

STATEWIDE FAMILY FORUMS 2014-2016

July 2016

Prepared by



On behalf of

 **FIRST THINGS FIRST**

Table of Contents

page

3

Statement of Need

page

5

Methodology

page

13

Family Forum Locations

page

14

Demographics

page

18

Issues by Category

page

31

Regional Issues

page

53

*Parents’
Recommendations*

page

57

*Raising Special Kids’
Recommendations*

page

63

Conclusion

Statement of Need

ECCS Grant

Purpose

There is a need to recruit and engage with families of children who might have a developmental, sensory or behavioral delays but are not eligible for the Arizona Early Intervention Program (AzEIP) as part of the Health Research Service Administration (HRSA) Early Childhood Comprehensive System (ECCS) grant.

Raising Special Kids is a statewide non-profit organization with a mission of strengthening families and improving outcomes for children at risk of developmental delays. Raising Special Kids serves as the AzEIP Central Registry for referrals to early intervention and has unique opportunities to identify children and families who would not be eligible or willing to participate in AzEIP services. Raising Special Kids was selected to conduct the First Things First Family Forums.

The purpose of conducting the family forums was to gain a better understanding of the family experience in navigating services for children with developmental concerns or delays, and to gather data and information on the current system of services during the three-year grant period.

Raising Special Kids

Families Helping Families

Raising Special Kids strengthens families to become effective advocates for children with special health care needs and helps systems of care become more responsive to those needs.

In 2015 Raising Special Kids served 9,057 families

40% of families had children ages birth to 5

These figures do not include over 18,000 referrals each year to Raising Special Kids through the AzEIP Central Referral and registry

Raising Special Kids helps families with:

- Parent Mentoring & Coaching
- Individual Consultations
- Reaching Underserved Parents
- Special Education
- System-Level Advocacy
- Training and Education
- Early Intervention Referral
- Youth Transition
- Healthcare Information
- Leadership Development

Methodology

Question Development

Recruitment

Family Forum Questions

*Supports to Increase
Family Attendance*

Process

Facilitation

*Identification of
Participants*

Locations

Methodology

Question Development

First Things First worked with a consultant team from Advocacy and Communication Solutions, LLC to develop a draft set of questions for the Family Forums.

A Conference call was held with FTF grantee staff, the consulting team, Raising Special Kids and AzEIP to further develop the questions. Advocacy and Communications Solutions, LLC sent a draft of the edited questions to Raising Special Kids and AzEIP who offered further suggestions.

Instead of asking if families had a medical home, families were asked if they had a primary care physician and if they were able to see the same physician each time they took their child to the doctor

Methodology

Family Forum

Questions

Here is the original set of questions. Some questions evolved as more forums were held. The Raising Special Kids facilitator used personal experiences and additional questions to encourage responses from families.

1. What brought you here today? What made you curious when you heard this session was geared to parents sharing experiences of their very young children?
2. Where do you get information about your child's development? Pediatrician/Home visitor/Childcare provider?
3. If your child has received developmental screenings, what was your experience with the referral process and getting access to services?
4. What types of resources or supports do families like yours need so your kids grow up healthy? What kind of information do you need before you leave today?
5. Do you have a pediatrician that you see on regular basis?
6. Do you visit the same doctor on a regular basis and/or do you use urgent care? For those of you using urgent care or not seeing the same pediatrician, what would make it easier?
7. When you have a concern about your child's development, what do you do? Who do you call?
8. Do you keep notes or records about your child's development and medical issues?
9. What concerns do you have about your child's development? Speech, nutrition, hearing, vision?
10. How do you know that your child is developing well and is healthy?
11. Is access to transportation a barrier for getting your child medical care or food?
12. What would you put on your wish list? What resources would you like to have available to help your child?

Methodology

Process

The purpose of the Forums was to gather input from families of children with developmental concerns and delays in order to provide improved support.

In planning each Family Forum, Raising Special Kids along with the FTF ECCS grantee staff communicated with the FTF Regional Directors and staff as well as other regional community resource staff about the registration process, participant qualifications, and goals so that they could support the recruitment process.

Raising Special Kids identified additional community partners by attending regional outreach events.

The purpose of the Forums was to gather input from participants who were recruited through community providers who identified and registered families so that they could attend the forums to share their experiences.

Raising Special Kids followed up with the families who were recruited in advance of the forums to confirm registration and attendance. If families needed more information, Raising Special Kids discussed options and services and offered assistance.

Locations were chosen to have representative populations. Some forums were located in more densely populated areas and others in areas where families could travel from surrounding areas that were less populated to gather for the Forums. Some families drove for several hours in order to attend the Family Forum closest to their homes.

There was no recording of the Family Forums as this was not a formal research study with IRB approval.

Methodology

Identification of Participants

The original methodology was to identify parents who were screened for the Arizona Early Intervention Program (AzEIP) and found not eligible for services, as well as to identify the supports these families needed.

Difficult to Identify

During the process of recruiting families to participate in the Forums, however, Raising Special Kids and First Things First discovered that parents who did not qualify for AzEIP were difficult to identify and recruit for the forums. Most parents attending forums had children who had been evaluated by AzEIP and were found not eligible. Many of them later became eligible.

A substantial number of families attending forums were having difficulties getting anyone to take their concerns seriously. Sometimes it was years before they could get a referral to a specialist to get a diagnosis for developmental delays or for other medical issues.

Flyers were developed to advertise the Forum, but publicity about the forum was not enough to gather parents.. It required a trusted contact in the community to extend invitations and encourage attendance.

"Sometimes it was years before they could get a referral to a specialist, a diagnosis for developmental delays or other medical issues."

Methodology

Recruitment

Raising Special Kids partnered with other agencies to identify families who were found not eligible for AzEIP, were not receiving services and/or who were having problems with the systems in their communities

The following community partners helped to recruit families:

- First Things First Regional Directors, regional programs and outreach staff
- Head Start Agencies
- Family Resource Centers
- WACOG
- MIKid
- Gila River Indian Community Early Childhood Special Services
- Resource Center outreach
- AzEIP
- Speech, OT and PT Therapist
- Kith and Kin
- Healthy Families
- St Jude's Foodbank
- Parenting AZ
- Teachers and their local school districts
- Project ABLE (part of Tucson Unified School District)
- Regional Community Resource Organizations

"Parents have been asked before what they needed and nothing changed. I want to know if the families I recruit for the forums are going to get more help."
Professional in Yuma

Methodology

Supports to Increase Family Attendance

The following supports were provided to families at the Family Forums

- Childcare was identified as a key need in order for families to be able to participate in the forums
- Bright Futures Pocket Guides published by Family Voices and the American Academy of Pediatrics and children's books were provided in Spanish and English to the families who attended
- \$50 gift cards were given to each family (not each individual) and light meals were provided.

Methodology

Facilitation

Raising Special Kids facilitated 10 Family Forums

Raising Special Kids staff who facilitated Family Forums provided their own personal parent perspectives of having a child with developmental concerns. This helped to connect to the families and make them comfortable in sharing their experiences about their children.

Where there were Spanish speaking families, Raising Special Kids provided bilingual staff to provide Spanish interpretation.

Questions were asked in a way that helped families understand what was being asked and to elicit the families' own experiences.

- 3 Forums included Spanish interpretation
- 1 Forum was facilitated entirely in Spanish
- 1 Forum facilitation began with an introduction in the Navajo language
- 5 Forums were facilitated entirely in English

Family Forum Locations

Family Forums were held throughout Arizona in rural, rural/migrant, tribal, urban, and urban/rural locations

South Phoenix: Maricopa County - urban (May 2014)

Yuma: Yuma County - rural/migrant Spanish (March 14, 2015)

Yuma: Yuma County - rural/migrant English (March 14, 2015)

Avondale: Maricopa County - urban (June 9, 2015)

Casa Grande: Pinal County - rural (June 24, 2015)

Tuba City: Coconino County - tribal (October 7, 2015)

Sacaton: Pinal County - tribal (November 16, 2015)

Lake Havasu: Mohave County - rural (March 1, 2016)

Show Low: Navajo County - rural (May 24, 2016)

Tucson: Pima County - urban/rural (June 7, 2016)



Demographics

Ethnicity

Children's Ages

Children's Diagnosis

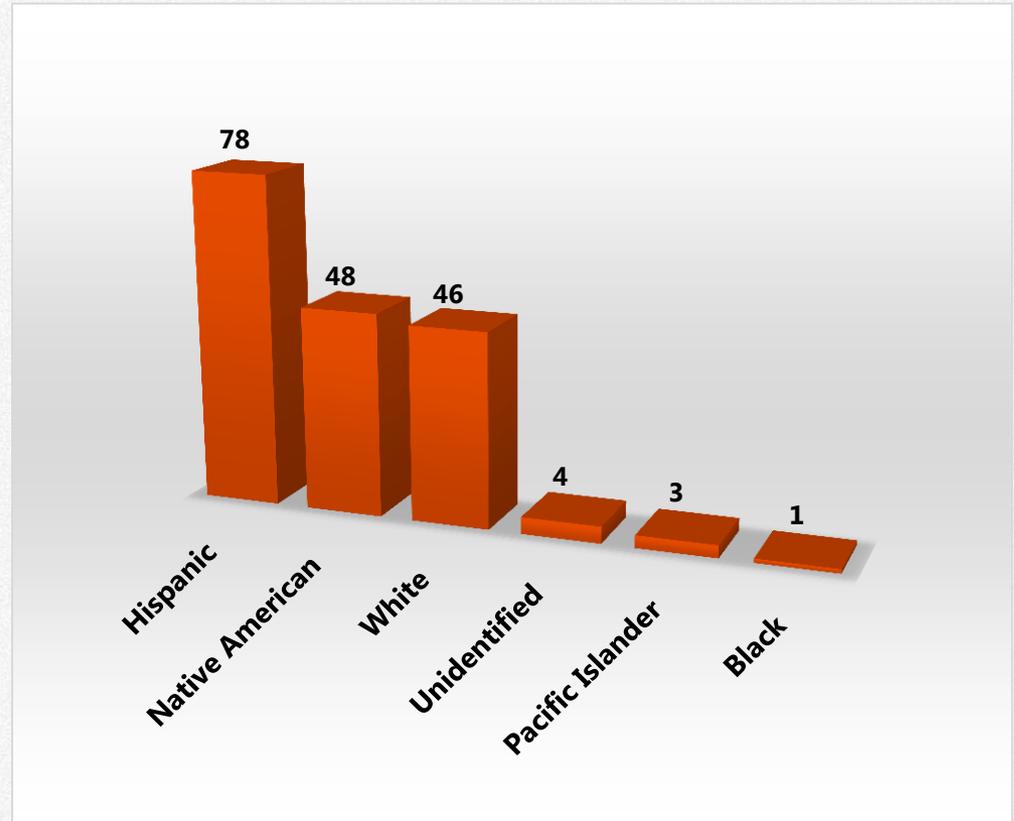
Demographics

Ethnicity/Race of Family Participants

The chart shows the ethnicity/race of the parents who attended the forums.

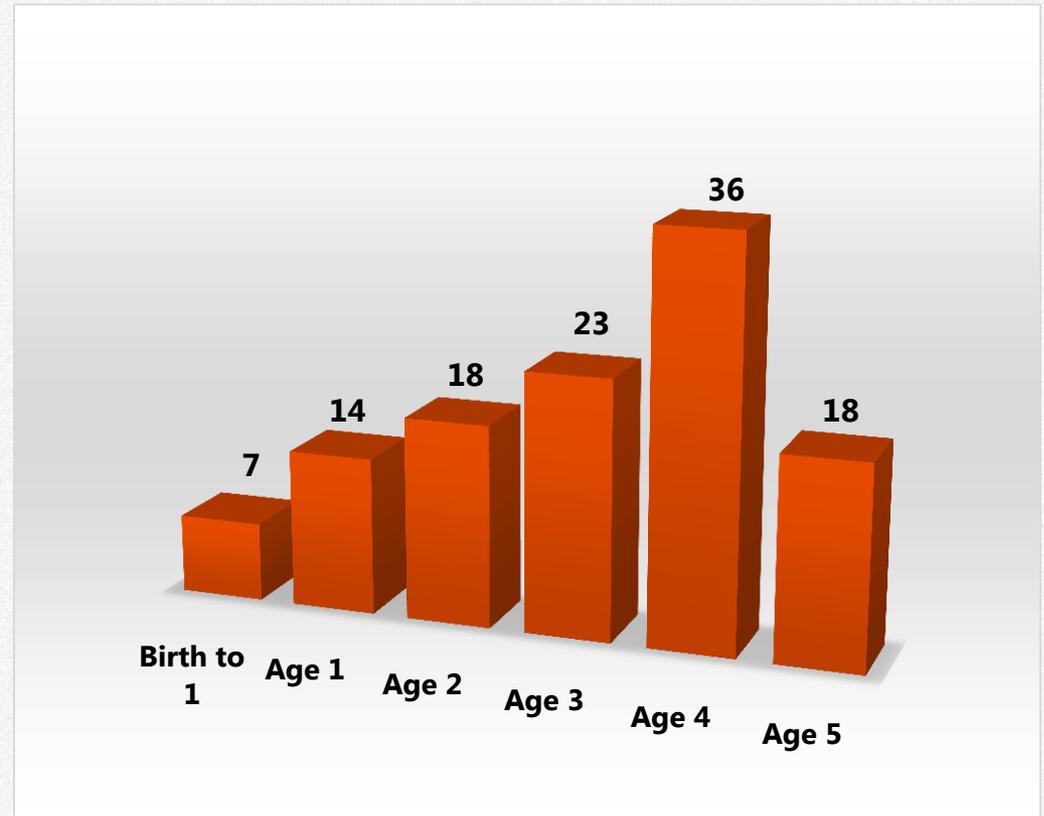
Forum locations had a high density of families who are Hispanic/Latino and Native American. The chosen locations helped ensure input from underserved populations.

The high number of families who were Hispanic and Native American were higher proportionally than the percentage of Hispanic and Native Americans in Arizona.



Demographics

Children's Ages



This chart shows the ages of children with developmental concerns or delays whose parents attended the Forums

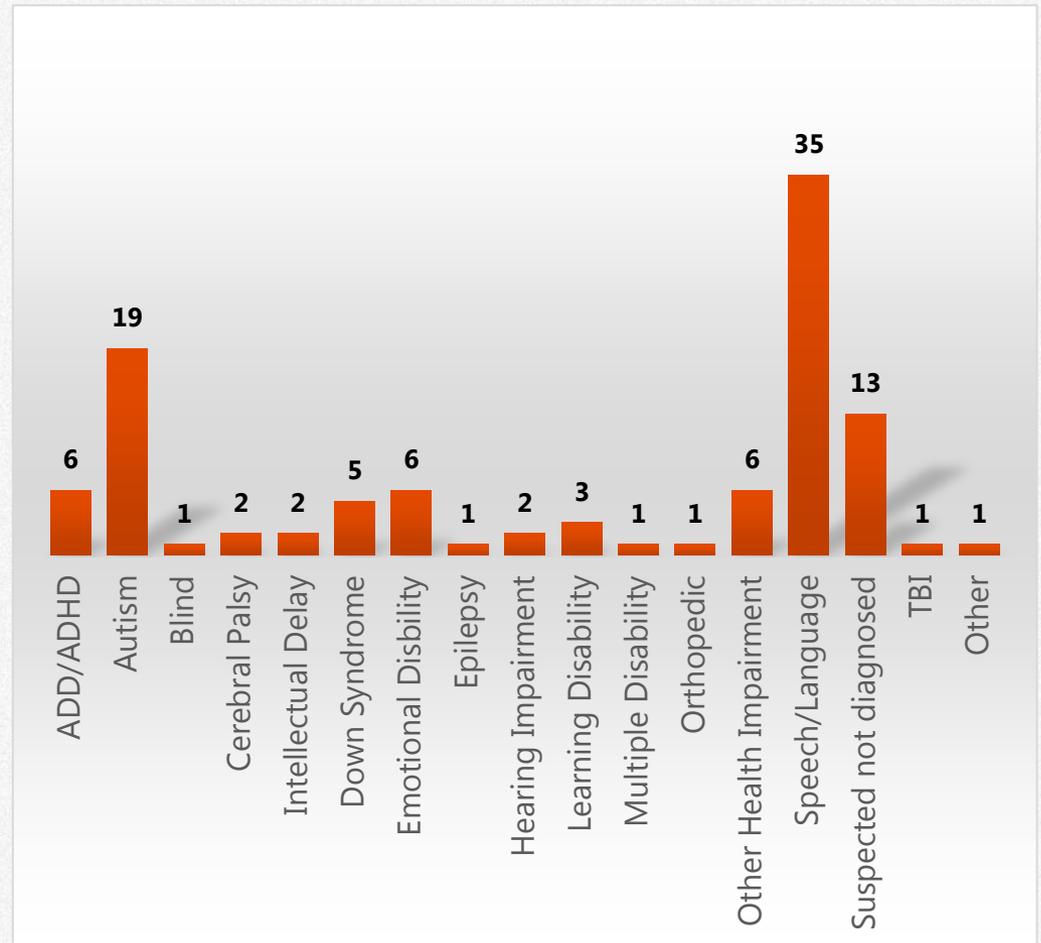
Demographics

Children's diagnosis

This chart shows the incidence of disability in children of parents who attended Forums

Some parents were still seeking a diagnosis

Parents said they heard other parents talking about their children at the Family Forum, and had not realized until then the problems or concern they had about their child



Issues by Category

Medical Home

- Primary Care Physician
- Concerns Not Heard
- Care Coordination
- Referrals
- Spanish interpretation and Translation
- Resources

Health Literacy

Social Determinants of Health

Transportation

Lack of Providers

School Issues

Emotional Support

Behaviors

Medical Home Primary Care

Some families in Yuma reported that they went to Mexico when their children were ill

Families in most regions reported not using primary care for sick visits because it takes too long to get in; sometimes up to 2 weeks

105 families who were looking for a physician were helped by Raising Special Kids in 2015.

Most families said that they have a primary care physician for their child's well visits.

Most families said that they see a pediatrician on a regular basis for primary care. A parent in Tucson said that their child's primary care physician works in an office with other physicians and they have to see a different physician each time who is not familiar with their child's needs.

Families in most areas complained that it is difficult to get an appointment when their child is ill. Many parents said they took their children to Urgent Care or the ER, which perpetuates lack of care coordination and monitoring health conditions that require further testing or treatment.

One parent reported that when she took her child to the ER that the ER sent her child's ER records to her primary care physician who followed up and provided additional care for her child. Some of the Spanish speaking families in Yuma report that they go to Mexico for their child's medical care when they are ill.

Most regions had at least one parent who said their child received good care from their child's pediatrician. Several parents in Phoenix said that they changed physicians and reported their children now receive good care.

Medical Home Concerns Not Heard

"It is great when you finally see a specialist and you finally find out that you were right all along." Parent from Show Low

"We knew from 18 months old that our son was different. People kept telling us. 'No, you're wrong, he's fine.' I would love for people to not have to go through what we went through." Parent from Show Low

"I have a son with a severe speech delay. His pediatrician said that he would catch up – I can't understand a word he says." Parent from Lake Havasu

Parents expressed frustration that their child's physician did not listen to them and take their concerns seriously

Numerous parents said that they felt they were:

- Unheard
- Not taken seriously
- Blamed for their children's problems
- Disregarded by the medical system and other providers
- Threatened to be turned over to DCS

Medical Home Care Coordination

Families expressed a desire for better care coordination.

Parents spoke of being overwhelmed trying to coordinate all of their children's medical appointments.

Parents said it would be helpful for pediatricians to have more knowledge and access to resources to give to parents.

One parent stated that she would like to have one service coordinator for all agencies versus a different person at each agency.

Other parents expressed frustration at the turnover of their child's support coordinators.

- One parent stated, "We are on our 7th Support Coordinator in just 3 years. Consistency would be better. It would help if support coordinators were matched based on the families' needs. I have 2 kids with autism with lots of different therapies. Now things are messed up, it is not going well anymore."

"We need better care coordination and communication between providers. I want to be a mom and not the person who has to coordinate my child's care."

Parent from Show Low

Medical Home Referrals

Many families said that they were unable to get referrals to specialists from their primary care physicians.

- Parent from Yuma said that when they finally received a referral to a specialist it had taken a long time for the primary care office staff to process the referral.
- Another parent from Yuma said that her child failed their hearing test at school and it was still difficult to get a referral from her child's physician for an official diagnosis, which complicated her child's ability to get an IEP
- Families said that once they received the referrals it took a long time until they could get an appointment.
- A parent complained, "The wait time for the specialist was months to over a year long."

"One of the blocks for referrals is getting the referral to begin with. But also, how do we get providers to listen to parents who are intuitively connected to their child and no one is listening to them?"

Professional from Show Low

Medical Home Spanish Interpretation and translated material

995 parents whose primary language was not English were helped by Raising Special Kids in 2015

Raising Special Kids has 9 staff members who speak Spanish and 1 staff member who speaks Navajo

657 families from tribal communities received family support services.

Inaccurate interpretation can result in significant health/disability issues going undetected or can result in an error in diagnosis. The lack of receiving translated materials affects the ability of some families to understand systems and to advocate for their child.

Spanish speaking parents have difficulty communicating their concerns to their children's pediatrician because of language barriers which are further complicated by inaccurate interpreting.

Families who speak languages other than English have added complications because of their children learning two languages. Being a dual language learner is sometimes used by providers as an excuse for not identifying a developmental or health issue that goes undetected. It is important that professionals can accurately communicate with and understand the parents' concerns to determine the underlying cause of their concern.

- A parent in Yuma shared that the interpreter at their child's doctor's office was not doing a good job interpreting word for word what the doctor was saying. The parent said that she had a good understanding of what was being said, but had trouble speaking English. The parent said that she told the interpreter that the information was not being interpreted correctly.
- A bilingual parent in Tucson said, "We need more information in Spanish. It's hard to find Spanish language information."

Health Literacy

Health Literacy is the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions. Approximately one-half of the adult population may lack the needed literacy skills to use the U.S. healthcare system. Low literacy has been linked to poor health outcomes such as higher rates of hospitalization and less frequent use of preventive services.

Reference: Institute of Medicine. 2004. Health Literacy: A Prescription to End Confusion. Washington, DC: The National Academies Press.

<https://www.cdc.gov/nceh/lead/tools/leadliteracy.htm>

Parents with low health literacy in general have the most difficulty obtaining the help that their child needs.

Parents with low health literacy in general often:

- Do not know how to access credible sources for developmental information
- Did not realize their child had developmental delays until after a professional identifies and diagnoses their child.
- Have trouble explaining their medical and developmental concerns in a way that medical providers can understand and take seriously enough to refer their child for evaluation or services.

A Spanish speaking parent of preschooler who also has a junior high age son said that her son has total hearing loss in one ear. This parent reported that her son only received help with his hearing loss through receiving a hearing assistance device at school that the school is no longer providing. The parent also said that her son has not received help for his significant orthopedic issues with his feet and legs. The parent was unaware that her son might qualify for services through DDD/ALTCS, CRS, and SSI or that that she could request a 504 plan for her child at school. If her son would have received services earlier he may have been able to obtain hearing assistance devices he could have used at school, home and in his community. , A 504 plan may have helped him to be more successful at school , and with DDD and CRS services, medical care, and durable medical equipment, the child may have seen improvement in his orthopedic issues.

Transportation

A parent who uses the public bus system arrives in Phoenix hours before her child's appointment. Parent from Lake Havasu

AHCCCS transportation can only have one parent and the patient. "...not siblings, not even a newborn who is nursing can be transported. As a stay at home mom with 3 kids I can't do it." Parent from Show Low

43 parents were helped with transportation issues by Raising Special Kids in 2015

Parents in rural regions experienced significant transportation barriers.

Parents who live in areas outside of Phoenix or Tucson expressed that there are insufficient providers in the rural and outlying areas. These parents who travel to their children's health and service providers struggle with cost and availability of transportation.

In some cases, transportation for the families for their children's appointments is available. However, the system is plagued with challenges:

- They are picked up late resulting in late arrival to their appointments, and providers require them to reschedule.
- Transportation does not show up even though the parent had scheduled and confirmed their transportation reservation date and time.
- AHCCCS' transportation only allows one parent and one child to be transported and parents have no one to care for their other children at home.
- In Sacaton the tribe provides transportation to Indian Health Services only and AHCCCS provides transportation to medical and behavioral health care. There is no transportation during weekends or evenings.
- Tuba City has no public transportation. AHCCCS transportation is only available for medical appointments and parents report that it is often unreliable.
- In Lake Havasu public transportation is available, but parents struggle with cost and other issues:
- In the Kingman area, parents were being instructed to take the midnight Greyhound bus. One parent said, "My child has an auto-immune disease and couldn't be put on a Greyhound because of possible exposure to illnesses, so they sent out a taxi."
- Parents can bring other children with them on the Greyhound but one parent reported it was causing problems because all 3 of her children were missing too much school.
- Private health insurance does not provide transportation.

Lack of Providers

Families in rural and tribal regions expressed their frustration with the lack of providers in their areas. This included therapists, developmental physicians, and primary care physicians who understand disabilities and special health care needs.

A mother in Yuma reported that her child now qualifies for services and she has been waiting to hear back from providers to deliver speech therapy, habilitation and respite for her child.

A parent in Casa Grande said that she had been driving to Maricopa and that the facility is now closed and has changed to all home-based therapies. The parent is worried that her child will regress while on the 6 month waiting list.

In Avondale, one parent stated because of AzEIP's heavy caseload there were no available therapists. As a result, the parent said that they left AzEIP and are now paying out of pocket through their private insurance.

One parent in Sacaton reported that there is a very long Head Start waiting list for children under 3.

A parent in Lake Havasu reported that she had been waiting for 2 years to get her son therapy. The parent said that there are 96 children on the waiting list for speech therapy and that does not include home-based therapies.

In Tucson, one parent said that her child was in the DDD system, but was not receiving services and felt they were not getting support, so withdrew from services. Another parent in AzEIP said they were supposed to receive therapy every week and never saw a therapist. They did see a DSI but said it wasn't enough.

Parent from Tucson reported the wait list for an appointment with a Developmental Pediatrician is 19 months.

Parent stated that her child was on a waiting list for 1 year to get "newborn services" in Sacaton.

70 families who have children birth to 5 who had issues with therapies were assisted by Raising Special Kids in 2015.

School Issues

Parents in most regions reported school concerns. Many parents were satisfied with school services. Some parents reported that they did not know their child had a disability until they started school.

Several parents in Northern Arizona had school transportation concerns:

- One parent said that they wished their child's school was closer to their home.
- Another parent said that her child was evaluated and found not eligible but then the parent said that she found out that they were testing her child at a higher age level.
- A mom expressed frustration that her child's school was not able to transport her child across school district lines for her after school program.

One parent complained that in Tucson children in Special Education could not get a variance to a school outside of their home district. The parent complained, "Children who are in self-contained classrooms are exempt from open enrollment. You should be able to get open enrollment, and not have to depend on private schools or hope for scholarships. Open enrollment is absolutely not an option."

A Spanish speaking parent of a 5 year old said that she needed help getting an evaluation for ADHD and behaviors so her child could qualify for supports from school.

One English speaking parent from Show Low said, "I would really like our local public school district to have a better understanding of ADHD, twice exceptional and the co-existing anxiety disorders and social struggles that get labeled as behavior problems."

153 parents of children birth to 5 were assisted with school issues by Raising Special Kids in 2015.

Emotional Support Parent to Parent Mentoring

Raising Special Kids connected 161 parents of children ages birth to 5 to another parent with a child who has a similar diagnosis for ongoing emotional support in 2015.

Raising Special Kids uses the Parent to Parent USA (P2PUSA) Evidence-Based Best Practice for parent mentoring.

<http://www.p2pusa.org/p2pusa/SitePages/p2p-home.aspx>

Many parents said that they felt isolated and alone and came to the Family Forums to talk with other parents. Below are some of their comments about how parent-to-parent support matters.

- Several parents expressed that because of their child's social issues they felt isolated and embarrassed.
- A mother said, "I want to find out more information and to find out what the Forum is about. I want to listen to different stories about what everyone is going through."
- A parent in a rural area said, "Hearing stories from other parents helps to get you through."
- "I wanted to come today to meet other parents that are sharing similar concerns and struggles, to hear what other parents are doing, and to learn about additional resources."
- "I came to the forum for resources and connections to other parents."
- "I feel I'm alone and I don't understand anything. I really need to come for help. It's good to hear from other people."
- "Other parents are really helpful with different approaches to behavior concerns; telling me what they tried, and who they spoke to."
- "Other parents are a great sounding board."
- "There are lots of people, but you feel alone. It would be nice to connect with somebody who knows what you are going through."

Behavior Issues

*2015
562 parents of children under five
received training, information, or
individual consultations from Raising
Special Kids to help with their children's
behavior issues*

Families in most regions reported they were struggling with their children's behaviors

- Several English speaking parents in Yuma said that they did not know where to get support for extreme behaviors.
- One parent in Casa Grande said that she thinks her son has a behavior problem, but her therapist says he's "just going through stuff." The parent said she wants to know what her steps would be to move forward to getting her child tested.
- Three parents in South Phoenix said they are looking for help with their children's behaviors.
- A parent from Coolidge said that her son has developed behavioral issues because of his speech problems and she has no idea where to go for help.
- A mother in Sacaton said that she was told that her son had behavior problems. The parent said that she had justified it by saying, "He doesn't listen, it's just a behavior problem like all kids have." The mother said that she now knows he needs help.
- A parent in Lake Havasu said that her son has temper and behavioral issues.
- Two parents in Show Low spoke of how their children were labeled as discipline problems by their behaviors in school.
- A parent with 8 children in Sacaton said, "I thought their behavior meant they were bad/naughty. When my other children were 3 they didn't talk and had behavior issues/tantrums. I didn't know something was wrong."
- A single father in Avondale has taken one of his five children to 29 different providers and daycare centers and no one will keep his child at their center because of his challenging behaviors.

What Raising Special Kids Can Do

Individual assistance over the phone

One-on-one in-person consultations

Training in self-advocacy

Information & Referrals

Intensive Services:

- *Parent Mentoring*
 - *Behavior Coaching*
 - *Meeting Attendance*
 - *Help with school issues*
 - *NICU Support*
-

Raising Special Kids serves families of children with the full range of disabilities and special health care needs from birth to 26. Services are provided at no charge, in Spanish and other languages.

Programs and Services for Families

- Accurate, authoritative information to help parents make informed decisions about their child's needs, services, and care
- Individual problem-solving support to understand and access the programs, health plans, and services a parent's child may need.
- Special education consultations, training, and problem-resolution services
- Parent coaching and mentoring programs
- Workshops and training to increase advocacy skills, health literacy and improve ability to work with professionals.
- Referrals to agencies, organizations, and community resources with expertise to meet families' needs.

Programs and Services for Professionals

- Programs for physicians, educators, and social service professionals offer training and information about the family perspective on disability.

Regional Issues

South Phoenix

Tuba City

Yuma Spanish

Sacaton

Yuma English

Lake Havasu

Avondale

Show Low

Casa Grande

Tucson

Family Forum

Regional Issues

The Family Forums had numerous similarities across regions; however, there were unique issues by region.

While Raising Special Kids heard similarities in parent concerns and challenges across the regions, there were some themes that emerged from each of the regions that seemed particular to that area. The following pages provide details on some of the region-specific concerns that emerged from the Family Forums discussions.

Each Family Forum page focused on the biggest issues that families had in their regions, and illustrated where the families were struggling the most.

Issues by Region

South Phoenix

The South Phoenix Forum was held at the Roosevelt Family Resource Center. 80% of the families were Spanish-speaking.

Families reported that their biggest issue was that physicians dismissed their concerns, or attributed their concerns to their children learning two languages. One parent reported that a lack of timely medical care resulted in a permanent disability for her child, and that some issues were not identified in a timely matter which resulted in delays of treatment and services for her child.

Most of these families had a medical home but some used the ER or urgent care because of lack of availability of same-day appointments for children who are ill.

While most families stated that they sought developmental information from their child's pediatrician, many indicated that they asked their family members for developmental information.

Several parents said that they had concerns about their child's behavior.

Some of the parents said that their children had received a diagnosis but did not qualify for services. Parents said they do not know where to get supports for their children who do not qualify.

Many of the families who also had children older than five said that they were having problems with school or educational services. Some parents indicated that their older children had never received needed services.

*Urban
Maricopa County*

35 parents attended

*Race/Ethnicity:
Hispanic 28
Caucasian 7*

Examples

South Phoenix

The physician dismissed her concerns saying it was just the food her child was eating.

Parent reported that her physician said her daughter's behavior was because she was learning two languages."

Physician dismissed parent's concerns by saying, "It is normal for children not to listen to their parents."

Physician not taking concern seriously

One English speaking parent whose child is on AHCCCS said that she told her child's primary care physician that she thought her child had something wrong with his ears. The physician dismissed her concerns saying it was just the food her child was eating. The parent reported that her son ended up with a serious infection which has resulted in problems with "listening and speaking."

Does not qualify for services

Spanish speaking parent said that her 5 year old has hearing impairments and autism and that she qualified for DDD only, not for ALTCS which means her child does not qualify for therapy or services.

Parent helped by Head Start

Another Spanish speaking parent stated that she had told her physician that her 18 month old daughter had lost her hearing. This parent reported that her physician said her daughter's behavior was because she was learning two languages. The social worker at her other child's Head Start agency helped her obtain hearing testing. The test determined that her child's right ear had no hearing and the left ear could hear a little. The child was later diagnosed with autism and has received surgery on her ears.

Physician dismissed concerns

Spanish speaking parent of 2 year old said that she had concerns with her child not responding when her name is called or when she is talked to. The parent said that she explained her concerns to her child's pediatrician and her pediatrician dismissed her concerns by telling her that it was normal for children not to listen to their parents.

Issues by Region

Yuma

Spanish Speaking Families

Yuma is a migrant community where families have difficulties attending activities. A professional in Yuma said, "When the farmers tell them they have to go to work they go, and as a result they miss events."

Parents in Yuma who speak Spanish were less aware of services and how to apply for them compared to the parents in Yuma who speak English.

Most parents in Yuma indicated that they received information about their child's development from their child's pediatrician or Head Start agency.

One parent in Yuma said that her child had qualified for AzEIP when there was cost sharing and she could not afford it. Now her child is 4 and no longer qualifies. Her child has since qualified for services through DDD ALTCS. The family's other child, a 2 year old, is getting AzEIP services.

Many parents complained there are no developmental specialists in Yuma and they have to go to Phoenix or Tucson for evaluations.

Parents struggle with transportation and the expense of going outside of Yuma.

Parents said that having physicians who speak Spanish and having better interpreters at their doctor's office would help their child receive better care.

*Rural/Migrant
Yuma County*

9 parents attended

*All parents were
Hispanic*

Examples

Yuma

Spanish Speaking Families

Parents said they came to the forums because they had concerns for their children and wanted to hear other families' experiences.

90% of parents had a regular pediatrician for well care, but went to Urgent Care or ER when children were ill. Three parents said that they go to Mexico when their children are ill.

One parent was concerned that the ER did not have a pediatrician and as a result feels her child does not receive appropriate care.

Spanish Interpretation

A parent shared that the interpreter at her child's doctor's office was not doing a good job in translating word for word what the doctor was saying. The parent said that she had a good understanding of what was being said, but she had trouble speaking English. As a result, the parent told the translator that the information was not being interpreted correctly.

Inadequate diagnosis

One parent indicated that the diagnosis given by a developmental specialist did not address all suspected areas of her child's disability. A second opinion was obtained. The child received a more complete diagnosis and is now receiving services. This parent said that too much valuable time was wasted that could have been used to provide timely therapies for her child.

Schools slow to provide services

Mom of a 4 and 10 year old shared that there was a significant delay from when the school district started the screening to when they actually provided services.

Parents took children to Mexico when children were ill

Three parents said they take their children to Mexico when they are ill. The parents said that they have confidence in the physicians in Mexico because there is no wait time for appointments, their child can see the same doctor each time, the physicians spend time listening to the parent's concerns, and they follow through with parents after the visit.

Issues by Region

Yuma

English Speaking Families

Parents reported the inability to get appropriate referrals when issues went outside of the scope of the regular clinic or doctor.

Parents shared that when they finally received a referral from their physician it took the office staff a long time to send it and once they were referred, it was difficult to get an appointment. Parents also reported that there is one ENT in Yuma and there is a 3-4 month wait for an appointment.

Parents have primary care for well visits only and it is difficult to get an appointment when their child is ill with a wait time of 3 days, at best. Parents stated that they take their children to urgent care if they have fever, flu, or need to get a same day appointment. A few parents felt the ER was their only option. As a result, issues like chronic ear infections were not being tracked and proper treatment and follow up care was lacking.

Families stated that the doctors at the clinics seem too busy to listen or talk with them about their concerns and rush them through appointments.

Parents reported that they were getting more care coordination/support from community agencies than their physician's office.

Some parents indicated that they need help with basic parenting skills and healthy nutrition.

While some parents reported they were happy with school services, others were not.

Some parents in this forum stated that they did not know why a child would need a developmental pediatrician.

Rural/Migrant

12 parents attended

Race/Ethnicity

Hispanic 10

Native American 1

African American 1

Examples

Yuma

English Speaking Families

Two parents said they needed help with understanding the nutritional needs of their child

Some families felt isolated and embarrassed because of their child's lack of social skills

A parent reported that her child has behavioral issues at home but the teachers at school don't see it. As a result their child has not received screening or an evaluation.

Difficulty getting referral

One mother took her child to her pediatrician because her child had significant sleep problems. The mother reported that the lack of sleep led to increased challenging behaviors. The mother said that the primary care physician's suggestions on how to get their child to sleep were not useful. The mother kept insisting her child needed a referral to an ENT for breathing issues. After receiving a referral to an ENT and after her child's tonsils were removed, the mother reported that the sleep and challenging behaviors improved.

Did not qualify for AZEIP

One grandparent has a 4 year old grandchild who has one hand that is smaller than the other. The child did not qualify during the Early Intervention screening. However, he now has a diagnosis of CP and nerve palsy. His grandparent thinks he should have gotten therapy to strengthen his hand earlier.

Parents told child is too young to screen

A parent shared with her physician that her 1 year old child had no speech or attempted speech and that she is very small and not growing. The parent reported that her physician told the family not to worry about it, that that their child was too young to do any type of screening.

Need for basic parenting and nutrition information

A young mother reported that her 2 year old has behavior problems and she "runs herself to sleep" until about 11:00 pm. The mother said that she can't enforce a bedtime and that she lets her 2 year old drink as much caffeinated soda as she wants all day/evening.

Issues by Region

Avondale

Parents reported that it was difficult to get their children's physicians to take their concerns seriously. Many said they did not receive a diagnosis in time to receive supports through AzEIP.

A few parents said that they need to have more therapists and better quality therapists in their area.

Several parents were frustrated when their children received a diagnosis and yet they did not qualify for services.

Several parents expressed the need for emotional support for themselves in addition to supports to help their children.

Many parents said that finances were an issue for them. Parents said that they needed money for therapies, medications, and nutritional supplements. A grandparent said that she couldn't work as much as she needed to because she had to take care of her children's and grandchildren's needs.

Urban

*20 parents attended
8 English Speaking
12 Spanish Speaking
(translation provided)*

Race/Ethnicity

*Hispanic 16
Native American 1
White 3*

Examples

Avondale

A grandparent said that she has to choose between taking her grandchildren to medical appointments, taking care of the kids and working to make money.

Parent used private insurance due to lack of AzEIP therapist in their area

Physician said cannot diagnose until age 5

Difficulty getting diagnosis

The parent of a 3 and 5 year old reported that her child's Developmental Pediatrician told her that her child was overly attached and that she was the source of her child's problem. Parent said that her child cannot communicate with other children. The Developmental Pediatrician told her to bring her child back for another appointment. Her child is scheduled for her 3rd appointment but her child still does not have a diagnosis. She said, "My child cannot get services without a diagnosis."

Lack of available therapists

Another parent had a baby born prematurely who qualified for AZEIP. This parent reported due to the lack of therapists in their area they used their private insurance to obtain therapy for their baby. This parent said that her child stopped receiving therapy when their private insurance stopped paying for the therapy.

Parent was told diagnosis can't be made until age five

One Avondale parent shared that her child's family physician was not listening to her concerns. She said the physician told her that he would not give a diagnosis until age 5. The parent reported that her child was evaluated by AzEIP and found eligible but only saw a therapist 12 times in 2 years. The parent said the therapist left the appointments early because her child was not cooperative and her child has since aged out of AzEIP services.

Conflicted between working and grandchildren's appointments

A grandparent has 2 children of her own and 4 grandchildren. Two of her grandchildren have significant medical issues. This grandparent said that she has to choose between taking her grandchildren to medical appointments, taking care of the kids and working to make money.

Issues by Region

Casa Grande

Families in Casa Grande had a wide range of issues

Some parents were frustrated about the lack of services in their area and the problem of not being allowed to cross boundaries where services are offered.

Other parents reported that concerns about their children's needs are not being taken seriously by physicians or therapists.

Parents reported that transportation is a big issue in Casa Grande. They have to go to Phoenix to see specialists and most parents attending the forum said that they do not drive and/or do not own vehicles.

Parents said that transportation makes families late to appointments and that transportation companies often do not pick them up even when the parents have scheduled and confirmed appointments.

Most parents were satisfied with their physicians and said that they listen to their concerns, were well connected with community supports, and made referrals to specialists when needed.

One parent said that her physician was wonderful for medical concerns but not for referrals to anything developmental. The parent said that the physician always had a wait and see attitude.

Some parents reported that they had good experiences with AzEIP screenings and services, saying that the professionals were supportive and gave them a treatment plan.

*Rural
Pinal county*

7 parents attended

Ethnicity/Race:

Caucasian 3

Hispanic 2

Native American 2

Examples

Casa Grande

"It is very difficult to take off work and to drive to Phoenix for an hour 2-3 times a month to see a physical therapist for 15 minutes."

"I wish I could get my child speech therapy outside of school."

"Some Support Coordinators don't give all of the information – my son still wears diapers and Arizona will cover the cost of the diapers, but his coordinator wasn't telling me about it. I found out from the CRS Clinic."

No services in Coolidge

A single Dad has 8 children; 6 who have learning disabilities, and 2 have speech issues. Dad reported that they moved from out of state 4 years ago where his children had speech therapy and other supports. Dad said that when his family lived in Casa Grande that he received help at the Early Childhood Community Center. This dad reported that when they moved mid-year to Coolidge there were no services. Dad said, "Casa Grande won't take us because we live in Coolidge. Coolidge has nothing."

Parent researched her child's rare disease

A parent of 6 children researched to find out what was causing her child's health concerns and identified Kawasaki disease. The parent shared the information with her child's physician. The physician tested her child and said, "She has Kawasaki disease. You need to go NOW to Phoenix." Her daughter is now receiving treatment and is doing well.

Transportation issue

A mother of 3 children said that her daughter had an appointment at a hospital in Gilbert to get ear tubes. The mother had scheduled transportation ahead of time, but when she called that day to confirm transportation, they said that she wasn't on the schedule. Mother said that she had to reschedule the appointment for her child's ear tubes. After the next appointment when the ear tubes were inserted, transportation services didn't have her on the schedule to get back home.

Health Concerns not addressed

One parent reported "My son is struggling to gain weight. He hasn't gained since January. He has been 26 lbs. for 6 months and he is not getting taller. His physician says, 'Don't worry about it.'"

Issues by Region

Tuba City

Families in Tuba City live in a very isolated area.

A Raising Special Kids staff member who is Navajo and lives in the community facilitated the Family Forum in Tuba City. She shared her story of being a parent of a child with a disability and shared some information in the Navajo language. She was well received and some parents felt more comfortable in sharing their concerns as a result.

Families expressed frustration about the physicians that come to their region and stay about a year, and do not have the experience to be able to provide good health care. Families said that they go to Flagstaff for more consistent and reliable services.

Transportation is a huge problem, "things are a great distance" and many families do not have vehicles or cannot afford the gas. There are no public bus routes. Transportation is provided for individuals on AHCCCS but parents report that it is unreliable.

There is a waiting list for Head Start.

One parent reported that the barrier to getting services is income eligibility; "You make minimum wage and are told you aren't quite poor enough to qualify."

Parents report that they have had many good programs but then the funding runs out.

*Tribal/Rural
Coconino County*

*10 Family Members
representing 9 families:*

3 Fathers

4 Mothers

3 Grandmothers

Ethnicity/Race:

Native American 10

Navajo 9

Hopi 1

Examples

Tuba City

"They come up here and practice on us. New doctors and residents come up here on short contracts and stay a year or two. They do not get to know the community very well, and sometimes miss things at the ER because they are new."

"The wait at the ER is 6-8 hours for something simple....it is faster to drive to Flagstaff."

"It would be good to go to the Village or Chapter houses if things were available there."

Does not have credible source for developmental information

"I asked the lady at the food bank (about my child's development) and she says he looks good."

Inexperienced physicians

Parents reported that because of a physician's inexperience they sometimes send families to Flagstaff to obtain a diagnosis for their medical issue. One parent said, "Once they couldn't identify what a rash was from their exam and my child had to be sent to Flagstaff." The drive from Tuba City to Flagstaff is about an hour and a half.

Physicians are only there for a few years

A Tuba City parent reported, "They come up here and practice on us. New doctors and residents come up here on short contracts and stay a year or two. They do not get to know the community very well, and sometimes miss things at the ER because they are new."

Faster to drive to Flagstaff

Another parent said, "the wait at the ER is 6-8 hours for something simple. If we have something complicated, or need to be seen right away, it is faster to drive to Flagstaff."

Parent learning to advocate

A parent of 4 kids stated that the older two have reading delays. She said that their youngest child, who is 3 years old, has speech issues and is in school. "I am learning my rights as a parent through the IEP process. My child speaks Navajo, but his English is poor. I work with him at home."

Issues by Region

Sacaton

Parents in Sacaton seemed to have low health literacy and limited understanding of child development.

Most parents in Sacaton did not complain about their physicians. Many parents expressed that they had not realized their child had any problems until they received a significant diagnosis of disability.

One parent said that, "the ER listens to you more than other doctors."

Several of the parents said that they had children in DCS. One parent said that she gave up her child because she was not capable of providing care for her daughter because of her significant medical issues. The parent described how the foster mother of her child was helping her to learn more about her child's care and how to get specialized services for her child, but it was quite a distance for her to travel to visit her child.

A single Mom said that her son was on a wait list for Head Start before he was able to start Head Start services.

Many parents expressed the need for the most basic information and training and were extremely overwhelmed. One parent explained that she has a disability herself.

The Tribal Director was present and told the families that he has an adult child with a disability. He told the parents that they would help the families get the help that they need .

*Tribal
Pinal County*

28 Family Members:

*24 Parents
2 Grandmothers
1 Grandfather
1 Sibling*

Ethnicity/Race:

*Native American 24
Caucasian 2
Hispanic 2*

Examples

Sacaton

"One day therapies just stopped."

"...we are in a generation now where we want to be knowledgeable and help our children vs. my grandparents who thought that they are a bad child and have a discipline issue. Now it's, 'Our children need help, how can I help my child?'"

"I still need to learn what Early Childhood Special Services is teaching him."

Not receiving services

A mother of 4 children reported that her 2 year old is now on her third case manager, but she not has met them yet. The mother stated that her children should be receiving therapies in their home. The parent said, "They were great the first few years. One day therapies just stopped." Early Childhood Services is following up for the parent.

Parent Mentors

"We need mentors for the parents. I have two younger sons who are perfectly fine – but I need that person like a mentor to help me with my other child."

How can I help my child?

A young mother of a 2 and 4 year old said, "This is showing that we are in a generation now where we want to be knowledgeable and help our children vs. my grandparents who thought that they are a bad child and discipline issue. Now it's, 'Our children need help, how can I help my child?'"

Pharmacy

The parent of a 2 year old with a traumatic brain injury said, "He can't stand on his own or sit up on his own. He is learning to hold things and eat table food. The problem is getting his prescription filled. I have to push the pharmacy here to fill it."

Behavior concerns

A young mother said that she has a disability herself and has 2 preschoolers. The mother said that her children have been in and out of DCS. The mother said, "I came today to find out what's the next step I can take with my son to control his anger, his emotional roller coaster when he gets mad. I still need to learn what Early Childhood Special Services is teaching him."

Issues by Region

Lake Havasu

*Rural
Mohave County*

*26 Family Members:
24 Parents
2 Grandparents*

*Ethnicity/Race:
Caucasian 19
Hispanic 2
Native American 1
Pacific Islander 1
Unidentified 3*

Parents reported that physicians and schools were not taking their concerns seriously and their specialists were not adequately trained.

Parents expressed concerns about the lack of medical care, therapists and help with behaviors in their area. One parent takes her child to Utah and also uses telemedicine from out of state for speech therapy. Many parents drive to Phoenix.

One parent reported that her son's teacher was always asking her what to do differently with her son. The parent reported that she needed guidance and direction herself but was not receiving it.

Parents expressed concerns about reporting their child's health and developmental problems and being threatened with action by DCS. One parent said that they were fearful of being turned over to DCS in response to taking their child to Urgent care or the ER.

100% of parents at the Lake Havasu Family Forum reported that they have a pediatrician and go to appointments on a regular basis. This was the only region who had 100% of parents reporting they have regular appointments with their child's pediatrician.

One parent reported that the emergency medical specialist at the hospital, urgent care, and Air Evac are not set up with pediatric equipment. The parent said that they used an adult size IV in a 3 year old's arm and adult size breathing tube in her newborn. The parent felt their infant saved their own life by pulling out the breathing tube.

Most parents in Lake Havasu said that they did not use their child's physician to obtain information about their child's developmental needs.

There are many low income families who struggle with the cost and lack of convenient transportation who need to travel to Phoenix for care.

Examples

Lake Havasu

"As a parent you know when something is not right."

"We found out that our local professional wasn't trained to do pediatric audiology testing."

"If my son was diagnosed sooner, I could have provided him with support."

Failure to identify health condition

One mother said, "I took my daughter to her doctor, they did x-rays. They told me that she had pneumonia and sent her home. Three weeks later she had trouble breathing, and they sent her home on meds. We went back to hospital again and they said nothing was wrong. I took her to Phoenix to get a second opinion. We found out that her heart was three times larger than it should have been – she would have died if we took her in one week later. Locally they had taken x-rays and didn't see it."

Lack of medical referral

A parent said that when she expressed concerns that her child had no language and just screamed, the physician checked his hearing and told her, "Nothing's wrong, give it more time." This parent explained that she took her child to a doctor in Phoenix for a second opinion. The mother said, "Finally she was seeing what I was seeing. As a parent you know when something isn't right, you know."

Inadequately trained audiologist

One parent explained that her son failed 4 newborn hearing screenings as well as a hearing screening retest at 1 week old. She said that her son was then referred to a local ENT-audiologist who tested him again and told the parent that her son had robust hearing and they would never have to worry. The parent reported that she was concerned that her son wasn't reaching developmental milestones at 9 months old and took him back again for hearing testing. Again, they told the parent that her son had great hearing. The parent expressed that she still had concerns so her son was then referred to Phoenix where testing determined that "he had profound hearing loss – he could not hear anything." The parent said, "We found out that our local professional wasn't trained to do pediatric audiology testing. If my son was diagnosed sooner, I could have provided him with support."

Issues by Region

Show Low

Many parents shared stories of physicians who left families feeling unheard after expressing concerns about significant medical issues. Numerous Show Low parents reported that they were threatened by others who claimed that they would call DCS on them. This theme seemed to emerge over and over again in Show Low.

Show Low seems to have a big issue with disrespecting parents and threatening to call DCS on families. One school official threatened a parent because they were trying to get bus service for their child. A dad reported that a neighbor called DCS and the police when his child with autism got out of the house and was wandering on the neighbor's property. A mom said that her child's physician threatened to call DCS because the parent told her child's physician that she knew that her child had a special health care need.

Parents reported being blamed when they expressed concerns about their children. A parent said that she was told that she was a bad parent and that she did not know what she was doing. Another parent said that he was told, "You do not know what you are talking about. You should have done your homework before you became a parent."

Parents expressed the need for a care coordinator who had previously been available at the Indian Health Services hospital. A professional at the forum said that the lack of care coordination at the hospital was due to lack of staffing. Care coordinators had been nurses who were needed as nurses on the floor when staffing needs increased.

A Show Low parent reported that they had received referrals to a specialist but after the specialist saw their child, no one communicated the results of the testing back to the parent.

Parents complained that transportation is an issue in Show Low. AHCCCS will only transport one parent and one child and there are no caregivers to leave their other children at home.

Rural Navajo County

12 Family Members:
8 Parents
2 Foster parents
2 Grandparents

Ethnicity/Race:
Native American 7
Caucasian 5

Examples

Show Low

The parent said that they did not have transportation so they could not go to Phoenix for the evaluation.

"The challenge is not in having a screening done. The challenge is the referral process to a specialist."

A child was born without an optic nerve but the parents were not told their child was blind until they she was 13 months old.

Difficulty getting referral

A parent said that she saw their pediatrician expressing concern about their child 5 times before receiving a referral to a pediatric neurodevelopmental psychologist. The parent said that they did not have transportation so they could not go to Phoenix for the evaluation. They said they waited 6 months for when the neuro psych was regularly scheduled to come to Show Low. The neuro psych diagnosed her son with autism.

Concerns dismissed

Another parent said when she saw her son having seizures, once she took him to the hospital and the next time she took him to Urgent Care. Both times they were told that he was fine and sent him home. When his seizures started again the parent said they took him to a different hospital who did a CT Scan and sent him to a Children's Hospital in Mesa where he was diagnosed with cortical dysplasia.

Hospitals missed health issue

A grandmother who is helping her teen son raise his baby said that when they brought the baby home from the hospital her granddaughter couldn't keep anything down. The grandmother said that she took her to two different hospitals in the area where the doctors could not find what was wrong. She reported that when they took her granddaughter back to one of the hospitals, they sent her by Air Evac to Phoenix. The grandmother went on to say that one of the girl's heart arteries that was supposed to close on its own didn't close and that her organs were slowly shutting down. At the hospital in Phoenix, her granddaughter had heart surgery to close off the artery and was in the hospital in Phoenix for almost 6 months.

The grandmother also said that her granddaughter was born without an optic nerve and is blind, but they were not informed until she was seen by a specialist in Phoenix when she was 13 months old.

Issues by Region

Tucson

*Urban/Rural
Pima County*

*22 Family Members:
19 Parents
2 Kinship Parents
1 Grandparent*

*Ethnicity/Race:
Caucasian 9
Hispanic 8
Native American 2
Asian 2
Did not identify 1*

Parents in Tucson seemed to have better connection to services/resources than the parents in the other FTF Family Forums.

Many parents indicated that they were frustrated by the long waiting list for Developmental Pediatricians.

Families said they had little help navigating systems and had to find resources by themselves. A military family said that physicians at the Air Force Base hospital were deployed or on special military mission trips and so it was very difficult to see the same physician twice.

Many of the physician offices had several pediatricians. Many families reported that they had to see a different pediatrician each time and each time the pediatrician would not be familiar with their child's special health care needs. One parent expressed that they loved their pediatrician but the office staff and nurses were uncooperative and judgmental.

One parent expressed frustration with the constant turnover of speech and occupational therapists, and said that some therapists would not allow her to be in the room during her child's therapy. She stated that parents need to watch their child's therapy sessions so that they can work on the same techniques at home.

A few parents wanted more specialized therapies like equine and animal therapy.

Examples

Tucson

"There is no open enrollment for kids in Special Ed. You should be able to look at other schools and not depend on private schools or hope for scholarships."

"I want to know how to stand up for the rights of my child when things are not going the way they should."

"I didn't realize the things he couldn't do until he was evaluated. That childcare leader coming forward spurred everything."

Physician not taking concern seriously

One parent stated, "I tried to get help for our child from our pediatrician at his first year checkup; our pediatrician told us it was all in our heads. At 18 months, he wasn't getting better. I didn't want to delay. I googled Project ABLE which is the preschool for Tucson Unified School District (TUSD) and referred myself. Now my child has an amazing teacher who has given me so much information. Parents do not know about the services that are available."

AzEIP Therapies

Another parent said, "I want to know how to stand up for the rights of my child when things are not going the way they should. A home visitor came to the house, she was lovely. I really liked her, and she was helpful, but my kid never saw speech or OT and was supposed to see someone every week."

Physician dismissed parent's concerns

A mother said that, "I initially had concerns about my son when he was 2.5 to 3 years of age and I brought it up to his primary care physician. He said 'don't worry' and he didn't do much of an assessment."

This parent said when her child was put in childcare because her job situation changed, after three weeks the teacher called a parent teacher conference and brought up her concerns. The teacher suggested to the parent that she have her son evaluated. The parent said that the teacher referred her son to a developmental preschool in his school district where he attends now. The parent said that the school district evaluation indicated that her son was deficient in all areas. She said, "I didn't realize the things he couldn't do until he was evaluated. That childcare leader coming forward spurred everything."

Recommendations

from Parents

Recommendations

Parents

"I would wish for people to know all of the things we heard here today, all these gems that people don't know about."

"To stop the conflict between home, work, therapy. I can't be everywhere at once."

"Respite care – to have someone trained to take care of the other two children. Someone you can trust who knows what they are doing."

Parents were asked if they had a wish/dream what would make their children's and their lives easier

Medical Home/Family Centered Care

Parents said they would like their pediatricians to:

- Have knowledge and access to resources to help families
- Listen and be able to hear their concerns
- Be aware of parents' feelings
- See the same pediatrician for each appointment
- Have appointments available after work and school hours

Care Coordination

Parents said they would benefit from more and better care coordination for their child:

- Parents expressed that care coordination would be vastly improved for their child to have the same care coordinator who would coordinate their child's services and supports
- "My ultimate dream would be that we would have collaboration between doctors and services, and that we would have more therapists who are local. I want to be able to communicate with our doctors about a problem that we see, that they can refer us to a place here, and that they are willing to refer us not only to services, but to collaborate with us so we as parents can work with them on the goals for our child."

Child Care

The need for available and qualified childcare:

- Trained childcare providers
- For children with behavior issues
- Providers who understand the special needs of children with disabilities
- For siblings while they take their child with a disability to appointments

Recommendations

Parents

"The information is not getting to everyone. We should know of all of these things. The information should be out there in the community."

"Therapy for me because I am so stressed out, also therapy for my other children."

"There are a lot of programs out there that I wish I would have known about for all of my other grandchildren. I wish I would have known so they could have accomplished much more."

Resources

- Parents want a central place where professionals or families can go to find resources and events. "Where support groups for different diagnoses and other community groups that support the special needs community could post their events. The information is not getting to everyone who needs it."
- More information in Spanish. "It is hard to find Spanish language information."
- One parent said, "When my child was discharged from the NICU they threw pamphlets at me. People called that were not clear about where my child should be and they didn't know what services are available. I needed easier ways to get information and resources. The focus in the NICU is survival and then afterward I found resources in the library."
- Opportunities for children to exercise indoors out of the heat/cold.
- Children's sensory museum.
- Place to network and get in touch with other parents.

Parent to Parent Support

- Parents in all regions expressed their need for parent to parent support
- Many said they came to the forums to connect with other parents
- Some parents had connections to other parents and expressed how valuable it is

Recommendations

Parents

"A center where we have alternative therapies; water therapy, equine therapy, something different than just speech."

"Community awareness about ADHD and associated behaviors, There is such a stigma about that. "

"I wish there was just one website to go to when I need information. I don't have time to scour websites to look for different information and organizations."

More Providers are needed in general and especially in rural and tribal regions

- Developmental specialists who can diagnose disabilities
- Speech, Occupational and Physical therapists
- Behavioral therapists who know how to work with children with autism
- Medical specialists in rural communities
- Treatment centers in rural communities
- Training/accreditation programs in rural tribal areas so that they can "grow our own" home visiting nurses and other specialists

School

- Someone to help parents advocate for their children's needs in school
- Special Education classes closer to where families live

Training

- Annual conference with vendors
- Nutritional classes with healthy recipes
- How to manage their children's challenging behaviors
- Social skills training for their children

Transportation

- Reliable, safe, non-smoking, clean transportation for medical appointments
- School transportation across boundaries not only for school programs but also for afterschool daycare

Recommendations

from Raising Special Kids

Recommendations

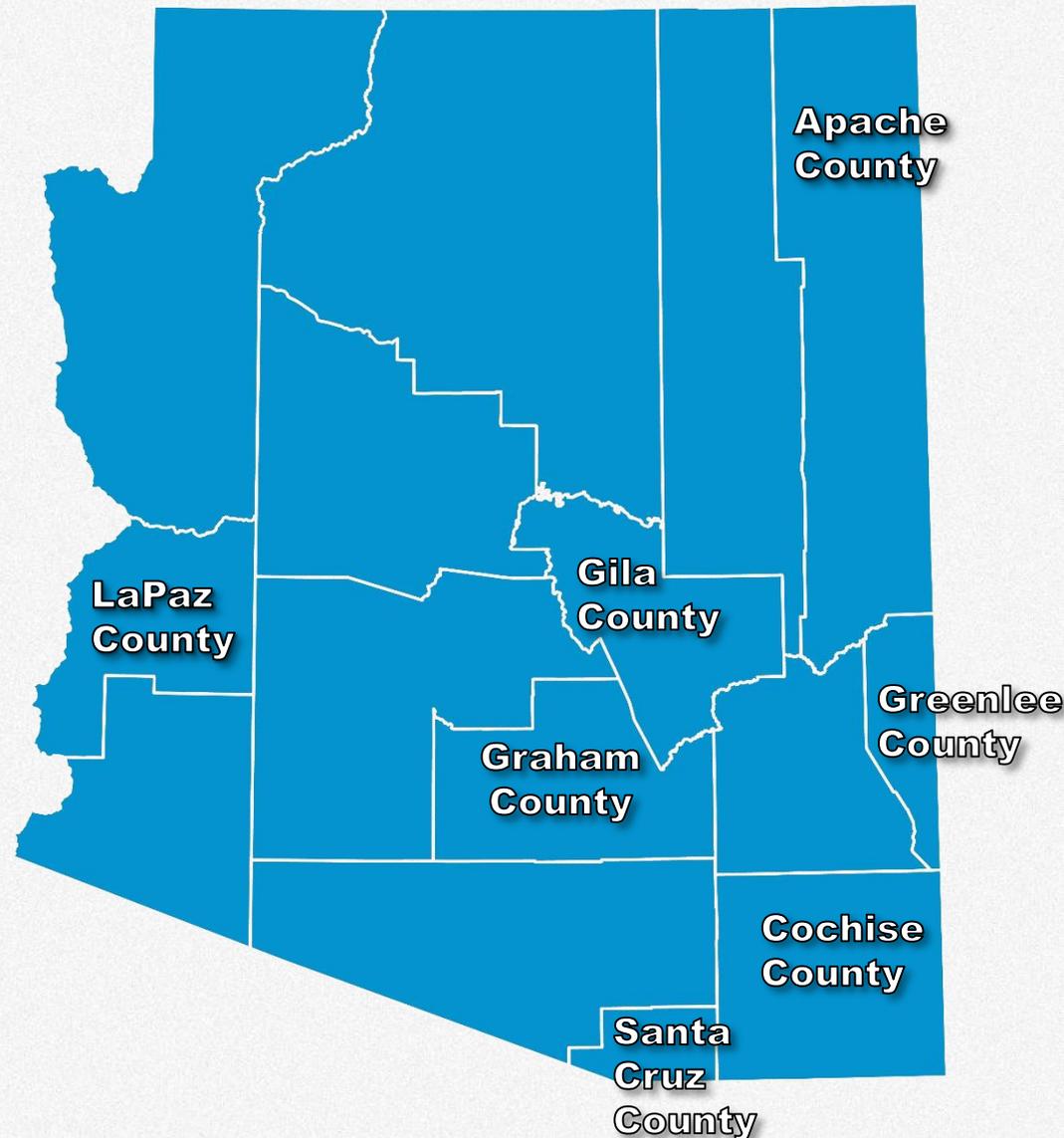
Raising Special Kids

Family Forums were held in nine counties throughout the state of Arizona.

The families were honest and open about their experiences. While issues were similar across most regions there were unique challenges in each family forum. It would be beneficial to know the experiences of the families in the remaining seven counties in Arizona to have statewide representation.

The following Counties have not had Family Forums:

- LaPaz
- Apache
- Gila
- Greenlee
- Graham
- Cochise
- Santa Cruz



Recommendations

Raising Special Kids

Family Forums highlighted areas where families are being helped through First Things First home visiting programs, Family Resource Centers, Head Start and schools.

Families at the Family Forums had some kind of connection to a “helping” professional but most expressed they were still having problems and unmet needs. Some families did not know that their children needed to be evaluated or did not have the skills or encouragement to keep trying.

Last year, 60% of the 18,000 children referred for early intervention were found not eligible for services. These families need to be helped and connected with community resources. There appears to be a critical need for additional system infrastructure to address this population of at-risk children.

We recognize that these responses are not fully representative samples of the population of each region, although the forums brought forth specific items and issues important to individual parents and specific to their areas. We also recognize that the parents who participated in the forums are, for the most part, highly motivated, resourceful, and have been capable of making their way through a complex and challenging system of diagnoses, referrals and interventions. We know that there are many other families who do not have the same capacity and resources, who may have even greater challenges getting the resources and help needed for their children.

How are the families who are not eligible for AzEIP going to be identified?

How are they going to get the help that their children need?

How will Arizona ensure that children not eligible for early intervention are ready to learn by age 5?

Recommendations

Raising Special Kids

In 2015 Raising Special Kids provided training on family-centered care for

- *51 medical residents in pediatrics and family practice*
 - *112 Speech Therapy Students*
-

Medical Home/Family-Centered Care

For children's optimum healthcare, professionals need to understand Family-Centered Care and acknowledge parents are experts on their children

- When parents voice concerns about their children's health, the parents' perspective needs to be heard and acted upon
- Interpreters need to have the skills to interpret specialized care needs in a medical setting, and to help parents communicate their concerns to the physician so that parents receive accurate diagnosis information and treatment plans for their children
- Families need to be able to see their children's primary care physician when they are ill so that the physician's office can track their children's healthcare needs to see if further testing or treatment is needed
- Physicians should refer families to community resources like Raising Special Kids and FTF Family Resource Centers to meet their children's needs

Medical Home/Care Coordination

Families need more availability and higher quality care coordination services, including recognizing when further testing or treatment is needed for chronic conditions and better communication between providers. Families need to have care coordinators who can refer their children to specialist and maintain all of their children's records of testing and results. Care coordination prevents fragmented care, eliminates duplicate invasive and unnecessary medical testing, and maintains accurate assessments of children's ongoing healthcare needs.

This may be accomplished by provider training which includes families who have moved from "me to we" and can relate their experience in positive ways that communicate what works best for them and other families. It would also be beneficial for families to have training to improve health care literacy so they understand the principles of family-centered care and how to effectively communicate what their children need to their physicians.

Recommendations

Raising Special Kids

Interpretation and Translation

Parents who speak languages other than English need to know they can request an interpreter and materials in their primary language. Parents need to have accurate interpretation in order to communicate their child's needs to professionals in all systems of care.

Increased Network Capacity

There needs to be an increase in the network capacity of professionals who can diagnose disabilities and provide services. ASQ Screening may help determine if children need to be referred to AzEIP or if they would not qualify for AzEIP to be referred to community resources to meet their needs.

Telemedicine is a necessary and vital option for rural areas. In areas with a shortage of HCBS providers to provide respite, habilitation, and attendant care for their children, parents need to know that they can recruit their own providers and have them hired and trained by a provider agency.

Transportation

Transportation issues for medical care needs addressed, ensuring scheduling is correct, intact, and on time with no smoke-filled, perfumed cars which could negatively affect children's health.

Emotional Support

Parents need to be connected to other parents for emotional support

- Through research-based parent mentoring and coaching programs
- Family Resource Centers
- Community resources, workshops, conferences, and events for families

2015

Raising Special Kids provided 8 weeks of coaching and mentoring for 379 parents. 93% said they would recommend the service to other parents.

<http://www.p2pusa.org/>

Recommendations

Raising Special Kids

In 2015 Raising Special Kids provided :

- *1,491 parents with IEP training in Spanish/English*
 - *74 parents were supported at their children's IEP meetings*
 - *193 parents received Positive Behavior Support training*
 - *11 parents received one-on-one intensive behavior coaching for 8 weeks of Positive Family Intervention*
 - *287 Special Education Students from 6 Universities and Community Colleges heard the parent perspective on children with disabilities*
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School

It is important that parents understand their rights and how to collaboratively advocate for their child's needs in school and that they know who to call if they are having problems

- Parents need to be aware that developmental preschool is available through their school districts.
- Once children are enrolled in school parents need to understand their rights and the IEP or 504 process. Some of the parents at the forums said the only services or support their child receives is at school, which may interfere with or reduce instructional time.
- When children are having behavior problems in school, parents need to know they can ask for a Functional Behavior Assessment and a Behavior Intervention Plan to help school personnel manage children's behaviors in a positive and effective way

Behaviors

Parents need help managing their children's behaviors. Possible supports are evidence based training like, Positive Behavior Support, Positive Family Interventions (PFI), and Triple PPP Positive Parent Program. Other solutions are to identify what supports are in the community, including FTF parenting classes.

Conclusion

Conclusion

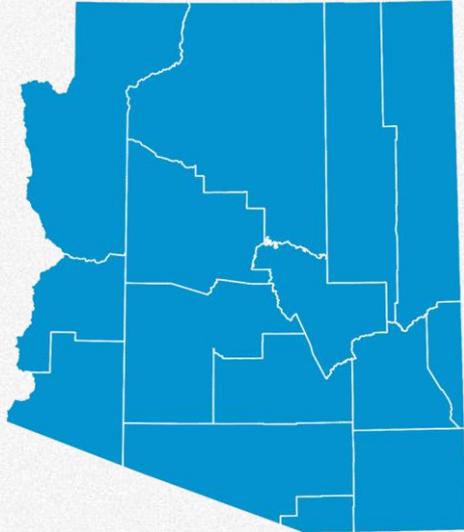
The parent's personal stories are unique but express similar issues with professionals and our system of care.

Parents expressed a need for:

- Effective communication and collaboration between professionals and parents especially in the area of healthcare
- For professionals to know what services and supports are available for families and to inform and assist families to access them
- That services and systems families are using will work as they are intended
- Families to have connections with other families, and have access to programs that develop their knowledge, skills, and advocacy.
- Families of children who are not eligible for AzEIP need connections to reliable sources of information and community supports

Parents are trying to do the best they can to find their children the help they need. It is essential that the family voice be heard, understood, and considered by those providing care to their children, and by those designing Arizona's system of services for meeting the needs of children at risk for developmental delays.

"I feel it is important to be aware of how my child is developing because I want him to have a healthy and happy future."



Raising Special Kids is grateful for the opportunity to connect to parents through facilitating the FTF Family Forums throughout Arizona. Raising Special Kids was able to provide assistance to many struggling families with system navigation, community resources, special education, developmental information and parent to parent support.

Raising Special Kids' hope is that all families who have children referred for early intervention and found ineligible will be provided with the support they need to grow up healthy and strong and be ready to succeed in school and beyond.

Prepared by



On behalf of



July 2016
