

## Alliance for Innovation on Maternal and Child Health Expanding Access to Care for Maternal and Child Health Populations California

### 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 four pediatrician leaders from two AAP California Chapters. 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>Public and private payers not covering recommended services or put a limit on the number of sessions; restrict covered providers; require high co-pays</li> <li>Limited number of providers, many not taking on new cases</li> <li>1-2 year waiting list for Autism specialists</li> <li>Primary care physicians managing behavioral and mental health services but cannot make a mental health diagnosis</li> </ul>
Bright Futures	<ul style="list-style-type: none"> <li>Strict payer guidelines for timing of care</li> <li>Not all plans cover the 30 month visit</li> </ul>
Medicaid	<ul style="list-style-type: none"> <li>Access can be problematic with public coverage (Particularly Medi-Cal)</li> <li>Shortage of specialists that accept Medicaid</li> <li>Re-enrollment turnover</li> <li>Assigned by county, very difficult to cross counties to access care</li> <li>Challenging to get kids enrolled on mother's insurance after 30 days</li> </ul>
Narrow Referral Networks	<ul style="list-style-type: none"> <li>Public payers have very narrow referral networks (either not including specialists or low payments discourage specialists from participating)</li> <li>Exchange plans have a limit on referrals to specialists</li> <li>Coordination of benefits is very complicated</li> </ul>
Maternal Care Challenges	
Maternal Mental Health	<ul style="list-style-type: none"> <li>Referrals are a challenge, many providers not accepting new patients</li> <li>Mother's asking pediatricians for antidepressants</li> </ul>
Pediatric Care Successes	
Bright Futures	<ul style="list-style-type: none"> <li>Children receiving most services</li> </ul>
Medicaid	<ul style="list-style-type: none"> <li>Very low uninsured rate</li> </ul>
Maternal Care Successes	
Maternal Mental Health	<ul style="list-style-type: none"> <li>Some pediatricians screen during early infancy visits</li> </ul>
Opportunities	
<ul style="list-style-type: none"> <li>Better access to accurate information &amp; education (Reduce misinformation about immunizations, obesity, etc)</li> <li>Create a better vaccine school based system (very poor pediatrician payment for vaccines)</li> <li>Increase payment for pediatrics on par with adults (Medicare) in private and public systems</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. 71 complete responses were received from patients/families in California. 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 (54%)</li> <li>• The recommended doctor or service is not available in my area (30%)</li> <li>• My provider does not accept / no longer accepts my insurance plan (24%)</li> </ul>
<b>Coverage</b>	<ul style="list-style-type: none"> <li>• A recommended service is not covered by my insurance plan (50%)</li> <li>• A recommended doctor / provider is out-of-network (37%)</li> <li>• There were problems getting a referral (32%)</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 (46%)</li> <li>• Out of pocket (deductibles / co-pays) costs are too high (43%)</li> <li>• I quit work or cut back on my hours to care for my child (27%)</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
  - *"My son had an urgent mental health care need but it took several weeks to first, find a provider who had the experience I sought (with autism, teens, severe depression) and then once I found one, it took several more weeks to get an appt, even though the need was urgent (threat of self-harm)."*
  - *"ABA is not covered. Very long waits for behavioral health care."*
  - *"My daughter has autism and some co-morbid \*medical\* conditions which should be treated medically. Yet the providers I've encountered are not up-to-date in their info, they believe autism is psychiatric and know little about evidence-based medical treatments. To truly get help, I have to pay out of pocket and see better doctors."*
- **Lack of Specialists:** Many do not accept public plans, very long wait time for appoints, high co-pay, some not accepting new patients
  - *"Our plan changed due to a job change, my son's specialist was no longer in network, and now my son is paying the price."*
  - *"The list of in- network is very limited. We cannot afford seeing the out of network service provider. The in-network has a long wait list and not local. Result, child does not get service for the condition."*

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- 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
  - *"We couldn't afford \$35 three times a week for PT."*
  - *"We could not afford to begin multiple recommended therapies at once due to cost. Some therapies had to wait."*
- Coordination of Care: Little to no coordination of care for complex cases, benefits unclear
  - *"I call the doctor and they direct me to the medical group who in turn refers me to the HMO carrier who then tells me to contact medical group. I go in circles at times and I can spend hours trying to reach one person that can give me an answer."*
  - *"Care coordination is a huge issue when you have multiple insurances and no one wants to pay the bill."*
- Cost: Unaffordable co-pays, do not qualify for assistance but cannot afford premiums and co-pays, high premiums (especially for private payers)
  - *"Financial assistance wasn't available to me but I wasn't able to pay for extended speech therapy for my daughter. Once I saw enough improvement I stopped taking her so that I didn't have to pay \$40 each session anymore."*
  - *"We have such high deductible that we do not access the care needed and I am a professional with a good salary, but it is never enough to cover all the expenses."*

### **Conclusion:**

Parents in California 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 California**

*Challenges Faced by Families: Interview with a Parent - 10/19/2015\**

Karen's story below highlights the difficulties in finding a diagnosis and accessing and paying for services for a child with a rare disease.

Karen is a mother of a seven year old daughter, Heather, who has a suspected diagnosis of Cockayne Syndrome. Cockayne Syndrome is a rare autosomal recessive, neurodegenerative disorder characterized by growth failure, impaired development of the nervous system, abnormal sensitivity to sunlight (photosensitivity), eye disorders and premature aging. Problems with any or all of the internal organs are possible. Cockayne Syndrome is a destructive disease usually resulting in death within the first or second decade of life.

As with many other rare conditions, this diagnosis was not immediately apparent in Heather's case. While overwhelming grief replaced anticipated joy in the birth of their newborn, lack of a diagnosis put Heather's parents, Karen and Don, on a frustrating journey of asking questions that could not be answered and searching for needed services that were not readily found or easily attainable.

While carrying Heather, Karen sensed that things were not progressing well with her pregnancy. At her insistence, an ultrasound was ordered at 30 weeks revealing that the baby was small, only 1lb, 6oz. Karen was put on bed rest. However, due to lack of growth, the doctors took Heather at 36 weeks. Heather spent 100 days in the Neonatal Intensive-Care Unit (NICU) at Lucile Packard Children's Hospital in Palo Alto. Karen remembers that Heather seemed to be a mystery to the doctors, but, as her parents, they both felt that their best recourse was to trust them completely.

Heather went home with a nasogastric tube (NG) tube—and Karen and Don had to learn how to maintain that. While the NG tube may have saved her life by providing her the necessary nutrition, it was not easily manageable for her parents. Heather would often pull it out and Karen and Don tried various strategies to keep it in. Heather's parents were learning many things: how to properly care for Heather; taking proper feeding measurements; recording weight gain strides, etc. Learning to care for Heather's complex medical needs was hard and it would take a while before her parents would feel confident in leaving her in the care of someone else.

For the first 3 years Heather had frequent doctor appointments. The focus of the medical community was on keeping her alive. Unfortunately, Heather's parents also needed support and other resources, but that was never part of the discussion. They were never told about regional California Family Resource Centers or the Family to Family Health Information Center (Family Voices of California @ *Support for Families*), organizations

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that could have helped the family connect with other families and locate peer support and community resources.

In addition to lacking support services, financing Heather's needs was also problematic. Heather was covered by private insurance for the first 5 years but that did not pay for all that Heather needed. She was put on goat's milk, expensive and only available at Whole Foods, which was not covered by private insurance. Although Karen was eligible to apply for the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC), Heather's Goat Milk was not covered by WIC in CA. Therapy services under Title V were not available to Heather because she did not yet have a diagnosis, a criteria for eligibility. Karen learned of an intensive physical therapy program that was only available in Michigan and flew there with Heather. In a two week period Heather learned to come to midline and how to sit up with support. Unfortunately it was all paid for out-of-pocket (with fund-raising) and after 2 weeks they had to leave. Karen is convinced that if they had been able to stay there longer Heather would have learned to crawl. After their trip to Michigan, they learned of California Children's Services (CCS) a state program for children up to 21 years old and with certain diseases or health problems. This program is intended to provide the health care and services for children and youth to live to live a better quality of life. Although CCS would not provide the intensity of Physical Therapy Heather received in Michigan, it allowed her parents to seek services/resources in their home state. In looking back, Karen recalls a conversation with a county official who was appalled that Heather and her family had to travel out of state for therapy services; she looked into their records and could not clearly identify why Heather "fell through the cracks." She wanted to apologize and informed them that that CCS systems have improved since then.

When Heather was 5 years old, Don lost his job and Heather lost private insurance and was subsequently covered by Medi-Cal, California's Medicaid program. As part of that program, Heather was assigned to a specific clinic (geographically based) and a specific doctor. While Karen and Don were reluctant to leave the care of the primary doctor who had cared for Heather for 5 years, they felt they had no option but to go the Medi-Cal clinic. From the outset, they experienced problems. Their first appointment to get a flu vaccine took more than 2 weeks to schedule. A subsequent visit to the clinic added to their frustration. The doctor was clearly afraid to touch Heather. She was not experienced with kids as medically complex as Heather and seemed to be confounded as to what to do. She ordered a blood test and Karen and Don were expecting it would be like Children's Hospital where parents can stay with their child for the lab. At the clinic they walked into a crowded hallway and a room not big enough for staff or patients. They had to sit in a straight-backed chair with little room to make Heather comfortable. However the most upsetting part of the visit was the test itself. The medical assistant didn't know how to do a heel stick. Because of Karen's nursing education she was able to show how it was done. As a result of this experience, Heather's parents decided they could not do this again. The people in the clinic were simply not trained to deal with a medically complex child, like Heather. Having to teach them how to do a heel stick was just not acceptable. Heather went back to being followed by her previous doctor, with Karen and Don paying out of pocket for those expenses. Heather's primary doctor "knew her, knew how to talk with us, knew what to do with her." They also began relying on the emergency room at Lucile

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Packard Children's Hospital in Stanford where her case was well documented and specialists were available. These emergency room visits were covered by Medi-Cal.

Today Heather weighs 18 lbs. She has hip dislocation, scoliosis, and difficulty keeping food down due to GERD. Karen explains that caring for her daughter has been a roller coaster ride. Recently, they exalted in her first normal milestone – adult teeth emerging – late at age 7. As Karen notes “the first indication of how much abnormality we'd seen to that point.” Over the last 6 years Karen has seen the system for identifying kids like Heather improve. And Karen herself has learned much that helps her advocate for her child's needs and the best ways to collaborate with all those involved in Heather's medical care. “We were first time parents, trusting that the providers were the experts. Today we know our kiddo. We have learned how to care for Heather's complex medical needs. We have taught others how to help Heather. Now we feel others are listening to us as parents. We also feel there is room for improvement in the ways providers, hospitals, and medical schools teach about caring for this population. However, there is a lack of doctors/residents who are willing to practice pediatric rehabilitation medicine, and understand how to properly care for CYSHCN.”

\* Names have been changed.

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### Family Story #2

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

*Challenges Faced by Families: Interview with a Parent - 10/22/2015\**

Susan's story about her daughter Pauline illustrates problems that many families of CYSHCN encounter in finding help for their child and support for themselves as they navigate a complex system of health care professionals and programs.

Pauline was born five weeks early and was just 5 ½ pounds at birth. By 2 months of age she was down to 4 pounds. As Susan remembers, the doctor diagnosed Pauline as 'failure to thrive' and seemed to think this was a result of a lack of good mothering skills. He told Susan he thought she might have a problem breast-feeding her daughter; that she appeared depressed and was an overbearing mother; and he recommended counseling. Susan was taken aback. She was not a first-time mother. She had a healthy 3-year old at home, but clearly she was upset about her daughter. She knew there was a problem and pushed the doctor for a diagnosis.

Genetic testing was done and news of those results was equally upsetting, not just because of the diagnosis, but the way it was communicated. The geneticist called Susan and matter-of-factly told her, via the phone, that Pauline had Prader Willi Syndrome. Susan asked for more information, asked about a follow-up appointment, and asked what the next steps were. The doctor simply indicated there was nothing else she could do for her except to suggest that she love her daughter, and find the best ways to cope as a family. She offered no referrals to other doctors or support services. Subsequent to this, Pauline also was diagnosed with autism.

Susan was able to get Pauline Early Intervention services through California's regional center system where she received speech and occupational therapy. This continued until age three when EI services ended. Susan pursued therapy services as part of Pauline's private health insurance coverage by Kaiser. But Kaiser denied therapy services indicating they were not medically necessary. Susan contacted CA's Department of Healthcare Services and fought Kaiser over this decision. She eventually had the decision overturned, but for two years she paid \$250 a week out-of-pocket for speech therapy. She had to forgo OT because she could not afford it.

When Pauline was five years old, Susan sensed that something was wrong. Pauline had a high threshold for pain and did not develop fevers when she was sick, yet she began to complain of a stomach ache. It took multiple visits to the doctor to convince the health care professionals that there was a serious problem. They eventually realized she had appendicitis and scheduled emergency surgery at Kaiser Oakland hospital. Susan had to demand that she accompany her in the ambulance to the hospital. Matters grew worse upon arrival at the hospital when they indicated that did not have a pediatric surgeon and anesthesiologist and no room in the ICU for post-surgery recovery. Staff said they needed to transfer Pauline to Oakland Children's Hospital. Again Susan needed to convince them that she had to stay with her daughter in the ambulance.

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After her hospital stay, Susan received a bill for \$45,000. Pauline's Medi-Cal insurance had been canceled and Susan found herself fighting another bureaucratic battle.

About this time, Susan finally got connected with other families and support services. She was referred to a clinic that studies patients with rare conditions. She was surprised that on the first visit, a clinic worker actually asked her how she was doing and what services her family needed and/or found helpful. Susan replied "someone should have said this five years ago."

Today, Pauline is nine years old and a happy third grader with many friends. Susan notes that it continues to be difficult when outside services are needed and she has, at times, continued to battle with her insurance company, particularly over seeking second opinions.

\* Names have been changed.