



First Things First
Interviews with Arizona Early
Childhood Comprehensive System
Professionals
August 2015

Project Objectives

- ▶ Gather feedback from professionals in the early childhood comprehensive system in Arizona.
- ▶ Gather insights on the screening, referral, and treatment options for young children with developmental concerns.
- ▶ Specifically focus on options for services for those children who do not qualify for AzEIP.
- ▶ Examine the existence of gaps in the system of identifying and treating developmental concerns among Arizona's young children. Help to identify:
 - Where gaps exist
 - Why gaps exist
 - Potential solutions for closing the gaps

Methodology

- ▶ Conducted 20 in-depth interviews with ECCS professionals within the State of Arizona.
 - Total of 23 respondents; some interviews contained more than one respondent.
- ▶ Potential respondents were recruited from a list provided by First Things First.
- ▶ Interviews were conducted by telephone by EMC Research and ranged in length from 20 to 60 minutes.
- ▶ Interviews conducted between July 16 and August 20, 2015.

Respondent Characteristics

▶ Respondents included:

(note: some respondents counted in multiple categories; total does not add to 23.)

- 9 employees of government programs
- 6 employees of regional social service/non-profit organizations
- 4 medical doctors
- 3 employees of statewide social service/non-profit organizations
- 2 parents of children with developmental concerns
- 2 employees of First Things First

▶ Respondents were from both urban and rural areas throughout the state.

Key Findings

- ▶ Respondents believe AzEIP provides a valuable and needed service in the state, but also see its limitations.
- ▶ There appears to be a lack of consistency in the way developmental screenings are conducted, results are interpreted, referrals are executed, and with follow-up if a child is referred for services or additional screenings.
- ▶ As expected, interviews revealed that there appear to be significant gaps in the system of identifying and treating children with a developmental concern.
- ▶ There are some challenges to accessing care, such as location, cultural barriers, or other concerns.
 - Cost, lack of insurance, and logistical issues (transportation, location) were identified as the most significant factors for why some children may receive services while others do not.
- ▶ Workforce issues, particularly shortages in qualified staff, make it more difficult to identify and treat all children with developmental concerns.



AzEIP

AzEIP Qualification

- ▶ AzEIP was viewed as a positive program, though many see room for improvement.
- ▶ Some complained that the program requires such a significant delay for eligibility that many children who could benefit are being left out.
- ▶ Others identified areas of confusion around eligibility criteria, along with inconsistencies in terms of interpretation of screening results.

"What families report, to me, anyway, is if you don't have somebody with you who's really sophisticated in going through the eligibility process, you'll get denied because you won't answer the questions right."

"I think there's an irrationality that's a huge barrier for 0-3 year olds... Eligibility isn't subjective."

Parents

- ▶ Respondents identified parents as vital in the success or failure of their child to get the services they need.
- ▶ Parents may not be aware that a child may still have a developmental concern if they pass the AzEIP screening – assume everything is fine.
- ▶ The AzEIP referral and services system can be very difficult to navigate – difficult for professionals, not just parents – causing some parents to give up or get lost in the system.

"In my experience, what happens is a family doesn't qualify for AzEIP services, then they leave that process thinking everything's fine. Then they seemed stunned that when that child enters kindergarten, that it's not."

"There is no voice for *a lot* of parents. There are so many kids out there ... parents don't know and don't have the wherewithal... they don't speak up. They don't feel as though their voice is important."

Expectations and Critiques of System and Services

- ▶ Differing expectations for AzEIP
 - Referral sources need to understand that it is not the only program for children with developmental concerns.
 - The program may not be the best way to serve all children with developmental concerns.
 - Appropriate medical staff are not always available, leading to inappropriate medical specialties or other professionals taking the lead on cases.

"That person in the library, that person in the doctor's office, their perspective is that a child with delay equals AzEIP. We have a more complex and sophisticated system, where there are a myriad of programs which a family may be interested in or eligible for."

"It's this one-size-fits-all solution and I think we could spend our resources better."



Screening Process

Mixed Responses on Screening Effectiveness

- ▶ Some respondents suggested the screening process is effective, while others suggested it misses too many children.
- ▶ While many organizations use the same screening tools, the screening process often varies across organizations.
- ▶ The lack of consistency in applying screening tools coupled with differences in interpretation of screening results can lead to inconsistencies in diagnoses and referrals.
- ▶ Effectiveness was also questioned as to whether screeners are properly trained and/or whether parents or caregivers are accurate in questionnaire responses.
- ▶ Respondents generally noted recent improvements in their ability to identify children.

Missing Children in Intervention Windows

- ▶ Some children are never screened, particularly those in childcare settings with a family member, neighbor, faith-based center, or other private daycare.
- ▶ Others are missed if they do not go to regular well visits with a doctor. Other times the doctors may not conduct certain screenings, particularly if they are not alerted to any potential issues by parents or others.
- ▶ Other times children fail screenings but are never referred to services, particularly if screeners are inexperienced or unfamiliar with available services.

"You have really busy primary care doctors who have to do a lot of screens... I think the practices, at times, are overwhelmed by what they are asked to do."

Screening Tools Used

- ▶ ASQ
 - Tool most commonly identified by respondents
- ▶ PEDS
 - Less commonly used, but some medical respondents favored it
- ▶ M-CHAT
 - Used to screen for autism



Referral Process

Referral Process

- ▶ Referral process is inconsistent.
- ▶ Referring professionals may be unfamiliar with options for services, particularly non-AzEIP services.
 - Referral may simply consist of being handed a brochure.

"I've been handed a piece of paper with some phone numbers on it."

"It's not about saying 'Here's a flier.' That's not going to work."

Referral Sources

- ▶ Doctors may not always know how or if to refer.
 - Do not have knowledge of programs available, both AzEIP and non-AzEIP.
 - Do not have adequate knowledge of developmental concerns, thinking children may “grow out of it” and subsequently missing a window for intervention.
- ▶ Referrals by Head Start, Child Find events, social workers, and social service organizations are either generally lacking, or may come from professionals with a lack of knowledge of all available services.

"It's only been through my own doing that I have found instruments to allow me to have conversations with my [child's] physicians."

"I got the classic 'Let's wait and see.'"

"Where we seem to not get referrals from tend to be child-care settings."

Referral Follow-Up

- ▶ Follow-up is critical to ensure a child receives needed services, but is generally viewed as lacking.
- ▶ Follow-up is left up to each organization, many of which simply do not have the resources to effectively handle follow-up. If a doctor makes a referral, they generally lack the staff or resources to follow up with the parents and don't see them again until the next well visit, several months or a year later.
- ▶ No clear identification of "who's in charge," leaving it to parents to attempt to navigate a cumbersome and confusing system on their own.
- ▶ Data-sharing between organizations is limited, with no central database of referrals, organizations, or available services.
 - Data-sharing could inject potential legal issues regarding privacy.

"Follow-up is huge."

"The challenge is... I give the family a phone number. They frequently don't call. I get permission from them to have someone call them, and I get a report back that they don't answer the phone."

"There's a real lack of circling back and closing the loop [of a referral]."



Barriers to Accessing Services

Gaps in Services

- ▶ Large gaps exist in terms of knowledge of services and regional availability. This is especially true for children with developmental concerns who are not in AzEIP.

Regional Gaps

- ▶ Services are limited anywhere outside of Phoenix.
- ▶ Many families have limited options and face long waitlists.

"[Access to services] completely depends on geography."

"It can take months and months for a child to get services."

Knowledge Gaps

- ▶ There is generally a perceived lack of sufficient public awareness of child development and intervention – covers all populations, including doctors and parents.

"Great, we're going to do a screening. What good is that going to do if we don't have anywhere to refer them to?"

"One of the biggest concerns we have all the time is do people understand child development well enough?"

"[Doctors] generally don't have the time and don't have the knowledge of all the various systems of care and how they work."

Quality of Services

- ▶ It can be difficult to find services that fit each child's needs, and even more difficult to find high-quality services.
- ▶ Working with young children on these issues can be difficult; appropriate staff not always available.
 - Lesser-qualified professionals having to provide services.

"I think it's really hard to get services in Arizona. Not just services, but services that will really, really be helpful."

Common Logistical Barriers to Services

▶ Cost

- Limited or no options for un- or underinsured patients.
- Cost to 'self-fund' is not realistic for many families.
- Cost of transportation, taking time off work, or other logistical costs are also an obstacle.

▶ Transportation

- Applies to both rural and urban populations.
- Round trips to Phoenix from outside of Maricopa County are prohibitively long; many may not have a car.
- Even within the Phoenix area, public transit can make it difficult with work schedules or for parents with multiple children.

"It's so hard for some of these families, from a transportation perspective, to get [to services]"

"Some people don't even have the gas money [to get to services]."

"It honestly boils down to whether or not they have private insurance."

Family Barriers

▶ Parents

- Process is intimidating.
- May not want to admit that their child has a problem.
- Do not always have time/money/energy/knowledge to deal with these complex issues and navigate a confusing system.
- Rely on doctors who may also lack the time or knowledge to untangle system intricacies.

"Sometimes the families just get lost. They don't know where to start."

"Navigating the broader early childhood system can be challenging because there are so many different programs with so many different eligibility requirements."

"When you use the words 'screenings' [and] 'developmental delays,' it can scare families."

Cultural and Language Barriers

- ▶ Cultural and societal differences
 - Not all populations are comfortable dealing with these issues.
 - Some populations do not believe in screenings or interventions.
 - Not everyone is comfortable with doctors or having strangers in their home.
- ▶ Language
 - “English-only” services limit some outreach efforts.
 - Lack of Spanish-speaking pediatricians was identified as a particular barrier.

"Many people want to be served by physicians of their own culture and you just don't see that. We have a shortage of physicians who just don't understand people's cultures"

"You don't go to the doctor unless something hurts, unless something's wrong"

"I see some people who don't want people in their house."

Under-Served Populations

- ▶ Children who do not qualify for AzEIP.
- ▶ Rural or smaller urban locations.
- ▶ Native Americans.
- ▶ Transient groups, such as undocumented immigrants, migrant workers, or children in foster care.
- ▶ Un- or underinsured patients.
- ▶ Non-English speakers.

"The kids who don't qualify for AzEIP don't get very much."

"There are more kids out there that we need to put into these high-quality experiences"

"There are quite a few who fall through the cracks."

"Our rural areas are in a very, very resource-poor place right now. I feel terrible for those folks."

Underdiagnosed and Undertreated Groups

- ▶ Particular types of developmental concerns
 - Behavioral, social, and emotional problems
 - Feeding issues
 - Speech and language
- ▶ Infants (0-1)
 - Harder to diagnose delays in this age group

"Speech and language [issues], especially if you look like a usual kid, are very easily overlooked."

"If it's more social or emotional, it's harder to get services"

Shortages of Qualified Practitioners

- ▶ Broad range of respondents identified professional shortages as a problem.
- ▶ Problem exists statewide, although is a particular issue outside of Phoenix.
 - Simply not enough professionals.
 - Small cities and rural areas face extra challenges in recruitment and retention.
- ▶ Shortages identified:
 - Therapists, particularly physical therapists.
 - Pediatricians, particularly developmental pediatricians.
 - Mental health practitioners.
 - Certified early childhood educators.

"There aren't enough of these doctors to meet the need."

"One of the obstacles we have [in a smaller city] is we're always losing teachers, professionals to our bigger cities. We're always kind of starting over."

"For two years I've been working on [finding an occupational therapist] for my child."



Proposed Solutions and Recommendations

Summary of Solutions – Respondent Driven

- ▶ Improve communication and collaboration – between agencies, between institutions, and with parents.
- ▶ Develop a centralized database of available services throughout the state.
- ▶ Develop an inter-agency database that houses data on patients to track screening results and follow-up.
- ▶ Standardize the screening process.
- ▶ Raise awareness of the issues and available resources.
- ▶ Workforce development.
- ▶ Help medical practices institute new systems for screenings, referrals, follow-up.
- ▶ Expand the use of Care Coordinators.
- ▶ Expand AzEIP eligibility.

Improving Communication & Collaboration

- ▶ To the extent possible, get all the agencies involved on the same page. They are all working toward the same goal – to help a child in need. They need to work together toward that goal, which includes collaborating and sharing information.
- ▶ Create better public-private interfaces between state and medical providers and between non-profit and government agencies.
- ▶ Partner with local organizations that have contacts and infrastructure in target communities to pool resources and reduce duplication.
- ▶ Build better relationships with medical practices and schools to help improve referrals and follow-up.
- ▶ Work together on events such as social services fairs where many children can be screened and referred at once.

"When you're making a referral to a government agency, sometimes it's hard to get that information back... The results are not automatically shared with [the doctor]."

"I think there needs to be a stronger willingness to collaborate across disciplines."

Centralized Databases

- ▶ Develop a database of available resources throughout the state, with user-friendly search options.
- ▶ Organize a centralized database or registry for screenings, referrals, and follow-up.
 - Would keep track of patients and log information on screening results and follow-up. Would be accessible by a patient's entire "team."

"[A centralized database] would help us identify where the problems are and what's needed where."

Raising Awareness

- ▶ Communicate with parents, families, caregivers, doctors, educators and other ECCS professionals about available resources and how to access them.
- ▶ Try to help people understand that there are services beyond AzEIP.

"As an early childhood community, everybody should take responsibility for knowing what are the potential programs families could be hooked up to. The default can't just be AzEIP."

Workforce Development

- ▶ Expand statewide recruitment and retention efforts for developmental pediatricians, early childhood educators, therapists, and other similar professions.
- ▶ Ensure people conducting screenings are well-trained and know how to screen and interpret results.
 - A standardized screening process could be helpful.

"Part of our issue is medical training. I think there needs to be a stronger curriculum around special health care needs."

"We need to do serious infrastructure development around professional development."

Care Coordinators / Helping Medical Practices

- ▶ Embed Care Coordinators in medical practices and schools
 - Care Coordinators are highly valued and viewed as a key support for helping children get the services they need.
 - Integration would ensure access to services for parents and families and aid them in navigating the system.
- ▶ Help medical practices institute a system to track screenings and follow-up.

"If I didn't have a care coordinator to help me wade through this bureaucratic junk? I don't have time to do six hours of paperwork a day. I need to see patients."

"A really nice model could look like a social worker within pediatric offices.... Someone dedicated to help families coordinate the care they need."



Conclusions

Conclusions

- ▶ There are notable gaps in the system of identifying and treating children with developmental concerns.
- ▶ Services are available for children who do not qualify for AzEIP, but access is limited largely by cost, geography and the ability to navigate the system.
- ▶ There are some identified actions – some more simple and direct, others requiring more systemic change – that recipients of the Early Childhood Comprehensive Systems (ECCS) grant can consider to help close some of the gaps.

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Appendix

Non-AzEIP Service Providers

The following are some of the service providers identified by interview respondents.

▶ **General early childhood services and home visiting program**

- First Things First and Regional Councils
- Child Crisis Center
- Southwest Human Development
- Strong Families AZ
- Easter Seals Blake Foundation
- Healthy Steps
- Association for Supportive Child Care
- Nurse-Family Partnership
- Child and Family Resources

▶ **Focus on special healthcare needs**

- Raising Special Kids
- Southwest Autism Research and Resource Center
- Feeding Matters

▶ **Focus on underserved populations**

- Campesinos sin Fronteras
- Tribal-specific programs

▶ **Literacy Programs**

- Arizona Literacy and Learning Center
- Read On Arizona

▶ **Educational Institutions**

- Head Start and Early Head Start
- Public libraries

▶ **Medical Providers**

Interview Guide

I. INTRODUCTION

Thank you for agreeing to participate in this research project.

The topic of our discussion is services in Arizona for children with suspected developmental delays or hearing or vision problems. The interview will be treated entirely confidentially – nothing you say today will be attributed in any of our reports or notes to you by name. In addition, I will not be asking you to discuss any confidential or protected information on this call.

With your permission, I would like to record our conversation, so that I don't have to worry about taking notes while I'm speaking with you. Remember your participation is confidential and this recording will not be shared publicly, it's purely for use when I'm writing my report. Let's get started.

II. SCREENING AND IDENTIFICATION

A. Can you describe how children with suspected development delays or hearing or vision problems are identified in Arizona?

B. Do you or your organization conduct developmental screenings?

1. **(IF YES)** What kinds of screening tools do you use?
2. **(IF NO)** Why does your organization not perform screenings?

C. Do you think that the current screening process works well? Why or why not?

1. How could the screening process be improved?

III. REFERRALS AND TRANSITIONS

A. Can you please describe the referral process when a child has a suspected developmental delay or hearing or vision problem?

1. **(PROMPT IF NEEDED)** How are results from developmental screenings used to help refer families to needed services?
2. **(PROMPT IF NEEDED)** Who typically makes the referrals?
 - a. **(PROMPT IF NEEDED)** What are the job titles or job descriptions of people who make referrals?

3. Do referrals take into account whether the child is likely to be eligible for the Arizona Early Intervention Program, also known as AzEIP (**AY-zip**)? **(IF RESPONDENT IS UNFAMILIAR WITH AZEIP:** AzEIP was established by Part C of the Individuals with Disabilities Education Act and is Arizona's statewide, interagency program for infants and toddlers with developmental delays or disabilities.)

4. After referrals are made, is there follow up to make sure that families connect to additional screenings or services?

- a. **(IF YES)** Please describe the follow up process.

B. Where can families get information about access to services when they are not likely to qualify for AzEIP?

1. In your experience, how well-informed are health providers about referral options for families who are not likely to qualify for AzEIP?
2. In your experience, how well-informed are schools about referral options for families who are not likely to qualify for AzEIP?

C. Do you think that the current referral process works well? Why or why not?

1. How do you think the referral process could be strengthened for families who are not likely to qualify for AzEIP?

IV. ACCESS TO CARE AND SERVICES

A. Where are families referred if a child has a suspected developmental issue and is **not** likely eligible for AzEIP?

1. **LIST ALL. FOR EACH, PROMPT FOR THE FOLLOWING:**
 - a. Name
 - b. Location/Service Area

B. Do you think families and children who do not qualify for AzEIP are able to get the services they need? Why or why not?

C. Whether or not you feel these families are getting the services they need, what are some of the challenges or barriers that these families face when accessing care?

1. **IF NEEDED, PROMPT FOR:**
 - a. Cost
 - b. Location and transportation
 - c. Language barriers
 - d. Financial considerations
 - e. Availability
 - f. Knowledge of Services
2. **(IF MENTION ANY CHALLENGES/BARRIERS)** Why do you think those barriers exist?
3. What changes could be made to address these or other barriers to make it easier for families to access needed resources?

Interview Guide

D. Do you think families and children who do not qualify for AzEIP have needs that are not being adequately met? Why or why not?

1. Please tell me about any gaps you believe may exist between needs and available resources.
 - a. What additional resources or services could benefit families and children who do not qualify for AzEIP?
 - b. Are there any services or programs that should be expanded to meet the needs of families and children who do not qualify for AzEIP?

E. Do you think there is an adequate workforce to address the behavioral, physical and developmental needs of young children with identified delays or challenges? Why or why not?

1. **(PROMPT IF NEEDED)** In what areas do shortages exist?
 - a. Professions?
 - b. Geography?
 - c. Training/ professional development for the existing workforce?

F. In your experience, are there any particular groups of children who appear to be underserved?

1. **(PROMPT IF NEEDED)** In what ways are those groups underserved?
2. **(PROMPT IF NEEDED)** How can services for those groups be improved?

V. WRAP UP

A. Is there anything else you would like to mention that would help us understand more about available services for families not likely to qualify for AzEIP, the screening and referral processes, or the needs of families and providers?

B. For analysis purposes only, can you please tell me:

1. the name of your organization
2. the location/service area of your organization
3. your position/job title
4. the number of years you have been involved with your organization.

C. Thank you very much for your time.