

PARENTS HELPING PARENTS FIGHT ASTHMA



TRAINING MANUAL FOR PARENT MENTORS

Glenn Flores, MD, Christina Bridon,
Amanda Schulte, RN, and Vanessa Brown



Pediatrics



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SECTION 1: WHY ASTHMA IS SUCH AN IMPORTANT ISSUE FOR AMERICAN CHILDREN

In this section you will learn about:

- ◆ Asthma in the United States
- ◆ Racial/Ethnic Disparities in Asthma
- ◆ Asthma in Milwaukee

Asthma is the most common **chronic** childhood disease in the United States. Asthma is called a chronic disease because it lasts for a long time and children often have asthma symptoms and attacks over and over again.

Asthma is:

- The number one reason for missed school days²³
- The cause of 1/3 of all child emergency room visits²³
- The fourth most common cause of children's visits to health care providers²³

Asthma affects minority children more than white children.

- Only 3% of white children have asthma, compared to 6% of African-American and 11% of Puerto Rican children⁵
- African-American children are hospitalized for asthma three times more often than white children¹
- African-American children are three times more likely than white children to be seen in the emergency room for asthma¹
- The death rate from asthma among African-American children is almost five times higher than that of white children¹

Minority children also receive poorer quality medical care for their asthma than white children.

- Among preschoolers hospitalized for asthma, Latinos are 17 times less likely than whites or African-Americans to be given a nebulizer to be used at home⁴.
- Both African-American and Latino children are less likely than white children to be prescribed inhaled steroid medication, one of the most effective asthma treatments^{5,6}

These differences in asthma rates and quality of medical care among racial/ethnic groups are called **disparities**. Little research has been done on why such disparities between minority and white children exist. The Parents Helping Parents Fight Asthma Project is the first program to try to eliminate asthma disparities between minority and white children by using parent mentors.

ASTHMA IN MILWAUKEE

Asthma affects many Milwaukee children. 1 out of 7 children in central city Milwaukee suffer from asthma.¹⁸ Asthma is the most common reason for emergency department and inpatient visits at the Children's Hospital of Wisconsin.¹⁸

The number of children with asthma is expressed using a number called a **rate**. Asthma rates are estimates of how many children have asthma in a given population or community. Asthma hospitalization rates estimate the number of children that have been hospitalized for asthma in a population or community. The asthma hospitalization rate for children in inner city Milwaukee is much higher than the rest of the city and surrounding suburbs.

Please see Appendix 1 for a Map of the City of Milwaukee Asthma Hospitalization Rates by zip code

SECTION 2: SHARING EXPERIENCES

In this section we invite you to share your experiences about being a parent with a child who has asthma.

PARENTS' PERSPECTIVES ON CHILDHOOD ASTHMA

Asthma is a complex disease that can cause stress for parents trying to manage their child's asthma. Parents' opinions and perspectives are very important, because no one has more experience with their children's asthma than the parents who care for their asthmatic children on a daily basis.



This brainstorming session will give you an opportunity to share with us the cultural issues that are most important in caring for your child's asthma.

Question 1: Why is it that minority children are more likely to have asthma, but get a lower quality of medical care for their asthma?

Question 2: What can parents do to make sure their asthmatic child has the healthiest, happiest life possible?

Question 3: What are the most important ways to keep children with asthma out of hospitals?

Question 4: What are the cultural issues that affect your child's asthma or asthma care the most?

SECTION 3: KEEPING CHILDREN OUT OF HOSPITALS

In this section you will learn about:

- ◆ Current research about how to prevent hospitalizations for asthma
- ◆ What to do to prevent children from being hospitalized for asthma
- ◆ Risk factors for hospitalizations

A hospitalization for asthma can be a sign that a child's asthma is out of control. Research has shown that many of these hospitalizations are preventable if the proper steps are taken early to control the child's asthma.



KEEPING CHILDREN OUT OF HOSPITALS STUDY¹³

A study called "Keeping Children Out of Hospitals" was done to find out how to prevent hospitalizations for children with asthma.

The following people caring for a hospitalized child with asthma were asked how the child's hospitalization could have been prevented:

- The child's parents
- The inpatient (hospital) doctor
- The child's regular (primary care) doctor

Parents and doctors answered these questions:

1. Do you think anything could have been done to prevent the child's hospitalization (If yes, what?)

2. Are you satisfied with the quality of care that your child received from your child's doctor?
3. Do you feel your child had easy access to health care?
4. Have you ever had any insurance problems that caused you not to bring your child into the doctor?
5. Have you ever had any problems getting medications for your child because of money or not having health insurance?

Children and Families

- The average age of the hospitalized children was four years old
- Most children had health insurance
- Most children were African-American and Latino
- The average family income was \$12,000 a year
- Most parents never graduated from high school

PARENTS' AND DOCTORS' SUGGESTIONS ON HOW TO KEEP CHILDREN OUT OF HOSPITALS

Taking Medication

Medications are extremely important in managing a child's asthma. Many parents and doctors said that the child's hospitalization could have been prevented if:

- Medications were taken regularly
- Equipment was working properly
- Medication refills were provided by doctors, easy to get, and filled by parents

Here are some of the comments parents in the study made:

Didn't take medication



Broken equipment

“Yes, it could have been avoided if she had a nebulizer at home, but it was broken”

“He has a nebulizer machine, but it was broken”

Ran out of medication/ No prescription refill

“Ran out of medication.”

“I was out of his medication. If he had had it, he would not need this admission.”

“The parent didn’t call for a med refill and the child was untreated for several days.”

Delayed Care and Follow-up Appointments

Many parents and doctors said that the child’s hospitalization could have been prevented if the child would have gotten care earlier, gone to a follow-up appointment, or called the doctor sooner when the child displayed early symptoms of an asthma attack.

“The child hadn’t come to the clinic in the past 4 months and the child needs more follow-ups.”

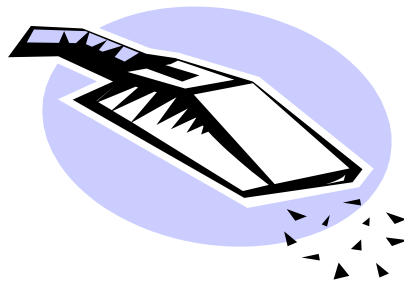
“He needed his follow-up check-up sooner.”

“This would have been avoidable if mom had brought the child in sooner.”



Avoid Exposure to Triggers

Being exposed to **triggers** can also cause asthma attacks. Triggers are things that set off a child’s asthma, like dust or animal hair. Both parents and doctors agreed that avoidance of triggers could prevent many hospitalizations for childhood asthma.



“She can’t be around cats, and someone at home smokes.”

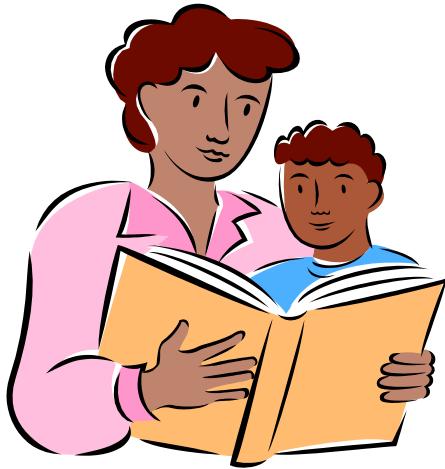
“The child needs to avoid triggers rather than just taking medications.”

“The attack came while the mother was vacuuming.”

“The child has a lot of environmental issues involved that are triggers, such as cats, dust, etc.”

More Asthma Education for Parents

Parents and doctors say that more education for parents would help prevent many hospitalizations for asthma. Doctors reported that some families needed more education about medications and how to provide the correct care for their children, and that sometimes the doctors themselves didn't give parents enough education.



“Mom doesn't understand the seriousness of teaching him [child] the importance of the medications, and she needs more education about that too.”

“It would have been helpful, if we had gotten information from his doctor sooner.”

“Parents need more education to avoid several hospitalizations.”

Housing Conditions

Housing conditions can greatly affect a child's asthma. Mold, cockroaches, carpet, and no heat can all trigger an asthma attack. Parents and doctors agree that good housing conditions could prevent a child from being hospitalized for asthma.

“I applied many times in housing to get a new one, but I haven't had any answer from them, and my apartment is in really bad condition.”

“The family needs to live in another apartment. You can see mold in the house. The city needs to be better at following housing rules.”

“The house produces a lot of dust and there is a problem with the ventilation system. The landlord is responsible for the apartment. There are mice and cockroaches too.”



HOSPITALIZATION RISK FACTORS

The Keeping Children Out of Hospitals Study found that there were certain **risk factors** or things that make it more likely for a child to be hospitalized for asthma. As a parent mentor, you will need to identify these risk factors for the children and families that you work with. Identifying these risks is the first step in preventing a hospitalization for asthma.

Risk factors include:

- **Adolescence**

Asthmatic children 11 years old and older (adolescents) are at higher risk of being hospitalized for asthma. Some reasons for this may be that they are:

- 1) In charge of their asthma care, yet may not be ready to handle the responsibility
- 2) Not supervised by their parents as often as younger children and may forget to take the proper medications
- 3) Exposed to environmental triggers, such as smoke, more often than younger children.



Parent Mentors should pay special attention to adolescents with asthma. Include adolescents as much as possible when interacting with family members. Talk with them one-on-one about what they can do to prevent asthma attacks.

- **No Health Insurance**

Children that do not have health insurance are more likely than insured children to be hospitalized for asthma. This may be because children without insurance often do not receive the proper care and medications for their asthma, which may cause more frequent visits to the hospital.

Parent Mentors that are working with uninsured children and their families should refer to Appendix 2 of the manual for tips on helping families to insure their uninsured children.

- **No contact with a regular (primary care) doctor**

Children that do not regularly visit their primary care doctor are at an increased risk for being hospitalized for their asthma. Regular visits

with a primary care doctor are key to effective management of a child's asthma. When children don't attend regular doctor visits, they and their parents miss out on getting important information that could prevent hospitalizations for asthma.

Please refer to Appendix 2 for more information on how to assist these families.

- **Finding medical care to be too expensive**

When parents can't afford their child's medical care, the child may not receive proper asthma care, putting the child at risk for an asthma hospitalization.

As a parent mentor, you will help families understand the importance of regular asthma care. Find out what problems exist: Does the family have insurance? Are co-pays too much for the family to afford? Encourage families to talk to their health care provider about difficulties paying for asthma care. Appendix 2 provides you with more information on these topics.



- **Families with “working poor” incomes**

Children from working poor families, defined as families that have trouble making ends meet despite working full-time, were found to be at increased risk for hospitalizations for asthma.

Parent Mentors that mentor working poor families should pay special attention to their needs. If a family is having financial difficulties, they may not be able to afford asthma or health care for their asthmatic children. Please refer to Appendix 3 for a list of free clinics.

SECTION 4: PARENTS HELPING PARENTS FIGHT ASTHMA PROJECT

In this section you will learn about:

- ◆ The Parent Mentor Project
- ◆ The goals of the Parent Mentor Project

- ◆ Other parent mentor programs in the United States
- ◆ Your job as a Parent Mentor
- ◆ Confidentiality

The Parents Helping Parents Fight Asthma project is called a **randomized controlled trial**. It will determine if parent mentors are better than usual asthma care in caring for children with asthma. There will be 300 children and families in the project, but only half will get a parent mentor. The other half will continue with the care that they would usually get (as if they were not in the project). These two groups will be compared to see if asthma in one group or the other improves.

The goal of the parent mentor program is to find out if Parent Mentors are better than usual asthma care in helping parents have a better quality of life, be more satisfied with their child's asthma care, feel more confident in caring for their child's asthma, and reduce:

- Asthma symptoms and attacks
- Missed school days
- Parents' missed work days
- Emergency department (ED) visits
- Hospitalizations

WHY USE PARENT MENTORS?

Parents have different experiences and knowledge about childhood asthma than doctors and nurses. They are very important because they care for their child everyday, making them the people that know their child's condition best. Experienced parents can teach the things they know to other parents that have children with the same chronic illness. They also can give valuable support to other parents because they understand better than anyone what it's like to care for a child with asthma.

There are a few parent mentor projects in the U.S. that help children and families, but none focuses on asthma. These programs are:

Special Needs Family Center, Milwaukee WI⁷

Parent mentors that have children with special needs provide other families that have children with special needs with emotional support, encouragement, strategies for coping, problem solving and links to community resources and health services.

Partnerships Empowering Parents and Professionals (PEPP) project, Palto Alto,CA¹⁷

Children waiting for a liver transplant (and their families) are paired with a parent mentor who provides support, information, and resources.

Akron's Parent Mentor Program, Akron OH(Cite)⁵

Parent Mentor volunteers offer support and friendship to other parents that have a child that has been recently diagnosed with a disease.

YOUR ROLE AS A PARENT MENTOR

As a team member of the Parents Helping Parents Fight asthma project, you will need to make a commitment to the program for 18 months. It's important that you be a parent mentor for the full 18 months because you will be working with children and families that desperately need your assistance and support. As a parent mentor you will be paired with 10 children and families of the same race/ethnicity and zip code, and will mentor each family for one year.

Your job as a Parent Mentor is to be a support and resource to families that have children with asthma. You will also help each family work with their doctors to get the best care possible for their children. By supporting each family, you will in no way be responsible for making a diagnosis, giving advice on how to treat asthma and take medications, or contradict any doctor's treatment.

As a parent mentor you will assist families with:

- Social support
- Education about their child's asthma
- Talking to doctors
- Making health care provider appointments
- Coping and problem solving skills
- Meeting other families that have children with asthma
- Creating a healthy home environment for children with asthma

Being a parent mentor requires that you:

- 1) Visit each of your families' homes two times
- 2) Contact families once a month by telephone
- 3) Meet with the Asthma Nurse once a month
- 4) Meet with all 10 families once a month over dinner at a community meeting site

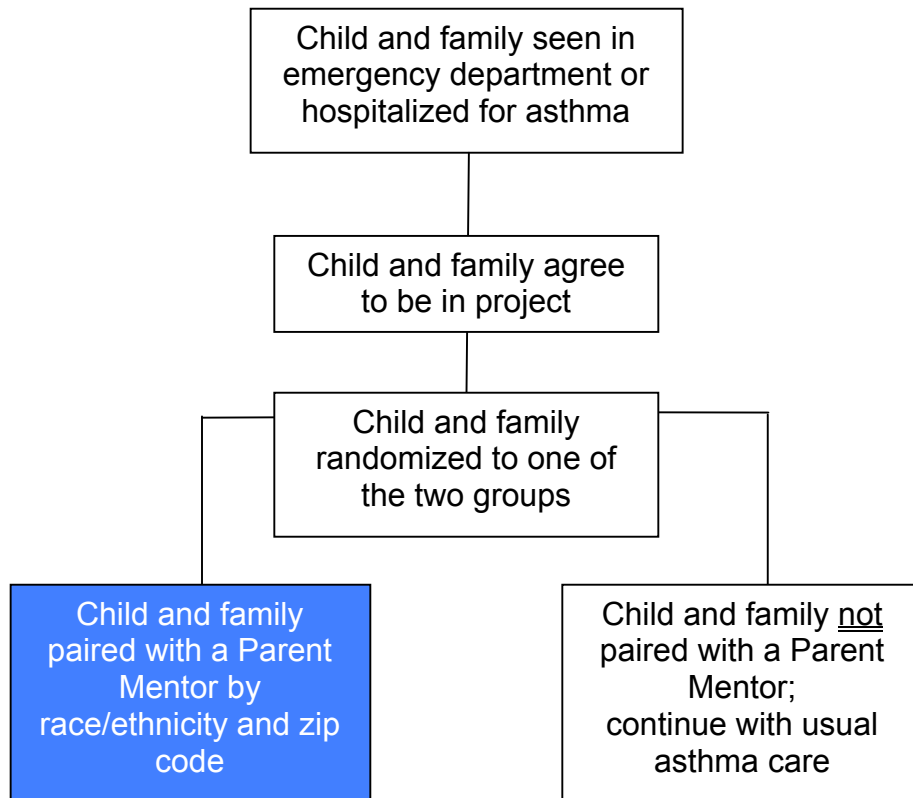
HOW AM I PAIRED WITH FAMILIES?

Only African-American and Latino children and families seen in the emergency department or inpatient ward at Children's Hospital or seen in the emergency department at Aurora-Sinai Hospital will be paired with you by race/ethnicity and zip code.

Zip Codes of Families in this Project

African-American	Latino
53206	53204
53208	53207
53209	53212
53216	53214
53218	53215

HERE IS HOW THE PROJECT WORKS



PARENT MENTOR PAY

You will be paid \$88 dollars per month per family that you are working with. The amount of money that you receive will depend on the *number of families* that you are mentoring and not the number of hours that you spend with families. You will probably average 2 hours a week per family, but may spend more or less time, depending on the needs of each individual family.

CONFIDENTIALITY²⁴

The rights and confidentiality of patients are protected not only by state and federal laws such as HIPPA, the Health Insurance Portability and Accountability Act of 1996, but also by the Joint Commission on Accreditation for Healthcare Organizations (JCAHO) and the American Nurses Association (ANA), among many other organizations. Parent Mentors must maintain confidentiality concerning health, financial, sexual and any other personal matters for all people involved in the Parents Helping Parents Fight Asthma Study. The federal Privacy Act and the administrative codes of all states pertinent to the federal act specify in detail the terms required for disclosure of medical information, medical records, addresses, phone numbers, race, social security numbers, and photographs.

The purpose of these laws is to prevent unauthorized sharing or misuse of any personal information relating to a patient. Information about the children and families *cannot* be shared with *anyone*, not even those closest to you, like your husband/wife or family members. When confidential information is given or received, it must be taken seriously. Confidential information should *only* be shared if it is in the best interest of the child and family to do so. Before releasing any information, you should always ask yourself:

(1) What is the minimum basic information I need to make known about a child and their family to get the results that I need?

(2) What should not be known about a child and their family?

The Privacy Act in particular protects these four things:

- Drug or alcohol abuse and its treatment
- Mental health
- Acquired immunodeficiency syndrome (AIDS)
- Sexually transmitted diseases and abortions

If a parent mentor has been found to breach the confidentiality of any of the children or families involved in the study, they immediately will be asked to leave the project.

SECTION 5: ASTHMA BASICS

In this section you will learn about:

- ◆ Causes of asthma
- ◆ What asthma is
- ◆ What happens during an asthma attack
- ◆ Warning signs of an asthma attack
- ◆ Asthma severity

WHY DOES MY CHILD HAVE ASTHMA?

This is a good question, and one you may get asked a lot. There are many ideas about why children have asthma. It is important to remember that each child is different, and that the cause of asthma is not the same for all children. Some of the causes of asthma include:

- **Family History or Heredity**

Heredity is the passing of physical qualities from parents to children. This is what is meant when people say “My daughter got her singing voice from me.” Physical traits like eye color, hair color and height can be passed down from generation to generation. Asthma can also be passed down from parents to children. If the mother or father has asthma, the child is more likely to also have asthma. It is important to remember that this does not mean that every child whose parents have asthma will become asthmatic.

- **Allergies**

Children may have what is known as the “**allergic triad**”: eczema, allergies and asthma. All three of these disorders involve an allergic reaction. A child whose parents or siblings have at least one of these conditions is at greater risk of developing asthma.

- **Exposure to tobacco smoke during pregnancy**

- **Certain viral respiratory infections as infants such as Respiratory Sincytial Virus (RSV)**

- **Smaller airways**

- **Too much or too little exposure to triggers**

Some experts believe that children who are exposed to too many triggers early in life (cockroaches, dust mites, mold) are at an increased risk of developing asthma. Others think that children who are not exposed to enough triggers (by living in too clean an environment) are at increased risk of developing asthma.

WHAT IS ASTHMA?

Asthma is a chronic inflammatory disease of the lungs. **Inflammatory** means irritation and swelling; in the case of asthma, it means irritation and swelling of the airways, or lungs.

The lungs are the organs in our body responsible for breathing. When we breathe in (inhale), oxygen is brought into our body through our upper airway (nose, mouth and trachea) to the lower airways (lungs). Oxygen is picked up by red blood cells in our body, which carry the oxygen to body parts such as the brain, heart, stomach and muscles. These body parts need oxygen to work. In these body parts, the oxygen is exchanged for carbon dioxide, which is exhaled

again through the airways into the air. When there is a problem with the airway, it affects the entire body.

WHAT HAPPENS DURING AN ASTHMA ATTACK OR EXACERBATION?

There are three things that happen during an asthma attack or **exacerbation**:

1. Inflammation (irritation and swelling)
The lining of the airways becomes irritated and swollen (inflamed.)
2. Mucous production (snot)
The airways produce thick mucus that clogs or plugs the airways.
3. Bronchospasm (muscle tightness)
The muscles that surround the airways tighten or constrict like tight rubber bands. This makes the airways smaller.



When these three things happen, the airway narrows. The small size of the airway allows less air into the lungs and makes it harder to breathe.

WARNING SIGNS

Now that you know what happens inside of the body during an asthma **exacerbation**, it's time to learn what happens on the outside. Symptoms of an asthma attack are like road signs on the highway, cautioning you about what lies ahead. Asthma signs can be broken down into early and late signs of an attack.



Early Warning Signs

Early signs are things that you may notice before the child is wheezing or short of breath, such as:

- Cough
- Mood changes

- Irritable, restless
- Tired, increased napping
- Not wanting to play
- Trouble sleeping
- Changes in facial appearance
 - Drooping mouth, nose flaring
- Verbal complaints
- Itchy, watery eyes or glassy eyes
- Runny nose
- Head stuffed up
- Sneezing
- Dark circles under eyes
- Chest pain
- Drop in peak flow meter scores

When you notice these early warning signs, it is time to take action! Parents should follow their written asthma action plan from their health care provider. This is when rescue medication is needed. If you act now, you may prevent a severe asthma attack, emergency room visit or hospital stay. Remember, each child is different, and each parent should know their own children's early warning signs.

As a parent mentor, you can help parents identify early warning signs by asking them what usually happens during their child's asthma attack, or by showing them this list and having them identify some of the things they notice in their child.

Late Warning Signs

Late signs of an asthma exacerbation are usually the things we notice most. Late warning signs include cough, wheezing and/or shortness of breath. Children may have all or some of these signs.

- **Cough-** Most children cough during an asthma attack. Children may have a dry harsh cough or cough up some of the mucus the airways produce. Cough also can be an early warning sign. Parents should follow their written asthma action plan to provide the best treatment for their child at this point.
- **Wheezing** is the high-pitched noise often heard inside the lungs during an asthma attack. This sound is made because the air is trying to get through swollen, tight airways. Wheezing can be heard in the lungs with a **stethoscope** by a health care professional. If the wheezing is extreme, you may hear it with your own ear.
- **Shortness of breath-** children may complain that they have trouble breathing or have chest pain. When the airways become narrow,

swollen and blocked, it is hard for air to go in and out. This can cause chest pain and make it hard to breathe. Rapid breathing and seeing the child's chest and stomach "heaving" when they breath also are important late warning signs.

These late signs of an asthma attack must be treated as soon as possible (and the earlier the better). Parents should follow the written asthma action plan to figure out how to help treat late warning signs. It is important that you as a Parent Mentor help children and parents to understand what these signs are and exactly what do when they happen.

ASTHMA SEVERITY

People with asthma may have different severity levels of asthma. Some children are affected more by their asthma, and some may hardly ever even have flare ups.

Severity levels are categories that health care professionals use to decide what type of medication and treatment children should receive. As a parent mentor, you may hear or see the health care provider talk about asthma severity. You will not need to "diagnose" or assign a level to a child, but understanding the severity will help you understand the child's needs. If you ever have questions about the asthma severity level of a child, please contact the family's doctor or the asthma nurse specialist.

Asthma Severity Levels

Step 1: Mild intermittent- Child has asthma symptoms less than 3 times per week, and less than 3 times per month at night.

Step 2: Mild Persistent- Child has asthma symptoms more than 2 times per week, but less than 1 time per day; and 3 times per month at night.

Step 3: Moderate Persistent- Child has asthma symptoms every day and more than 1 night per week.

Step 4: Severe Persistent- child has asthma symptoms continually throughout the day and frequently at night.

These levels are called steps because children can step up or down in asthma severity. The severity level may change over their lifespan.

Medical treatment of asthma should be based on the severity of the child's asthma. As a parent mentor, you can help parents understand severity levels and the appropriate treatment for their child. Parents can talk to their doctor about their child's asthma severity and what medications are recommended.

Appendix 4 has more information about severity levels.

ASTHMA MANAGEMENT

Asthma usually is a chronic, lifelong disease. Children usually do not grow out of asthma, although the severity of the asthma may change as their bodies change. Asthma cannot be cured, but it can be managed. If asthma is not managed, a child's lungs can be permanently damaged, leading to lifelong problems and even death.

As a parent mentor, it is important for you to educate parents about the risks of asthma and how to manage asthma.

Children with asthma should be able to **sleep, learn and play without being affected by the asthma**. These are signs of good asthma management. Good asthma management is the responsibility of the health care provider, parent, and child. All three need to work together, by prescribing correct medications, taking the medications correctly at home, avoiding triggers, coming in for health care provider visits, communicating, and knowing what to do in case of an emergency.

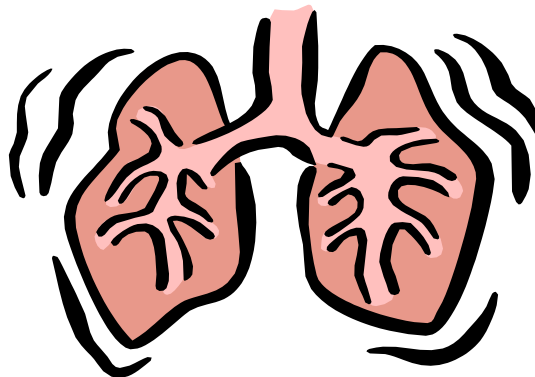
SECTION 6: ASTHMA MEDICATIONS

In this section you will learn about:

- Asthma Medications
- Asthma Equipment
- Barriers to Medication Use
- Peak Flow Meters
- Asthma Care Plans
- Triggers
- Asthma and School/Day Care

For this section, you need to keep in mind the three things that occur during an asthma exacerbation:

Inflammation
Mucus
Bronchospasm



The first step in asthma management is taking medication. There are two types of asthma medications:

1) Controller medications

Taken every day to prevent asthma exacerbations.

2) Rescue medications

Taken during an asthma exacerbation.

[ASTHMA MEDICATIONS](#)

Controller Medications

Control medications are long-term, daily preventative medications. They should be taken every day, whether the child is sick or not. These medications help the child's asthma stay in control.

Controller medications are anti-inflammatory, reducing the swelling/inflammation of the airways, and some can reduce mucus production.

These medications will not relieve symptoms quickly; it may take days to weeks to see a change.

All patients with persistent asthma should have at least one controller medication. As a parent mentor, you should encourage parents to talk to their health care provider about which medications are most appropriate for their child.

Appendix 5 includes specific teaching sheets for each medication.

The following are the types of controller medications:

[Inhaled corticosteroids](#)

- **Beclovent/ Vanceril (Beclomethasone), Flovent (Fluticasone), Azmacort (Triamcinolone), Pulmicort (Budesonide), Qvar, Aerobid / Nasarel (Flunisolide)**
 - Anti-inflammatory medicines contain a small amount of steroid that is inhaled directly into the lungs
 - Used for mild persistent, moderate persistent and severe persistent asthma.
 - Most effective long-term control medication for asthma
 - Need to be taken for days or even weeks in order to work
 - Side effects: Hoarseness, thrush (yeast in the mouth, characterized by the formation of whitish spots)
 - Mouth should be rinsed out after use to prevent thrush
- **Inhaled steroids have fewer side effects than oral steroids because they are inhaled directly into the lungs, not absorbed in the stomach. Taken in the usual prescribed doses, they do not affect growth.

[Inhaled anti-inflammatories \(non steroids\)](#)

- **Intal (Cromolyn), Tilade (Nedocromil)**
- Anti-inflammatory medicines that do not contain a steroid
- Prevent inflammation and block the reaction to triggers
- Need to be taken for more than one week to work
- Used for mild persistent asthma as an alternative treatment

Leukotriene modifiers

- **Singulair (Montelukast), Accolate (Zafirlukast), Zflo (Zileuton)**
- Prevent swelling, inflammation and mucus
- Pill or liquid form
- Used with inhaled corticosteroids to treat asthma
- Side effects: headaches or stomachaches

Long-acting beta-2 agonists

- **Serevent (Salmeterol), Foradil Aerolizer (Formoterol)**
- Relieve bronchoconstriction
- Work in 1 hour and last for 9-12 hours
- Not used for rescue or quick relief
- Used with an inhaled corticosteroid, not alone
- Side effects: shaky hands, fast heartbeat, headache, “hyper” feeling
- Side effects should only last a short time and may go away after using the medication regularly

Anticholinergics

- **Atrovent (Ipratropium)**
- When used in combination with other medications, it relaxes the airways and reduces mucus production.
- Side effects: dry mouth, fast heartbeat, flushed (red) skin

Combination Medication

- **Advair (Flovent + Serevent)**
- Controls both airway swelling and bronchospasm
- Contains both an inhaled corticosteroid and a long acting beta-2 agonist
- Side effects: chest pain, fast heartbeat, hives, rash, thrush

Oral corticosteroids

- **Prednisone, orapred, pediaped, prenisolone, methylprednisolone, prelone**
- Anti-inflammatory medicines (steroid) used to decrease inflammation
- Pill or liquid form
- Used for short periods of time to treat a child who had an asthma exacerbation. Not usually taken long term (except when asthma is extremely severe.)
- If taken for more than 5 days, oral steroids should not be stopped immediately. They should be tapered. If they are taken for more than 5 days and stopped immediately, the adrenal glands and hormones may be affected.

- Take 6-12 hours to work
- Side effects: increased appetite, stomachache, mood changes, fluid retention, facial flushing
- Long term (months to years) use may cause other severe effects such as osteoporosis, vision changes, and ulcers
- Should be taken with milk or food to avoid stomachache

Oral Bronchodilators

- **Slobid/TheoDur/Uniphyll (Theophylline)**
- Relieve bronchoconstriction
- Must be taken regularly, every day
- Work in 4-6 hours and last 8-12 hours
- Side effects: nausea, vomiting, tremors, sleep problems, bedwetting, behavior changes (usually occur with high doses)
- Because of the sometimes harsh side effects and availability of other treatment options, this medication is not used often anymore.



Rescue or quick relief medications

Rescue medications are used for quick relief. They act fast, usually within 15-20 minutes.

Rescue medications relax the smooth muscles around the bronchial tubes in the lungs. When a child experiences bronchospasm in an asthma attack, these medications relieve the bronchospasm.

All children with asthma need to have access to rescue medications. This is the only medicine that will quickly help a child breathe easier.

Appendix 5 includes specific teaching sheets for each medication.

The following are types of Rescue or quick relief medications:

Short acting Beta-2 agonists

- **Proventil / Ventolin (Albuterol), Maxair (Pirbuterol), Alupent (Metaproterenol), Xopenex (Levalbuterol)**
- Relieve bronchospasm quickly
- Begin working in about 5 minutes, and last 4-6 hours
- Used for all types of asthma during an asthma exacerbation
- Can also be used before exercise to prevent an exercised-induced exacerbation
- Should be taken first if taken with daily medications
- Should not be used daily- used only for asthma symptoms. If the child is using it more often, it may be a sign that the asthma is not under good control, and he/she may need a daily controller medication
- Side effects: shaky hands, “hyper” feeling, fast heartbeat, headache
- Side effects usually last a short time and may go away after using the medication regularly

ASTHMA EQUIPMENT¹⁰

Inhalers

Inhalers are used to get medicine into the lungs. If the inhaler is not used correctly, the medicine will not get into the lungs and therefore, it will not work.

There are two different types of inhalers:

1. **MDI- Metered Dose Inhaler**
2. **DPI- Dry Powder Inhaler**

METERED DOSE INHALERS (MDI)

How to use a Metered Dose Inhaler

- Use with spacer/holding chamber
- If you don't have a spacer/holding chamber
 - Open-mouth technique with inhaler 1-2” away
 - In mouth (not for use with corticosteroids)

Maxair™ Autohaler™ is a special type of metered dose inhaler

Maxair™ Autohaler™

Step 1: Remove cover and shake

Step 2: For the first use, or if not used for 48 hrs, the inhaler should be primed. This means a dose needs to be loaded before the first inhalation can be taken.

Step 3: Load Dose

Step 4: Place lips tightly around mouthpiece

Step 5: Take deep steady breath in and hold for 10 seconds

Step 6: Remove from mouth and exhale

Step 7: Lower lever and repeat if needed

Autohaler™ Cleaning

- Turn Autohaler™ upside down, and wipe mouthpiece with clean dry cloth
- Tap so flap drops down; with flap down clean surface of flap with dry cotton swab
- Turn right side up, make sure flap is down, and replace cover
- Clean every week or as needed

Spacers/Holding Chambers

Spacers/holding chambers are recommended with all medium to high dose inhaled corticosteroids.

Why use a spacer/holding chamber?

- Decreases the amount of steroids taken in through the mouth
- Reduces the side effect of thrush (yeast in the mouth)
- Reduces chance of tasting the medicine
- Helps medicine get delivered to the lungs, especially with children
- Minimizes adverse effects from inhaled corticosteroids



How to use a MDI with Spacer

Step 1: Remove MDI cap, attach mouthpiece to a spacer and shake

Step 2: Breathe out and put spacer between lips

Step 3: Press canister one time

Step 4: Take deep breath in slowly and hold for 10 seconds

Step 5: Breathe out

Step 6: Take one more deep breath without pressing canister

Step 7: Wait 60 seconds before taking next puff

Step 8: Rinse mouth if using inhaled corticosteroid

How to use an MDI with Spacer and Mask*

*Only use this technique for children who cannot close their lips around a mouthpiece

Step 1: Remove cap, attach MDI to spacer and shake

Step 2: Place mask tightly on child's face (cover nose and mouth)

Step 3: Press canister one time

Step 4: Hold mask tightly on face for 6-10 breaths

Step 5: Assure valve is opening with each breath

Step 6: Take mask off and wait 60 seconds before giving next puff

Step 7: Wash face and rinse mouth if using inhaled corticosteroid



Spacer/Holding Chamber Cleaning

When cleaning your spacer/holding chamber, be sure to follow the manufacturer's directions. The spacer/holding chamber should be cleaned at least weekly with mild soap and water (some can be placed in the dishwasher) and allowed to air dry before putting it back together.

MDI Cleaning

- Look at hole where the medicine sprays out
- If you see "powder" in or around the hole, clean the inhaler
- Remove the metal canister from L-shaped mouthpiece
- Rinse mouthpiece and cap in warm water
- Let them air dry overnight
- In morning, put canister back inside and put cap on

Parents may ask how they will know when the inhaler is empty or how much medicine is left in the inhaler. Unfortunately, there are no easy ways to tell. It is important to have medication in the inhaler and to always get prescriptions filled promptly.

When you get a prescription filled, look on the canister. The number of puffs in the inhaler should be listed. If the new inhaler holds 200 puffs and you are told to take 8 puffs a day, you can divide the number of puffs in the canister by 8.

Puffs in canister (200) divided by puffs per day (8) = 25 days.

This means that the inhaler will last for 25 days. You can track this on a calendar to remember when to get a refill.

If the inhaler is an albuterol or rescue medication, there will be no prescribed number of puffs per day. In this case, you can keep track of the number of puffs used on a calendar and refill when the inhaler is almost empty. For example, if there are 200 puffs in a full canister, refill when it gets to 75.

DRY POWDER INHALERS (DPI)

Dry powder inhalers (DPI) are a different way to take medication through an inhaler. These are better for the environment. The inhaler stores medication in the form of a dry powder, rather than the aerosol forms of an MDI.

A child must be able to use a mouthpiece to use a DPI, so they are rarely used for children under 4 years of age. Spacers are not used with a DPI. Along with being able to use a mouthpiece, a child must be able to take a very quick deep breath to use a DPI correctly.

There are three types of DPI's:

1. Turbuhaler®
 - a. Prime it if this is a new Turbuhaler (twist and click twice)
 - b. Load a dose (twist and click)
 - c. Turn head away and exhale
 - d. Place in mouth tightly, take deep, quick breath
 - e. Hold breath for 10 seconds
 - f. Repeat as needed

2. Diskus®
 - a. Push grip to open Diskus®
 - b. Push lever away until hear and feel click
 - c. Turn head away and exhale
 - d. Place in mouth tightly, take deep, quick breath
 - e. Hold breath for 10 seconds

3. Aerolizer™
 - a. Remove cover and open Aerolizer™ Inhaler
 - b. Remove capsule from foil, place in capsule-chamber
 - c. Twist mouthpiece to closed position
 - d. With mouthpiece upright, press buttons ONCE (hear click), which will break the capsule
 - e. Turn head away and exhale
 - f. Place in mouth tightly, take deep, quick breath (if there's no whirling sound, it may be stuck)
 - g. Hold breath for 10 seconds
 - h. Check Aerolizer™ for left over medicine. If there's some left, close it, and breathe in the rest of the medicine

HAND-HELD NEBULIZER

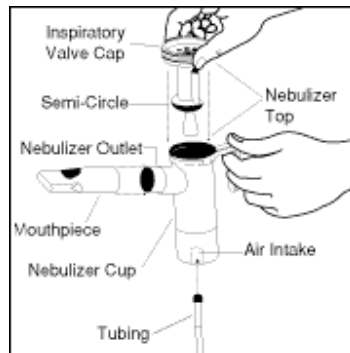
A hand-held nebulizer is another way to get asthma medications into the lungs. This is a machine that turns the medication into a mist, and this mist is then breathed into the lungs.

Children of any age can use a nebulizer. Children under five years of age can use a mask, and children five years and older can use a mouthpiece to breathe the mist into the lungs. Used correctly, a nebulizer and MDI are equally effective. A nebulizer does not necessarily give the child more medicine; it just gives it in another way.

Follow these steps to use a nebulizer:

- Assemble equipment. Sit child upright
- Put mouthpiece in mouth between lips and teeth (if using mask, cover nose and mouth.)
- Turn on machine. Take slow deep breaths (mist should disappear when the child inhales.)

- The treatment is over when medicine is gone. You may need to tap the mouthpiece or mask to make sure there is no more medicine.
- Rinse mask/mouthpiece and tubing with water and let air-dry.
- Disinfect mask/mouthpiece with soap and water one time per week.
- Change filter when dirty, based on recommendations from manufacturer or home health agency.



REPLACING EQUIPMENT

You should always get refills well before the medicine is completely gone. This way, you will always have medication for an emergency.

To replace inhalers/ spacers/ peak flow meters:

Call your health care provider and explain why the medication/equipment is lost or broken or that you need another refill, then ask for another prescription for the medication/equipment.

To replace Nebulizers:

Call the home health agency that provided the equipment to you. This phone number should be on the nebulizer itself. That company will provide you with tubing, filters, and replacements when necessary. You should call the company monthly to replace the tubing and filter, as needed.

MEDICATION ADHERENCE

Medication adherence means taking medication correctly and exactly as prescribed by your health care provider. This means taking medication on the days and times prescribed and using equipment correctly.

Because there are so many different medications and ways to take them, it is important to teach families the correct way and the importance of taking medications. You should have the family/child show you all of their medications, and review with them how to correctly take them. After this training, you will have learned how to use each piece of equipment. If a family does not know how to take the medication, you will be able to teach them the correct way to take it.

If the family does not have medications at home, they need to call their health care provider or pharmacy to get the medications.

It is also important to find out who is in charge of the medication administration- Is it mom/dad? Siblings? The child him/herself? Focus the education on that person, but remember to teach any family member who might care for the child.

To identify things that get in the way of the child taking his/her medications, get answers to the following questions:

Is the child taking the medication correctly?

Have the child/family demonstrate what they do when they take their medication. Then ask when, how often, and at what time they take it. Use this time to teach the proper way to take the medication.

Does the family have insurance? Is the medication covered by insurance? If so, is the co pay too high?

If the child does not have health insurance, find out why. There may be resources to help this family insure their child. Please refer to Appendix 2 and 3 for resources available in your community.

Sometimes asthma medications are not covered by insurance. Sometimes medications are covered, but also have a large co-payment (or “co-pay”). Some physicians can help to get the medication covered, figure out an alternative, or even give free samples.

Does the child/family forget to take the medication or get refills?

This is a great time to educate families about the importance of prevention and what the medicine does in the body. Use all your new knowledge to help the family understand how important it is to take medication correctly. Encourage the family to make medication part of a routine, such as bedtime or morning rituals.

Calendars or charts are great tools to use as medication reminders. Use calendars to help families remember to take the medication daily, and to remember when a prescription refill is needed. Please refer to Appendix 6 for Medication Reminder Calendars that you can give to the families you are mentoring. Also, please refer to Appendix 7 for the reminder card; a small post card reminding families of when they have a scheduled appointment with a health care provider.

Does the family understand why it is important to take the medication?

Again, use your new knowledge to teach the family how important it is to take medication to control the child’s asthma.

Does the child have enough medication to take to school/day care/grandma's house?

Children need to have access to rescue medication everywhere they go. Health care providers can write a prescription for albuterol as “one for home and one for school.” This way children can keep one at home and one in their backpack for school, play, overnights or child care. You can ask your health care provider for this during a clinic visit.

The state of Wisconsin has a law that allows children to carry their own inhaler with them at school. A copy of this law is attached in Appendix 6.

ASTHMA CARE PLANS

An asthma care plan is a written plan from the child's doctor or nurse detailing how to manage the child's asthma. Every child with asthma should have a written care plan. Families should ask their health care provider for an asthma care plan, if they don't already have one. Once a child has a written care plan, it should be shared with schools, childcare, babysitters, and anyone else who cares for the child.

What a care plan should include:

1. Daily management
2. Exacerbation (attack) management
3. Medication names, doses and when to take medication
4. What to do in case of an emergency

When a child goes to the emergency room or hospital, he or she may receive another written asthma care plan from the health care provider at that time. This care plan may not be the same as the plan from your primary health care provider, but should be followed strictly until the child's regular health care provider says to stop. The family should bring this care plan to the follow-up visit to have it reviewed by the primary health care provider.

See Appendix 9– for a sample written asthma care plan.

PEAK FLOW METER

A peak flow meter is a small tool used to measure how much air is flowing out of the lungs. It can be used by a child that can physically stand up, blow into the meter, and follow directions, usually starting at five or six years old.

The peak flow readings are numbers. Children and families should work with their health care provider to find out where their child's peak flow should be and what to do if it is not where it should be.

A peak flow meter:

- Provides **objective** information
- Documents the child's personal best
- Detects worsening asthma *before* changes occur
- Is useful only if breathing is monitored regularly
- Indicates need for quick-relief medications
- Assists in trigger identification
- Aids in communication
- Tells parents when a child's asthma is so bad that they need to go to the emergency room

Peak flow meter tips:

- Early mornings are a good time for daily peak flow measurement
 - Use before and 20 minutes after bronchodilator (albuterol)
- Use the same peak flow meter over time- different peak flow meters may give different readings
- Peak flow meters are an important part of written asthma action plan
 - They tell families when the child's breathing is normal (green zone), when the child needs his/her rescue medications (yellow zone), and when the child needs to go right to the emergency department (red zone)
 - They provide the child with a personal best and allow for a "zone management" system

Proper Peak Flow Meter Technique:

- 1- Set the meter to zero
- 2- Stand up straight
- 3- Breathe in deeply
- 4- Wrap lips tightly around the mouthpiece
- 5- Blow out as hard and as fast as possible
- 6- Repeat two more times
- 7- Write down the highest number in the peak flow meter logbook



Cleaning the Peak Flow Meter:

- Follow manufacturer's directions
- Should not need daily cleaning, but should be done every week
- Most peak flow meters can be cleaned with mild soap and water, and some can be put in dishwasher (always check the instructions first)
- Shake out excess water and allow to air dry before using

TRIGGERS/ENVIRONMENTAL CONTROL

What are asthma triggers?

Asthma triggers are things in the environment that “trigger” or cause an asthma exacerbation (attack). Some examples of triggers are:

- Tobacco smoke
- Mold
- Strong smells
- Pets
- Dust
- Exercise
- Certain foods
- Cockroaches
- Dust mites
- Colds or flu
- Pollution
- Grass
- Flowers
- Trees
- Cold or hot weather/ changes in weather
- Humidity
- Ozone

Remember, every child is different, and may only be affected by certain triggers. It is important for parents and children to figure out what their triggers are, and to avoid them. If a parent is unsure of what their child's triggers are, they can ask the child what makes it hard for them to breathe. They can start an asthma diary, writing down each time the child has asthma symptoms, and what triggers the child might have been exposed to before the symptoms developed. Or, they may can look at the above list and identify some of the triggers.

What to do about triggers

Children should try to avoid their individual triggers. Here are some ways to avoid common triggers:

Tobacco smoke

Do not allow cigarette, cigar or pipe smoke around the child, not even in the car or garage. If there are smokers in the household, encourage them to quit smoking, and provide them with information on smoking cessation programs. Please refer to your Community Resource Binder for smoking cessation resources you can give to your families.

Mold

Keep areas free of water and dampness (bathrooms, basements, and wet eaves). Make sure bathrooms have a window or ventilation fan. Areas that have mold on them can be cleaned with a bleach and water solution. Make sure this is not done when the child or anyone else with asthma is present.

Strong smells

Avoid exposing the child to strong smells, such as perfumes, scented lotions, cleaning supplies, bleach, and candles.

Pets

Cats, dogs, and birds can be very bad for children with asthma who react to their fur or feathers. If you cannot get rid of pets, keep them out of the child's room, off their lap and beds, and restrict time spent playing with them. Vacuum at least once per week to help keep animal dander off the floor, pillows, blankets, and quilts.

Dust

Damp dust frequently to avoid dust in the home.

Exercise

Children with asthma should be able to exercise, but be prepared by having albuterol on hand or by taking it before exercise (if instructed to do so by the child's health care provider.)

Foods

Avoid foods that your child is allergic to or that are known to trigger asthma.

Cockroaches

Keep food covered and stored away. Integrated pest management is available for a cost to professionally get rid of cockroaches. Refer to your Community Resource Binder for integrated pest management and housing resources.

Dust mites

A dust mite is a microscopic organism that lives in dust that is found in the environment (most of which is actually human skin flakes.) Cover

mattresses, box springs and pillows with dust mite covers. Wash bedding in hot water every week. Keep stuffed animals and pillows to a minimum.



House dust mite

Colds and the flu

The child should get a yearly flu shot from his/her health care provider. Practice good hand washing when using the restroom, preparing foods or after coming in contact with germs or bodily fluids.

Pollution

Keep windows shut, use an air conditioner instead of fans, re-circulate the air conditioning in the car, and stay inside on ozone action days (*occur when the air quality is predicted to exceed EPA health-based standards.*) During ozone action days, pollution is very strong and children with asthma should stay inside.

Grass

Grass can be a trigger for some children. Do not have the asthmatic child mow the grass. Grass should be cut in the morning or evening, not during the heat of the day.

Flowers

Keep child away from fresh flowers because the pollen can trigger an asthma attack.

Trees

Keep the child away from flowering trees and other outdoor triggers.

Cold or hot weather / Changes in weather

Stay inside during extremely hot or cold temperatures. If you do not have air conditioning at home, try to visit a library, movie theater, mall or a friend's house that does have air conditioning.

Ozone

Stay inside or in an air-conditioned environment during ozone action days (*occur when the air quality is predicted to exceed EPA health-based standards*) and know when the air quality is rated as “unhealthy.”

ASTHMA ISSUES IN SCHOOLS AND CHILDCARE

It is important to remember the child’s school, childcare or babysitters when talking about asthma management. Every person that takes care of a child should know whether the child has asthma and if so, how to manage it.

The child’s written asthma care plan should be shared with his/her school and childcare. Along with the care plan, the school/childcare should have access to the child’s quick relief or rescue medications and know how to use them.



Triggers at school/child care

Teachers should be aware of the things that trigger the child’s asthma so they can help the child avoid them. They can remove triggers from the school environment and avoid outdoor field trips and recess on ozone action days.

There are many triggers in the school/child care environment:

- Stuffed animals
- Pillows
- Dust on bookshelves and toys
- Classroom pets
- Plants or flowers
- Chalk dust
- Strong scents like cleaning supplies, scented markers or the teacher’s perfume

Physical Activity

Some children have exercised-induced asthma, or asthma that flares up with physical activity. These children should take their rescue inhaler 20-30 minutes before activity to prevent an asthma attack (if directed to do so by their doctor). When these children participate in physical activity, they should have their inhaler with them during the event.

School and childcare personnel should be aware that physical activity might affect a child’s asthma and should be aware of children diagnosed with exercise-induced asthma. That doesn’t mean that the child should not participate in gym

or recess, but everyone should know the written care plan in case of an attack. Teachers should be aware of when the child should stay inside and participate in indoor activities such as on hot, humid days or days following a hospital stay or illness.

Parents are usually the best source of education for a child's teachers about the child's asthma. Have the parent share as much information as you can with the teacher about the child's asthma. Teachers will be happy to know how best to care for your child and keep them safe.

Develop an action plan (based on the written care plan) with the parent, child, child's health care provider, teachers and school nurses for what to do when the child has an asthma attack.

SECTION 7: REGULAR AND FOLLOW-UP APPOINTMENTS

In this section you will learn about:

- The importance of regular and follow-up appointments in asthma care
- The different types of health care provider appointments
- How and when to schedule follow-up appointments
- How to identify contact information for physicians
- How to get a primary care health care provider
- How to communicate with health care providers

REGULAR AND FOLLOW-UP APPOINTMENTS IN ASTHMA CARE

Regular and follow-up appointments are very important in managing childhood asthma. Regular and follow-up appointments with health care providers allow parents to:

- Learn more about their child's asthma
- Ask questions about their child's asthma care
- Get the best medicine for their child's asthma
- Learn how to identify asthma symptoms and prevent attacks
- Keep their asthmatic child physically active
- Learn what to do after an ED visit or hospitalization for asthma

Parents should feel comfortable asking their child's health care provider about asthma and getting questions answered in a clear, understandable way.

WHEN SHOULD A CHILD GO TO THE HEALTH CARE PROVIDER?

There are different types of health care provider appointments that children go to as they grow. A child with asthma may have to go to more health care providers

than a child that does not have asthma. Below is a list of the different types of health care providers' appointments for children and families.

Well-Child Visit

Well-child visits are visits to health care providers for things like general physicals ("check-ups") and to get shots. This type of health care providers' appointment is a check-up, meaning that a child does not have to be sick to be seen. This appointment can be thought of as a way to prevent a child from getting sick. Children are expected to go to their well-child visit at ages:

- 2 weeks old
- 2 months old
- 4 months old
- 6 months old
- 9 months old
- 12 months old
- 15 months old
- 18 months old
- 2 years old
- 3 years old
- Once a year after they turn 3 years old

Sick Visit

Parents can make an appointment with their child's health care provider for a sick visit whenever their child is ill. Parents should contact their health care provider to decide when it is necessary to be seen for a sick visit. It is very important that parents make an appointment with their health care provider when their child is sick, because if the child worsens, he or she could end up in the hospital or emergency room for something that could have been prevented.

Follow-up appointments

After a child has been in the hospital or seen in the emergency department (ED), they must follow-up with their health care provider, especially if they were seen for asthma. A hospitalization or ED visit for asthma sometimes indicates that healthcare providers, parents, and the child need to change how the child's asthma is being managed. At this visit, parents and health care providers can talk about how to prevent hospitalizations and emergency department visits. Follow-up appointments may also be necessary after a recent sick visit for asthma, if the child's medications have been changed, or simply so that the health care provider can see how the child is doing.

Asthma Visit

All children that have asthma and their families should be going to regular appointments with their health care provider. At these visits, children and their families can talk and learn more about asthma, medications, and better ways to control their asthma.

Specialist Visit

Some children with asthma may need to go to a specialist in addition to their regular health care provider. Such specialists can include a

pulmonologist, asthma doctor, allergist, or allergy/ immunology doctor. For parents whose children see a specialist, stress the importance of the child attending all scheduled visits.

How often should a child with asthma be going to an asthma visit? (Pediatric asthma promoting best practice. A guide for managing asthma in children p. 40-41)

- A child with asthma that is under control should generally see a health care provider **at least two times a year**
- A child taking medications for asthma every day should see a health care provider at least **3 to 4 times a year**
- A child that has asthma symptoms and attacks often should be seen by a health care provider **at least every two weeks** until his/her asthma gets better.

If a parent is ever unsure about how often their child should be seen by a health care provider, he or she should call the health care provider and ask.

CONTACTING HEALTH CARE PROVIDERS

PLEASE SEE CONTACT RESOURCE SHEET, APPENDIX 10.

If a family does not already have contact information for their child's health care provider, you can look up either the name of the health care provider or name of the clinic in the phone book.

The insurance company is another place to get contact information for health care providers. If a family has insurance, they can contact their insurance company and get the phone number and address for their child's health care provider.

Families should feel comfortable calling the clinic or doctor's office and talking with the receptionist.

Scheduling Appointments

To assist the families you mentor in scheduling appointments, have them contact their health care provider's office and tell the receptionist what they would like to be seen for and when they would like to be seen. There are different types of health care providers that they can make an appointment with. Doctors are the people we think of most of the time when we want to make a doctors' appointment, but parents can also schedule an appointment for their child to see a Nurse Practitioner or Physician's Assistant. All three types of professionals can do an excellent job of taking care of children's asthma. Whatever type of provider parents choose for their child, always try to have parents schedule all subsequent appointments with the same provider, so the child will have the best continuity of care.

Parents should record the date and time of each appointment in their calendars. You should also record the date to remind families of when they need to attend their appointment. Have the parent put a post-it note on the refrigerator as a reminder, and if the child is old enough, have him or her write down the date and time on his or her calendar. You should also remind the family of an upcoming appointment when you see them at the monthly community meeting.

PMs – CALL TO REMIND FAMILIES OF THEIR CHILD’S APPOINTMENT A DAY BEFORE THE APPOINTMENT!

OBTAINING A PRIMARY CARE HEALTH CARE PROVIDER

As a parent mentor, you may be working with some families that do not have a primary care health care provider for their child. One of your tasks will be to help them find one. Here’s what to do:

Does the family have insurance?

 **YES**

The family contacts their insurance company using the telephone number on the back of their insurance card. The family should tell the insurance representative that they would like to find a primary care health care provider for their child. The insurance representative will tell them what they should do next.

The family may have a booklet from their insurance company that lists all primary care providers that they can go to. They should be looking for a provider that: 1) is a pediatrician, family practitioner, or other provider that regularly works with children, and 2) has an office in a convenient location (for example, located near the family’s house or parents’ workplace). Once the family has chosen the child’s primary care provider, they should contact the primary care provider’s office to make an appointment, and call the insurance company to inform them whom they have chosen as their child’s primary care provider.

 **NO**

When working with families that do not have insurance, you should:

- Repeatedly encourage them to obtain insurance, no matter what the reason for not having it. Explain how important health insurance is in helping them to manage their child’s asthma. Explain that studies shows that uninsured children are at high risk for not getting needed medical care.

- Give the family a list of free clinics where they can go until their child gets health insurance. A list of free clinics can be found in Appendix 3
- Assist families in obtaining insurance by helping them contact Wisconsin Badger Care (a program to help eligible, uninsured families)

To learn more about Badger Care, please contact 1-800-362-3002. Please see Appendix 2 for information on eligibility and how to apply for Badger Care.

HOW TO COMMUNICATE WITH YOUR HEALTH CARE PROVIDER

Going to your child's health care provider's appointment may be overwhelming. Parents may feel rushed, or not understand things that their health care provider tells them. This is why it is important to learn things that you can teach your families to help them have a better health visit and learn more about their child's asthma.

Remember the word SPEAK in assisting families you mentor:

Stay honest

You should always be honest with your child's health care provider. Let your health care provider know if you have skipped a dose of your child's medications, cannot afford medications, smoked around your child, use alternative therapies such as folk remedies, or something else happened to affect your child's asthma. Share how you feel with your health care provider. If there is something that he or she did or said that you don't like or understand, express this in a respectful way. Staying honest will allow your health care provider to provide your child with the best possible care.

Prepare and ask questions

It is important to ask your health care provider any questions you have about your child's asthma. It may help to write them down before your visit, so you don't forget them, and then you can ask your health care provider when you see him or her. You or the health care provider can also write down the answers to those questions so you can refer to them later.

Educate yourself and your child

Learn as much as you can about asthma, your child's medication, what to do when your child is sick, and what to do in an emergency. Learn by talking with doctors, nurses, and pharmacists. Read pamphlets, handouts, magazines, and books. You can also use the internet and your local library.

Act and be assertive on behalf of your child

When your child is ill, contact or visit your health care provider immediately, because delays in care can make your child sicker. If you feel your doctor is missing important information about your child or your child's medication, be assertive and let your child's doctor know by speaking up.

Keeep a positive attitude

Your child will feel better and calmer if you show a positive attitude. Be upbeat around your child and about how asthma can be kept under control if the proper steps and medications are taken. Let your child's provider know when he or she is doing a good job. Just like anyone else, health care providers like to hear when they are doing a good job. If you are happy with your child's care, make sure your health care provider knows how you feel.

SECTION 8: CULTURAL ISSUES THAT AFFECT ASTHMA CARE

In this section you will learn about:

- Cultural issues that affect a child's asthma care
- Helping families address cultural differences with their health care provider
- Cultural issues and communicating with health care providers
- Language issues and communicating with health care providers

CULTURAL VALUES AND PERSONAL BELIEFS THAT CAN AFFECT A CHILD'S ASTHMA CARE

Cultural issues can affect the asthma care that a child and his or her family receive^{4,21,22}. It is important for children, families, and health care providers to learn about and understand these cultural differences, so that the child can receive the best care possible. As a parent mentor, you will help families understand how culture can affect asthma care.

African-American and Latino cultural values that influence health care

Fatalism

Fatalism, or *Fatalismo* as it is referred to in the Latino community, is when parents may feel that there is nothing that can be done to change their child's fate^{14,25}. This is important in health care because if a family feels that there is nothing that can be done about their child's asthma, they may not take the proper

steps to prevent future asthma symptoms and attacks, and the parents or caregivers may not give the child prescribed medications, because they feel that their child's condition is in "God's hands."

When children and families feel this way, it is crucial to point out in a culturally sensitive way the importance of taking prescribed medications and going to the health care provider for regular asthma care

Example:

A parent says, "There is nothing I can do about my child's asthma. It is in God's hands."

You as a Parent Mentor can respond by saying, "Maybe God would want you to help your child feel better by taking him/her to the doctor."

Friendliness

African-American and Latino families often expect to develop a warm, personal relationship with their child's health care provider (this is known as *personalismo* in the Latino community, which is Spanish for "formal friendliness"^{14,25}). Such a relationship includes interactions at close distances, and appropriate physical contact between the parent and physician, including such things as handshakes, a hand on the shoulder, and even, in certain circumstances, hugging. When parents feel their child's physician is not showing enough of this formal friendliness, problems that can happen include families being unsatisfied with the child's medical care, not providing important medical information, not taking prescribed medications, and not coming in for needed medical visits.

Sometimes families encounter a health care provider of a different race or ethnicity whom they feel lacks personal qualities such as warmth, friendliness, listening skills, thoughtfulness, and concern. Children and families need to understand that this may simply be a difference in cultures because different cultures are taught to interact in different ways. This does not mean that the child's health care provider is uninterested in his or her care.

It is crucial for Parent Mentors to be aware of the cultural importance of displaying personal friendliness when mentoring families. This will allow for positive experiences for both you and the child and family with asthma.

To achieve personal friendliness or *personalismo*:

- Decrease the physical distance while interacting with your families
- Use socially appropriate physical contact, such as handshakes, a hand on the shoulder, and even, in certain circumstances, hugging
- Show that you are available to and interested in your families by giving them information about when and where they can contact you.
- Ask questions about the child and family's daily life such as school, work, etc.

Kindness

African-American and Latino families often expect their health care provider to be polite and pleasant, even when the provider is under stress (this is called *simpatía* in Spanish, which means “kindness”), and this expectation includes avoiding hostile confrontations^{14,25}. Physicians and other health care providers are thus expected to have a positive attitude. American health care providers, however, are often taught that the best way to behave with patients and families is to show a “neutral attitude,” which means being as “detached” and “uninvolved” as possible, but this can easily be viewed by African-American and Latino families as unfriendly or a “bad attitude.” This can then result in problems for minority children with asthma and their families. For example, a family may feel resentment towards a “detached” doctor, causing them to withhold key information about their child’s illness, not take important medicines, not make follow-up visits, and to be unsatisfied with care.

To ensure that the families that you are working with feel that they are being treated with kindness or *simpatía*, emphasize:

- Courtesy
- A positive attitude
- Social amenities (greetings and handshakes)
- Health care providers are often taught to act “neutral” and “detached.” Although the families’ provider may not show the kindness that they expect, the child’s provider may still care very much about their child’s well being. Understanding this cultural difference may reduce the tensions some families might feel about this

Respect

All people want to feel respected in a health care setting, regardless of what culture they come from. In the African-American culture, respect can be defined as being polite and not arrogant²⁶. When respected, many African-Americans report feeling supported by their health care provider, which is especially important when facing a chronic condition such as asthma²⁶.

Respect goes by different names in different cultures. In the Latino culture respect is known as *respeto*^{14,25}. Health care providers are often viewed as people of authority who must be shown respect. Health care providers also must show that same respect to their Latino patients.

Some families may feel that showing proper respect may include “not asking too many questions,” because questioning authority can be seen as disrespectful. The “nod of the head” in response to a health care provider’s instructions or comments may be done to show respect, but the parent may not understand or agree with what’s being said.

There are several consequences to being or feeling disrespected both in the African-American and Latino cultures^{14,25}:

- Families may withhold important information about their child's illness that health care providers need to know to provide good medical care
- Children and families may not listen to, understand, or follow medical directions
- Children and families may not be happy with the quality of care that they received
- There may be a lack of trust between the patient and provider

As a Parent Mentor, you need to earn and maintain the respect of the families, so that you can assist them in the best way possible.

To earn respect or *respeto*, and to maintain respect/*respeto* in interactions with health care providers:

- Pay special attention to helping families express all of their concerns^{12,14,25},
- Show personal qualities such as thoughtfulness, acceptance, and patience²⁶
- When working with Latino families, use Spanish words of respect such as *usted* (the polite form of "you") rather than *tu* (the informal "you"), appropriate titles (*señor* [Mr.] and *señora* [Mrs.]), and formal greetings (*buenos días* [good morning] and *buenas tardes* [good afternoon])^{12,25}
- Encourage families to be involved in making medical decisions with their child's health care provider whenever possible
- Explain to families that their health care provider will welcome their questions and not view a question as disrespectful
- Explain to families that they should not nod their head unless they agree with or understand what is being said by their health care provider

Family Loyalty or *Familismo*

Family loyalty (known as *familismo* in Spanish) is a cultural value seen in both African-American and Latino cultures. This is when important decisions are made by a person's extended family rather than by any one person^{14,25}.

Collective family loyalty can cause:

- Delays in medical care because all family members must be consulted before any decisions can be made
- Families not being happy with the care they receive because health care providers don't understand the importance of extended family
- Conflicts between families and physicians because of not understanding or acknowledging family values

If you encounter family loyalty that affects a child's asthma care, include all family members in the household or extended family in the child's asthma care. This will allow for important decisions to be shared and discussed by all family members. Encourage families to explain to their health care provider that they need to consult their family to make important medical decisions.

Changing Family Roles

Family roles are changing in response to changing family arrangements¹⁴. Families that traditionally contained a mother, father, and child may now contain a mother, child, and grandparent. Family roles must remain flexible between grandparents, parents and children to maintain a strong family structure.

Changing family roles can greatly affect a child's asthma in several ways:

- Important family members may not be included in a child's asthma care
- A child or adolescent could be left to manage their own asthma without the help of an adult

As Parent Mentors, you must be aware of who helps to manage the asthma of the children you work with. Include such persons whenever possible in decisions by building a relationship and rapport with them. If it is clear that a child is managing his/her asthma on his/her own, make sure to spend more time with the child discussing things they can do to make their asthma better. You should also encourage an adult in the house to assist in asthma management.

Folk Remedies for Asthma

For some Latino families, folk treatments for asthma go hand-in-hand with or replace regular asthma care provided by health care providers (which is called "biomedical care")^{4,21,22}. One study found Latino mothers preferred folk remedies over biomedical treatments such as an inhaler (Bearison).

Common home and folk remedies for asthma include (Pachter):

- *Vicks Vaporub*
- Vaporizers or humidifiers
- *Siete jarabes* (seven syrups)
 - A combination of sweet almond oil, castor oil, tolu, wild cherry, licorice, cocillana, and honey
- Aloe vera juice, cod liver oil, honey/royal jelly, and onion/garlic

Many folk remedies are harmless and have no adverse affects on asthma care. They only become a problem when they are harmful, replace the child's biomedical asthma medications, or when too much of the remedy is taken^{4,21,22}.

To bring up the subject of folk illnesses and remedies with your assigned parents, do the following:

- Tell the family that you understand that there may be conditions in the communities that doctors don't know about. Then ask the parent whether the child has such a condition
- If the child does have such a condition, ask what it's called, what causes it, who treats it, and what remedies are used for treatment
- Encourage the parent to discuss folk treatments being used for the child with the child's health care provider, to determine whether any of the folk treatments are harmful

Encourage parents to tell you and their health care provider if the family uses an ethnomedical (folk) healer to treat their child's asthma. It is acceptable to see both a folk healer and a health care provider, but the health care provider should be aware of this, to make sure that the child is not taking any harmful folk remedies.

You should be aware of when and how often children are taking folk remedies for their asthma. Encourage parents to always share this information with their child's primary care provider, and learn ways to incorporate traditional therapies with regular asthma care. For example, if the child is taking a toxic folk remedy, you and the health care provider can determine what culturally-acceptable alternative folk treatment, such as an herbal tea, can be used to replace the toxic remedy.

Language Issues

Language issues have a huge impact on health care^{12,25}. More than 19 million Americans cannot speak the same language as their health care provider, which affects the quality of care that they receive^{12,25}.

- A California study found that Latino mothers in an emergency department felt that staff being unable to speak Spanish interfered with them being able to get the proper health care⁹
- Another study found that mothers with Latino children that had trouble communicating with their health care provider because of language issues also had trouble managing their child's asthma (cite).

Serious consequences of language issues can include children and families^{12,25}:

- Having poorer health
- Having no primary care health care provider
- Not being happy with the quality of health care

You as a Parent Mentor can help families that speak no or very limited English by assisting with:

- 1) Scheduling and making appointments with health care providers

- 2) Finding interpreter services at their health care provider's office and in the hospital
- 3) Providing bilingual handouts, peak flow charts, asthma action plans, prescription labels and medication instructions
- 4) Finding adult education classes for English

SECTION 9: BEING A SUCCESSFUL PARENT MENTOR

In this section you will learn:

- ◆ General Parent Mentor Skills
- ◆ Helpful tips on being a good parent mentor

GENERAL PARENT MENTOR SKILLS

Be a support system

As a parent mentor, you will be a resource and a support system for families dealing with their child's asthma care. You will help them with things like:

- Scheduling health care provider appointments
- Identifying triggers in their home
- Identifying emergency contacts
- Identifying the names and dose information for asthma medications
- Being a supportive friend

You also must be comfortable referring families to their primary care health care provider if you are unsure exactly how to help them.

The goal of the parent mentor program is to help families be **self-sustaining**. We want families to eventually be able to manage their own child's asthma without the use of a Parent Mentor. This is why as a Parent Mentor you will assist families and not do things for them, but rather serve as an experienced role model and mentor.

While helping families, you will in no case act as a child's health care provider. Please **NEVER**:

- Give advice on how to treat a child's asthma
- Give any advice or instructions contrary to any treatment plans of health care providers

These decisions can only be made by health care providers. If you feel that families need more education about treating their child's asthma, asthma medications, and/or treatment plans, contact the Asthma Nurse Specialist at (414) 456-4976.

Please see Appendix 11 for a table that lists what Parent Mentors can and cannot do.

Listening

As a Parent Mentor, it is important to listen to families that you mentor. Listening is important because it let families know that you understand what they are experiencing and you value what they have to say.

Here are tips you can use in working with your families:

1) Be understanding

As a Parent Mentor, you already have experience with children that have asthma, so it will be easy for you to understand what your families are going through. Give them support and advice based on your experiences as a parent with an asthmatic child.

2) Let the speaker finish before you talk

Make sure the parent or guardian that you are working with is finished speaking before you talk. This allows the parent to finish what they want to tell you and to feel that their concerns are being heard.

3) Finish listening before you talk

You can't listen to families if you are thinking about what to say. Let them finish, and then address any concerns they have.

4) Ask Questions

If you do not understand something a family says, ask questions. This will help you be a successful Parent Mentor.

5) Give families positive feedback

Make sure that you give families positive feedback. You can tell a family they are doing a good job by saying "you are doing a great job with your child's asthma." You can also tell a family where they may need some improvement by saying something like, "I can see you're trying really hard to make your child feel better." "To get rid of the asthma triggers in your home, you need to___."

6) Give Suggestions

If you find something works for your child, suggest it to the families you mentor. If you learn something new from another family, share it with the remaining families that you mentor.

Problem Solving

You and the families you mentor may be confronted with problems or issues related to their child's asthma care. To assist families with these problems (issues), follow these steps:

- 1) Identify the problem.

You can only work towards solving the problem if you know what the problem is.

- 2) Think of ideas that would eliminate the problem or make it better.
Brainstorm ideas with the family about the best approach to solving the problem.
- 3) Pick one idea that is the best way to solve your problem.
That idea will become your goal to solving your problem.
- 4) Identify ways to accomplish your goal.
Along with identifying ways to accomplish your goal, identify things that may get in your way, and what you can do about them.
- 5) Remember, the Asthma Nurse and Program Coordinator will always be available to address any of your questions or concerns.

SECTION 10: PARENT MENTOR RESPONSIBILITIES

In this section you will learn about your job as a Parent Mentor.

As a parent mentor, you will be required to do the following things:

1) Visit each of your family's homes twice

When do I go to the homes of the families I mentor?

Each visit to the children's and family's homes is called a **home visit**. You will conduct two home visits for each family that you mentor. The first home visit will be within the first three days of the child's emergency department visit or hospitalization, and the second will be six months from the date of the first home visit.

Example: A child was seen in the emergency department on January 5th, 2004. You will conduct your first home visit between January 6th and January 8th 2004. You will conduct your second home visit between July 6th and July 8th 2004. If the child was hospitalized, you would see them based on their **discharge date**. Their discharge date is the date they left the hospital.

What do I do during the home visit?

During the home visit, you will complete a **HOME VISIT CHECKLIST** with the parent/guardian of the child. See Appendix 12. The home visit checklist asks questions about:

- Asthma medications
- Triggers

- Environmental control
- Regular and follow-up appointments
- Asthma and the school or day care

When doing the survey:

- Complete the survey with a black pen
- Make sure ALL questions are answered
- Write any comments you and the family have in the comment section
- Review the importance of each topic

REMEMBER: The goal of the parent mentor study is to get families to be self-sufficient and to manage their child's asthma all by themselves!

Ask yourself... is the family learning or being reminded of information that they can use in the future?

2) Contact families once a month by telephone

How and when do I contact each of the families that I mentor?

You will contact each family you mentor once a month. The time of day that you call them will be up to you and the family that you are working with. It should be a time that is most convenient for the both of you. You should arrange this mutually convenient appointment at least several days in advance.

If a family does not have a telephone, you will to make a home visit monthly until they are able to get a telephone.

What do I do when I call them?

When you call each family, you will complete the **MONTHLY TELEPHONE CONTACT CHECKLIST FOR PARENT MENTORS**. See Appendix 13. The checklist will ask questions about:

- Triggers
- Peak flow meters
- Asthma Care Plans
- Symptoms of an asthma attack
- Regular and follow-up health care provider's appointments

When going through the survey:

- Complete the survey with a black pen
- Make sure ALL questions are answered
- Write any comments you and the family have in the comment section
- Review the importance of each topic

If your phone call gets interrupted, contact the family again as soon as possible to complete the checklist.

3) Meet with all 10 families once a month at a place in the community

You will meet with all 10 of the families you are mentoring once a month at a local community meeting site. At each meeting, families will be provided with dinner, asthma education, and a chance to network with other children and families with asthma. At each meeting, you will give a 5-minute update about the work you have been doing with the families, then there will be a brief presentation about asthma, and finally there will be an opportunity for families to share their experiences.

At the end of each monthly meeting you will meet with each family individually to discuss any issues or concerns about the child's asthma.

Please see Appendix 14 for a list of the community meeting sites.

4) Meet with the Asthma Nurse once a month

One hour before each of the monthly meetings, you will meet with the Asthma Nurse Specialist to go over any issues that may have come up while working with your families. The Asthma Nurse Specialist will be a resource to you for any of your questions and concerns.

Please see Appendix 15 for contact information for the Nurse Specialist and the Program Coordinator.

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Definition of Terms

Allergic triad: when a child has related allergic disorders such as eczema, allergies and asthma

Asthmatic: a term used for a person who has asthma

Chronic: Something that lasts a long time and frequently reoccurs

Controller medications: Medications that are taken everyday to prevent asthma exacerbations.

Discharge Date: The date that a child is sent home from being in the emergency department or in the hospital.

Disparity: Differences between two or more groups

Dry Power Inhaler: (DPI) Equipment used to deliver dry powder medication to the lungs.

Exacerbation: asthma attack

Heredity: The passing of physical qualities from parents to children

Inflammatory: Swelling

Metered Dose Inhaler: (MDI) Equipment used to deliver aerosol medications to the lungs.

Randomized-Controlled Trial: Describes the set-up of the Parent Helping Parents Fight Asthma Project. Children and their families will be put into either an intervention or control group chance. It is like flipping a coin. Children and families paired with a Parent Mentor will be in the intervention groups and those not paired with a Parent Mentor will be in the control group.

Rate: an amount of something in a given population or community.

Rescue medications: Medications that are taken only during an asthma exacerbation.

Risk Factors: Something that makes another thing more likely to happen.

Severity levels: levels that health care professionals use to decided what type of medication and treatment children should receive.

Mild intermittent- Child has asthma symptoms less than 2 days per week, or 2 nights per month.

Mild Persistent- Child has asthma symptoms more than 2 days a week, but less than 1 time per day; or more than 2 nights a month.

Moderate Persistent- Child has asthma symptoms every day or more than 1 night a week.

Severe Persistent- child has asthma symptoms continually throughout the day and frequently at night.

Sterile: When something is very clean and contains no germs. This can be harmful to a child with asthma when their bodies are not used to a too clean environment

Stethoscope: an instrument used by a doctor or nurse to hear sounds produced in the body.

Thrush: yeast in the mouth, characterized by the formation of whitish spots.

Trachea: the main trunk of the system of tubes by which air passes to and from the lungs in vertebrates.

Triggers: Something that will set off a child's asthma like dust or dog hair

Appendix 1

Map of City of Milwaukee

Appendix 2

Information on Badger Care

Appendix 3

A List of Free Clinics in the Milwaukee Area



Appendix 4

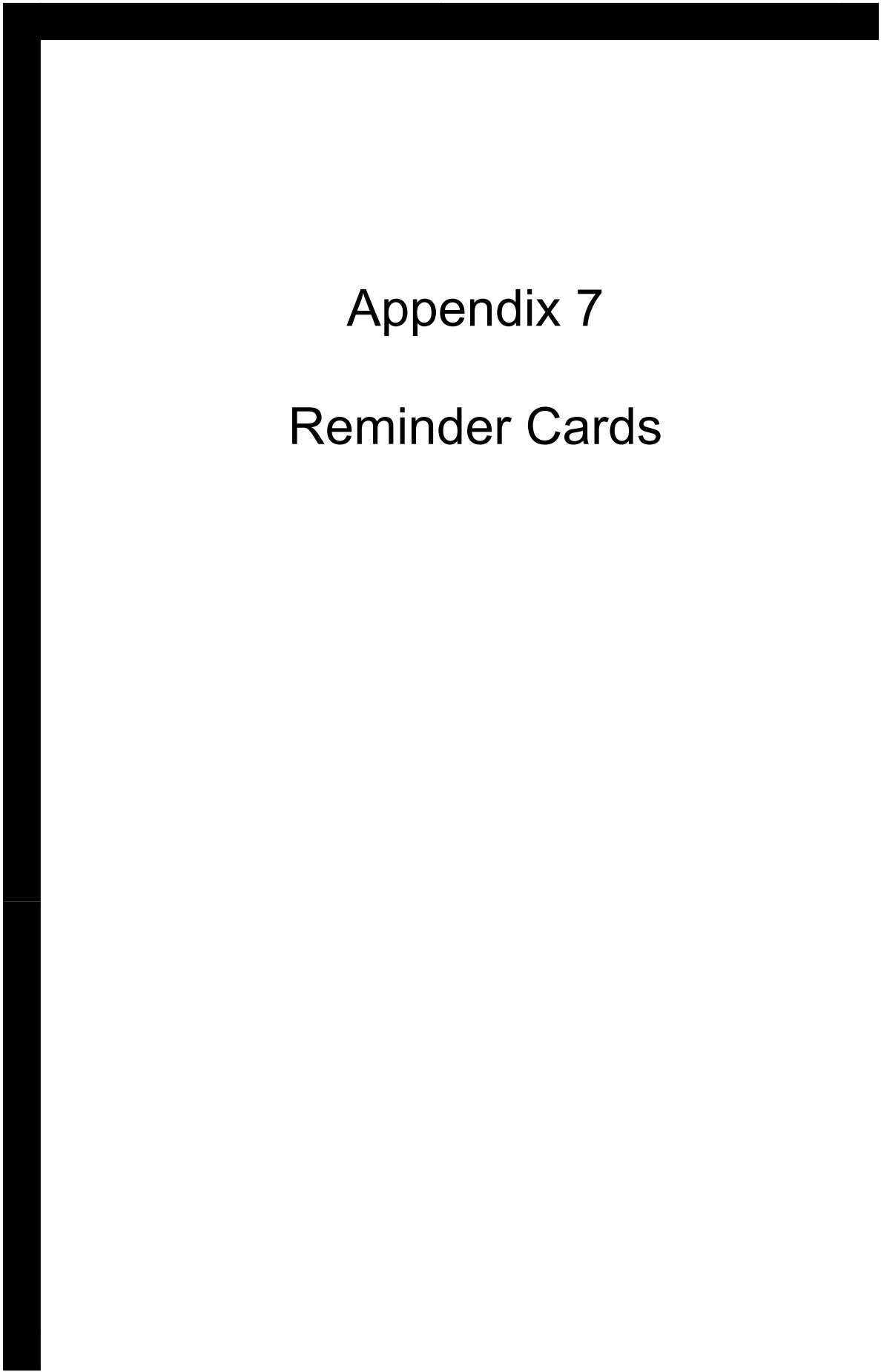
Severity Levels

Appendix 5

Medication Teaching Sheets

Appendix 6

Reminder Calendar for Health Care Provider Appointments

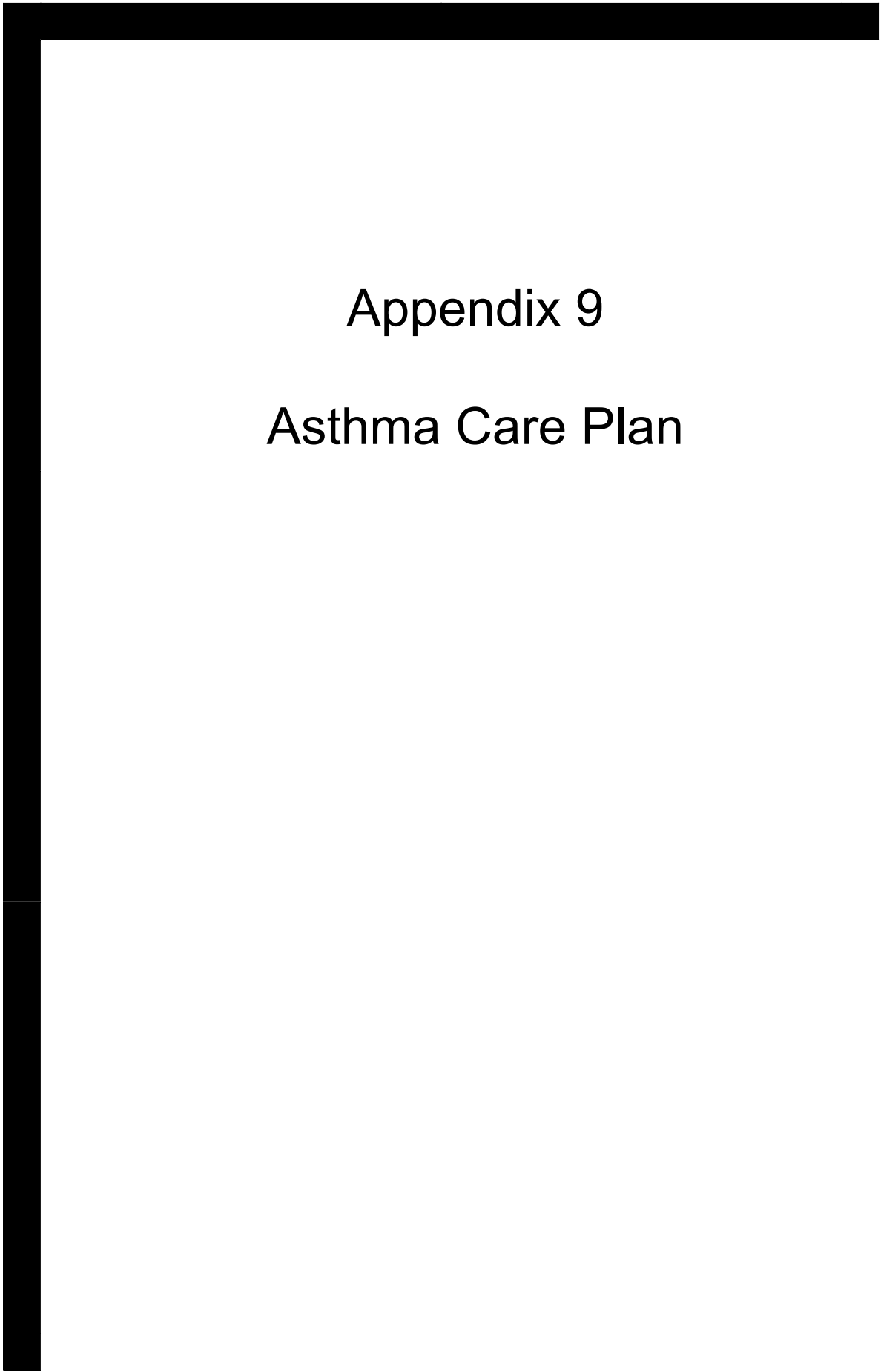


Appendix 7

Reminder Cards

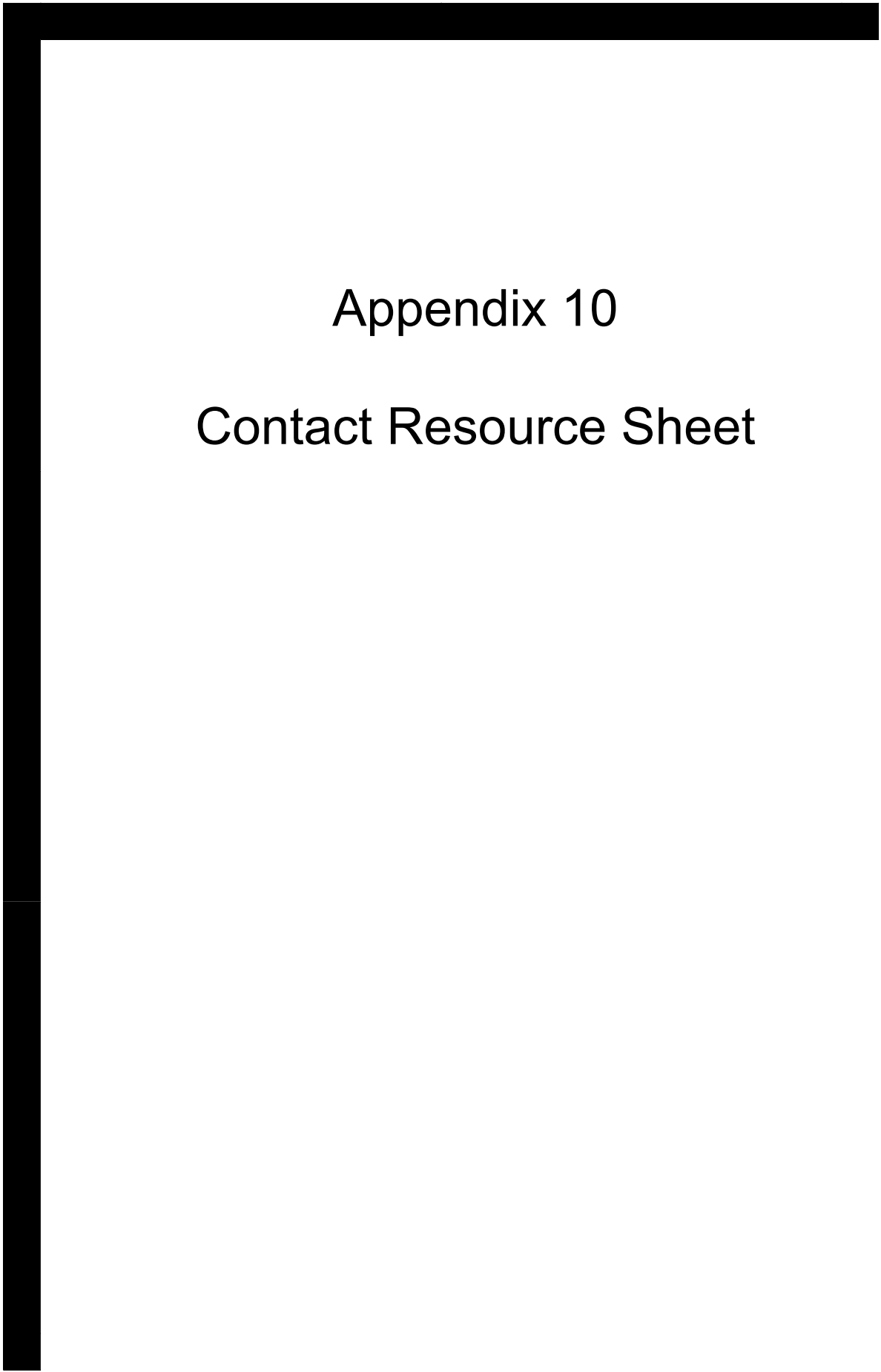
Appendix 8

Wisconsin Act 77



Appendix 9

Asthma Care Plan



Appendix 10

Contact Resource Sheet

Appendix 11

Table of What Parent Mentors Can and Cannot Do

Appendix 12

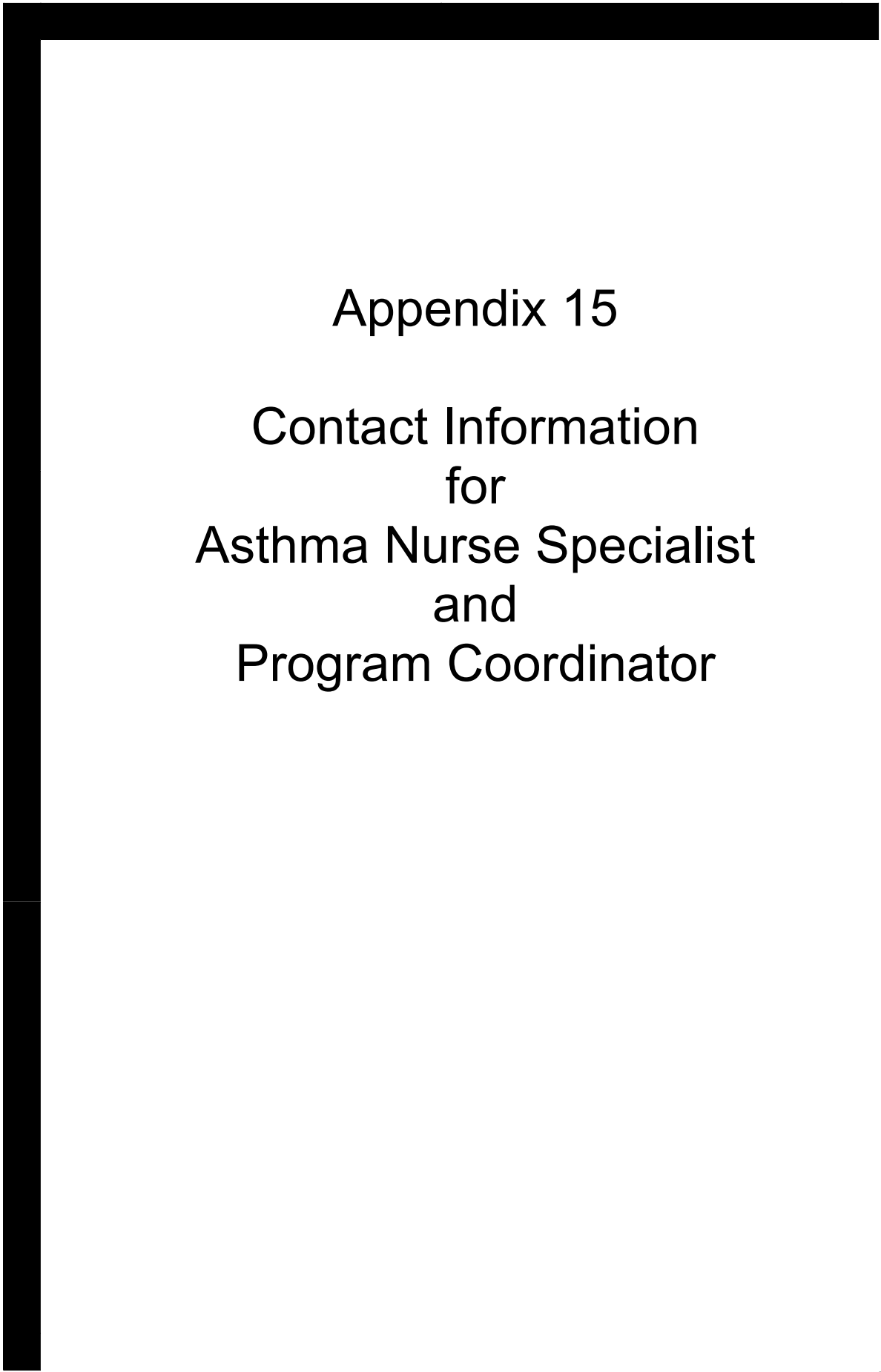
Home Visit Checklist

Appendix 13

Monthly Telephone Contact Checklist for Parent Mentors

Appendix 14

List of Community Meeting Sites



Appendix 15

Contact Information
for
Asthma Nurse Specialist
and
Program Coordinator