Faced by Families: Interview with a Parent - 10/23/2015\**

Nancy's story below documents some of the problems families have in seeking and obtaining services for their children on the autism spectrum.

Nancy is mom to Sam, age 9, who has Asperger's syndrome and Ashley, age 5, who has severe autism. Over their lifetime, Nancy has had insurance coverage with three different private plans, but none covered services for children on the spectrum, despite what Nancy has had to pay. Currently, her monthly health insurance premium is \$900 a month for her private plan and she must meet a \$5000 deductible to be reimbursed—and this is over and beyond whatever she pays for any spectrum-related services or treatment for either child. Nancy took Ashley to the Walter J. Beupre Speech and Hearing Center at the University of Rhode Island for speech therapy but eventually had to stop as paying for this as the out-of-pocket became prohibitive.

Nancy was successful in obtaining a Katie Beckett waiver to fund services for her daughter Ashley. That program covers Applied Behavior Analysis (ABA) therapy in the home and speech therapy. These have been critical to Ashley's progress. As a result of the therapy she has received, Ashley is able to attend 5-day Kindergarten; she can follow simple commands; has some vocabulary; and knows her colors, letters, and numbers. Nancy notes "Now she's able to sit with her peers in classroom and interact with peers and hold it together. It has been a long road. Not everybody likes ABA but it has worked for us." While the Katie Beckett program has been invaluable to Nancy, it requires fighting for the program every year, and filling out extensive paperwork just to continue the waiver.

Health care services have been more problematic for her son, Sam, partly due to uncertainty over a diagnosis and partly due to not knowing what services would help him. At age 7, Sam's doctor diagnosed him with Social Pragmatic Communication Disorder and indicated he had mild anxiety and ADHD. Nancy disagreed with this diagnosis, describing his repetitive behavior at home. Eventually Nancy took him to another doctor, who diagnosed Sam with Asperger's syndrome. Sam also has sensory issues and aversions to many foods. Because her son's condition is not "severe enough," the Katie Beckett Waiver is unlikely to be approved for him. His need for services is still great, and Nancy notes that in many ways, her son is more of a challenge than her daughter, as far as figuring out exactly what kind of services and therapies might help him. She has been able to get some funding through the Shriners. "Without their help we couldn't do these things." Nancy also commented that the Social Pragmatic Communication Disorder diagnosis does a disservice to children who need services but because of the diagnosis don't qualify for Katie Beckett.

Nancy has pursued hippotherapy for both her children and was able to get some funding from Shriners to pay for that. Nancy feels strongly that Sam would benefit now from cognitive behavioral therapy. Nancy is very frustrated because she feels there are services Sam could be accessing but they would have to pay out of pocket and that's too expensive for their family.

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### Family Story #2

#### **Health Care Systems for Children/Youth with Special Health Care Needs (CYSHCN) in Rhode Island** *Challenges Faced by Families: Interview with a Parent - 10/23/2015\**

In the following story, Debbie highlights several issues with our healthcare financing system today.

Debbie has a five year old daughter with autism. It has not been easy getting services to help her daughter, Caitlin. Caitlin was diagnosed at age 2 ½ with autism and received services through Early Intervention. Debbie credits the physical therapy (PT) Caitlin received through EI as the turning point in helping her learn to walk. Debbie attempted to continue PT for Caitlin at Hasbro Hospital but her private insurance only paid for those services for a limited time. They tried Debbie's husband's insurance plan, but that was also denied. Debbie paid for this PT out-of-pocket. Since the therapy took place at Hasbro, they were billed the outpatient hospital level of care - \$300 per visit.

After EI, Debbie enrolled Caitlin at the Groden Center, an organization that provides services for children and adults on the autism spectrum. Through a mother's group that Debbie attended there, she learned about the Rhode Island Parent Information Network (RIPIN) and the Katie Beckett (KB) program. Debbie applied for and was able to enroll Caitlin in the KB program, which has provided ongoing occupational, physical, and speech therapy. Caitlin has made much progress as a result.

Debbie notes, however, that the KB program provides challenges for families. It is difficult to find providers who take Medicaid (though KB) and she has, at times, been forced to be put on a waiting list. Debbie has learned to make calls to verify provider reimbursement but she has found that sometimes those who answer the phone either don't know or provide erroneous information. She has learned to document conversations and the names and roles of those with whom she communicates.

The process of billing KB is also complex. Debbie needs to first submit a claim to her private insurance—knowing that it will be denied—before she can submit the bill to KB. It is intimidating as the cost of some of many services for Caitlin is very expensive. Hospital bills she has received tally up to thousands of dollars. After receiving the denial from the private insurance company, it can take quite a bit of time for the claim to process through Medicaid. Often, she receives threatening letters from providers demanding payment while waiting for KB to pay.

The KB program also requires yearly paperwork that Debbie must submit to document Caitlin's condition. Debbie notes that it takes over a week to compile this information and, she has learned to send this mail with return receipt requested. Almost every year, Debbie joins efforts with other families to educate policy makers about the benefits of the program to ensure that it is continued in Rhode Island. Debbie feels that the KB program is always under scrutiny. State officials continually raise the issue of co-premiums. The thought of not having the services provided by KB is indeed troubling for Debbie.

Because of the care that Caitlin has needed, Debbie had to leave her job. As a result they had to short sell their house and thus take a loss on the real value of the home. As Debbie summarized what many families like her face as they try to get services for their children. "Our health care system today has such high deductibles and coinsurance that providers usually ask that payment is received upfront and going forward to have continued services a credit cards must be on file. Having worked in my previous

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job processing medical claims for an insurance company, I know that some billing codes are excluded from policies, (ex: Aetna excludes autism-related services) and most people have no idea what a provider is really billing until you receive a bill in the mail. We are forced to must keep an expensive family medical plan in place for my daughter knowing nothing is covered as Medicaid is just a supplemental. Katy Beckett has been a God-send and we are happy to have access to it. “ Debbie concludes “My daughter is in a good place and making progress but it took a lot of full time work. I had to be a stay-at-home mom. However it is still such a long road but I am blessed by the team that is in place for my daughter. There are many families who have no experience in how claims process, insurance and resources available. So organizations like Rhode Island Parent Network, Autism Network and Family Voices and many more. . . just to name a few . . . need more credit for the work they do. I am proud to be a part of this and look forward to helping. I am wondering if more advertising and more knowledge at the pediatrician offices would help spread support. Just curious and want to help more.”

\* Names have been changed.

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### Family Story #3

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

*Challenges Faced by Families: Interview with a Parent - 10/30/2015\**

Spanish-speaking families face additional challenges when seeking health care for their children with special needs.

Luis and Maria are the parents of a 9 year old son with ADHD, and have worked hard to help him overcome his problems. They have found specialists, including a neurologist, who have provided satisfactory services, and are able to communicate with their son's teachers at school. They have not thus far had problems with getting their son's needs covered by insurance.

It hasn't been an easy road, however. When their son was 4, he had significant hearing loss, and an approach to this was not clear. Providers gave conflicting advice. When the parents learned that he needed tubes in his ears, they had to insist on this surgery, arguing with pediatricians. Their son did finally get the tubes and his hearing improved dramatically. It was challenging to find a doctor who would help them understand his hyperactivity. At one point they were told that because of his delays, he would never attend college, years down the road. Luis and Maria did not think that this was true, and were upset at the way this doctor seemed to be closing off future possibilities for their son. Their son is now a model student, and Maria and Luis are very proud of him and his progress.

Luis and Maria are now parent leaders in a support group for Hispanic families with children with special health care needs, including autism, ADHD, cerebral palsy, and other diagnoses. The group meets once a month to help Spanish-speaking families educate themselves about services and systems and to provide peer support from other families. They advertise the group through flyers they deliver in their community. They schedule speakers to come and talk about important topics such as insurance. "We look for things that will help people out."

Language barriers often present problems for Spanish-speaking families seeking health care. A trip to the emergency room can take much longer than usual if a family has to wait for an interpreter who can help them understand what is happening. Even regular doctor appointments can be challenging. If a doctor allows only 15 minutes per patient, and the family needs an interpreter to translate both what they are telling the doctor and what the doctor is saying, 15 minutes isn't enough to allow the parents to ask the questions that they have. It would help if pediatricians were more sensitive to the needs of families who speak another language, and would respect the knowledge parents have about what is going on with their child.

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