

CHILDREN WITHOUT HEALTH INSURANCE

Listening to Arizona's Parents



CHILDREN'S ACTION ALLIANCE



About Children's Action Alliance

Children's Action Alliance (CAA) is a private, nonprofit, nonpartisan research, education and advocacy organization dedicated to promoting the well-being of all of Arizona's children and families. Through research, publications, media campaigns, and advocacy, we act as a strong and independent voice for children. Our fundamental goal is to bring about a greater understanding by policymakers, business leaders, the media, and the general public of the high economic and social stake that all Arizonans have in the well-being of our children.

CAA focuses on the need to build broad support for public and private investments in successful policies and programs that improve the lives and life chances of Arizona's children and their families. Our board of directors includes business, civic, and community leaders who believe that the quality of life of our state's children is the single most important determinant of Arizona's future. CAA is supported by individual donations, foundation grants, and corporate contributions.

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Introduction



More than 300,000 Arizona children lack health insurance. Studies show that uninsured children do not get the health care they need when they need it. They often go without preventive health care such as well-child visits and immunizations.¹ Children who lack health insurance are more likely to have an untreated health problem and are less likely to see a doctor when they need one. They are also less likely to get care for injuries, see a physician if chronically ill, or get needed dental care.

Cost is the most significant barrier to accessing health insurance. Many working parents are simply unable to afford health insurance for their children. To help parents overcome the cost barrier, Arizona has created several opportunities for free or low-cost children's health insurance. The largest of these programs, Medicaid, managed by the Arizona Health Care Cost Containment System (AHCCCS), currently provides almost 250,000 children with free health insurance.² In addition, Arizona's KidsCare program, initiated in the fall of 1998, offers low cost health insurance to thousands of children who would otherwise go without health care coverage.

The cost of insurance is not the only barrier to children getting health care coverage. Across the nation, about 3.4 million children who are uninsured are actually eligible for Medicaid but not enrolled. Here in Arizona, it is estimated that 70,000 uninsured children are eligible for AHCCCS but are not enrolled.³ National research demonstrates that most uninsured Medicaid-eligible children come from working poor or near poor families. Their parents are often employed by small firms, and are themselves uninsured.⁴

There is much speculation about the reasons that Arizona parents do not enroll their eligible children in AHCCCS. Some hypothesize that disdain for welfare programs or a simple lack of knowledge of eligibility may be the most significant barriers.⁵ However, no research exists which directly asks parents of AHCCCS-eligible children to identify enrollment barriers.

Listening to Arizona’s Parents

Children’s Action Alliance (CAA) held 11 focus groups with low-income parents from across Arizona to discuss their experiences and perceptions of the AHCCCS application and eligibility process handled by the Department of Economic Security. Between October and December, CAA met with 117 parents from Phoenix, Tucson, Douglas, Somerton and Prescott.

While participating parents came from different kinds of communities and households, they consistently and repeatedly described three perceptions of the AHCCCS enrollment process that discourage them from enrolling their children:

- Excessive, intrusive and complicated paperwork
- Time-consuming and burdensome appointment procedures
- Demeaning interactions with eligibility staff

This report summarizes the main findings from the focus groups and describes potential solutions. While some solutions can be implemented through administrative changes, others require statutory change or funding through the state legislature. The report is intended to help state officials and community organizations better understand the barriers to enrollment in existing health care coverage programs, so that we can succeed in reducing the number of uninsured children and improving children’s health in Arizona.

CAA has discussed the findings with state officials from the governor’s office, the Department of Economic Security (DES) and AHCCCS. All have expressed interest in addressing the barriers parents experience. Changes are already under way to streamline the application process, provide flexible hours for appointments, and allow a 12-month period between eligibility appointments for families who are receiving medical assistance and no other benefits.

In each community where a focus group was held, CAA worked with a local contact (social service provider, local health department, clinic, or health outreach coordinator) to find parents to participate. Parents were informed about the focus group discussions through flyers and personal invitations from health and social service providers. Invitations to participate were targeted at working parents earning low wages who had uninsured children. These parents were invited to a discussion of health insurance for children.

Participating parents were paid \$20 and child care was provided when needed. Almost all the parents who participated had uninsured children who were not currently enrolled in AHCCCS. Most had some experience with the AHCCCS system, although a few did not.

Of the 117 parents we spoke with in the focus groups, 17% were Caucasian, 15% were black, and 68% were Hispanic. Collectively, participating parents had 240 children. Participants had incomes ranging from \$10,000 to \$28,000 per year, with an average of \$15,000.

Location	Total Number of Focus Groups	Total Number of Participating Parents
Phoenix	4	41
Tucson	4	39
Douglas	1	18
Prescott	1	8
Somerton	1	11

In each focus group session a variety of questions were asked and the discussion covered a broad range of issues associated with enrolling in AHCCCS. We asked participants to describe:

- their awareness of and general opinion of AHCCCS
- the enrollment process
- positive and negative aspects of enrollment
- reasons why their children were not enrolled
- suggested strategies to reduce barriers to enrollment
- suggested strategies to increase awareness of AHCCCS and KidsCare

These questions provided a rich description of parents' perceptions of the enrollment process, enabled participants to provide examples of their experiences with the enrollment process, and facilitated discussion among parents on potential solutions to enrollment barriers.

AHCCCS Enrollment Process

The current AHCCCS enrollment process has been shaped by the history of the program. When AHCCCS was first established as Arizona's Medicaid program in 1982, eligibility was limited to families who were enrolled in cash assistance programs (Aid to Families with Dependent Children or the Supplemental Security Income program). Although new categories of eligible children have been added to AHCCCS through the years, a strong link remained between welfare and AHCCCS. The enrollment process evolved to meet two major objectives: 1) ensuring that the rules were met and families received only the benefits for which they were eligible; and 2) combining procedures for AHCCCS and welfare so that families didn't have to go through the process two or three times in different places.

Today, families can apply for AHCCCS at DES eligibility offices or at county eligibility offices.⁶ The application process includes several stages. First, parents must complete a 15-page preliminary application which includes questions about income, assets, and family composition. Parents must collect supporting documents such as copies of birth certificates, social security cards, and pay stubs or other proof of income. Next, there is an in-person interview with DES eligibility staff to verify the information on the application, answer supplemental questions, and provide the supporting documents. DES staff has 45 days to act on the information gathered.

If a family applies at DES, the application families complete to enroll in AHCCCS will also determine their eligibility for TANF cash assistance and the Food Stamps program. Therefore, the information families are asked to provide for the application goes beyond the information that is needed for AHCCCS enrollment itself.

In 1996, federal welfare reform disconnected Medicaid eligibility and enrollment from cash assistance eligibility and enrollment. With this change, it has become increasingly important to make families aware of their eligibility for AHCCCS and to make the enrollment procedures accessible. Now that the policy objectives have shifted toward reducing the number of uninsured children, it is important to reexamine the AHCCCS enrollment procedures.

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Focus Group Findings & Recommendations



Several overriding themes emerged from the focus group discussions that help us to better understand the barriers to enrolling in AHCCCS. Most important, it became clear that there is no single barrier that prohibits parents from enrolling. Indeed, it is a combination of barriers that discouraged parents. Fortunately, as several parents noted, we need not eliminate all the barriers in order to significantly improve the enrollment process. If we can eliminate several of the barriers, the process will become less overwhelming to parents and enrollment will increase.

It also became clear that the existing barriers are quite significant. Many parents said that the barriers were so significant that they would not even attempt to enroll their children. These barriers not only affect the probability of enrollment for a parent who has experienced them first hand, but also discourage those who have heard about problems from neighbors, friends and relatives. As two parents said:

“

I won't apply for AHCCCS because of all the stories I've heard. It just sounds terrible. I won't go. It just isn't worth it...going through all that hassle. Prescott Parent

This is why I don't apply anymore for AHCCCS. Because I don't want to go over there and be treated the way these women have been treated, and the way that I have been treated before. So when my kids get sick, I just have to take them to the emergency room. Phoenix Parent

”

While the parents participating in the focus group discussions represented a diverse group of Arizonans, three key perceptions of the enrollment process were consistently raised: 1) excessive, intrusive and complicated paperwork; 2) time-consuming and burdensome appointment procedures; and 3) demeaning interactions with eligibility staff. In this section we identify the key barriers to enrolling children in AHCCCS and outline proposed solutions. Several of the solutions affect more than one barrier to enrollment.

Time-Consuming and Burdensome Appointment Procedures

Problems

- Long waits
- Inconvenient hours
- Offices not child-friendly

Solutions

- Mail in application
- Improved scheduling
- Out-stationing
- Extended hours
- 12-month coverage

Barrier:

Parents frequently spoke about the need to spend many hours at the DES eligibility office. Parents reported that they never knew how long they were going to have to wait. Even when they had a scheduled appointment, they often waited several hours to be seen. This time-consuming appointment process requires parents to take a whole day off work and the loss of a day's pay imposes a very real financial hardship.

In addition, DES eligibility offices are generally open weekdays from about 7:30 a.m. to 5:00 p.m. These hours are burdensome for working parents. As one parent said:

“...you would think that they would be more cooperative about your schedule and respect the fact that you are struggling and don't make you take a day off. Because that day off may mean that I lose a day's pay. And that means that I may not be able to pay the electric bill.”
Tucson Parent

Many parents also noted that DES eligibility offices are not child-friendly. While parents reported being discouraged from bringing their children to appointments, often they had no reliable child care and no option but to bring their children to the DES eligibility office. Several parents noted that DES-AHCCCS enrollment workers reprimanded children who were unattended, drinking at the water fountain, or playing with papers. Not having adequate child care and knowing that bringing children to the office was going to be a problem increased parents' frustration with the process. One parent said:

“They tell you when they sign you up for the interview that you need to find someone to watch your kids. But it is not that easy. Some single parents, some teenagers, and even me – there is no one to watch them. All the responsible people are working during the day. I won't leave my kids with dangerous people no matter what AHCCCS says.”
Phoenix Parent

Solutions:

There are several possible options that would make the enrollment procedure less burdensome and time-consuming for parents who are working, caring for their children, and struggling to make ends meet.

A **mail-in application** and mail-in paperwork for redetermining eligibility would remove a barrier for parents who work during regular business hours. It would also relieve the need for parents to find reliable child care during the day or bring their children to an enrollment appointment. A two-page mail-in application is already in use for KidsCare.

An examination of scheduling procedures may result in ideas to reduce both the waiting time and the unpredictability of enrollment appointments. Although it is often difficult to predict the flow of applicants, historical scheduling information may help to improve the rate of on-time appointments.

Out-stationing, the placement of eligibility workers in non-traditional settings such as schools or medical clinics, was recognized by several parents as being helpful to them in the enrollment process. One parent who was able to enroll at her children’s school stated:

“ It is helpful to have the office here at the school. It is much better because I come here anyway. So even though the workers they may not be so nice, at least the office is close by. Phoenix Parent ”

Although some schools have discontinued out-stationing on campus due to security concerns, other sites such as food banks or community centers could be explored.

Extended eligibility office hours would help some parents enroll their children. Currently, DES makes off-hours appointments available to clients upon request, but this has not been well publicized. Our focus group participants were not aware of this opportunity. Steps are now under way to publicize the availability of evening appointments.

Finally, **allowing a 12-month period before recertification** would reduce the frequency required for in-person appointments. Currently, parents must return to the DES office every six months for an in-person appointment to provide updated eligibility information. New federal regulations allow a twelve-month period between eligibility redeterminations precisely to limit the number of children who become uninsured due to the burdens of repeated appointment and documentation requirements. The DES policy is being changed to allow families who are receiving AHCCCS only to reapply every 12 months. However, families who receive TANF or Food Stamps in addition to AHCCCS will continue to have eligibility redetermined every six months.

Excessive, Intrusive, and Complicated Paperwork

Problems

- Difficult paperwork requirements**
- Many detailed and personal questions**
- Repeat the process every 6 months**

Solutions

- Staged application**
- 12-month coverage**
- Clarify or eliminate documentation requirements**
- Transfer information among state agencies**

Barrier:

Parents described the sheer volume of required documentation as overwhelming and extremely difficult to pull together. For example, parents talked about the difficulty of obtaining old pay stubs from previous employers. Parents also said it was difficult to contact former landlords to get copies of rental agreements to verify rent paid in the past. Several parents described receiving letters asking for specific documentation within a very short time frame. When parents were unable to meet the deadline, they did not continue with the application.

In addition, parents noted being asked some very personal questions about the members of their household. Several parents reported that the application process required them to describe how they bought toothpaste, deodorant and diapers. Parents described these questions as embarrassing and inappropriate and said that the questions discouraged them from applying.

“ They want to know everything. Who your old man is or who your boyfriend is. All the details. One interviewer asked me when the last time I had sex was. Now that was just too personal. But you know, you got to answer. Phoenix parent ”

Although it may have been the Division of Child Support Enforcement that asked these questions as part of an evaluation, the questions are perceived as being related to AHCCCS eligibility.

Finally, parents described the challenge of starting the paperwork process all over again every six months for recertification. Parents felt this repeated requirement was onerous and unnecessary. As one parent said:

“ See, you don't have any money for food and other stuff, but you somehow can find enough money to make copies of a ton of papers. Ones that they already have copies of! Prescott Parent ”

Solutions:

It is important to note that when parents apply for AHCCCS they are filling out a form and completing a process that also determines eligibility for cash assistance and Food Stamps. Many of the questions and information requirements that parents described as excessive and intrusive are not, in fact, required for AHCCCS enrollment but are included for the other programs. Although there is no minimum assets requirement for AHCCCS, for example, the enrollment application includes declarations and proof of savings, home ownership, and car ownership. Therefore, parents trying to enroll their children in AHCCCS perceive assets tests as part of the enrollment process.

A staged application could diminish the problem of excessive paperwork by allowing a family to apply for the program with the fewest documentation requirements first. Once that portion was complete, they could choose whether or not to continue with the more rigorous documentation requirements for additional programs. A completely separate Medicaid application would also reduce the perceived paperwork burden, but, at the same time, could result in the loss of other benefits families need and qualify for. DES and AHCCCS have agreed to begin using a simplified application such as the one currently used for KidsCare for Medicaid-only applicants.

Allowing a 12-month period before recertification would decrease the frequency with which parents must produce paperwork. Currently, a child must be re-evaluated for eligibility every six months. To remove barriers for families, the DES policy is being changed to allow 12 months before recertification for families who are receiving AHCCCS and no other benefits through DES.

Allowing continuous AHCCCS coverage for a 12-month period would allow a child to be insured continuously for one year, despite fluctuations in family income. Twelve-month coverage improves the continuity of care for children and potentially decreases the capitation rate for health plans that would be able to better implement cost-effective preventive services during a year-long period.

Separate information checklists for initial applications and eligibility recertification would greatly ease the perceived paperwork burden. More communication with families could clarify that some documentation is needed only once upon initial enrollment. Families may not realize, for example, that copies of the child's Social Security card and birth certificate are not required every six months to continue enrollment.

Some documentation requirements could be eliminated. Several states, for example, have eliminated the need for a parent to provide documentation of family income, relying instead on a parent's declaration of income. Verification is then performed through periodic audits. It would be useful to examine which of the existing documentation requirements are mandated by federal law, state law, and state policy and to reevaluate the effectiveness of those that can be altered.

Finally, **information-sharing among state agencies** can diminish paperwork difficulties for parents. It is a significant barrier, for example, for a parent to have to go to the Department of Health Services to get a copy of their child's birth certificate before they can complete an AHCCCS enrollment appointment. Alternatively, AHCCCS could request copies of birth certificates through inter-agency transfers.

Demeaning Interactions with Eligibility Staff

Problems

- Demeaning interactions with eligibility staff**

Solutions

- Mail-in application**
- 12-month coverage**
- Staged application**
- Shift staff incentives to encourage enrollment**
- Address staff working conditions**
- Increase customer service focus**

Barrier:

Parents across the state described negative interactions with DES eligibility workers as a significant barrier to enrollment in AHCCCS. While occasionally a parent mentioned a particularly helpful worker, eligibility staff overall were consistently described as rude, disrespectful, and simply difficult to interact with. As two parents said:

“ They treat everyone so poorly. Many people leave there in tears.
Phoenix Parent

They treat you like you are trash...as if you are trying to steal something from them. It is just awful to go there. Somerton Parent ”

Clearly, parents bring their own stress and discomfort to the eligibility process, and the application process creates tension between workers and applicants. However, most parents described their interaction with workers as making these problems worse, rather than better. Because of the perceived poor treatment and rude behavior by workers, parents described the enrollment process as degrading and demeaning. These feelings create an incredibly strong barrier, discouraging parents from beginning the enrollment process, attending scheduled appointments, and remaining enrolled.

A Tucson parent said:

“ They make you feel offended. You already go with your hands in your pockets, with nothing, asking these people for help. Then they make you feel even worse. I'm not likely to go back. I just said forget it. It was too much hassle. Tucson Parent ”

Solutions:

There are three possible solutions that have been identified earlier in this report that may make the enrollment process less daunting for parents. An additional three solutions could also reduce the tension in the process for both workers and applicants.

First, **mail-in applications** or applications that can be partially completed by parents at home will decrease the number of required face-to-face interactions. Second, **allowing 12 months before recertification** would also decrease the number of in-person appointments necessary. Third, the amount and type of information required for the application can be changed, **removing or re-ordering the most intrusive and burdensome questions**.

Shifting the incentives for eligibility workers could also help reduce the tension between workers and applicants. The current emphasis on reducing the rate of application errors encourages workers to focus on detailed procedures and to deny enrollment for all procedural reasons, even if a family is eligible. Alternatively, an emphasis on completing successful applications could help change workers' attitudes about their jobs and could motivate workers to help families complete the enrollment process.

Working conditions for eligibility staff should be examined as well. If workers suffer from overwhelming caseloads, unrealistic productivity expectations, low salaries, or a lack of technical or staff support, addressing these problems could reduce tension and negative interactions in the enrollment process. Improvements in these types of working conditions would require increased state funding.

Finally, **development of a customer service orientation** could make the enrollment process more positive. Parents now perceive that workers view them as incompetent people who are spending other people's hard earned tax dollars. With attention and training, a more positive culture could be encouraged that views AHCCCS as a critical and well-deserved service and treats applicants with greater respect and dignity.

Issues Not Identified as Barriers

There were several issues that we expected to hear in these discussions that did not emerge as significant barriers. The items that were not mentioned give us additional insight into what keeps parents from enrolling their children in health care coverage.

Welfare stigma: Some have argued that because AHCCCS is seen as a welfare program, working parents do not want to enroll. However, parents did not identify this as a barrier to enrollment. In fact, parents noted that even though they knew that some people looked down on parents who accepted public benefits, they needed the help and were motivated to apply. In addition, parents described signing up for other programs for low-income families, such as WIC, without significant problems. Seeing AHCCCS as a “welfare” program was not keeping these parents from enrolling.

Not all family members covered: There is some speculation that because all members of the family may not be eligible for AHCCCS, parents do not want to enroll their eligible children. This did not emerge as a barrier to enrollment in any of the focus groups. In fact, parents noted that even if they were not able to enroll themselves, it would be helpful to get coverage for their children.

Additional Issues

Some parents discussed other issues as barriers to enrollment.

Child-support enforcement: Several parents noted that having to provide information on the non-custodial parent in order to apply for AHCCCS was difficult. Often the custodial parent does not have the requested information about the non-custodial parent, such as a Social Security number, address, and employer's name. Although Medicaid coverage is not ultimately denied to a child on the basis of a parent's lack of cooperation with child support enforcement, these questions delay the provision of health coverage and act as a barrier to the custodial parent.

In addition, some parents fell through the cracks between the DES-AHCCCS eligibility system and the Division of Child-Support Enforcement. Although DES policy states that child-support income and health insurance are only counted if actually received, parents report differing experiences.

“ He (the father) is not paying. So I've been on services until they located the father. And when they located the father they dropped me from AHCCCS—even though he hasn't paid any child support. Not a dime. The court ordered that he pay child support and medical for the child—but he has no insurance and has no job. And I can't get anything. Tucson Parent

”

Assets: Several parents described being discouraged from applying for AHCCCS because they had assets such as a car. Parents described this problem as a "Catch 22" – the state system wants them to get a job, for which you need a car. But if you have a car, you are not eligible for AHCCCS. In fact, state law does not prohibit parents who are applying for AHCCCS for their children from owning a car. It is only when applying for other programs such as Food Stamps or cash assistance that owning a car of a certain value affects eligibility. However, because the AHCCCS application process encompasses several benefit programs, the stricter rules governing the other programs discourage families from enrolling in AHCCCS as well.

Language: Although all DES offices have some bilingual staff, several Spanish-speaking participants noted that they were asked by DES-AHCCCS workers to provide their own interpreter. Unfortunately, it is difficult for these parents to find an adult friend or relative who is able to take a day off of work to help them through the process. An insufficient number of bilingual staff is especially a problem in the offices that are located in largely Spanish speaking neighborhoods.

Citizenship issues: In several communities, parents reported that their fear of being deported prohibited them from applying. Parents said that eligibility workers threatened them with deportation for trying to enroll their children in AHCCCS – even though their children were citizens. Similar concerns affected legal immigrants who are permanent residents in the United States. Parents who wanted to become naturalized citizens were often discouraged from enrolling their children in AHCCCS because the use of public health coverage programs might adversely affect their chances to become citizens.

In late May 1999 (after the focus groups were completed), new federal guidelines were issued that specify that neither AHCCCS nor KidsCare enrollment will be counted against an individual in the citizenship process. Widespread and clear communication of this policy will be needed to change parents' perceptions and, ultimately, to remove this barrier to enrollment.

Conclusion



Thousands of Arizona children who are eligible for AHCCCS are not enrolled. While it would be easy to simply blame parents for this missed opportunity, it is important to examine the reasons for non-enrollment so that we can reduce the number of uninsured children. Through focus groups conducted by Children's Action Alliance, Arizona parents of eligible children have identified three perceptions of the enrollment process that discourage them from enrolling their children:

- ❑ Excessive, intrusive and complicated paperwork
- ❑ Time-consuming and burdensome appointment procedures
- ❑ Demeaning interactions with eligibility staff

These characteristics of the enrollment process present significant, tangible barriers that limit children's access to health care. The barriers in the DES eligibility process have arisen largely because of the historical link between Medicaid and welfare. Concerns about welfare recipients cheating the system led to numerous cumbersome documentation requirements. In addition, a desire to coordinate benefits for needy families led to application procedures that cover a number of different benefit programs and go beyond what is needed for Medicaid enrollment alone.

Both national and state priorities for health care coverage have shifted since AHCCCS was created in 1982. It is becoming more and more common for children's health insurance to be unaffordable for working parents. There is also a growing recognition that a lack of health care coverage not only threatens the health of the affected children, but also imposes tremendous costs on our community.

Over the past several years, as employer-based health care coverage has diminished, Medicaid eligibility has expanded to include many children who live in families that are not eligible for welfare benefits. The 1996 federal welfare reform law formally disconnected Medicaid from welfare. Yet, Arizona's Medicaid enrollment process remains based in the welfare system, with its accompanying procedural burdens.

This evolution requires a reexamination of our existing enrollment procedures and some redesign to effectively reduce the number of uninsured children. Fortunately, the focus group research indicates that changes in the enrollment process need not be dramatic or sweeping. Parents suggested that simple changes to several steps in the process could make a real difference in enrollment.

Many of the suggested changes are already under review and development by state officials. Examples of these changes include: using an application form that does not require information about car ownership or other assets for a family seeking health care coverage only; allowing a 12-month period between certification appointments; and making appointment times available for families beyond normal business hours. Although these are each small changes in the enrollment process, they may have significant impact on a family's ability to get enrolled and remain covered.

Increased AHCCCS enrollment is a critical component in closing the gap in children's health care coverage. We have the opportunity to listen to Arizona's working parents who desperately want and need health insurance for their children. Simplifying the AHCCCS enrollment process with these parents in mind can help their children get the health care they need.

ENDNOTES

1 Charles N. Oberg. "Medically Uninsured Children in the United States: A Challenge to Public Policy." *Pediatrics*. Vol. 85:5 (1990).

2 For the purposes of this report, we will refer to the Arizona Medicaid program as AHCCCS.

3 US GAO. "Medicaid: Demographics of Nonenrolled Children Suggest State Outreach Strategies." March, 20 1998. USGAO HEHS-98-93.

4 Ibid.

5 Families USA "Outreach Strategies in the State Children's Health Insurance Program." June 1998.

6 Families who apply for KidsCare but are actually eligible for AHCCCS may become enrolled in AHCCCS through the mail-in application for KidsCare. However, after the initial enrollment, the usual DES eligibility redetermination process is required every six months.

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CHILDREN'S ACTION ALLIANCE

Statewide Office

4001 N. 3rd Street, Suite 160

Phoenix, AZ 85012

Tel. 602-266-0707

Fax 602-263-8792

Email: caa@azchildren.org

Web address: www.azchildren.org

Southern Arizona Office

3610 North Prince Village Place, Suite 100

Tucson, AZ 85719

Tel. 520-795-4199

Fax 520-795-5499