

## **Attachment B Stakeholder Interview Summary**

The Consortium of Children's Asthma Camps Board of Directors commissioned a study, beginning, mid-September 2004, to determine the value of asthma camps. This multi-method study included interviewing key stakeholders involved with children's asthma camps. This document describes the process and key findings from those interviews.

### **Methods:**

Twenty-six interviews were conducted, via telephone or in-person, with children's asthma camp stakeholders. A stakeholder was defined as someone who would do their job differently tomorrow, based on study findings presented today; a sponsoring organization representative; or a key leader in the asthma camp community. The Consortium of Children's Asthma Camps Executive Director originally developed a list of stakeholders representing established and new camps, small and large camps, organizations who recently quit sponsoring asthma camps, and Consortium of Children's Asthma Camp board members and consultants. This list was supplemented through stakeholder recommendations or referral of the interview to another individual. The asthma camp roles of the stakeholders ranged from camp director/coordinator, medical director, medical volunteer, organization board member, parent of camp participant, and higher-level leadership/administrative oversight.

The interviews were conducted between September 29, 2004 and November 1, 2004. The interviews varied from 10 minutes to 45 minutes in length, depending on the role of the stakeholder, their familiarity with asthma camps, and their willingness to share details.

The stakeholders were queried about their role, length of involvement with asthma camps, perception of what the children, families, health care professional volunteers, and organizations receive from camp, their perception of the value of asthma camp, what the impact would be on various sectors if their camp was eliminated, organizational motives for sponsoring camps, partnership development, educational components of camp, camp budget, and the impact camp has on their organization's fundraising efforts.

### **Findings:**

A variety of themes emerged from these stakeholder interviews. Below is a summary and supporting statements for each theme. To maintain confidentiality of the interviewee, organizational names were withheld.

### **Stakeholders perceive that children's asthma camps provide a variety of experiences that children with asthma could not receive anywhere else.**

Feeling of normalcy: 14 (54%) stakeholders indicated that by attending asthma camps, children with asthma have the opportunity to spend significant time with other children with asthma. This allows the children to feel normal and realize there are other children with asthma just like them.

- "It provides a realization that they are not alone."

- “Children find they are not all that different from other children.”
- “They receive a feeling of inclusion. They aren’t alone in the world.”

Opportunity for intensive asthma education: 14 (54%) stakeholders indicated that by attending asthma camps, the children receive quality, intensive asthma education in a variety of formats.

- “We provide one-hour of asthma education per day. The lessons are reinforced throughout the day. The education is age appropriate.”
- “We provide one-hour of formal education per day. Then the lessons are integrated into camp day through different formats. There is direct teaching through one nurse per cabin, small group activities based on age, large group activities, and one-on-one teaching if needed.”

Opportunity for a total camp experience: Fourteen (54%) stakeholders shared that asthma camp provides children with asthma a total camp experience in a medically safe environment.

- “The children are able to fully participate in the camp experience.”
- “The children are at camp and safe with their disease.”
- “Camp is an opportunity for children with asthma to enjoy the outdoors free of worry and restrictions due to their asthma.”

Independence from their parents/primary caregiver: Nine (35%) stakeholders indicated that asthma camp provides an opportunity for children to develop self-confidence and independence from their primary caregiver.

- “Often, camp is the first time away from home for this child because of medical concerns.”
- “They gain confidence. They learn they can be away from their primary care providers. As a Mom, I gained independence that someone else can take care of my child. It is difficult to give up your most prized possession for one week.”
- “Children learn ‘I can help take care of my asthma without my parents’.”

Opportunity for kids can be kids: Eight (31%) stakeholders mentioned that asthma camp provides children with asthma an opportunity to do activities that they are not normally able to do because of their disease.

- “We do things they are not normally able to do, such as swimming and sports.”
- “We never let kids use asthma as an excuse not to participate.”
- “Our purpose is to show kids what they can do with controlled asthma.”
- “Kids can be kids.”
- “Camp is a unique ‘I can do’ attitude.”

Opportunity to build the child’s socialization skills, self-confidence, and self-esteem: Five (19%) stakeholders shared that asthma camp assists in the personal development of the child.

- “Children gain self-assurance.”
- “The children build their confidence level for asthma self-management so they can leave home and go to mainstream camps in the future.”

Other benefits of the asthma camp experience mentioned by stakeholders included:

- Camp provides an opportunity to reach children from limited-income and inner-city families. (4)
- Children often cannot attend a mainstream camp because of their asthma. (3)
- There is a positive impact on the parents and families ability to manage asthma. (2)

**Stakeholders perceived that asthma camps are valuable for a variety of reasons.**

Stakeholders perceived the greatest value of asthma camp to be an opportunity to provide intensive asthma education for children with asthma: Twelve (46%) stakeholders described the opportunity to provide asthma education as camp's greatest value.

- "Camp is an alternative source for asthma education, skill building, and changing asthma-related behavior."
- "To kids, camp is a great experience coupled with great education on management."
- "We have medical volunteers teach children how to manage asthma outdoors, to pre-treat, carry and use rescue medications, use spacer properly, zones, medications, triggers, and how to identify early warning signs."
- "It is a typical camp experience plus asthma education."

Opportunity for interaction with peers: Six (23%) stakeholders indicated that interaction among peers with asthma is the greatest value of asthma camp.

- "Children see their peers also have asthma."
- "Camp shows children they are not alone and not weird."

Opportunity to experience a camp specifically for them: Five (19%) stakeholders indicated that having a camping experience specifically for children with asthma is the greatest value.

- "Every kids dreams of going to camp and staying away from their parents overnight."

Further the development of the child: Four (15%) stakeholders mentioned that the value of children's asthma camps is the development of the child's independence and self-esteem.

- "Children excel individually, they learn not to be embarrassed."
- "We teach that children with asthma can achieve anything!"
- "Camp builds independence and stretches their horizons."

The sponsoring organization and asthma community also receive benefits from asthma camps: Four (15%) stakeholders mentioned that the value of asthma camp is reaped by the sponsoring organization and broader asthma community.

- "Asthma camp is the cornerstone of building the asthma community. It connects (my organization) to the medical community, it provides a research opportunity, and it is a direct service of our organization for the public to see."
- "Camp sends the public message that asthma can be controlled. Camp sends little ambassadors for asthma out."
- "It is a feel good experience for (my organization), volunteers, and families of kids with asthma."

- “Camp provides a ‘warm fuzzy’ product to do fundraising.”

**A variety of local camp evaluations and research projects have been conducted.**

Seventeen (65%) of the stakeholders mentioned that one or more evaluations or research projects had been conducted through the asthma camp with which they were involved. Examples of the types of evaluation or research conducted at individual camps includes:

- Pre-post test of children’s asthma knowledge and skills (5)
- Pre-post (or simply post-test) of parent’s asthma knowledge (4)
- Post-camp participant and/or parent satisfaction survey (4)
- Evaluation of the asthma education content and delivery (2)
- Post-camp quality of life questionnaire (2)
- Cost-benefit analysis (1)

Please see the summary of published and unpublished research for a description of the above research activities and related findings.

**Stakeholders indicated the primary motive for their organization to sponsor asthma camps is to help children with asthma (10 or 38%).**

- The following testimonial was written on the back of one camper’s post-camp satisfaction form. She has severe persistent asthma and had low self-esteem. She wrote this when she was 14 years old. “I have been coming (to asthma camp) since I was eight. Before then I was rejected from others and had no self-confidence. Since I have gone, I have made my first best friends here, and have felt special, and no longer have to hide my disease from others. Without this camp, I would not be the person that I am today. I can’t thank everyone enough for giving me a place I think of everyday and smile because of the memories and lessons I have come back with. I love it with all my heart and soul. I will never forget it or the people that helped me to enjoy my life.”

Other organizational motives for asthma camp provided by stakeholders included:

Tradition (4):

- “We continue because of tradition. Tradition needs to be woven into the foundation of an organization.”
- “For some organizations, it may simply be tradition. It is expected by the volunteers.”

Part of organizational mission (2):

- “So many things we do are not visible to the community. This one is visible.”
- “Camp is a visible manifestation of carrying out (my organization’s) education mission.”

To fill a community need (2):

- “No one else was doing it. Parents were calling with concerns and asking where they could send their children.”

Publicity/outreach (2):

- “The hospital started camp because it was good publicity, a win-win situation, and provided huge outreach to the community.”
- “Camp is marketing tool, it brings in donors and cash.”

Three of the stakeholders indicated that they did not know their organization’s motive for sponsoring asthma camps.

**The asthma camp experience impacts the day-to-day practice of health care providers in a variety of ways.** (Note: All but one of the health care providers interviewed were physicians.)

- “When I see kids away from the office, it is a real world experience and I see real behaviors.”
- “I get to know what kids are like in the real world. The clinic is an artificial environment. Camp makes me more aware of the real life challenges and barriers.”
- “Camp reinforces the idea that you must teach something three times.”
- “I have a special bond with the kids I also see at camp. This is what I do everyday, then I go to camp for three days a year.”

**Asthma camps provide organizations the opportunity to develop community partnerships.**

Stakeholders often first described partnerships as financial sponsorships (6 or 23%).

- “In 2005, camp will be paid for completely by the Kansas City Royals. People will donate for kids.”
- “The Minnesota Vikings donate \$100 for each touchdown they make throughout the year.”

Several unique, non-financial partnerships were described by stakeholders.

- “The four largest health care organizations, Children’s Hospital, National Jewish, Kaiser, and ..... come together annually to develop the asthma education curriculum.”
- In (our state), four hospitals provide the volunteer medical staff while on the hospital payroll. How? We simply asked!”
- “We work with prep programs (RN and RT) to have the students volunteer at camps. They learn a lot!”

Two stakeholders described partnerships that extend beyond camp.

- “When we go into a community for camp, we talk with the elected officials. We interact with these folks in a close manner. It feels like we are doing something together. We work with the elected officials in a non-policy/advocacy manner. It sets the stage for the remainder of the year. Later, they may listen or support (my organization’s) policies or bills.”
- “The University School of Respiratory Science Center sends two MDs to camp. One of them is the camp director. This makes for good partnerships outside of the clinic setting. We were able to partner on a COPD project later. This wouldn’t have happened without our previous partnership experience.”

**The extent to which stakeholders believed there was a community expectation for their organization to provide direct service varied.**

- “It is part of the expectation. If the community donates money, it is expect there is a program or specific result.”
- “This is our 19<sup>th</sup> year. It is the expectation of the community that we hold camp. Period.”
- “There is no strong community expectation. The city government doesn’t have a clue that we do camp. However the asthma community feels strongly about camp.”

**Asthma camp impacts the fundraising efforts of an organization**

- All stakeholders indicated that their sponsoring organization raises money for asthma camp.
- Fundraising in some organizations is often done in the name of asthma camp.
- Fundraising for asthma camp is relatively easy.
- Fundraising may or may not meet the camp budget. Stakeholders indicated that fundraising usually meets the out-of-pocket expenses, however it is reportedly less common that fundraising cover the administrative/support staff time.
- Three of the stakeholders questioned whether all of the money raised under the heading of asthma camp goes directly into a camp specific budget.
  - “We always fundraise in the name of kids with asthma and asthma camp. Not all funds raised in the name of camp go to the camp budget.”
  - “We combined two of our overnight camps. Before, all of our funds went to (an organization) to be managed. We started questioning what happened to the surplus. Now, these two camps are going to get their own tax ID number. Another (camp in our state) had the same experience and now has their own tax ID number and system.”

Raising funds for camp may not translate into raising funds for other issues.

- “Asthma camp for children is a very easily understood sell. Money for research is more difficult. You can’t translate the \$500 for camp into \$500 for research.”
- “It is easier to raise money for kids than research animals.”

**Stakeholders reported a variety of impacts that would occur if their organization quit sponsoring asthma camps.**

The sponsoring organization would be impacted (18 or 69%):

Organizations would lose a fundraising opportunity. (8)

- “Other physicians in my community would set up their own camps and use (my organizations’) volunteers and fundraising partners.”
- “People identify us with asthma camp, it is an easy way to raise funds.”
- “We would loose something valuable for fundraising and partnerships.”

The sponsoring organization’s public image would be negatively impacted. (7)

- “It would decrease our public image.”
- “It benefits (my organization). It is the most visible thing we do.”
- “Our organization would lose their direct tie to the family. We would lose passion if we get too far away from the patients. It would hurt (my organization’s) reputation.”
- “For the amount of money raised, (this organization) does almost nothing for the allergy/asthma community. There is very little activity this (organization) does for asthma. (This organization) fundraises to be an entity. Once per year they hold a dinner to raise funds, then we don’t see them again in our community for a year.”
- “Without camp, (my organization) is just fundraising to be an entity. There is a perception of too many staff without something good to do.”

Sponsoring organizations may lose their volunteer base. (5)

- “We would lose our medical and lay volunteers.”
- “Camp connects and brings new medical professionals into camp and (my organization).
- “We would lose health care professionals as volunteers. This is the entry into volunteers for other programs.”

Closing asthma camps would significantly impact children with asthma. (13)

- “(My organization) would lose a great program that benefits kids.”
- “It would cause a void for a lot of the kids. Many are repeat campers.”
- “We wouldn’t be able to educate kids, because these kids are not involved with other community programs.”

Other comments made by stakeholders regarding closing asthma camps included:

- Camp provides respite care for parents. (3)
- Asthma camp is their organization’s only asthma-related or largest program. (2)
- Stakeholders indicated that they would expect to see kids in more acute or severe settings. (2)
- “It would free up staff time for other projects.” (1)

### **Summary:**

Stakeholders perceived asthma camp to be a valuable opportunity to provide intensive asthma education to children with asthma in a medically safe, family-friendly, and peer-to-peer environment. In addition to sponsoring organizations being able to help kids with asthma, asthma camp also provides an excellent fundraising, partnering, volunteer recruitment, and public/medical community outreach opportunity.

