

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

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 a pediatrician leaders from Nevada’s Chapter. The physician was asked questions about access, coverage and payment issues they or their patients encounter and encouraged to share other successes or challenges they are facing. The interview highlights are documented below.

Pediatric Care Challenges	
Lack of Providers / Hospitals	<ul style="list-style-type: none"> • Not enough pediatric providers per capita to ensure children have pediatric care • Rural areas have very few pediatric providers • Not enough subspecialists – only one pediatric geneticist and one pediatric cardiology group in the state (requiring a 6 month wait for referrals) • Lack of providers and specialists for CYSHCN • No pediatric hospital in the state
Bright Futures	<ul style="list-style-type: none"> • Most insurance carriers pay for recommended BF services
Medicaid	<ul style="list-style-type: none"> • One Medicaid program throughout the state – easier to understand / deal with • Very low payment – so low many physicians do not sign up as providers
Population	<ul style="list-style-type: none"> • Very transient population • Many illegal immigrants without insurance

Pediatric Care Successes	
Bright Futures	<ul style="list-style-type: none"> • Some small self-funded plans (union plans) do not cover all BF services
Medicaid	<ul style="list-style-type: none"> • Re-enrollment is often a challenge and families fail to do it • Many illegal immigrants in the area and are afraid to enroll their children • Very low payment rates for physicians

Opportunities	
	<ul style="list-style-type: none"> • Improve the retention of providers: Nevada does not have a pediatric fellowship program so many residents leave the state • Better Medicaid payment by reinstating the Medicaid fee increase • Open a pediatric hospital (has been voted down by tax payers)

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

Access	<ul style="list-style-type: none"> • The wait time to get an appointment is too long (57%) • The recommended doctor or service is not available in my area (37%) • My provider does not accept / no longer accepts my insurance plan (23%)
Coverage	<ul style="list-style-type: none"> • A recommended service is not covered by my insurance plan (41%) • Recommended services were limited (41%) • A recommended doctor / provider is out-of-network (38%)
Payment	<ul style="list-style-type: none"> • Out of pocket (deductibles / co-pays) costs are too high (50%) • 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%) • Premiums are too high (34%)

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 daughter’s ABA is only covered by my insurance and not her Medicaid. With copays alone we are charged about 600 dollars a month. I thought that Medicaid was supposed to have figured this out by now as the law now says that they have to cover it!”*
 - *“My insurance does not cover ABA therapy for my son who is in the autism spectrum.”*
- **Lack of Specialists:** Many do not accept public plans, very long wait time for appoints, high co-pay, some not accepting new patients
 - *“A required procedure was not available in our area. We had to travel to Salt Lake City for the treatment.”*
- **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 have to wait a long time to get into any therapy programs and it costs us over \$100 per month for doctors who are necessary. I also need in home therapy equipment that I have to cover out of pocket and they all cost over \$100.”*

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- Coordination of Care: Little to no coordination of care for complex cases, benefits unclear
 - *"Billing from doctors was a MESS. Child is dual insured and they kept billing wrong then billed us. I spent a lot of time and still am talking between doctor offices and insurance getting it cleaned up."*
 - *"It is so complicated to bill insurance for out of network services needed by my child that I had to hire someone to do this for me. Yet, it still requires many hours of my time to follow up with everything to ensure his care is continued. At this point I have not received reimbursement from the insurance company for 4 months and will have to terminate the services for my child within the next 4 weeks if I do not receive reimbursement."*
- Cost: Unaffordable co-pays, do not qualify for assistance but cannot afford premiums and co-pays, high premiums (especially for private payers)
 - *"Covered services covered at a rate/copay too high to afford the care. Cannot go to provider as often as recommended/necessary for health problem, as too expensive to go more than once/twice a month. What is said to be covered by my insurance, is denied and billed towards deductible instead of as a copay, sticking me with bills after the fact that I have to make payments on. Large standing bills at doctors' offices that I have to make payments on."*

Conclusion:

Parents in Nevada 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.

FAMILY STORIES

Family Story #1

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

*Challenges Faced by Families: Interview with a Parent - 10/23/2015**

Beth's experiences in Nevada illustrate some of the problems families are facing in learning about autism and getting services needed by their child.

When her son, Mike, was about 10 months old, Beth expressed concerns about his development to his primary care physician. Although the doctor was unable to provide a diagnosis, he referred Beth to Early Intervention (EI) and Mike began receiving speech therapy and the services of a developmental specialist once a week. At age 2 ½ the EI staff told Beth that Mike probably had autism. Beth noted "this was devastating to us." Her limited knowledge of autism was based on the movie Rain Man.

Early intervention was very helpful but at age three Mike transitioned to the school system where he began receiving speech therapy in a group, a scenario that was less than optimal because of the severity of Mike's problems. Beth also tried putting Mike in daycare so that she could continue to work. But daycare staff called her everyday with concerns about his crying, biting, and lack of communication. Daycare was stopped after two weeks and Beth eventually had to stop working. At age 4, Mike began receiving Applied Behavior Analysis (ABA) therapy funded through the school district and Desert Regional Center. Beth credits ABA therapy with significant advances in Mike's development: talking, potty training, listening, social skills, and handling noise and crowded situations. "It has helped us be a family."

Beth struggled to learn more about her son's diagnosis and how to best help him. She attended every conference she could and connected with Family TIES (Nevada's Family-to-Family Health Information Center and Family Voices State Affiliate Organization) which Beth indicated was "amazing." Family TIES provided support, information, and helped her connect to other parents. Through those connections, Beth learned about the Autism Treatment Assistance Program (ATAP) and was able to enroll Mike about one year ago. This program has helped Mike very much by providing 15 hours of in-home assistance to help train tutors to work with him in Applied Behavior Analysis (ABA) therapy.

Mike is now 12 years old and although he has limited verbal abilities he is able to express his needs. Cognitively he is at 2nd grade level. Beth feels that Mike would benefit from physical therapy (PT), but there are no therapists in her area who work with children on the autism spectrum. She also feels he would benefit from occupational therapy (OT), but their private insurance denied this request and Medicaid will not cover it because of that denial.

Mike continues to make progress and clearly benefits from the ATAP program. However the state has announced that, as of January 2016, ATAP services will be transitioned to Medicaid. This implementation comes 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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with changes to the program: required provider certification; mandatory 40 hours of provider training; and a significant reduction in provider payment rates. Currently that rate is set at \$29/hour, much lower than the national average of \$50/hour. These changes have Beth very concerned. At the very least, the certification and training requirements will reduce the number of providers available to work with children like Mike and perhaps there may be none at all due to the extremely low reimbursement rate. Without the valuable services provided by this program, Beth fears that Mike will no longer make progress.

* Names have been changed.

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Family Story #2

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

*Challenges Faced by Families: Interview with a Parent - 10/26/2015**

In the story below, Kate shares her struggles trying to find a diagnosis and treatment for her daughter.

When Brittany was a young girl, her mom, Kate, discussed concerns about her development with the primary care physician. The doctor, however, did not detect any issues, noting that Kate had so far met all her developmental milestones. However, Brittany's problems began to take on added significance when she started school. Her Kindergarten teacher noticed that Brittany had difficulty paying attention and that her hearing and vision seemed to be "off." Additionally, her gait was strained, her speech was difficult to understand, and she had a great deal of trouble in social situations and seemed to prefer being alone.

Kate eventually took Brittany to another doctor who diagnosed her with Attention Deficit Disorder (ADD). Brittany began to have meltdowns and demonstrate a lot of anxiety. The ADD diagnosis did not seem to fit and Kate took her daughter to several doctors searching for answers. Brittany was seen by a number of psychiatrists regarding her anxiety. Although these doctors were interested in treating the anxiety, none seemed to be able to identify the underlying cause. Kate also took Brittany to be evaluated by a neurologist, as she was concerned about her lack of coordination. The neurologist diagnosed Brittany with autism.

Brittany's primary care doctor recommended that she receive occupational therapy (OT) but Brittany's private insurance company said it wasn't necessary. After several discussions, the insurance company agreed to pay 20% of the cost with Kate paying for 80% out-of-pocket. After only 3 months, the OT therapist noted "you are up to where you can work on it at home because we are over-booked." In the short time with the OT therapist, Brittany's walking had substantively improved along with her confidence. Facing OT bills of \$200 per month, Kate decided to try to provide Brittany with OT exercises herself and has purchased OT equipment to do this.

Kate sought out support and resources from Family TIES of Nevada (Nevada's Family-to-Family Health Information Center and Family Voices State Affiliate Organization) and Rave (Respite and Volunteer Experiences) Family Foundation. RAVE currently provides respite services and has helped Brittany with her social skills. Kate also works with a mentor at Family TIES who has provided invaluable information about autism and potential programs that may help Brittany.

Because of bullying issues at school, Brittany is now home-schooled. Kate participates in a home school group with other parents and this has provided a social network for Brittany.

Looking back on her experiences, Kate wishes her daughter's doctor had been more knowledgeable. "We had a diagnosis but we didn't know where to go." Brittany is now doing pretty well, and her mom credits her psychiatrist with helping Brittany with the anxiety and self-confidence. The psychiatrist provides Applied

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Behavior Analysis (ABA) therapy every other week. According to Kate “This therapy helps a lot. It was like Brittany used to walking on an alien planet but it is not so alien anymore!”

* Names have been changed.