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ABSTRACT

Head Start program performance standards require that children not be excluded from Head Start solely on the basis of their health care needs. This guide is designed to build staff capacity to make Head Start a safe and welcoming place for children with chronic conditions and their families, and to create a framework for individual planning to meet the special health needs of children with chronic conditions. Following an introductory section, the guide presents three modules. Each module details expected outcomes, key concepts, background information, learning activities, and next steps. Handouts are included for each module. Module One, "Understanding Chronic Conditions," provides an introduction to chronic conditions and guidelines for assessing programs when caring for children with chronic conditions. Module Two, "Essential Principles for Care," demonstrates that responsive, responsible care for children with chronic conditions is family-centered, designed around individual needs, and is safe and legal. Module Three, "Putting It All Together--Caring for Children with Asthma," applies the principles discussed in the first two modules to caring for a child with a common chronic condition. The final sections of the guide contain information for continuing professional development and resources. (SD)

HEAD START®

Training Guides for the Head Start Learning Community

Caring for Children with Chronic Conditions

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Administration for Children and Families
Administration on Children, Youth and Families
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Photo courtesy of Harry Cutting Photography, of Fort Myers, Florida.

1998

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Putting It All Together: Caring for Children with Asthma

Contents

Preface

"What if I give the wrong amount of medicine to Malik?"

"What if Lianne has an asthma attack and I don't know what to do?"

"What if..."

Many of the fears about caring for children with chronic medical conditions begin with "what if...". Let's imagine for a moment another set of "what ifs...".

- "What if every child with a chronic medical condition could learn and play together with other children?"
- "What if parents took their children to Head Start confident that the staff could handle a medical crisis safely and sensitively?"
- "What if all children learned that everyone has unique strengths and challenges, and that by appreciating these strengths and accommodating these needs, we emerge a stronger, richer, and more humane community?"

As seen by these "what if" questions, there are responsibilities and risks–as well as rich rewards–in trying to make our schools and communities safe and welcoming places.

Caring for Children with Chronic Conditions is intended to help Head Start programs answer the "what ifs." Our commitment is to inclusive, family-centered programs that support family strengths. To achieve this, we must know ourselves and our programs, as well as the individual children and families. Then we can engage in creative, individual planning so that each classroom teacher, parent, and child can feel safe and confident. The teacher will know how to make sure she gives Malik the right amount of medicine. Lianne's Mom will know that the health coordinator has information from Lianne's doctor in case her asthma flares up and she needs treatment. And when those "what ifs" are answered, we can learn the answers to the next set of "what ifs."

The concepts and activities in this guide build on each other, so users should proceed from the beginning to the end. However, the learning activities can be adapted to each program's situation. For example, any workshop activity can be adapted to use with a smaller group, or you can insert stories and issues from your own program.

Training materials are most effective when applied to the everyday work setting. Knowledge and skills developed during training must be supported by follow-up activities. This guide contains sections titled "*Next Steps: Ideas to Extend Practice*" and "*Continuing Professional Development*," to help users design long-term learning plans.

Many Head Start programs across the country helped to develop this guide. Our sincere thanks to the Head Start staff and parents who discussed the challenges they faced, shared their stories, participated in trainings, and provided feedback on the activities. We appreciate the feedback from the Head Start Bureau, Regional Offices, Training and Technical Assistance Network, and National Training Contractors. We especially value the detailed review and input provided by the guide's development team of Head Start staff and health professionals.

We hope that ***Caring for Children with Chronic Conditions*** helps you to develop an effective partnership among Head Start staff, parents, health professionals, and children that will prepare you to answer the "what ifs" faced by Head Start programs and families. Because when frightening scenarios are faced head-on and planned for, dreams can–and do–come true.

Overview

Purpose

Children with chronic conditions and their families have the same needs, rights, and dreams as all young children and their families.

The purpose of this guide, ***Caring for Children with Chronic Conditions,*** is to:

- build staff capacity to make Head Start a safe and welcoming place for children with chronic conditions and their families.
- create a framework for individual planning to meet the special health needs of children with chronic conditions.

Audience

This guide is for Head Start management teams responsible for the design and coordination of integrated curriculum/service plans for children as well as for teachers and family service workers who implement those plans.

Performance Standards

Head Start Program Performance Standards require that:

- children not be excluded from Head Start solely on the basis of their health care needs;
- health conditions identified through screening or health history reviews at enrollment be followed by helping the family get necessary services; and
- an individualized approach be taken for each child's education. This means making reasonable accommodations in program policies, protocols, or procedures to enable a child with special health care needs to participate in Head Start.

Introduction

Orientation to the Guide

The specifics of any medical condition and its symptoms are different for each individual–each child's medical condition is unique. Consequently this guide does not represent a comprehensive resource about any specific chronic condition. **The guide is designed to use some common conditions to illustrate essential principles of care that are relevant to most programs and relevant across conditions.** The examples provide a process that your program can use to get the information to meet the needs of children in your program. The guide is divided into the following sections:

- ***Module 1: Understanding Chronic Conditions***

  This module provides an introduction to chronic conditions. What is a chronic condition? What do chronic conditions mean in the lives of children and families at different developmental stages? What does it feel like for a teacher to care for a child with a chronic condition? The module closes with a brief activity to help programs assess their training needs when caring for children with chronic conditions.

- ***Module 2: Essential Principles for Care***

  This module demonstrates that responsive, responsible care for children with chronic conditions is family-centered, is designed around individual needs, and is safe and legal. This module introduces material to help create programs that include these essential principles.

- ***Module 3: Putting It All Together–Caring for Children with Asthma***

  This module takes the principles discussed in Modules 1 and 2 and applies them to caring for a child with a common chronic condition: asthma.

- ***Continuing Professional Development***

- ***Resources***

Module Sections

Each module provides learning opportunities for workshop (12-25 people) and coaching (two-three people) sessions. Each module has the following sections:

- **Outcomes:** The skills to be acquired by staff who participate in a module's activities.
- **Key Concepts:** The main ideas the module covers. These sections can be used as handouts or overheads.
- **Background Information:** Elaborates on the Key Concepts. This section can be used as a coaching resource or as an outline for a presentation to a group. Background Information sections can also be used for handouts or as overheads in workshop sessions.
- **Questions for Discussion/Reflection:** Listed at the end of each Background Information section. These questions can be used to initiate discussion in workshops and coaching sessions, or serve as prompts for staff journals.
- **Learning Activities:** Build the skills needed to achieve the module's outcomes. Managers can choose to use workshop activities, coaching activities, or a combination. Activities should be adapted to a group's size and composition: the management team, staff from one component area, or staff and board members together.
- **Points to Consider:** Issues listed at the end of each activity to keep in mind or to use as discussion prompts while working through the activity.
- **Next Steps: Ideas to Extend Practice:** Additional activities to reinforce the expected outcomes and help to transfer skills from the training sessions to the work setting.
- **Handouts:** Included at the end of each module. Trainers should reproduce the handouts as needed for participants.

Definition of Icons

Coaching	A training strategy that fosters the development of skills through tailored instruction, demonstrations, practice, and feedback. The activities are written for a coach to work closely with one to three participants.
Workshops	A facilitated group training strategy that fosters the development of skills through activities which build on learning through group interaction. These activities are written for up to 25 participants working in small or large groups with one or two trainers.
Next Steps: ***Ideas to Extend Practice***	Activities assigned by the trainer immediately following the completion of the module to help participants review key information, practice skills, and examine their progress toward expected outcomes of the module.
Continuing Professional Development	Follow-up activities for the program to support continued staff development in the regular use of the skills addressed in a particular training guide. They include: 1) opportunities tailored to the participant to continue building on the skills learned in the training; and 2) ways to identify new skills and knowledge needed to expand and/or complement these skills through opportunities in such areas as in higher education, credentialing, or community educational programs.

At A Glance

Modules	*Activities*	*Time*	*Materials*
Module 1: Understanding Chronic Conditions	Activity 1: What Does "Chronic Condition" Mean? *(W)*	60 minutes	Handouts A 1-3; Handout B
	Activity 2: Alike and Different *(W)*	45 minutes	Handouts C 1-2; Handout D
	Activity 3: Taking Development Into Account *(C)*	45 minutes	Handout E; Handouts F 1-3; Handout G
	Activity 4: How Are We Doing? *(C)*	Over time	Handout H
Module 2: Essential Principles for Care	Activity 1: Is This Family Centered? *(W)*	60 minutes	Handout I; Handout J; Handout K; Handout L
	Activity 2: Assert Yourself *(C)*	90 minutes	Handout M; Handout N
	Activity 3: Are We Prepared? *(W)*	30 minutes	Handout O; Handout P; *Key to Activity 3*
	Activity 4: Making It Our Own *(C)*	Over time	Handout Q
	Activity 5: Listening To Learn *(C)*	Three 60 minute inter-views	Handouts R 1-3
	Activity 6: Taking Medicine *(C)*	120 minutes	Handout S
	Activity 7: Whom Do I Tell? *(W)*	45 minutes	Handout T; Handout U

Modules	*Activities*	*Time*	*Materials*
Module 3: Putting It All Together– Caring for Children with Asthma	Activity 1: How Does It Feel? *(W)*	45 minutes	Handout V
	Activity 2: Developing The Individualized Health Plan *(W)*	90 minutes	Handouts W 1-4; Handout X; Handout Q (from ***Module 2***); *Key to Activity 2*
	Activity 3: What Would You Do? *(C)*	45 minutes	Handout T (from ***Module 2***); Handout Y

(W) = Workshop Activity

(C) = Coaching Activity

Understanding Chronic Conditions

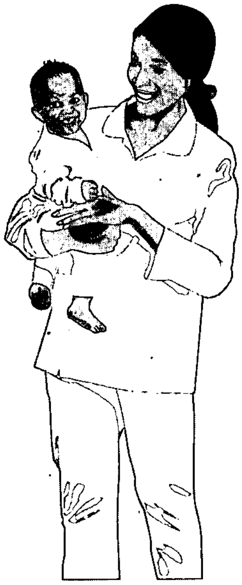
Outcomes

After completing this module, participants will:

- *understand how chronic conditions affect children and families; and*
- *assess their program's needs for policies, training, and planning to better serve children with chronic conditions and their families.*

Key Concepts

- **Children with chronic conditions and their families are more alike than different from other children and families. Each child and family has unique strengths, dreams, joys, and needs.**
- **When a child has a chronic condition, it can affect everyone: the child, parents, siblings, classmates, and teachers.**
- **Head Start staff can build on skills they already have to individualize care for children with chronic conditions.**



Background Information

A. What Are Chronic Conditions?

Chronic conditions are health conditions that continue over a long period of time, often for life. Although the terms "chronic condition" and "chronic illness" may be used interchangeably, a person with a chronic condition may or may not be unwell from day to day.

Chronic conditions vary widely. Some examples of chronic childhood conditions include allergies, asthma, hearing loss, diabetes, seizures, cerebral palsy, cancer, spina bifida, and HIV/AIDS. A child might be diagnosed with a single chronic condition or multiple conditions. For example, children born premature and very low birth weight may have multiple conditions such as developmental delays, cerebral palsy, and asthma.

Children's symptoms of chronic conditions can range from mild to severe. They may need few or many adaptations in daily activities. For example, a child with allergies and asthma might be well on a daily basis with only seasonal episodes requiring treatment; whereas a child with diabetes might need daily medication and monitoring of diet, exercise, symptoms, and blood sugar levels.

The course of chronic conditions can also vary over time. A chronic condition may stay the same or change, either getting better or worse, over time. For example, a child's visual impairment from birth might be stable over time; a child successfully treated for leukemia might go into remission; and a child with HIV disease might progress from having no symptoms to frequent illnesses.

If a child in Head Start has a chronic condition, find out what you need to know to care for the child and support the family. You don't need to become a medical expert. But you do need detailed information on the child's condition and daily care needs. Simply knowing a child's diagnosis doesn't explain all you need to know to care for the child. For example, one child with a seizure disorder might be well-controlled on medication and never have a seizure or need special accommodations in Head Start, whereas another child with the same diagnosis might have frequent seizures and require many accommodations. And remember, too, that knowing a child's diagnosis doesn't tell you *who* that child *is*–her favorite color, food, book, song, or game.

Like any other child, the child with a chronic condition is a unique individual. Head Start's responsibility is to get to know each child and family and to individualize the child's care.

B. How Are Chronic Conditions Different From Other Kinds Of Illnesses?

Every child periodically experiences acute illnesses–those that last only a short time. A child with the flu might be quite sick but usually gets better within a few days. To give the ill child the extra attention needed, parents might temporarily put aside some usual responsibilities, get a little less sleep than usual, and get help from friends or family for a few days until the child recovers and the routines are back to normal.

When a child has a chronic condition that continues over time, however, families can't simply overextend themselves for a few days to care for the child's needs. The family must develop strategies to care for the child's needs as part of their daily lives over an extended period of time. They must continually mobilize energy, finances, and support from family and friends who may provide child care, transportation, and a sympathetic ear.

Caring for a child with chronic conditions also typically demands extensive involvement with service agencies. Many different health care, education, and social service providers may be involved and managing the child's care can be very complex and time-consuming.

C. What Do Chronic Conditions Mean For The Family?

Life can be a delicate balancing act for all families, but particularly for families that have children with chronic conditions. The child's special health care needs must be balanced with his normal developmental needs as well as the needs of caregivers and other family members.

Parents of children with chronic conditions are more likely to report headaches, depression, anxiety, and marital stress–although they are no more likely than others to divorce. Chronic conditions often strain families' finances. The child's primary caregiver may have a limited ability to work outside the home. Even when medical costs are covered, and often they are not, other needs such as transportation, child care, special foods or equipment, and respite care are rarely provided. Recurring health crises and uncertainty about the child's and family's future can cause fatigue, worry, anger, and sadness. Family members can alternate between periods of resolution and anger, sorrow and calm.

While chronic conditions can be a profound stress, most families learn to cope. Family members often discover hidden strengths and learn new skills. Shy and unassertive parents can learn to become fierce advocates for their children. Children with chronic conditions, siblings, and classmates may become more sensitive and compassionate as a result of their experiences.

D. Developmental Understanding Of Chronic Conditions

Children with chronic conditions, siblings, and classmates have many questions such as, “Why can’t I eat what the other kids do?” “What is that medicine that Simone gets?” “Do those braces hurt Lamar?” Children need honest explanations from the adults they trust at a level they can understand. To provide appropriate explanations, parents and teachers need to understand how children’s development influences their understanding of health conditions. For example, since a five-year-old might have fantasies or fears of having caused an illness by something “bad” she did, it can be helpful to respond to her “why” questions in more detail than you would for a three-year-old.

Chronic conditions also affect families in different ways depending upon their stage of family development. Parents develop from being a childless couple to being parents of an infant, toddler, and preschooler; and an only child becomes a big brother. Just like child development, family development can also be affected by their child’s chronic condition. For example, when first-time parents have anxiously awaited holding their newborn, the birth of a small and fragile premature infant can lead to shock, fear, and uncertainty that could interfere with their bonding with the baby. Head Start staff can play a key role in facilitating the development of families of children with chronic conditions.

(See Handout E: Development and Chronic Conditions.)

Questions for Discussion/ Reflection

- Does anyone in your family or among your friends have a chronic condition?
- How might your personal experience affect your feelings about caring for a child with a chronic condition in your program?
- What are your concerns and fears about becoming an important person in the life of a child with special health care needs? Take a moment to reflect on your own feelings.

Activity 1: What Does "Chronic Condition" Mean?

Purpose: This activity helps participants appreciate the emotional impact of chronic conditions on children, parents and Head Start staff.

For this activity you will need:

- Handouts A-1, A-2, and A-3: Characteristic Cards for Child, Parent, and Staff
- Handout B: How Does It Feel?
- Three different colors of paper or card stock
- Three envelopes
- Flip chart and markers
- Name tags and markers

> ***Trainer's Preparation Note:***
>
> *Before beginning this activity you will need to:*
>
> 1. *Copy Handouts A-1, A-2, and A-3 onto three different colors of paper or card stock.*
> 2. *Cut along the horizontal and vertical lines to make separate cards for Child, Parent, and Staff.*
> 3. *Label the envelopes "Child," "Parent," and "Staff" and place the cards in the appropriate envelopes.*
>
> *This makes enough cards for 45 participants. If there are more participants in this activity, make two copies each of Handouts A-1, A-2, and A-3.*

Step 1: Start this activity by asking participants:

- What does "chronic condition" mean?
- What are some examples of chronic conditions that children in your Head Start program have had?

Step 2: Discuss how each child with a chronic condition is a unique individual. The family and the Head Start staff people caring for the child and family have unique characteristics and circumstances as well.

Explain that this activity helps participants experience what chronic conditions mean, particularly how they feel, from everyone's perspective–the child, parent, and Head Start staff–based on their own characteristics and circumstances.

Step 3: Have participants divide into groups of three. Groups should decide among themselves who will play the role of a child, a parent, and a Head Start staff person. Distribute name tags and markers and have participants write their role on their name tag.

Step 4: Pass around the envelopes labeled "Child," "Parent," and "Staff" and have participants take two cards from their role category. Ask them to quickly review their cards. If they've drawn contradictory characteristics, they should draw again.

Step 5: Explain to participants that they've just been dealt their current life circumstances. The characteristics on the cards are part of who they are in their role. Ask them to take a minute to imagine their identity more fully.

Step 6: Explain that each group is preparing for the child to enter Head Start. Distribute Handout B: How Does It Feel? Have the groups spend about 10 minutes discussing the questions on the handout.

Step 7: Return to the large group. Write the headings Child, Parent, and Staff on three pieces of flip chart paper and post them.

Ask participants:

- What are some of the feelings and concerns that you discussed from the child's perspective? From the parent's perspective? From the staff perspective?

Write their responses down on the appropriate flip chart.

Step 8: Ask participants:

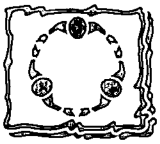
- What did it feel like to be dealt a situation without any control?

- Consider the feelings and concerns from the different perspectives of the child, parent, and Head Start staff. What are the common concerns and common needs? What are the differences?
- What attitudes, policies, and practices could Head Start build to help make children with chronic conditions, families, and staff feel comfortable and confident?

Points to Consider:

- To include children with chronic conditions, Head Start needs honest communication and respect for the feelings and concerns of everyone involved: the child, family, classmates, staff, and service providers. With good communication and collaboration, including children with chronic conditions can be a rewarding experience for the entire Head Start community.
- Caring for a child with special health care needs is a serious responsibility, and it is appropriate for families, Head Start staff, and health care providers to approach it with concern and careful attention. Staff need support including close communication with parents and service providers, and good supervision.
- The Characteristics Cards in this activity described functional characteristics rather than simply listing diagnoses. To care for a child with chronic conditions, Head Start staff need to know the child's characteristics, abilities, and care needs.

Activity 2: Alike and Different



Purpose: This activity helps participants appreciate the similarities and differences in the needs of children with chronic vs. acute illnesses. It also helps staff realize that they already know how to make many of the accommodations needed to care for children with chronic illnesses.

For this activity you will need:

- Handout C-1: Alike and Different–Acute (front and back) and Handout C-2: Alike and Different–Chronic (front and back)
- Handout D: Alike and Different Discussion Guide
- Flip chart and markers

> ***Trainer's Preparation Note:***
>
> *Before beginning this activity you will need to:*
>
> 1. *Make two-sided copies of Handouts C-1 and C-2: Alike and Different. (Note that the front sides of the handouts are the same but the back sides are different.)*
> 2. *Cut along the horizontal lines to make 10 strips.*
> 3. *Make 10 copies of Handout D: Alike and Different Discussion Guide.*

Step 1: Start the activity by asking participants:

- What does "chronic condition" mean?
- What are some characteristics of chronic conditions?

Briefly list the responses on flip chart paper (e.g., it lasts a long time, it probably cannot be cured but it can be managed or controlled, it usually is not contagious, it can stay the same or change over time).

Step 2: Divide participants into 10 groups of two to four people, depending on the number of participants. Give each small group a story strip from Handout C-1: Alike and Different–Acute or C-2: Alike and Different–Chronic and a copy of Handout D: Alike and Different Discussion Guide.

Step 3: Instruct the small groups to read their story strip, front and back sides, and answer the questions on the Discussion Guide. Allow 10-20 minutes.

Step 4: Bring the participants back together. Ask each group to say the name of the child in their story and have the groups with the same child's name come together. Instruct the small groups to compare their two story strips, front and back, and their responses to the questions on the Discussion Guide.

- Which responses are similar?
- Which responses are most different?

Step 5: Bring the whole group back together. Have each small group read aloud their story on the front of the strip, then the two different back sides. Ask participants:

- What did you learn from this activity?

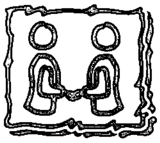
Step 6: Return to the original flip chart list of characteristics of chronic conditions. Ask participants:

- After completing this activity, is there anything you would like to add to your list of what chronic conditions mean?

Points to Consider:

- Many things are the same for children with chronic and acute conditions, such as how they might feel and what caregivers need to do. Some things may be different, such as the child's and family's ongoing needs from Head Start and other service providers. Families with children with chronic conditions may need closer communication, more accommodations, and more emotional support.
- The accommodations needed to care for children with chronic conditions are often similar to those made for children with acute conditions (e.g., giving more individual attention and comfort, modifying activities or diet, giving medications, and assisting with movement). To care for children with chronic conditions, Head Start staff can build on the skills that they already have.

Activity 3: Taking Development Into Account



Purpose: This activity helps participants understand how children's and families' development influences their experience of living with a chronic condition.

For this activity you will need:

- Handout E: Development and Chronic Conditions
- Handouts F-1: Infant; F-2: Toddler; and F-3: Preschooler
- Handout G: Kid Talk

Step 1: Explain that this activity uses what we know about child and family development to consider how children of various ages and their families might experience a chronic condition.

Step 2: Give out Handout E: Development and Chronic Conditions. Explain that this handout describes the relationship between development and chronic conditions for typically-developing children and their families. Since many chronic conditions can affect children's and families' development, however, the examples in the chart may be different for different children and families.

Step 3: Briefly review Handout E. Highlight how children and families develop through stages and how chronic conditions can affect both child and family development. Ask participants to describe another example from their own experience of how a chronic condition affected the development of an infant, toddler, preschooler, and family.

Step 4: Give out Handout F-1: Infant, and read the story aloud. Discuss the questions on the handout.

Repeat for Handout F-2: Toddler, and Handout F-3: Preschooler. Allow approximately 30 minutes to discuss the three stories.

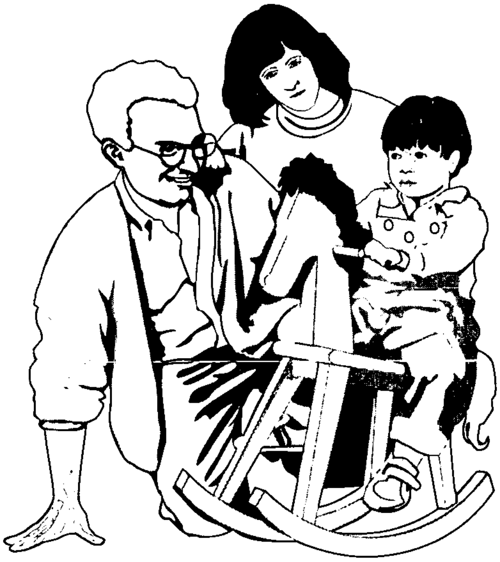
Step 5: Ask participants:

- How did these stories help you understand the role of Head Start in facilitating the development of children with chronic conditions and their families?

Step 6: Give out Handout G: Kid Talk. Review the handout briefly. Ask participants if they have any additional tips, from their own experience, for talking with children and families about chronic conditions.

Points to Consider:

- Head Start plays a very important role in facilitating child and family development, particularly for children with chronic conditions and their families.
- Religious or spiritual ideas about chronic conditions are best left to the family. Head Start can support a family's beliefs but should not introduce religious or spiritual interpretations as they may be in conflict with those of the family.



Activity 4: How Are We Doing?

Purpose: This activity helps assess how well the program is caring for children with chronic conditions, and determine what policies, protocols, training, and planning might be needed to improve the care. This activity is helpful as both a needs assessment and action plan–beginning the school year or opening a training, and ending the school year or concluding a training.

For this activity you will need:

- Handout H: How Are We Doing?
- Flip chart paper and marker

Step 1: Set up a meeting of the management team to develop a plan to assess how well the program is caring for children with chronic conditions and how their care can be improved. Briefly discuss some of the children with chronic conditions in the program:

- What chronic conditions do the children have?
- What are the children's care needs in Head Start?
- What do you think the program does well to care for and support these children and their families?
- What are your concerns and what could the program do better to care for and support these children and families?

Step 2: Develop a plan to do a more detailed assessment of the program's care for children with chronic conditions:

- *What are the questions that we need to ask* to find out how we're doing and what we need to do better to care for children with chronic conditions?

Review Handout H: How Are We Doing? Add any other questions that you may have.

- *What are the sources of information* to assess how we're doing and what we need to do better to care for children with chronic conditions?

Make a plan for who to interview (e.g., staff, parents, children, service providers) and what records to review (e.g., child health records, family assessments, IEPs, and IFSPs).

- *Who will be responsible* for which interviews and record reviews?
- *What is our timeframe* for completing our assessment?

Step 3: Complete the interviews and record reviews according to the plan.

Step 4: Set up another meeting of the management team to review the information gathered:

- What are the children's care needs in Head Start?
- What is the program doing well to care for and support these children and their families?

List on flip chart paper under the title, "Successes." Next, ask the team:

- What could the program do better to care for and support these children and their families?

List on flip chart paper under the title, "Needs." Ask:

- Did you discover anything in the needs assessment that you were not previously aware of? If so, how could we increase our awareness of these things in the future?

Step 5: Congratulate yourselves on the program's successes in caring for children with chronic conditions.

Then focus on the needs for improvement. For every need, discuss and write down which of the following might be needed:

- Improved Communication among Staff, Families, and Service Providers
- Policies, Protocols, and Procedures
- Staffing
- Curriculum and Activities

- Training
- Technical Assistance
- Supplies and Equipment
- Facilities

Be as specific as possible (e.g., Training for the classroom teacher, aide, and bus driver to administer Hayley's inhaled medication for asthma).

Step 6: Present the needs assessment to the Health Services Advisory Committee. Discuss the priorities and work together to develop a more detailed action plan. Identify resources in the training guides, local community, and Head Start training and technical assistance providers to help address the needs.

Step 7: Repeat the needs assessment within the year to evaluate progress toward the goals and revise the plan for improvement.

Points to Consider:

- Caring for children with chronic conditions often requires accommodations in many areas including communication, policies, staffing, training, technical assistance, supplies, and facilities.
- Improving the care of children with chronic conditions in Head Start requires an ongoing process of assessing the needs, planning actions, following through on actions, re-assessing the needs, and revising plans.
- General training for staff about caring children with chronic conditions is helpful, but it can never replace individualized planning for the health care of a specific child in Head Start.

Next Steps: Ideas to Extend Practice

1. ***Search the WWW for Resource Information***

In order to understand the affect of a chronic illness on a particular family, one must listen to the family and its experience of the illness. It can also be helpful to get additional information about the condition. One excellent source of information about resources is the World Wide Web (WWW; also called the Web).

Learn how to use the Internet to search the Web to find information and resources about a specific chronic condition. Several sites on the Web have very useful and practical information.

- First you need access to a computer that can connect to the Internet via a dial-up service provider (e.g., Slipnet.com or Sprynet.com) or an on-line service (e.g., America On-Line or Prodigy) and a web-browser (e.g., Microsoft Explorer or Netscape) that allows you to access information on the Web. If there is no computer at your program, community resources such as libraries or schools might provide Internet/WWW access.
- Discuss with the family any issues that they may have regarding the illness. Is there a specific illness or issue that they would like to have more information about?

You can search the entire Internet for a specific topic, such as childhood asthma, or for a general topic, such as children's health. Using your on-line service to access the Internet will allow you to use a search engine (e.g., Yahoo, Excite, Lycos, Hot Bot) to look for a link to relevant documents or a Web site that covers your topic.

Many Web sites will allow you to do additional searches for information contained at that site. For example, using your search engine, if you enter a search for "children's health," you will retrieve thousands of Web sites. From there you can choose to go to one particular site, for example, KidsHealth.org. Once at KidsHealth.org, you can search for "asthma" and retrieve even more documents, from published articles to helpful hints on handling emergencies.

You can print out this information and share it with the parents or you can use the information to make handouts to share with staff members and other parents in your program.

The best way to learn about the Internet is to sign on-line and surf the Web!

Trainer's Note:

The WWW is rapidly growing and more and more individuals and organizations are creating home pages; practically anyone can design a home page. So, information and resources retrieved from sites should be viewed with caution; some information may be more reliable than others. Medical information retrieved from a Web site should be reviewed by the Health Services Advisory Committee before it is shared with parents and staff.

Much of the health information on the WWW is public domain, which means it can be reproduced. However, always verify whether information you retrieve is protected by copyright laws before distributing it to staff and parents.

2. *Share the Information You Found on the WWW*

Are there other ways that these skills can be useful to your program?

- Check with other programs, parents, or staff to see if they know of any other Web sites about children's health, a specific condition, or parent networks.
- Search the Web for support groups for parents of children with specific conditions. There may be statewide support groups for families of children with special needs. Parent support groups on the Web may be particularly helpful for parents of children in rural programs, who feel isolated in dealing with their child's chronic condition. There may be an Internet news group (sometimes called Usenet groups) that will allow parents to exchange information with other people with similar issues. Online providers, such as America On-Line, may also have similar discussion groups.
- Train other staff on how to access information from the Internet and the Web.

Handout A-1: Characteristic Cards—Child

Makes friends easily	Needs daily oral medications
Has a sense of humor	Is friendly and outgoing
Tires easily	Knows a lot about her condition and what she needs to do
Needs blood tests and injected medications	Uses inhaled medications
Has a supportive extended family	Has dietary restrictions
Is hopeful and optimistic	Requires urinary catheterization
Has frequent hospitalizations	Has a terminal illness
Has high expectations for self	Has a very loving relationship with parents
Has a good relationship with the teacher	Has a good relationship with the doctor
Has a significant language delay	Has a facial disfigurement
Has challenging behavior	Fed by gastrostomy tube
Requires urgent care in a crisis	Has moderate developmental delay
Has limited mobility	Has an infectious disease
Needs help toileting	Gets taken out of class for therapy

For use with Activity 1

Handout A-2: Characteristic Cards—Parent

Is friendly and outgoing	Has a sense of humor
Lives with child's other parent who is supportive and helpful	Is a single parent without extended family support
Is a teenager	Has a chronic illness
Is well informed about the child's condition and skilled in procedures	Has four children
Is in a physically abusive relationship	Has a supportive extended family
Has a job and some financial resources	Has another child with special needs
Has an addiction to alcohol	Has not developed a strong relationship with a staff person
Speaks a foreign language and only limited English	Has a good relationship with the doctor
Has bouts of depression	Is hopeful and optimistic
Has a good relationship with the teacher	Is homeless
Has high and appropriate expectations of the child	Does not fully understand the child's condition
Understands own limitations and asks for help when needed	Has unrealistic expectations of the child
Has unrealistic expectations of self	Is very loving toward the child
Family does not have a primary health care provider	Works long days and is unable to participate in the classroom

For use with Activity 1

Handout A-3: Characteristic Cards—Staff

Has her own child with special needs	Has five other children in the class with special needs
Feels overwhelmed in the job	Has a sense of humor
Is well informed about the child's condition and skilled in procedures	Has limited mobility and difficulty performing special procedures
Speaks a foreign language and only limited English	Is happy in the job
Is hopeful and optimistic	Has an addiction to alcohol
Does not fully understand the child's condition	Has bouts of depression
Has high and appropriate expectations of the child	Has unrealistic expectations of the child
Has unrealistic expectations of the parent	Is very loving toward the child
Is not afraid of catching an infectious disease from the child	Is irritated by the child's behavior
Feels faint around medical procedures, needles, tubes, blood	Is comfortable doing medical procedures
Is comfortable dealing with terminal illness and death	Has chronic back pain
Is afraid of doing something wrong and harming the child	Has a supportive health coordinator
Has a good relationship with the child's doctor	Is uncomfortable dealing with terminal illness and death
Has not developed a strong relationship with the parent	Has a good relationship with the parent

For use with Activity 1

Handout B: How Does It Feel?

Child

- How do you feel?
- What are your concerns about starting Head Start?
- What do you want other children, parents, and Head Start staff to know about you?
- What do you want them to do?

Parent

- How do you feel?
- What are your concerns about your child starting Head Start?
- What do you want other children, parents, and Head Start staff to know about your child and family?
- What do you want them to do?

Head Start Staff

- How do you feel?
- What are your concerns about caring for this child and supporting the family in Head Start?
- What do you want the parents and Head Start management to know about you and your classroom situation?
- What kind of support do you need?

For use with Activity 1

Handout C-1: Alike and Different–Acute *(front)*

Marisol

Marisol is three-years-old and new to Head Start. All this week–off and on–she's complained of a stomach ache. Today after lunch, she said that her stomach hurt more. She went to the bathroom and had a very loose stool.

Travis

Travis is 18-months-old and in Early Head Start. When the home visitor arrives at Travis's house she becomes worried. Travis is coughing a lot. He seems to be breathing fast and sucking in his tummy with every breath. He needs to stop to catch his breath while playing.

Kenji

Kenji is five-years-old. He's had a really frustrating day! When he was getting off the bus this morning, his crutches slipped on the wet sidewalk and he fell down hard. Then at lunch he couldn't find a comfortable way to sit at the table. Now he wants to watch the jump rope game, but it's too hard to get across the gravel on the playground. He throws his crutches down and starts crying.

Tiare

Tiare is four-years-old. She's playing with Sarita in the block area. When Sarita pushes Tiare aside to reach for a block, Tiare screams, "No!" She shoves Sarita hard, and Sarita falls to the ground crying. Tiare crawls under the block table rocking back and forth and sucking her thumb.

Govind

Govind is three-years-old. When the teacher calls that it's time to come in from playing in the park, all the children line up with their buddies. But Govind is still playing alone in the sandbox at the far end of the park. The teacher calls to Govind again. Then she walks over and sits down in front of him to tell him he needs to join the other children in line. When she asks Govind if he heard her calling his name, he looks surprised and says he didn't hear her.

For use with Activity 2

Handout C-1: Alike and Different–Acute *(back)*

Marisol has the stomach flu.

Travis has pneumonia.

Kenji broke his leg last week and has a cast that will be on for a month.

Last night there was a shooting in front of Tiare's apartment house. Tiare saw the big boy from upstairs fall down all bloody. She was very scared when her Mom knocked her down to the ground to protect her. Tiare wonders what happened to the big boy, but nobody will talk to her about it.

Govind has an ear infection and started treatment yesterday.

For use with Activity 2

Handout C-2: Alike and Different–Chronic *(front)*

Marisol

Marisol is three-years-old and new to Head Start. All this week–off and on–she's complained of a stomach ache. Today after lunch, she said that her stomach hurt more. She went to the bathroom and had a very loose stool.

Travis

Travis is 18-months-old and in Early Head Start. When the home visitor arrives at Travis's house she becomes worried. Travis is coughing a lot. He seems to be breathing fast and sucking in his tummy with every breath. He needs to stop to catch his breath while playing.

Kenji

Kenji is five-years-old. He's had a really frustrating day! When he was getting off the bus this morning, his crutches slipped on the wet sidewalk and he fell down hard. Then at lunch he couldn't find a comfortable way to sit at the table. Now he wants to watch the jump rope game, but it's too hard to get across the gravel on the playground. He throws his crutches down and starts crying.

Tiare

Tiare is four-years-old. She's playing with Sarita in the block area. When Sarita pushes Tiare aside to reach for a block, Tiare screams, "No!" She shoves Sarita hard, and Sarita falls to the ground crying. Tiare crawls under the block table rocking back and forth and sucking her thumb.

Govind

Govind is three-years-old. When the teacher calls that it's time to come in from playing in the park, all the children line up with their buddies. But Govind is still playing alone in the sandbox at the far end of the park. The teacher calls to Govind again. Then she walks over and sits down in front of him to tell him he needs to join the other children in line. When she asks Govind if he heard her calling his name, he looks surprised and says he didn't hear her.

For use with Activity 2

Handout C-2: Alike and Different–Chronic *(back)*

Marisol is allergic to milk.

Travis has asthma.

Kenji has Cerebral Palsy. He has leg braces and walks with crutches.

Tiare has been diagnosed as Severely Emotionally Disturbed (SED).

Govind had many ear infections as a baby and has significant hearing loss in one ear.

For use with Activity 2

Handout D: Alike and Different Discussion Guide

1. What does this child need right now?

2. What do this child and family need from Head Start staff over time?

3. What do this child and family need from their health care provider?

4. What are your goals for the child's health and wellness?

5. How does the child's diagnosis affect your hopes, fears, and expectations about the child's future?

For use with Activity 2

Handout E: Development and Chronic Conditions

Child's Age	Child's Development	Family's Development	Effect of Chronic Conditions on Child/Family Development
Infant (birth to one year old)	Develop relationships with special people Feed, make sounds, move, and touch to learn about self and the world Develop trust that their needs will be met	Develop a relationship and fall in love with the new baby Integrate the baby into family life Adjust to new family roles, e.g., from being a couple to being parents, from being an only child to being a big brother or sister	Infant's frailty or parent's fear of loss may inhibit physical contact and bonding Siblings may be jealous of extra attention parents give to infant
Toddler (one to three years old)	Develop a sense of independence and control, e.g., "I can do it myself!" Test the boundaries of being separate from special adults	Encourage exploration and growing mastery of skills Help siblings accomodate the growing abilities of the toddler	Child's condition might limit play and exploration Family may be afraid to allow child to explore and face challenges
Pre-schooler (three to five years old)	Develop a sense of mastery and success Feel like an important member of the family and group of friends	Encourage child's growing independence Create a bridge for child from the world of home to the world outside	Child may think he caused the condition, e.g., "I have diabetes because I ate candy" or "My brother has hemo- philia because I hit him" Child becoming aware of differences between self and other children Family may have lower expectations of child's behavior and achievement

For use with Activity 3

Handout F-1: Infant

Jenny and Her Baby, Cameron

When Jenny got pregnant, her high school counselor told her about Early Head Start and she enrolled right away. She was glad to get help finding prenatal care. She even learned how good breast-feeding was and she planned to breast-feed her baby, even though none of her friends had. She hoped that having her baby in Early Head Start would also help her finish her education.

Now she's afraid that dream may not come true. Her baby, Cameron, was born premature and weighed only three pounds. His lungs were not developed and he was on a ventilator for almost three months. He ended up having pneumonia and other complications.

Cameron is still in the hospital but he's doing a lot better. He's breathing on his own and starting to take a bottle. Because of all the complications, Jenny couldn't breast-feed Cameron. But the nurses helped Jenny pump her breastmilk and freeze it during the first month so she could use it to bottle-feed him. The doctor said Cameron could go home from the hospital when he weighed five pounds. But Jenny would have to take him back to the clinic frequently to check his growth, development, and breathing because he might have chronic lung problems and developmental delays.

1. What is **Cameron** doing in his development as an infant? How might Cameron's condition affect his development as an infant?

2. What is **Jenny** doing in her development as a teenager and a new mother? How might Cameron's condition affect Jenny's development as a teenager and new mother? What concerns, fears, and questions might she have?

3. How can **Early Head Start** help Jenny and Cameron in their development?

For use with Activity 3

Handout F-2: Toddler

Deatrice

Deatrice is 2½ and always on the go! She and her four- and five-year-old brothers live with Granny and Grandpop. At Head Start, Deatrice slows down just long enough to flash her big smile before she races off to do her favorite things: play with blocks, run, climb, and dance.

Deatrice doesn't like having to stop playing to take her medicine. And it tastes awful. Sometimes Deatrice runs away when they try to give her the medicine and they have to chase her. They say she has to take her medicine every day so she doesn't have seizures and fall down and hurt her head again. Last week the ambulance came to Head Start to take Deatrice to the emergency room and she had to get stitches. Deatrice's brothers were also at Head Start and saw the ambulance take her away. Grandpop was really worried about Deatrice and Granny was really worried about Grandpop. Grandpop says he was always so healthy that he hardly ever had to go to the doctor. But he's been going to the doctor a lot since his heart attack and since they've had Deatrice and her brothers.

1. What is **Deatrice** doing in her development as a toddler? How might Deatrice understand her chronic condition? What concerns, fears, and questions might she have?

2. What are **Granny and Grandpop** doing in their development as senior citizens and as Deatrice's and her brothers' caregivers? How might Deatrice's chronic condition affect Granny's and Grandpop's development? What concerns, fears, and questions might they have?

3. What are **Deatrice's brothers** doing in their development as preschoolers? How might Deatrice's chronic condition affect her brothers' development? What concerns, fears, and questions might they have?

4. How can **Head Start** help Deatrice, her brothers, Granny, and Grandpop in their development?

For use with Activity 3

Handout F-3: Preschooler

Sergei

Sergei is five-years-old. His best friend is having his birthday party at Head Start today. Sergei is so proud that his friend asked him to sit right up next to him at the table. He loves parties, but he hates that he can't eat cake and ice cream like his friends. Sergei has diabetes so he can't have foods with a lot of sugar.

Sometimes Sergei gets so mad that he has a little candy when his parents aren't looking. He thinks maybe that's why he has diabetes. Sergei's parents taught his teacher how to do the fingerstick test. He didn't used to mind it, but lately Sergei has been feeling embarrassed when his friends watch. It's not so bad at home because his parents do the fingerstick and give him his insulin shots when his friends aren't around. It's his three-year-old sister that's really had problems with her temper tantrums at home.

1. What is **Sergei** doing in his development as a preschooler? How might Sergei understand his diabetes? What concerns, fears, and questions might he have?

2. What are **Sergei's parents** doing in their development? How might Sergei's chronic condition affect his parents' development? What concerns, fears, and questions might they have?

3. What is **Sergei's sister** doing in her development? How might Sergei's chronic condition affect his sister's development? What concerns, fears, and questions might she have?

4. How can **Head Start** help Sergei, his classmates, parents, and sister in their development?

For use with Activity 3

Handout G: Kid Talk

Be open and honest.

- Let the child know you're open to talk. Encourage him to express his concerns and questions. Never make him feel that anything is too "bad" or too scary to talk about. If something is going to hurt, say so. It's easier to comfort a child who trusts you.

Start from where the child starts.

- Before launching into an explanation, ask the child what she understands. She might have wrong information and scary fantasies that you can correct. This helps build a strong base of understanding.

Answer questions.

- Take the child's questions seriously–this lets him know that you think he is important. Every question is okay; and he may even need to ask again and again. Answer as much as you can. If a question surprises or flusters you, you can say, "I need to think about it," or "I don't know, but I'll try to find out." If you promise to discuss it later, remember to do it.

Keep it simple.

- Respond to the child in simple words and short explanations. Explain as much as the child needs to know and can understand. Don't burden the child with too much information.

Keep talking.

- Let the child know that you're open to talk at any time.

Adapted, with permission, from *Family Power: Building Skills for Families with HIV and Drug-Affected Children*. Family Welfare Research Group, Berkeley, Calif. April, 1992.

Handout H: How Are We Doing?

1. What chronic conditions do children in our program have?

2. What are the children's health care needs in Head Start? Has the program gotten all the information needed to care for these children?

3. Is there a process to develop an individualized plan for the care of the children's health needs in Head Start? If these children have IEPs or IFSPs, do they include health plans?

4. How has the program adapted services and procedures to care for the children's health needs?

5. What additional supports have helped staff care for children with chronic conditions (e.g., staffing, training, planning, communication with parents and health professionals)?

For use with Activity 4

Handout H: How Are We Doing? *(continued)*

6. Are Head Start staff confident that they provide the routine care the child needs and are prepared to handle an emergency situation?

7. Are parents of children with chronic conditions comfortable that Head Start staff provide the routine care their child needs and are prepared to handle an emergency situation?

8.

9.

10.

For use with Activity 4

Essential Principles for Care

Outcomes

After completing this module, participants will be able to:

- *assess whether the services they provide to children with chronic conditions are family-centered;*
- *develop a system for individualized planning to meet children's special health care needs; and*
- *develop policies that ensure safe and legal care for children's health needs, including administration of medication.*

Key Concepts

Head Start can best meet the needs of children with chronic conditions by providing services that are:

- **Family-Centered**
- **Individualized**
- **Safe and Legal**

Family-centered care is driven by the needs and preferences of the family rather than the convenience of the system or simply the needs of the child.

Individualized health planning involves a partnership among Head Start staff, families, and service providers to plan the child's routine and emergency care.

Since caring for children with chronic conditions is a serious responsibility, careful attention to safety and legal issues is critical.

Background Information

What does it take to care for children with chronic conditions in Head Start? There's no single recipe for all situations. What it takes–more than any policy, list of services, or staffing plan–is a commitment to communication, collaboration and creative problem-solving, and a determination to make it work. The essential principles that should guide the care of children with chronic conditions in Head Start are: care should be family-centered, individualized, safe and legal.

A. Family-Centered Care

Over the last 15 years, children's health care and the relationship between families and health professionals have changed significantly. The role of parents has shifted from being patients to partners with the health care provider; and the "good patient" has changed from unquestioningly following advice to being a good partner, who actively participates in decisions and advocates for services for their child.

"Family-centered care" involves providing the family health care and other services based on the family's needs, priorities, and convenience rather than those of the service providers or the child alone. Family-centered services are consistent with Head Start's approach to family partnerships and supporting child and family development.

Services are family-centered when*...

- the family is recognized as the child's most constant and important caregiver.
- the family and professionals collaborate as partners.
- communication is open and honest, in both directions, between the family and professionals.
- individual strengths and differences are respected among families.
- services are flexible and responsive to the family's needs.
- family-to-family support is encouraged.
- children with chronic conditions and their families are treated like other children and families, and not defined by their condition.

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* Adapted from Shelton, Terri, and Jennifer Smith Stepanek. *Family Centered Care for Children Needing Specialized Health and Developmental Services*. Association for the Care of Children's Health. Bethesda, Maryland, 1994.

B. Individualized Planning for Health

Head Start aims to individualize services for all children and families from comprehensive screening to individual planning and ongoing assessment. Individualizing means…"recognizing the characteristics that make each child unique and planning a program that responds to these differences. Individualizing allows families and staff to respond to each child's built-in time clock for development, as well as culture, family, home language, life experiences, strengths, needs, skills, and abilities.**"

Head Start can best meet the needs of children with chronic conditions by following a systematic process of Individualized Health Planning. For children who are eligible for an Individualized Education Program (IEP) or Individualized Family Service Plan (IFSP), the IEP or IFSP may or may not include planning for the child's health care needs. In addition, many children with special health needs who are not eligible for an IEP or IFSP would, in fact, benefit from individualized health planning. They might be eligible for case management services under Section 504 of the Rehabilitation Act, "Crippled Children's Services," EPSDT, or other programs.

Individualized health planning for children with chronic conditions involves close communication and collaboration among parents, Head Start staff, and service providers. It is a process of collecting all the necessary information from screening and evaluations, developing plans for the child's routine and emergency care, conducting ongoing assessment, and revising the plans as needed. The plan should be documented in writing to serve as a clear guide for Head Start staff, parents, and health care providers on meeting the child's health needs.

The Individualized Health Plan is **not** specifically required by the Head Start Program Performance Standards. However, the process of developing Individualized Health Plans is an effective tool to facilitate Head Start's goal of individualizing the care of all children, including those with chronic conditions.

- *Who should have an Individualized Health Plan?*

  Children who would benefit from an Individualized Health Plan include any child who:

  — requires adaptations in daily activities because of a medical

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** From ***Individualizing: A Plan for Success***, an Education series guide from *Training Guides for the Head Start Learning Community*. Department of Health and Human Services, Administration for Children, Youth and Families, Head Start Publications Center, Washington, D.C., 1997.

condition; daily activities to be considered include feeding, playing, sleeping, toileting

- needs medication regularly
- requires a specialized emergency plan

The decision to develop an Individualized Health Plan for a child should be made collaboratively by the parent, health specialists, and classroom teacher.

- *What are the benefits of an Individualized Health Plan?*

— Health Promotion and Prevention of Complications:

Children with chronic conditions remain healthiest when all possible measures are taken to promote their general health and manage the chronic condition closely. These steps are very effective in preventing complications of chronic conditions. For example, for a child with diabetes, it is better to closely monitor her diet and blood sugar levels than to cope with a medical emergency resulting from too low or too high blood sugar levels.

— Communication and Collaboration:

Optimal health care for children with chronic conditions requires close communication and coordination among families, Head Start, and health care providers. A systematic process of developing and following the Individualized Health Plan helps clarify the roles and responsibilities of all caregivers and facilitates collaboration.

— Training and Skills:

An Individualized Health Plan identifies the specific procedures needed to care for a child with chronic conditions. Head Start management can use the Individualized Health Plan to identify what specific training and supervision must be available for caregivers.

— Confidence:

With an Individualized Health Plan, families and Head Start staff can feel confident that they are doing everything possible to keep the child healthy on a routine and daily basis. Also, if health problems or emergencies occur, they can feel confident that they are prepared to manage them in the best way possible. Children with special medical needs feel more secure and able to learn when their caregivers know what to do.

— Protection from Liability:

Individualized health planning, staff training, and supervision can improve the care of children with chronic conditions and reduce the chance of medical complications. In the event of complications, the Individualized Health Plan may help provide legal protection for program staff by specifying procedures and clarifying responsibilities.

- *What should be included in an Individualized Health Plan?*

Caring for children with chronic conditions is a serious responsibility. Staff are commonly concerned about meeting the child's daily care needs: "How can I be sure to give him his medicine at the right time? Do we have enough staff to do his tracheostomy care while also supervising the other children? Will I have all his asthma supplies on the field trip?" Staff are also commonly concerned about emergencies: "What if I give her the wrong amount of medicine? What if she stops breathing? What if I can't reach her father on the phone?" The Individualized Health Plan should include the information necessary to respond to the most likely "what-ifs."

Many people are afraid to care for children with chronic conditions. It can raise anxieties to discuss and plan for the "what-if" situations. It is important to remember, that anticipating and planning for a situation doesn't make it happen; it just allows you to be prepared if it does.

At minimum, an Individualized Health Plan should be a guide to:

— what accommodations in daily programming are needed, including meals and snacks, playing, sleeping, and toileting

— when and how to give medication, and who may give it

— when and how to perform any required medical procedures, and who may perform them

— what procedures to follow in the event of a medical emergency

The Individualized Health Plan should be developed with the participation of families, medical professionals, classroom staff, and relevant members of the Head Start management team (e.g., health, disabilities, nutrition, and education specialists). All parties should sign the form as an indication of agreement with and commitment to plan. *(See sample Individualized Health Plan forms in the activities and handouts in Modules 2 and 3.)*

C. Ensuring That Services Are Safe And Legal

Compliance with legal requirements means not discriminating against children with special medical needs in enrollment, and ensuring that children's care needs are met in a safe and legal manner.

The decisions about the enrollment and care of children with chronic conditions in Head Start should be based on a careful assessment by the program, service providers, and families. It should include a realistic assessment of the child's strengths and needs, and the program's ability to make the accommodations needed to care for the child. Programs, families, and service providers must be committed to making it work, and honest about any limitations in their capacity to provide safe care.

Head Start Program Performance Standards state that programs "…must not deny program admission to any child, nor exclude any enrolled child from program participation for a long-term period, solely on the basis of his or her health care needs or medication requirements unless keeping the child in care poses a significant risk to the health or safety of the child or anyone in contact with the child and the risk cannot be eliminated or reduced to an acceptable level through reasonable modifications in the grantee or delegate agency's policies, practices or procedures, or by providing appropriate auxiliary aids which would enable the child to participate without fundamentally altering the nature of the program." This Standard is consistent with the Americans with Disabilities Act, which protects the rights of individuals with disabilities including chronic conditions.

There must be clear agency-wide policy in compliance with all relevant Head Start, state licensing, and health professional practice regulations. It is crucial that the policy addresses, at minimum:

- administration of medication
- performing medical procedures
- handling emergencies
- record keeping and confidentiality

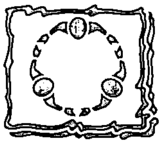
Good policy development takes advance planning and should be accomplished with the leadership and participation of the Health Services Advisory Committee. The Head Start Program Performance Standards, state child care licensing regulations, and state Medical and Nursing Practice Acts must all be taken into consideration.

All medical information about enrolled children and their families is confidential. Records must be handled and stored in a way that protects confidentiality. Confidential information should be shared only with those persons who "need to know" in order to care for the child, and only with the consent of the family or legal guardian. While disclosure of medical information often helps provide good care, disclosure can also result in negative consequences for families because of fear and stigma associated with certain conditions. Before sharing any medical information, families should be helped to consider the risks and benefits of disclosure. Certain medical conditions have special legal requirements concerning disclosure. Some communicable diseases require reporting exposure, and in some states HIV disease has special confidentiality protections.

Questions for Discussion/ Reflection

- Think about your own experiences receiving health care services:
  - — How family-centered has it been?
  - — Have you ever had contact with a health care provider where your feelings and opinions were ignored? How did that feel? Was it hard to be assertive?
  - — Why might it be difficult for health care and other service providers to treat patients or clients as equal partners in decision-making?
- Have you ever been in a situation where a medical emergency occurred that had not been anticipated? How did it feel for everyone involved? How might an emergency plan have helped?

Activity 1: Is This Family-Centered?



Purpose: This activity helps participants understand the principles of family-centered care and how it applies to caring for children with chronic conditions in their Head Start program.

For this activity, you will need:

- Handout I: Family-Centered Services
- Handout J: Driving Forces of Services Delivery
- Handout K: Is This Family-Centered?
- Handout L: How Family-Centered Is Our Program?
- Pencils or pens
- Flip chart paper and markers or
  Overhead projector, transparencies, and screen (*optional*)

> ***Trainer's Preparation Notes:***
>
> *If you are using an overhead projector, copy Handout J: Driving Forces of Service Delivery onto an overhead transparency. If an overhead projector is not available, copy the handout onto flip chart paper.*

Step 1: Explain that this activity will help participants consider how Head Start services can better meet the needs of families that have children with chronic conditions.

Step 2: Distribute Handout I: Family-Centered Services. Ask participants:

- How do these principles compare to the principles of family involvement in Head Start?

Step 3: Explain that, in any system or program, services can be organized around the needs and convenience of the system, the child, or the family. We think about these as different "driving forces" of service delivery.

Display the overhead transparency or flip chart version of Handout J: Driving Forces of Service Delivery. Review the definitions of "system-centered," "child-centered," and "family-centered" services.

Explain that Head Start services are generally done for the benefit of the child and family as well as for requirements of the system under the Performance Standards. While there may be more than one driving force, the needs and convenience of one party often predominates in the **way** the service is provided. (For example, delivering services at home tends to be more family-centered whereas delivering services at the Head Start center tends to be more system-centered.)

Ask participants:

- What are some examples of specific Head Start services that demonstrate each driving force?

Step 4: Divide participants into small groups of four to five people. Distribute Handout K: Is This Family-Centered? Instruct the groups to analyze each of the services and decide if it is primarily system-centered, child-centered, or family-centered. Be prepared to explain the decision. Allow 10-15 minutes.

Step 5: Bring the groups back together. Have each group share their response to each statement and their reasons in a round-robin fashion. Remember, groups may identify different driving forces for some of the services.

Step 6: Distribute Handout L: How Family-Centered Is Our Program? Have participants return to their small groups. Instruct them to take a few minutes to discuss the services their program provides for children with chronic conditions and their families. Then, using the handout as a guide, complete the middle column with specific ways their program provides family-centered services; and complete the right column with ways their program could be even more family-centered.

Allow approximately 20 minutes.

Step 7: Bring the groups back together. Proceed through the seven components of family-centered services, asking each group to share (from the middle column) one way that they currently do this. Congratulate each other.

Step 8: Proceed again through the seven components of family-centered services, asking each group to share (from the right column) one way their program could do it better. List these on flip chart paper.

Have participants agree on one or two suggested improvements that are most important and/or most achievable. Have them work together to develop actions steps to bring about the improvement.

Points to Consider:

- Family-centered care is neither a destination nor something that services instantly become–it is the continual pursuit of being responsive to the priorities and choices of families. We should continue to ask ourselves:

  — Why are we doing things this way?

  — Is this the only way to do it?

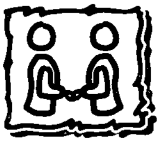
  — Is there a better way to do it?

  Recognizing what drives our practices allows us to imagine new possibilities and provide services in a more family-centered way.

- The Head Start Program is a large system with many requirements under the Performance Standards. But there is flexibility in **how** each program implements services. Each program can aim to provide quality services in a responsive, family-centered way.

Activity 1: Is This Family-Centered? adapted from an activity in *Getting on Board: Training Activities to Promote the Practice of Family-Centered Care*. Larry Edelman, Editor. Association for the Care of Children's Health, Bethesda, Maryland. 2nd Edition, 1995.

Activity 2: Assert Yourself



Purpose: This activity helps participants develop skills in being assertive. This activity is especially helpful for family advocates and home visitors who can assist families that have children with chronic conditions to advocate for their needs.

For this activity you will need:

- Handout M: Tips For Assertive Behavior
- Handout N: Tips For Working With The System

Step 1: To begin this activity ask:

- What does it mean to be "assertive?"
- How is being assertive different from being passive or being aggressive?

Review the following definitions:

- **Assertive behavior:** Expressing your feelings, opinions, needs, and rights clearly and firmly while respecting those of others.
- **Passive behavior:** Failing to express your feelings, opinions, needs, and rights, and allowing them to be discounted or ignored.
- **Aggressive behavior:** Expressing your feelings, opinions, needs, and rights in a hostile or coercive manner that fails to respect the feelings, opinions, needs, and rights of others. This may include verbal or physical intimidation.

Step 2: Have the participant think of a situation in her life where she would like to be more assertive (e.g., interactions with health care or other service providers; resolving conflicts with family members or co-workers). Make sure it is something that she feels comfortable discussing.

Ask the participant to describe the situation in which she would like to be more assertive. Ask:

- What would you want to accomplish in the situation?

- What makes it hard for you to be assertive in this situation?

Step 3: Review Handout M: Tips For Assertive Behavior, and Handout N: Tips For Working With The System. Ask:

- How could you apply some of these suggestions to help you be more assertive in your situation?

Step 4: Help the participant prepare for the interaction. Ask:

- How do you want to express your feelings, opinions, needs, and rights clearly and firmly while respecting those of the other party?

- What questions do you anticipate needing to ask?

- What response do you anticipate?

- How might you feel if the person responds in a passive way? In an aggressive way?

- Are there predictable patterns of interaction that might get in the way of your being assertive?

Brainstorm some strategies.

Step 5: Role play the interaction with the participant being assertive. Have the participant make plans for when to address the real situation. Schedule a coaching meeting to follow-up afterwards.

Step 6: At the follow-up meeting, discuss how the interaction went. Congratulate the participant on any steps toward being assertive. Ask:

- How did it feel?

- Did you use any assertiveness strategies you had developed in the role-play?

- What was difficult about trying to be assertive?

- How did the person respond?

- What might you like to do differently next time?

Points to Consider:

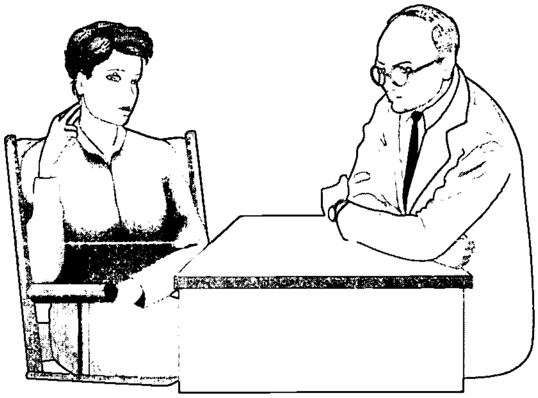
- Being assertive may or may not lead to the outcome that you desire. However, even if you don't get what you wanted, you can feel satisfied that you did everything possible to express your needs clearly and respectfully.
- People who tend to be aggressive may find that being assertive can be more effective because the other person will feel respected and be able to listen without becoming afraid, defensive, or angry in return.
- Is assertive behavior interpreted differently when it...

  — comes from men rather than from women?

  — comes from someone wearing a suit as opposed to someone in jeans and a t-shirt?

  — occurs between members of the same cultural group rather than between individuals from different cultures?

  — occurs between individuals with equivalent power in the situation as opposed to between individuals where one has more power?



Activity 3: Are We Prepared?

Purpose: This activity helps participants recognize the value of a written Individualized Health Plan in promoting health, preventing illness, and improving the care of children with special health needs in Head Start.

For this activity you will need:

- Handout O: Jabari's Child Health Record
- Handout P: Jabari's Individualized Health Plan
- Key to Activity 3: The Story of Monique and Jabari–*For Trainer Only*

Step 1: Explain that this activity helps to identify what is needed to care effectively for a child with a special health need.

Step 2: Ask participants to imagine they are a Head Start classroom teacher for a four year old boy, Jabari.

Read aloud Part 1 of the Key to Activity 3: The Story of Monique and Jabari (the first week of school). When you get to the sentence about Jabari's Child Health Record, distribute Handout O: Jabari's Child Health Record, and give participants a minute to review it. Then finish Part 1 of the story.

Step 3: Ask participants:

- How does it feel...
  - — for Jabari?
  - — for you as the Head Start teacher?
  - — for Jabari's mother, Monique?
- What would you do?
- What might happen to Jabari now?

Step 4: Begin reading aloud Part 2 of the story. When you get to the sentence about the Individualized Health Plan, distribute Handout P: Jabari's Individualized Health Plan. Briefly review the handout with participants.

Step 5: As you read the rest of the story, ask the participants to yell "STOP" at any point that they might consider taking some action. *(**Note:** There is an asterisk at every point in the story where action is indicated.)* Ask them to describe what action they would take.

Complete the story.

Step 6: Ask participants:

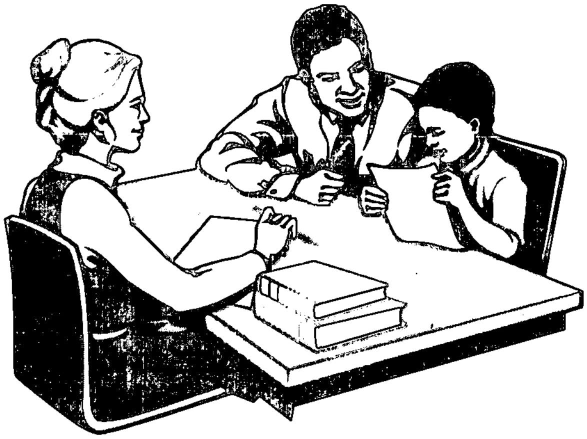
- How did the second half of the story feel differently...
  - for Jabari?
  - for you as the Head Start teacher?
  - for Jabari's mother, Monique?
- How might the second half of the story end?
- What made the difference in the two stories?

Step 7: Ask participants: Does your Head Start program currently develop Individualized Health Plans for children with special health needs?

- If yes:
  - What have been the benefits of using them?
  - What have been the difficulties in using them?
- If no:
  - Do you see a value in adding an Individualized Health Planning process to your program?
  - How would you decide which children would benefit from an Individualized Health Plan?
  - Who would be involved in developing such a plan?
  - Who would be involved in implementing and following up on such a plan?

Points to Consider:

- In order to provide effective care for children with special health care needs, it is important to develop an Individualized Health Plan with specific information on the child's diagnosis, conditions that typically trigger medical problems, signs and symptoms, medications, and an emergency response plan.
- The Individualized Health Plan should be developed by those individuals responsible for the child's health care: the family; the health care provider; and the Head Start health coordinator, management team, and lead teacher.
- Implementing the Individualized Health Plan requires that responsible staff receive protocols, training, equipment, supplies, supervision, and support.
- It is important to periodically follow-up on how the Individualized Health Plan has been working and to revise the plan as needed.



Key to Activity 3: The Story of Monique and Jabari–*For Trainer Only*

Part 1

It is the first week of school...

Monique is glad that her son, Jabari, is starting Head Start. She's going back to school to get her GED, so both she and Jabari are looking forward to school. Jabari is four. He is small, a bit shy, and very smart. Jabari has Sickle Cell Disease.

Monique discussed Jabari's health history with the home visitor and helped complete Jabari's Child Health Record when they enrolled him in Head Start. *(Distribute Handout O: Jabari's Child Health Record and give participants a few moments to review.)*

The health coordinator told you that Jabari has Sickle Cell Disease, but you don't really know what that means. You notice that Jabari is small and seems hesitant to play, but that is not unusual the first week of school. One day he seems tired and has a runny nose and a cough. He appears to be a little flushed. At free play time, you notice him hunched over and crying. He looks scared and says his arms and legs hurt a lot. You try to comfort him but he's inconsolable and proceeds to wail in pain.

Part 2

During the first month of school, the health coordinator called a meeting to develop an Individualized Health Plan for Jabari. The meeting included the health coordinator, Monique, you (Jabari's teacher), Jabari's primary care nurse practitioner, and a nurse from the local hospital's Sickle Cell Disease program. Everyone shared information on Jabari's condition and his health care needs in routine and emergency situations. Together you developed an Individualized Health Plan to care for Jabari in Head Start. *(Distribute Handout P: Jabari's Individualized Health Plan and briefly review it with the participants.)*

It's eight months later and Jabari's class is getting ready for summer...

It's a hot day and you're preparing to take the children out to the playground.* *(Remind Jabari that it's hot out and he needs to try to stay cool and keep drinking water. Ask him to fill up his water bottle to take with him outside. Make sure he's not overdressed. Watch him closely.)*

After playing for a few minutes, Jabari comes up to you. He looks a little tired and flushed, and he says he's thirsty.* *(Give Jabari more water to drink. Ask him if anything hurts him. Ask Jabari if he'd like to play near you in the shade where it's cooler. Feel his forehead–if he feels warm, take his temperature. Have him rest indoors in a cool place. Call the health coordinator. Watch him closely.)*

While watching Jabari play quietly with a truck, you notice that he's guarding one hand and not using it much, as though it might hurt.* *(Ask Jabari if his hand hurts. Call Monique–describe Jabari's symptoms, tell her that you're concerned about him, ask if she has any other recommendations, and suggest she pick him up. Have Jabari rest in a cool room. Give him water and Ibuprofen. Watch him closely until Monique picks him up.)*

Activity 4: Making It Our Own

Purpose: This activity helps Head Start staff customize an Individualized Health Plan form to meet the needs of their program.

For this activity you will need:

- Handout Q: Sample Individualized Health Plan
- Your program's health plan forms
- Other programs' health plan forms that you may have collected (Your Head Start training and technical assistance providers may have sample forms.)

Step 1: Review the material in the ***Background Information*** section *"Individualized Planning For Health."*

Step 2: Think about some children in your program that have special health care needs. Ask:

- What are the "what if" questions that most worry your teachers and your parents?
- Which children in your program might benefit from an Individualized Health Plan?

Step 3: Discuss the issue further with parents of children with special health needs, teachers, managers, and members of your Health Services Advisory Committee. Try to determine:

- What is the criteria for determining which children with special health care needs get an Individualized Health Plan?
- What information do you want included on your program's Individualized Health Plan form?

Step 4: Review your program's health history forms:

- What information has been helpful?
- What additional information is needed?

Step 5: Using your own health history forms, Handout Q: Sample Individualized Health Plan, and other programs' health forms that you may have collected, draft an Individualized Health Plan form that meets your program's needs.

Step 6: Choose one classroom in your program to test out the process. Using the criteria that you developed in **Step 3**, identify which children in the class should have an Individualized Health Plan.

- What proportion of the children in the class need an Individualized Health Plan?
- If every classroom in your program had the same proportion of children needing an Individualized Health Plan, could the program manage it?
- Might you need to revise your criteria for which children should have Individualized Health Plans?

Step 7: Choose one child you identified in **Step 6**. With the consent and participation of his parent, try to complete the form you drafted in **Step 5**. If you find that some parts of the form are too difficult to complete, revise the form as needed.

Step 8: Repeat **Step 7** for another child and family, if possible.

Step 9: Present your draft criteria and draft form for the Individualized Health Plan to your Health Services Advisory Committee. Have the management team and the HSAC work together to determine whether and how to implement individualized health planning in the program.

Points to Consider:

- The process and forms for Individualized Health Plans are most effective when they are tailored to the needs of the program.
- After drafting plans and forms, it is important to test how well they work. Often the strengths and weaknesses become apparent only upon implementation. Review and revise the process and forms yearly, if needed.

Activity 5: Listening To Learn

Purpose: This activity helps Head Start staff get feedback from families' experiences to improve the care of children with chronic conditions. It is particularly useful for health and disabilities specialists.

For this activity you will need:

- Handouts R 1-3: Interview Guidelines

> ***Coach's Note:***
>
> *This activity involves interviewing a Head Start family with a child with chronic conditions, at three different times across the program year, to help identify how to improve services.*

Step 1: Explain that we have many ways of learning how to improve our practices in Head Start–reviewing the Head Start Program Performance Standards, seeking guidance from supervisors, sharing strategies with co-workers, attending trainings, and reading written materials. These are good ways of learning, but they often leave out an important voice: that of individual families.

Step 2: Review Handouts R 1-3: Interview Guidelines. Ask:

- Are these the questions that you want answered?
- Are there other aspects of the program that you want the family to comment on? If so, make changes to the interview guidelines.

Try to ask open-ended questions rather than those answered with "yes" or "no." Also, try to limit the number of questions so each interview will last less than an hour.

Step 3: Select a family to interview. Explain to the family that you'd like their help to learn how the program can best serve children with chronic conditions and their families. Explain that you'd like to do three 1-hour interviews with them over the course of the year, at times and places that are convenient for them. Stress that the information is confidential, and they should participate only if they want to.

Step 4: If the staff member is new to interviewing skills–engaging, listening, prompting for additional or more focused information–do a practice role-play interview. Then conduct the actual interviews.

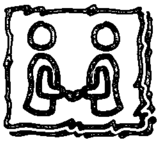
Step 5: Schedule follow-up meetings to review the family's feedback:

- What are the strengths of the program? Are there people or actions who merit acknowledgment for their excellent practice? Give it.
- How could the program improve? Make recommendations to the management team and Health Services Advisory Committee (HSAC).

Points to Consider:

- One family's story never tells the whole story of a program, but it can bring insight and point out possible problem areas. It also develops staff skills of listening and incorporating families' feedback into the program quality improvement.
- It is helpful to survey all families as they exit the program to get feedback about what is working well and what needs to be improved.

Activity 6: Taking Medicine



Purpose: This activity helps Head Start staff improve their program's medication policy. It is most helpful for the program's director and health, disabilities, and education managers.

For this activity you will need:

- Handout S: Medication Policy and Procedure Checklist
- Your program's medication policy, procedures, and forms

Step 1: Call together a meeting of the program's management team (in particular the health, disabilities, and education managers) to assess the program's medication policies and procedures. Explain that many children with chronic conditions need to take medicine on a routine and/or emergency basis. In order to make "reasonable accommodations" to care for children with disabilities (as required by the Americans with Disabilities Act), and to comply with the Head Start Program Performance Standards, programs need thorough policies and procedures for administering medications.

Step 2: Distribute Handout S: Medication Policy and Procedure Checklist. Explain that this checklist summarizes the current "best practice" guidelines from national child care and health authorities for accepting, storing, and administering medications in early childhood programs. Review all of the items on the checklist.

Step 3: Using Handout S as a guide, develop a plan for how you will assess your program's medication policies and procedures. The sources of information should include:

- medication policy, procedures, and forms
- documentation of medications given
- observation of medication storage and administration
- discussion with staff about accepting, storing, and administering medication
- discussion with parents about bringing medications

Step 4: Make arrangements to collect all the information you need. For example, arrange a time to talk with staff designated to handle medication, check medication storage and records, and observe when medication is given. Prepare staff for the discussions and observations by emphasizing that your goal is to learn how medications are handled to improve medication practices throughout the program, not to single out any individual for criticism.

Try to observe as broad a range of medication practices as possible, such as several classrooms, children of different ages, and medications given by different routes (e.g., oral and inhaled).

Step 5: When the management team has collected the information and completed the checklists, bring the group back together. Review the information. Identify the medication procedures that the program is doing well, and congratulate the team.

Identify where there are gaps in the medication policy or inconsistencies between policy and practice.

Step 6: Meet with the Health Services Advisory Committee (HSAC) to discuss your review of medication policies and practices. With the HSAC, determine which are the priority issues to address. Develop strategies to make the needed improvements:

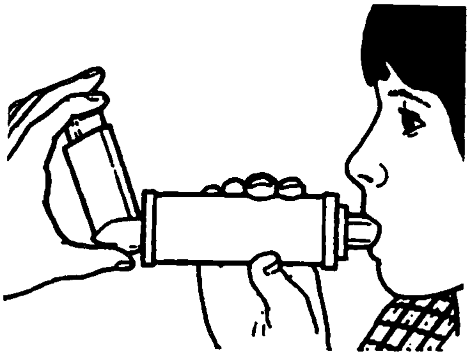
- Should the medication policy and procedures be revised?
- Should the medication documentation forms be revised?
- Are additional supplies, equipment, or facilities needed for storing and administering medication?
- Do staff need a training update on accepting, storing, and administering medication?
- Is parent education needed on Head Start policy on medication?

Step 7: Be sure to report back to any staff whom you observed or interviewed. People deserve to know what they are doing well and where they can improve.

Points to Consider:

- Early childhood programs are commonly concerned about liability for administering medication–both administering medication (if it is done improperly) and *not* administering medication (if it is needed). Programs can take a big step toward making medication practices safer by:
  - having a comprehensive and up-to-date written medication policy that is approved by the Health Services Advisory Committee and Parent Committee;
  - updating staff training on medication practices; and
  - keeping complete records of children's medication plans, health care providers' instructions, parents' consent, and documentation of medications given.
- For Head Start programs that have RNs or MDs on staff as health coordinators and/or health directors, the medication administration procedures must comply with state Medical and Nursing Practice Acts. State Nurses Associations, School Nursing Associations, and Medical Associations are good sources for information on state Practice Acts.
- The best policy doesn't necessarily help you get medication into a wriggling, spitting, unhappy child. In addition to training on policies and procedures, staff need training and supervision on helping children cooperate in taking their medication.

  Most toddlers and preschoolers cooperate better when they are allowed reasonable choice and participation (e.g., "We need to do your eyedrops in the next few minutes, please tell me when you are ready." or "You can hold the nebulizer mouthpiece yourself.") Also, parents can usually tell you what makes taking medicine easier for their child.



Activity 7: Whom Do I Tell?

Purpose: This activity helps program staff become familiar with the regulations and policies to protect the confidentiality of medical information. It also helps increase sensitivity to families' concerns about the disclosure of medical information.

For this activity you will need:

- Handout T: Confidentiality
- Handout U: Whom Do I Tell?
- Your agency's policy on confidentiality and medical record-keeping
- Flip chart paper and marker

Trainer's Preparation Note:

Before beginning the training:

1. *Copy the questions from* ***Step 5*** *onto flip chart paper.*
2. *Make two charts on flip chart paper:*
   - *Down the left-hand column, copy the list of people from Handout U.*
   - *Proceeding to the right, title the columns: "Would Tell," "Would Not Tell," and "Why/Why Not."*

Step 1: Explain that this activity helps make us more aware of both the legal and personal considerations regarding the confidentiality of families' medical information.

Step 2: Ask participants:

- What does "confidential" mean?
- Have you had any concerns about confidentiality in your Head Start program?

Step 3: Distribute Handout T: Confidentiality. Briefly review the information, especially "Who Needs to Know." Briefly review your agency's policy on confidentiality.

Step 4: Divide participants into groups of three or four people. Explain that you will read them a story about Theresa, a two-year-old, who is entering Early Head Start. Instruct participants to imagine that they are Theresa's parent, either her mother or father. Have them close their eyes and take a moment to settle into the role of the parent. Then read aloud Theresa's Story from the top of Handout U.

Step 5: Distribute Handout U: Whom Do I Tell? Explain that this handout lists some of the people in Theresa's life. Instruct participants to decide, as Theresa's parents:

- Would you tell this person about Theresa's diagnosis? (Does this person "need to know?")
- Why or why not? (What are the benefits and risks of telling this person?)

Explain that there are no right or wrong answers. Group members may disagree in their feelings and opinions, and should discuss their considerations honestly. Allow approximately 15-20 minutes for discussion.

Step 6: Bring the participants back to the large group. Post one of the charts with the list of people down the left-hand column. For each person on the list:

- Ask groups to raise their hands to indicate "Would Tell" or "Would Not Tell." Make a tally on the chart.
- Ask a group that said "Would Tell" to explain "Why;" and a group that said "Would Not Tell" to explain "Why Not." Write the reasons briefly on the flip chart.

Step 7: Ask participants:

- What did you feel and observe in this activity?
- What would it be like, as a parent, to feel worried about sharing important health information about your child with others?

Step 8: Instruct participants to step out of their role as Theresa's parent and back into their *own role* in Head Start.

Ask participants:

- In your role as a Head Start staff person which of the people on the list do you think need to know about Theresa's diagnosis?
- Why or why not?

Record the answers on the chart.

Step 9: Ask participants to consider the different perspectives, between Theresa's parents and Head Start staff, on who "needs to know" about Theresa's medical condition. Ask:

- How can Head Start best bring together the different concerns–to best preserve the family's confidentiality ***and*** to share important health information with people who "need to know"–to best care for the child?

Points to Consider:

- HIV/AIDS is a disease that carries a particular fear of discrimination. However, the same principles of confidentiality apply to all sensitive information about children and families in Head Start.
- In working with children with chronic conditions and their families, Head Start staff must be sensitive to parents' concerns about confidentiality. We should aim to develop trust between parents and staff–to help parents move beyond the fear of discrimination and enable them to share necessary information–so they can be true partners in the care of their child.

Activity 7: Whom Do I Tell? adapted with permission from *Family Power: Building Skills for Families with HIV and Drug Affected Children.* Family Welfare Research Group. Berkeley, Calif., 1992.

Next Steps: Ideas to Extend Practice

1. *Observe and Analyze How Behavior is Portrayed in The Media*

What messages does your culture give you (and the children) about being assertive? The next time you watch television, notice how people like you (same gender and sociocultural and/or ethnic background) are portrayed. Do they tend to be portrayed as assertive, aggressive, or passive? Which behavior is more effective on TV? Help children be more media literate by teaching them to observe and analyze these types of portrayals on the shows that they watch. If your classroom has access to a VCR, tape a popular children's TV show and watch it with the class. Help the children identify stereotypes and messages (both positive and negative) about the consequences of assertive, aggressive, and passive behavior.

2. *Develop Individualized Health Plans for Children with Special Health Care Needs*

Review screening results from your program and check to see that all children with special health care needs have an Individualized Health Plan.

Use the criteria for family-centered services to assess any part of your program identified as needing improvement.

3. *Review Your Program Health Policies*

How is health information stored at your program? Review your procedures and make sure that only people who "need to know" and are authorized have access to a child's health information records.

Also, remember that adults in Head Start–staff, parents, and volunteers–may also have chronic medical conditions such as asthma, diabetes, and heart conditions. Make sure that your Head Start program has adequate health policies regarding adults (e.g., confidentiality of sensitive information, safe storage of medications, and emergency health care plans).

4. *Check Stored Medication at Your Program*

Return any children's medication that is no longer required or that is past the expiration date to parents. Tell them that the medication should be disposed of properly. Make sure that all staff know that personal medications should be stored out of reach of children (e.g., not in handbags or briefcases) when on-site.

Handout I: Family-Centered Services

- The family is recognized as the child's most constant and important caregiver.
- The family and professionals collaborate as partners.
- Communication is open and honest, in both directions, between the family and professionals.
- Individual strengths and differences are respected among families.
- Services are flexible and responsive to the family's needs.
- Family-to-family support is encouraged.
- Children with chronic conditions and their families are treated like other children and families, and not defined by their condition.

For use with Activity 1

Adapted from Shelton, Terri, and Jennifer Smith Stepanek. *Family Centered Care for Children Needing Specialized Health and Developmental Services*. Association for the Care of Children's Health. Bethesda, Maryland, 1994.

Handout J: Driving Forces of Services Delivery

Services are delivered according to...

• the needs and convenience of the system or program:	**System-Centered**
• the needs and comfort of the child:	**Child-Centered**
• the priorities, needs, benefits, and convenience of the family:	**Family-Centered**

For use with Activity 1

Handout K: Is This Family-Centered?

*Place an **S, C,** or **F** next to each statement. Be prepared to justify your choice.*

S = System-centered

C = Child-centered

F = Family-centered

______ A complete assessment is done on the child and family.

______ A doctor from the community comes to the Head Start site at the beginning of the year to do the medical exams and identify children that may have chronic conditions.

______ A comprehensive service plan is developed by a multi-disciplinary team and given to the parents.

______ The meeting to develop the child's Individualized Health Plan is arranged according to the parents' schedule.

______ Child care is provided for the Head Start child and sibling while his parent participates in the individualized health planning meeting.

______ When the nutrition coordinator is told that a child has allergies, she sends a revised nutrition plan home with the child.

______ A family must bring their child to the health coordinator's office to demonstrate the procedure for the child's gastrostomy tube feeding.

______ The support group of families of children with chronic conditions may use the Head Start meeting room in the evenings.

______ The school nurse is on-site in each center once a day to administer medication to children who need it.

For use with Activity 1

Handout L: How Family-Centered Is Our Program?

Family-Centered Services	How Are We Doing This Now?	How Could We Do This Better?
The family is recognized as the child's most constant and important caregiver.		
The family and professionals collaborate as partners.		
Communication is open and honest, in both directions, between the family and professionals.		
Individual strengths and differences are respected among families.		
Services are flexible and responsive to the family's needs.		
Family-to-family support is encouraged.		
Children with chronic conditions and their families are treated like other children and families, and not defined by their condition.		

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For use with Activity 1

Handout M: Tips For Assertive Behavior

Be direct.	Use clear statements that begin with “I need...”, “I think ...” Don’t minimize your statement by saying, “It’s probably a dumb question, but...”
Ask questions.	You have the right to get the information you need in a way you understand. Ask the same question again and again, if necessary, until you understand.
Be firm.	If you don’t understand the choices, ask for more information. If you’re not ready to make a decision, ask for more time. Take as much time as you need to make a decision, and then stick to it.
Don’t get hurt.	Don’t let yourself be verbally or physically abused. Be direct and firm about your right to be respected. If that doesn’t stop the abuse, walk away.
Don’t hurt others.	Show respect and listen to others completely without interrupting. You can disagree without insulting the other person. People find it easier to accept your opinion when you show that you heard and respect their point of view.
Make sure you’ve been understood.	Ask people to repeat what you’ve said.
Be kind to yourself.	It’s okay to make mistakes sometimes—everybody does.

For use with Activity 2

Handout N: Tips For Working With The System

Be persistent.	It can be difficult to find the right person to talk to, or even to talk to a "real" person on the phone. Expect that you'll have to call several times to make an appointment or get the information you need. Don't give up when you don't get through the first (or second or third) time.
Be informed & prepared.	Try to find out what you need to know and do in advance. It can be frustrating to sit in a waiting room for a long time only to be told that the doctor can't do the exam without the school forms.
Get help.	If you know that certain situations make you nervous, bring a friend or family member to support you. If language or reading may be a problem, bring someone who can help or ask for assistance from the agency.
Save your energy.	You may have many different service providers. Try to schedule appointments to do as much as possible in the same location and in one trip. If having several "case managers" is too confusing, say so. Your service providers should cooperate with each other to help make things easier and clearer for you.
Write it down.	If you have questions, write them down at home as you think of them, and take them to the appointment. If your health provider tells you important information, such as how to give a medication, write it down or ask her to give it to you in writing. It's best not to rely on your memory alone, especially when there's a lot of information and you may be nervous or stressed.
Go to the top.	If you feel you're being treated badly or given incorrect information, politely ask to speak to a supervisor. Make sure to get the name of the employee with whom you're having a problem. The supervisor has more authority and may be more helpful.

For use with Activity 2

Handout O: Jabari's Child Health Record

CHILD HEALTH RECORD: **FORM 2A, HEALTH HISTORY**

TO BE COMPLETED BY HEAD START STAFF DURING PARENT/GUARDIAN INTERVIEW. HEAD START CENTER:

CHILD'S NAME: Jabari Williams SEX: M BIRTHDATE: 8/5/94
PERSON INTERVIEWED: Monique Williams DATE: 7/16/98 RELATIONSHIP: Mom
NAME OF INTERVIEWER: Kathy Hallissey TITLE: Health aide

PREGNANCY/BIRTH HISTORY	YES	NO	EXPLAIN "YES" ANSWERS
1. DID MOTHER HAVE ANY HEALTH PROBLEMS DURING THIS PREGNANCY OR DURING DELIVERY?		X	
2. DID MOTHER VISIT PHYSICIAN FEWER THAN TWO TIMES DURING PREGNANCY?		X	
3. WAS CHILD BORN OUTSIDE OF A HOSPITAL?		X	
4. WAS CHILD BORN MORE THAN 3 WEEKS EARLY OR LATE?		X	
5. WHAT WAS CHILD'S BIRTH WEIGHT?			6 lbs., 8 oz.
6. WAS ANYTHING WRONG WITH CHILD AT BIRTH?		X	
7. WAS ANYTHING WRONG WITH CHILD IN THE NURSERY?		X	
8. DID CHILD OR MOTHER STAY IN HOSPITAL FOR MEDICAL REASONS LONGER THAN USUAL?		X	
9. IS MOTHER PREGNANT NOW?	X		*(If yes, ask about prenatal care, or schedule time to discuss prenatal care arrangements.)*

HOSPITALIZATIONS AND ILLNESSES	YES	NO	EXPLAIN "YES" ANSWERS
10. HAS CHILD EVER BEEN HOSPITALIZED OR OPERATED ON?	X		pneumonia (1), sickling crises (2)
11. HAS CHILD EVER HAD A SERIOUS ACCIDENT *(broken bones, head injuries, falls, burns, poisoning)*?		X	
12. HAS CHILD EVER HAD A SERIOUS ILLNESS?	X		sickle cell disease, anemia

HEALTH PROBLEMS	YES	NO	EXPLAIN *(Use additional sheets if needed)*
13. DOES CHILD HAVE FREQUENT ___ SORE THROAT; ___ COUGH; ___ URINARY INFECTIONS OR TROUBLE URINATING, ___ STOMACH PAIN, VOMITING, DIARRHEA?		X	
14. DOES CHILD HAVE DIFFICULTY SEEING *(Squint, cross eyes, look closely at books)*?	•	X	
15. IS CHILD WEARING *(or supposed to wear)* GLASSES?		X	*(If "yes")* WAS LAST CHECKUP MORE THAN ONE YEAR AGO? ___
16. DOES CHILD HAVE PROBLEMS WITH EARS/HEARING *(Pain in ear, frequent earaches, discharge, rubbing or favoring one ear)*?	•	X	
17. HAVE YOU EVER NOTICED CHILD SCRATCHING HIS/HER BEHIND *(Rear end, anus, butt)* WHILE ASLEEP?		X	
18. HAS CHILD EVER HAD A CONVULSION OR SEIZURE? IS CHILD TAKING MEDICINE FOR SEIZURES?	•	X	*If "yes" ask:* WHEN DID IT LAST HAPPEN? ___ WHAT MEDICINE? ___
19. IS CHILD TAKING ANY OTHER MEDICINE NOW? *(Special consent form must be signed for Head Start to administer any medication).*	X		WHAT MEDICINE? Vitamin, penicillin, Ibuprofen, Tylenol/Codeine *(If "yes")* WILL IT NEED TO BE GIVEN WHILE CHILD IS AT HEAD START? yes HOW OFTEN? ___
20. IS CHILD NOW BEING TREATED BY A PHYSICIAN OR A DENTIST?	X		(PHYSICIAN'S NAME: Mary Lafferty)
21. HAS CHILD HAD: ___ BOILS, X CHICKENPOX, ___ ECZEMA, ___ GERMAN MEASLES, ___ MEASLES, ___ MUMPS, ___ SCARLET FEVER, ___ WHOOPING COUGH?	X		
22. HAS CHILD HAD: ___ HIVES, ___ POLIO?	•	X	
23. HAS CHILD HAD: ___ ASTHMA, ___ BLEEDING TENDENCIES, ___ DIABETES, ___ EPILEPSY, ___ HEART/BLOOD VESSEL DISEASE, ___ LIVER DISEASE, ___ RHEUMATIC FEVER, X SICKLE CELL DISEASE?	• X		*If "yes", transfer information to Forms 1 and 5.*
24. DOES CHILD HAVE ANY ALLERGY PROBLEMS *(Rash, itching, swelling, difficulty breathing, sneezing)*? a WHEN EATING ANY FOODS? ___ b WHEN TAKING ANY MEDICATION? ___ c WHEN NEAR ANIMALS, FURS, INSECTS, DUST, ETC.? ___	•	X	*If "yes", transfer information to Forms 1 and 5.* WHAT FOODS? WHAT MEDICINE? WHAT THINGS? HOW DOES CHILD REACT?
25. *(If any "yes" answers to questions 14, 16, 18, 22, 23, or 24 ask:)* DO ANY OF THE CONDITIONS WE'VE TALKED ABOUT SO FAR GET IN THE WAY OF THE CHILD'S EVERYDAY ACTIVITIES?	X		DESCRIBE HOW: Tired a lot, pain, sick often
DID A DOCTOR OR OTHER HEALTH PROFESSIONAL TELL YOU THE CHILD HAS THIS PROBLEM?	X		WHEN? tested at birth
26. ARE THERE ANY CONDITIONS WE HAVEN'T TALKED ABOUT THAT GET IN THE WAY OF THE CHILD'S EVERYDAY ACTIVITIES?			DESCRIBE:
DID A DOCTOR OR OTHER HEALTH PROFESSIONAL TELL YOU THE CHILD HAD THIS PROBLEM?		X	WHEN?

For use with Activity 3

Handout P: Jabari's Individualized Health Plan

ROUTINE CARE

Today's Date: October 5, 1998

Review no later than: April 5, 1999

Child: Jabari Williams

Birthdate: August 5, 1994

Parent(s) or Guardian(s): Monique and John Williams

Phone #: 643-1292

Primary Health Care Provider: Mary Lafferty, PNP

Phone #: 929-5435

DIAGNOSIS: **1.** Sickle Cell Disease **2.** Anemia **3.**

REGULARLY-SCHEDULED MEDICATIONS

Medication	Schedule (When)	Dose (How much)	Route (How)	Possible Side Effects
Penicillin	2 x per day (at home am/pm)	250 mg (1 tsp.)	Oral	
Children's Multivitamins	1 x per day (at home am)	1 tablet (chewable)	Oral	

Describe accommodations the child needs in daily activities:	**Check** whether accommodations needed at: HOME	SCHOOL
• **Diet or Feeding:** Lots of water and juicy fruits, especially with hot weather and exercise to prevent sickling crisis. High calorie food to make more blood cells.	X	X
• **Classroom Activities:** May fatigue easily. Don't push into activities if low energy, especially at end of day. Have alternative quiet activities.	X	X
• **Naptime/Sleeping:**		
• **Toileting:** May need to urinate frequently. Give unlimited access to bathroom.	X	X
• **Outdoor Activities/Field Trips:** Take bottled water or juice on outings. Remind him to take breaks and drink during active play. Watch for over-heating on hot days and keep warmly dressed on cold days. See Other.	X	X
• **Transportation:** Have bottled water in bus or car. Have Ibuprofen on bus and train bus driver in use.	X	X
• **Other:** Take emergency medicines on field trips.	X	X

For use with Activity 3

Handout P: Jabari's Individualized Health Plan *(continued)*

EMERGENCY CARE

Child: Jabari Williams **Birthdate:** August 5, 1994

Parent(s) or Guardian(s): Monique and John Williams **Phone #:** 643-1292

Primary Health Care Provider: Mary Lafferty, PNP **Phone #:** 929-5435

DIAGNOSIS: 1. Sickle Cell Disease **2.** Anemia **3.** ________

CALL PARENTS FOR:

- listlessness, unusual fatigue
- complaint of mild pain (e.g., hands/arms, feet/legs, back, abdomen)
- complaint of mild headache
- marked change in behavior or appetite

While waiting for parent(s) or medical help to arrive:

- have him rest
- keep him in a cool place if over heated
- give fluids
- provide comfort

GIVE AS NEEDED OR EMERGENCY MEDICATION FOR:

Medication	Schedule (When)	Dose (How much)	Route (How)	Possible Side Effects
Ibuprofen	pain	100 mg (1 tsp.)	Oral	
Tylenol with Codeine	severe pain 30-60 minutes after giving Ibuprofen	12.5 mg (1 tsp.)	Oral	Drowsiness

GET MEDICAL ATTENTION FOR:

- fever >101.5° F. (oral)
- chest pain, rapid breathing or heart beat after 20 minutes rest
- repeated vomiting, diarrhea
- swelling in penis

CALL 911 (Emergency Medical Services) FOR:

- severe headache, loss of balance, weakness, dragging foot or limping, not using hand, seizures, not able to awaken, loss of consciousness
- pale, gray, or blue lips or fingernails
- severe stomach pain or swollen abdomen

I have helped develop this health plan. I understand it and will try my best to follow the plan. I will communicate any changes in the child's condition or treatment. Plan completed: 10/5/98 (date). Plan will be updated on or before: 4/5/99 (date).

Parent(s) or Guardian(s): Monique Williams

Head Start Staff Name(s) & Title(s): Sammie Lincoln, Lead Teacher, Janine Brown, Health Coord.

Health Care Provider Name(s) & Title(s): Mary Lafferty, PNP

Other: Donna Winters, RN, Children's Hospital Sickle Cell Clinic

For use with Activity 3

Handout Q: Sample Individualized Health Plan

ROUTINE CARE

Today's Date: ______________________ **Review no later than:** __________

Child: ______________________ **Birthdate:** __________

Parent(s) or Guardian(s): ______________________ **Phone #:** __________

Primary Health Care Provider: ______________________ **Phone #:** __________

DIAGNOSIS: 1. __________ 2. __________ 3. __________

REGULARLY-SCHEDULED MEDICATIONS

Medication	Schedule (When)	Dose (How much)	Route (How)	Possible Side Effects

Describe accommodations the child needs in daily activities:

Check whether accommodations needed at:

	HOME	SCHOOL
• **Diet or Feeding:**	____	____
• **Classroom Activities:**	____	____
• **Naptime/Sleeping:**	____	____
• **Toileting:**	____	____
• **Outdoor Activities/Field Trips:**	____	____
• **Transportation:**	____	____
• **Other:**	____	____

For use with Activity 4 (& Activity 2 in Module 3)

Handout Q: Sample Individualized Health Plan *(continued)*

EMERGENCY CARE

Child: ______________________ **Birthdate:** ______________

Parent(s) or Guardian(s): ______________________ **Phone #:** ______________

Primary Health Care Provider: ______________________ **Phone #:** ______________

DIAGNOSIS: 1. ______________ **2.** ______________ **3.** ______________

CALL PARENTS FOR:

While waiting for parent(s) or medical help to arrive:

GIVE AS NEEDED OR EMERGENCY MEDICATION FOR:

Medication	Schedule (When)	Dose (How much)	Route (How)	Possible Side Effects

GET MEDICAL ATTENTION FOR:

CALL 911 (Emergency Medical Services) FOR:

I have helped develop this health plan. I understand it and will try my best to follow the plan. I will communicate any changes in the child's condition or treatment. Plan completed: ________(date). Plan will be updated on or before: ________(date).

Parent(s) or Guardian(s): ______________________

Head Start Staff Name(s) & Title(s): ______________________

Health Care Provider Name(s) & Title(s): ______________________

Other: ______________________

For use with Activity 4 (& Activity 2 in Module 3)

Handout R-1: Interview Guidelines—Beginning of Year

Interview the parent(s) of a child with chronic conditions shortly after the assessment and planning is completed. The interview should take no more than an hour.

- How was the Head Start enrollment and assessment for your child and family?

- How did Head Start staff get to know your child's special health care needs?

- How did Head Start staff work together with you to make sure your child got the best health care, both at school and at home?

- What accommodations did Head Start make to care for your child's special health care needs?

- What has Head Start done well in enrollment, assessment, planning, and accommodating your child's health care needs?

- What could Head Start do better in enrollment, assessment, planning, and accommodating your child's health care needs?

For use with Activity 5

Handout R-2: Interview Guidelines—Mid-Year

Interview the parent(s) of a child with chronic conditions in the middle of the Head Start year. The interview should take no more than an hour.

- How has your child's and family's experience in Head Start been so far?
- How have you been able to share important information about your child's special health care needs with Head Start staff? (Do they ask you questions about your child's health? Do they let you know how your child has been during the day?)
- If your child's health care needs have changed, how has Head Start kept up-to-date on how to best care for your child's needs?
- How do you feel the level of trust and privacy has been with Head Start staff?
- What has Head Start done well in meeting your child's health care needs?
- What could Head Start do better in meeting your child's health care needs?

For use with Activity 5

Handout R-3: Interview Guidelines—End of Year

Interview the parent(s) of a child with chronic conditions at the end of the Head Start year. The interview should take no more than an hour.

- Where will your child be going to school after Head Start?
- What has Head Start done to share information about your child's health care needs with his/her next school?
- How were you involved in working with your child's next school to care for your child's special health needs?
- How do you feel the trust and privacy has been with Head Start staff?
- What has Head Start done well in meeting your child's special health care needs?
- What could Head Start do better in meeting your child's special health care needs?

For use with Activity 5

Handout S: Medication Policy and Procedure Checklist

Item	Is there a policy?		Do we do it?		Comments
	Yes	No	Yes	No	
Accepting Medications					
Prescription medication requires the original container and prescription label; non-prescription medication requires written instructions from the child's health care provider. All medication should include: name of child, health care provider, medicine, date, when to give it (i.e., specific times, # times/day, or as-needed for specific symptoms; with food or without), dose, how to give it, how many days, storage, and expiration date.					
Medication requires written consent of the parent.					
Medication is transferred directly from the parent or adult transporting the child to the child's teacher (i.e., not in child's backpack).					
There is a mechanism for communicating about medication between school, families, and health care providers.					
If medication is prescribed for a child once or twice a day, it is preferable that the parent give the medication at home.					
If parent is on-site and plans to give their child medication, it should be communicated to staff and documented in the medication record.					
Storage					
Medication is stored in child-proof containers.					
Medication for children and adults is stored in anchored, locked containers out of reach of children.					
Medication is stored as directed (e.g., refrigerated, or room temperature).					
Refrigerated medication is away from food and the locked container is clearly labeled as containing medication.					
When the course of medication is complete or reaches its expiration date, unused medication is returned to the parents for disposal or properly disposed of at the center.					

For use with Activity 6

Handout S: Medication Policy and Procedure Checklist *(continued)*

Item	Is there a policy?		Do we do it?		Comments
	Yes	No	Yes	No	
Administration					
Only designated and trained staff administer, handle, and store medication.					
Training for medication administrators includes: agency medication policy; reading labels; techniques for administering medication; documentation; communicating with parents; and procedures for questions, errors, and emergencies.					
Staff wash hands before and after giving medication.					
Before giving medication, staff explains to the child what is going to happen and why, and the child is allowed a few moments to prepare.					
Before giving medication, staff check the "Five Rights:" the right child, the right medication, the right dose, the right route, and at the right time.					
Medication is given as instructed on the label.					
A medication record is kept that includes the child's name, date, time, medication, dose, route, who gave it, any complications (e.g., "spit up dose"), errors, and side effects.					
Medication errors are immediately reported to the appropriate supervisor.					
Before field trips, staff assess the medication needed, and plans are made for proper storage and equipment.					
Medication handling, administration, documentation, and storage are supervised and monitored regularly, and training updates are available.					

For use with Activity 6

Handout T: Confidentiality

What does confidentiality mean?

All medical information is confidential. This means that it should not be shared with anyone unless you have permission from a parent or legal guardian. Medical information should only be shared with a signed consent form—often known as a "release of information" form. Consent to share information should be obtained only when someone has a "need to know."

All records containing medical information must be handled and stored in ways that protect the families' confidentiality. Know your program's policy on confidentiality and record-keeping.

Who needs to know?

People "need to know" about a child's medical condition if knowing helps best provide the care that the child needs. Most parents want their child's caregivers to know about the child's medical conditions so their child gets the best care possible. Some parents may choose not to tell staff about a child's medical condition because they are afraid their child might be treated differently.

Head Start staff may not share medical information about anyone without the consent of the parent or legal guardian, even if you feel that person has a need to know. The exception is that emergency medical personnel should always be given medical information about a person they are treating.

What else do I need to know about confidentiality?

Know your agency policy and any laws and regulations governing confidentiality in your area. In some jurisdictions, HIV/AIDS has special confidentiality protections.

Public health departments require schools to report certain communicable diseases known as "Reportable Diseases." Make sure your program has the list of reportable diseases and a process for reporting. Staff and parents should also be notified about communicable disease exposures, but without disclosing the identity of the ill person.

For use with Activity 7 (& Activity 3 in Module 3)

Handout U: Whom Do I Tell?

Theresa's Story:

Theresa is an active, curious, and lovable two-year-old. She is small and has mild developmental delays. When Theresa was nine months old, she was diagnosed with HIV infection; and when she was 15 months old, she was hospitalized with pneumonia and diagnosed with AIDS. She takes daily medication and stays healthy between brief periods of illness—in all, she's doing very well.

Up until now, you haven't told many people about Theresa's HIV/AIDS diagnosis. You want to protect her from discrimination and make sure that she has as normal a childhood as possible. The only other people so far that know are the doctors, nurses, and social worker at the clinic. Now you're enrolling Theresa in Early Head Start and you're thinking about who to tell about Theresa's HIV/AIDS.

The Head Start Agency Director
- Would you tell this person?
- Why or why not?

The Head Start Health, Nutrition, and Disabilities Specialists
- Would you tell these people?
- Why or why not?

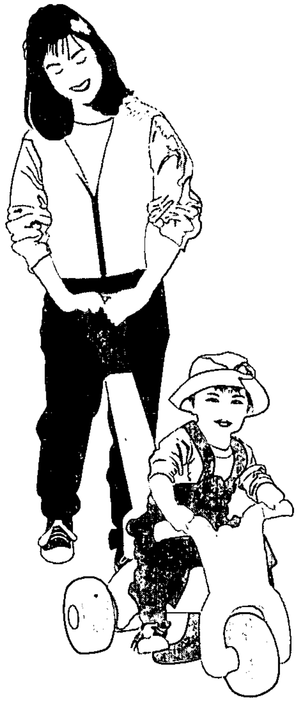
Theresa's Head Start Classroom Teacher
- Would you tell this person?
- Why or why not?

Theresa's Head Start Classroom Aides
- Would you tell these people?
- Why or why not?

The parents of Theresa's classmates
- Would you tell these people?
- Why or why not?

Theresa's Early Intervention Home Visitor
- Would you tell this person?
- Why or why not?

Theresa's six-year-old brother
- Would you tell this person?
- Why or why not?



For use with Activity 7

Putting It All Together: Caring for Children with Asthma

Outcomes

After completing this module, participants will apply the essential principles to plan the care of a child with a chronic health condition. This module demonstrates the example of caring for children with asthma.

Key Concepts

Head Start staff must work with the family and health care providers to ensure that the care of the child with asthma is...

- **Family-Centered:**
  - **Recognize families as primary caregivers and key participants in developing the child's health plan.**
  - **Provide emotional support and assistance in advocacy for the child and family.**
- **Individualized:**
  - **Get all of the information needed about the severity of the child's asthma, the triggers, signs and symptoms, medications, and emergency response.**
  - **Develop an Individualized Health Plan for each child which includes accommodations needed in the child's and staff's daily activities to:**
    - **prevent asthma triggers**
    - **recognize and respond to asthma episodes**
    - **administer medications and emergency care**
- **Safe and Legal:**
  - **Provide staff with protocols, training, equipment, supplies, supervision, and support to care for the child.**
  - **Ensure confidentiality of sensitive medical information.**

Background Information

A. Understanding Asthma As A Chronic Condition

Asthma is a chronic respiratory condition. It is the most common cause of children's absence from school and hospitalization. Current estimates are that 5-10% of children have asthma. The prevalence of asthma has been increasing dramatically over the past decade, and it is anticipated that it will continue to increase in the near future.

Asthma is a condition in which the airways in the lungs are more "reactive" than normal. It can be caused by hereditary factors associated with allergies, and other family members often also have asthma and/or allergies; and it can be caused by lung damage, for example from premature birth or pneumonia.

Increased reactivity of the airways means that certain things in the environment can set off an asthma attack or episode. The environmental factors that bring on asthma episodes are known as "triggers." They include respiratory illnesses, cigarette smoke, air pollution, dust, pollen, animals, exercise, cold air, cockroaches, and emotions.

In an asthma attack, the airways react to the triggers by constricting the airway muscles, swelling the lining of the airways, and producing increased mucus. These result in a narrowing of the airways and the signs and symptoms of an asthma episode which include coughing, wheezing, and difficulty breathing.

Asthma can be successfully controlled and treated. Families, Head Start programs, and health care providers must work together to prevent asthma episodes, recognize early signs, and promptly treat asthma episodes. With effective management, children with asthma should be able to lead active and healthy lives. They should be able to sleep through the night, attend school, engage in normal activities and exercise, and avoid hospitalization.

Asthma is a varied disease. The underlying causes of the condition, the triggers of asthma episodes, the signs and symptoms, the severity of the disease, the medications used, and the responses needed are different for different children. The degree to which asthma affects children's lives is also varied. Some children need daily medications and daily modification of their activities, while others only need medications and modifications during asthma episodes. While children's asthma is commonly characterized as "mild," "moderate", or "severe," it can remain constant in severity or it can come and go or change over time.

Asthma is not contagious. Although one of the symptoms of asthma is coughing, which can also be a symptom of a communicable disease, the asthma itself—the underlying increased reactivity of airways—cannot spread from one person to another.

B. What Head Start Programs Should Do

Head Start programs must work with families and health professionals to provide proper care for children with asthma.

- *Provide family-centered care:*

  Children and families' success in managing asthma depends on a complex interaction between the child's stage of development, the characteristics and course of the illness, the family's strengths and challenges, and the availability of medical, social, and emotional support.

  Head Start programs can support family strengths by recognizing that parents know a great deal about their child and can educate staff about how to best care for their child. For example, staff need to rely on parents for details such as, "When Jamal scratches at his throat, that's his first sign of an asthma attack," and "Veronica takes her inhaled medicine best while I'm reading her a book."

  Head Start staff can help provide emotional support and assistance in advocating for the child and family, depending on their particular needs. For example, if a family needs assistance navigating the health care system, Head Start staff can offer families guidance and support with asking questions and getting information at health visits.

  Through coping with asthma, many families gain valuable knowledge and skills and feel that the experience makes them more informed, closer as a family, and more effective advocates for the needs of their children.

- *Individualize care of the child:*

  Get all the necessary information on the child's condition. Get complete information from the parents during the initial Child Health History. In addition, make sure that the child receives a full health assessment, diagnosis and treatment plan, and get detailed information from the child's health care provider. The information should include:

  - How severe and frequent are the child's asthma attacks?
  - What are the child's asthma triggers?
  - What are the signs and symptoms of the child's asthma episodes?

- How should staff respond to asthma episodes (e.g., changes in activity, peak flow meter, medications, observations, emergency plans)?

Develop an Individualized Health Plan for each child. The health plan should include the following:

- The specific accommodations needed in the child's daily activities (diet, classroom activities, outdoor activities, field trips, etc.) to prevent and respond promptly to asthma attacks.
- The child's regular and emergency medications: the name, dose, route, schedule or indications for giving it, and possible side effects.
- The signs and symptoms of an asthma attack and appropriate responses (e.g., removal from triggers, use the peak flow meter, medication, observation, emergency plan).

Since the child's medical condition and special needs may change over time, periodic review of the Individualized Health Plan is needed. The frequency of review should depend upon the child's condition, but most medical conditions should be reviewed at least every three to six months. Head Start should also request that parents and health care providers promptly inform the program about any changes in the child's diagnosis and treatment plan so that the health plan can be updated on an ongoing basis.

- *Provide safe and legal care:*

Information about the child with asthma must be shared with Head Start staff and volunteers who need to know in order to care for the child. To respect the confidentiality of the child and family, information should only be shared with the consent of the family.

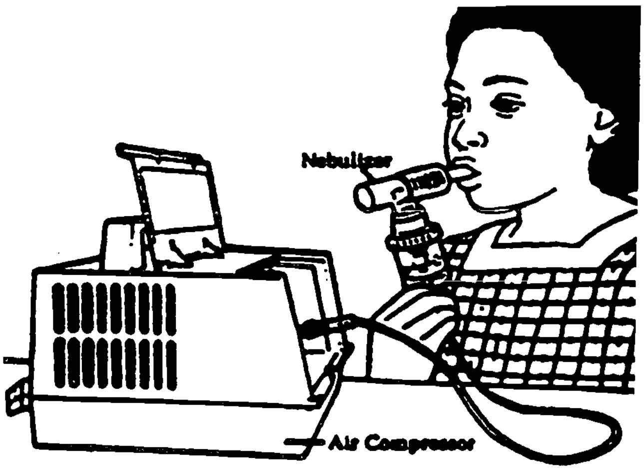
Head Start staff must have the protocols, training, equipment, supplies, supervision, and support to care for a child with asthma. Head Start programs must investigate their state child-care licensing regulations and Nurse Practice Acts in order to determine what procedures may be done and who can do them. If equipment is needed, it must be in working order; if medications are needed, Head Start must have a current supply. After staff is trained in performing the procedures, there must be a plan for supervision, monitoring, and backup in case of questions or problems.

Head Start should also facilitate the transfer of the child's health records and health plan upon transition to another program or school. By maintaining clear documentation (i.e., the child's assessment, diagnosis, treatment, and Individualized Health Plan) and facilitating transfer of the health records to the next program that cares for the child, Head Start can make a significant contribution to promote the child's future health and welfare.

Questions for Discussion/ Reflection

Since asthma is a common chronic condition among children, most Head Start programs have cared for children with asthma.

- What experience have you had caring for children with asthma in your Head Start program?
- Have these children received an IEP/IFSP or Individualized Health Plan?
  - If yes, how was that process helpful in caring for the child?
  - If no, what were the gaps in the care of the child?



Activity 1: How Does It Feel?

Purpose: This activity helps participants recognize the concerns of staff, parents, and children and develop strategies to sensitively care for children with asthma.

For this activity you will need:

- Handout V: How Does It Feel?
- Pens or pencils
- Flip chart and markers
- Name tags and pens

Step 1: Review the ***Background Information*** on asthma, in particular *"Understanding Asthma As A Chronic Condition."*

Step 2: Since asthma is so common, both among children and adults, nearly everyone has had some experience with asthma—either your own illness or that of your own child, another family member, a friend, co-worker, or a child that you care for.

Ask participants:

- What experience have you had with asthma?

Step 3: As a respiratory illness, many of the symptoms of asthma are similar to those of acute respiratory illnesses such as colds and flu. However, asthma is a *chronic* respiratory illness.

Ask participants:

- How is a chronic respiratory illness, such as asthma, different from an acute respiratory illness, such as a cold?
- How is the experience different from the standpoint of...
  - the child with asthma?
  - the parent of the child with asthma?
  - the teacher of the child with asthma?

Step 4: In caring for children with asthma in Head Start, everyone—staff, parents, the child with asthma, other children, and parents—may experience many feelings, fears, and concerns.

Explain that this activity will explore people's feelings about asthma.

Step 5: Divide participants into groups of four. Distribute name tags and have participants in each group choose one of the following roles:

- Pedro (a child with asthma)
- Pedro's parent
- Head Start staff person or parent volunteer
- Another child in Pedro's class

Tell participants to take a minute to imagine their role.

Step 6: Distribute Handout V: How Does It Feel? to participants. Ask for a participant to read aloud Pedro's Story.

Step 7: Instruct participants to discuss the questions on the handouts from the standpoint of their roles. Begin with the first question and allow each person to speak, then proceed through the other questions in a similar manner.

Allow approximately 15 minutes.

Step 8: Ask participants:

- How can understanding how everyone feels help Head Start staff to care for children with asthma in a more sensitive and effective manner?
- How can Head Start programs incorporate the opportunity for everyone to express their feelings and have their concerns addressed?

Points to Consider:

- Everyone involved in the care of a child with asthma—including the child with asthma, the parent, Head Start staff, and other children and parents—can have significant feelings and concerns that need to be addressed.

- While everyone has slightly different concerns, some common fears include not knowing enough about the child's condition, not providing adequate care, and that the illness might interfere with the child's activities and friendships.

- Head Start staff should develop strategies to address everyone's concerns about caring for the child with asthma, including:

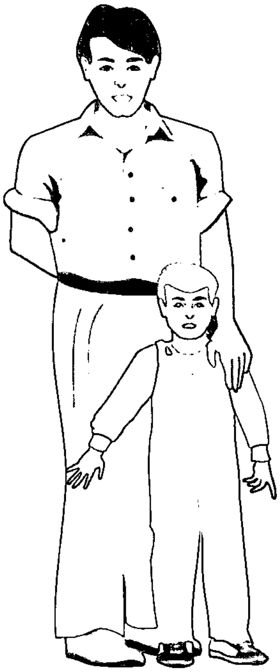
  - listening to and addressing everyone's feelings;

  - getting all of the necessary information;

  - working cooperatively with the parents, child, and health provider to develop a health care plan that allows the child to participate as fully as possible in program activities;

  - helping the child develop a sense of confidence in parents and teachers to care for him and in his own mastery of the illness; and

  - sharing necessary information with others who need to know—after getting the consent of the parents and child.



Activity 2: Developing the Individualized Health Plan

Purpose: This activity helps participants increase their skill in developing an Individualized Health Plan to ensure effective care of a child with asthma.

For this activity you will need:

- Handouts W 1-4: Role Assignments (one set for each group of four)
- Handout X: Special Care Plan For A Child With Asthma—James (one copy for each participant)
- Handout Q: Sample Individualized Health Plan (from ***Module 2: Essential Principles for Care***)
- Key to Activity 2: James' Individualized Health Plan—*For Trainer Only*
- Name tags, markers, pens

Trainer's Preparation Note:

Before the training, attach four copies of Handout X: Special Care Plan For A Child With Asthma—James to the back of each Handout W-4: Role Assignment—James' Doctor.

Step 1: Explain that this activity will give participants the chance to role-play developing an Individualized Health Plan for James, a child with asthma.

Step 2: Read aloud the following:

James, a four-year-old, has been in Head Start for six weeks and he loves it! His health and development assessments have just been completed and reviewed. The Health Coordinator is concerned about James' health since he has asthma.

The Health Coordinator calls a meeting to develop an Individualized Health Plan for James. Present at the meeting are: the

Health Coordinator, James' Dad, the classroom Lead Teacher, and James' doctor. We will role play the meeting. Your assignment is to work together to complete an Individualized Health Plan for James.

Step 3: Divide participants into groups of four. Distribute name tags and have participants in each group choose a role and write it on the name tag:

- James' Dad
- Lead Teacher in James' Classroom
- Health Coordinator
- James' Doctor

Step 4: Distribute Handout Q: Sample Individualized Health Plan to each participant. Give each group a set of Handouts W 1-4: Role Assignments, and have participants take the handout that corresponds to their role.

Handout W-4: Role Assignment—James' Doctor, should have four copies of Handout X: Special Care Plan For A Child With Asthma—James attached in back.

Step 5: Imagine that it's October, 1998. Explain that it will be the job of the Health Coordinator to facilitate the meeting to develop James' Individualized Health Plan.

Each participant has unique and important information to share about James' health. Everyone should participate just as they would in an actual meeting. Allow participants a few minutes to review their information and get into their role assignment.

Allow approximately 40-60 minutes for the groups to meet and develop James' Individualized Health Plan.

Step 6: Call the groups back together when they have completed James' Individualized Health Plan.

Ask participants:

- What was the process of developing the Individualized Health Plan for the different roles? In particular, how did it feel to be the parent?
- What would the Individualized Health Plan be like if it was completed by the Health Coordinator alone?
- How might the Individualized Health Plan be helpful in a program?
- What might be the challenges in developing Individualized Health Plans in your program?

Points to Consider:

- Health plans for the child must include accommodations for daily activities, medications, and emergency response.
- Parents have a great deal of information about their child. It is crucial to get detailed information from parents and involve them in developing health plans for their child.
- Health care providers have important information about the child's condition, medications, and emergency response. Parents and Head Start staff must feel comfortable asking medical providers to explain their recommendations clearly.
- Head Start must pay close attention to the confidentiality of medical information. Parents should be asked for consent to share information with caregivers who need to know in order to care for the child. Medical information should not be shared with those who do not need to know.

Key to Activity 2: James' Individualized Health Plan—*For Trainer Only*

ROUTINE CARE

Today's Date: October 1, 1998

Review no later than: Jan. 1, 1999

Child: James Jefferys

Birthdate: June 24, 1994

Parent(s) or Guardian(s): Clark and Kelly Jefferys

Phone #: 292-1249

Primary Health Care Provider: Maria Martinez, MD

Phone #: 534-5929

DIAGNOSIS: **1.** Asthma **2.** **3.**

REGULARLY-SCHEDULED MEDICATIONS

Medication	Schedule (When)	Dose (How much)	Route (How)	Possible Side Effects
Cromolyn	every 4 hours	2 puffs	Inhaler with spacer	Cough

Describe accommodations the child needs in daily activities:	**Check whether accommodations needed at:** **HOME**	**SCHOOL**
• **Diet or Feeding:** Drink plenty of water	X	X
• **Classroom Activities:** Avoid furry animals in classroom. Watch James closely when he has a cold and days with high pollen count.	X	X
• **Naptime/Sleeping:**		
• **Toileting:**		
• **Outdoor Activities/Field Trips:** Watch James closely with outdoor play, especially cold days, grassy areas, and high pollen count days. Take medicine and equipment on field trips.	X	X
• **Transportation:** Bus driver must transport James' emergency medicine and equipment, and be trained in use.	X	X
• **Other:**		

Key to Activity 2: James' Individualized Health Plan *(continued)*

EMERGENCY CARE

Child: James Jefferys **Birthdate:** June 24, 1994

Parent(s) or Guardian(s): Clark and Kelly Jefferys **Phone #:** 292-1249

Primary Health Care Provider: Maria Martinez, MD **Phone #:** 534-5929

DIAGNOSIS: **1.** Asthma **2.** ______ **3.** ______

CALL PARENTS FOR:

- frequent coughing, wheezing
- sucking in at neck or ribcage with each breath
- rapid breathing > 40 breaths/minute at rest

While waiting for parent(s) or medical help to arrive:

- remove James from the asthma triggers if possible (e.g., outdoor air, grass, pollen, animals)
- have James rest seated
- offer sips of water

GIVE AS NEEDED OR EMERGENCY MEDICATION FOR:

Medication	Schedule (When)	Dose (How much)	Route (How)	Possible Side Effects
Albuterol	frequent cough, wheezing, > 40 breaths/min. @ rest	2 puffs	Inhaler with spacer	cough, shakiness

CALL 911 (Emergency Medical Services) FOR:

- if no improvement 15 min. after treatment, and parents can't be reached
- after receiving treatment for wheezing, James is working hard to breath or grunting; breathing fast at rest; won't play; has trouble walking/talking; has nostrils open wider than usual; has sucking in of skin (chest or neck) with breathing; has gray or blue lips or fingernails; cries more softly and briefly; is hunched over to breath; is extremely agitated or sleepy.

I have helped develop this health plan. I understand it and will try my best to follow the plan. I will communicate any changes in the child's condition or treatment. Plan completed: 10/1/98 (date). Plan will be updated on or before: 1/1/99 (date).

Parent(s) or Guardian(s): Clark Jefferys

Head Start Staff Name(s) & Title(s): Sammie Lincoln, Lead Teacher, Janine Brown, Health Coord.

Health Care Provider Name(s) & Title(s): Maria Martinez, MD

Other: ______

Activity 3: What Would You Do?

Purpose: This activity gives staff the chance to practice using the Individualized Health Plan to know how to care for a child with a chronic condition. It is particularly helpful for classroom and transportation staff.

For this activity you will need:

- Handout T: Confidentiality (from ***Module 2: Essential Principles for Care***)
- Handout Y: What Would You Do?
- James' Individualized Health Plan developed in ***Module 3***, *Activity 2: Developing the Individualized Health Plan* or Key to Activity 2

Step 1: Explain that this activity uses the Individualized Health Plan to know how to care for James, a child with asthma.

Step 2: Make sure that all participants have James' Individualized Health Plan (either developed in ***Module 3***, *Activity 2: Developing the Individualized Health Plan*, or the Key to Activity 2: James' Individualized Health Plan). Briefly review the major sections of James' plan—his diagnosis, routine care needs (including regular medications and program accommodations), and emergency plan. Imagine that it's October, 1998.

Step 3: Briefly review the ***Background Information*** section on *"Ensuring That Services Are Safe and Legal"* in ***Module 2: Essential Principles of Care***. Distribute Handout T: Confidentiality, and briefly review the main points.

Ask the participant(s):

- Who needs to be informed about James' health plan?
- Who needs training in how to administer James' medications?
- Where must medication supplies and equipment be kept?
- What consent is needed to share information about James' health?

Step 4: Distribute Handout Y: What Would You Do? For each scenario, ask:

- What you would do based on the instructions in the Individualized Health Plan and your own experience and judgment?

Step 5: Ask the participant(s):

- With the information in James' Individualized Health Plan, do you feel comfortable that you could prevent and manage James' asthma episodes?
- Is there any additional information, training, policies, health consultation, or supplies that you might need? Who could help?
- How often might you need to review and revise the plans?
- What are some issues for transitioning James to kindergarten?

Points to Consider:

- Each child with asthma has specific triggers to avoid, signs and symptoms of asthma attacks, and recommended responses to an attack. The Individualized Health Plan can help staff know what to do to care for the child's health needs.
- General strategies to care for children with asthma include:
  - trying to avoid asthma triggers
  - observing children carefully for signs of illness
  - training staff on the care plan and administration of medications
  - having the care plan, medications and supplies, and emergency contact information available
  - providing emotional support to the child and family for their special health needs

- The Individualized Health Plan should be an active, ongoing process and document. The parents and health care providers should be involved with regular communication and updates. It should not be simply filed away. The plan should be followed for routine and emergency care.

- Individualized Health Plans should be reviewed periodically and revised as needed. In particular, after a medical emergency, Head Start staff should assess how well the care plan worked and make any changes that are needed.

- The Individualized Health Plan should be used to help plan for an effective transition of the child to another program or kindergarten.

Next Steps: Ideas to Extend Practice

1. *Take Another Look at Your Children*

Head Start programs serve many children with asthma—both those diagnosed with asthma and those with symptoms consistent with asthma who have not received adequate diagnosis and treatment.

Take another look at the health records of children in your Head Start program who are diagnosed with asthma. Do you have all of the information that you need to care for them? Is the information clearly documented? Has an Individualized Health Plan been developed for each of these children? Do you periodically review and revise the Health Plan? Do you have plans for transitioning the child to another school?

Take another look at children in your Head Start program who have chronic respiratory illnesses. Have they received adequate medical assessment and treatment? If you have some concerns about the child's health care, refer the child to his/her primary health care provider for follow-up assessment.

2. *Extend the Example: Care for Children with Other Special Health Needs*

This module used the example of caring for children with asthma to demonstrate the main principles of caring for children with special health needs in Head Start. Extend this example to develop effective care plans for all children with special health needs in your Head Start program.

Review the process that your Head Start program uses to assess children's special health needs. What questions do you need to ask? How do you need to document the information? Who should be involved in assessing the child's health needs and developing a specific health plan for each child with special health needs?

What other special health needs do children in your program have? Use written, computer, and human resources to gain a greater understanding of the health conditions. Review and revise the health forms that you have used, if needed. Make sure that every child with special health needs has an Individualized Health Plan, follow-up and transition plan.

Handout V: How Does It Feel?

Pedro's Story

Pedro is four-years-old. In enrolling Pedro in Head Start, his mother tells a little about him:

"Pedro is very excited about going to Head Start. He loves to run around outdoors, build sand castles, and play on climbing structures. He also has asthma. In the winter, whenever he catches a cold, his asthma gets bad. He also has trouble on cold days. And in the spring and summer, with all the pollen in the air, his asthma can get bad. When his asthma gets bad, Pedro coughs a lot, has trouble breathing, and gets really tired. He takes some medicines for his asthma every day, but when the asthma gets bad he needs special medicines. A few times, his asthma got so bad that he had to be hospitalized."

1. How does it feel for you? What are you hopeful about? What are your fears and concerns?

2. What do you want to tell or show others?

3. What do you want to know?

4. How do you want to help make the situation healthy and happy?

For use with Activity 1

Handout W-1: Role Assignments—James' Dad

You're feeling a little anxious about this meeting. Since your wife went back to full-time work, you've had to take over more responsibility for James' care. You're happy that James got into Head Start—he's really enjoyed it. But he's been pretty sick with his asthma since starting school. You're worried: Can you trust that Head Start staff will watch James' as closely as you do? Do they really understand how sick he can get? If it gets too hard for Head Start to care for James, might they decide that he can't come anymore?

Some things you want to share at the meeting:

- James has been very happy in Head Start.
- James loves to play outdoors. When he doesn't have outdoor activity, he gets restless.
- James' asthma is triggered by colds, playing in cold air, pollen, grass, and animals.
- James' doctor prescribed Cromolyn by metered dose inhaler with spacer every four hours (at 8 AM, 12 PM, 4 PM, 8 PM).
- You're worried that Head Start staff wouldn't know how to give him the inhaled medicine. So you and your wife have been giving it to him before and after school, even though that means waiting more than six hours—which really is too long—between his daytime doses.
- James used to fuss about taking his Cromolyn but he cooperates when he can hold the mask and spacer himself.
- James has been sick with colds, coughing, and asthma off and on since starting school.
- At the beginning of an asthma attack, James coughs a lot. Then he begins breathing fast and his neck and ribs suck in with each breath. When he gets an asthma attack, he needs to be given his inhaled Albuterol.

For use with Activity 2

Handout W-2: Role Assignments—Lead Teacher in James' Classroom

You've enjoyed having James in your class and you've developed a nice relationship with him. You're a little worried, though, about his asthma. You have a busy classroom with 20 children and it's difficult to observe James every minute. You're feeling a little nervous about giving him inhaled medications and being able to handle an emergency.

Some things you want to share at the meeting:

- You enjoy James a lot. When he's feeling well, he's active and enthusiastic. You can recognize his heartwarming laugh from across the playground.
- James has made some good friends in Head Start. He especially enjoys outdoor play and mastering self-care tasks.
- You feel badly that James has been so sick since the start of school. You noticed it takes James several days to get back into the classroom rhythm after his absences.
- You have two children with diagnosed disabilities in the classroom as well as several exceptionally active and disruptive children. You feel you're working at maximum effort and you still aren't handling everything as well as you'd like.
- You've never given a child medication by an inhaler with a spacer.

For use with Activity 2

Handout W-3: Role Assignments—Health Coordinator

You're a strong advocate for including children with chronic conditions in Head Start. You also appreciate the seriousness of medical conditions such as asthma, and feel that Head Start staff need information, training, and support to safely care for children. You're somewhat worried about your own liability for medication administration in the centers. You want to ensure that the Individualized Health Plan brings together all of the necessary information from the family and health care provider into a clear and effective care plan for James in Head Start.

Some things you want to share at the meeting:

- You observed James in the classroom and he seemed very happy and eager to participate in activities.
- In reviewing James' health history and assessments, you noted that James seems to be quite healthy, other than his asthma. He's growing and developing well, and his language skills are particularly strong.

Remember, you are responsible for facilitating the meeting:

- Facilitate this meeting as you would a real meeting among the participants.
- Make sure that the group stays on-task for sharing their information and working together to complete the Individualized Health Plan.
- Remember that the parent knows his child the best. The parent's and child's feelings, concerns, and needs should guide the care of the child.
- Be aware that all members of the group have their own concerns. Allow participants to express whatever positive feelings and concerns they may have. Try to help resolve any conflicts that may arise in the discussion.
- Try to make sure the plan is realistic and safely meets James' needs.

For use with Activity 2

Handout W-4: Role Assignments—James' Doctor

You're really committed to help Head Start work for James and his family. You've cared for James since birth and you've watched him develop into a bright and eager child. You think that Head Start would be a wonderful opportunity for James and his family.

You empathize with James because you had asthma as a child. Back then, there wasn't as good an understanding of how to prevent and treat asthma attacks. You remember being so sick that you missed a lot of school, they kept you indoors a lot, and you were in and out of the hospital. That's a big reason why you became a doctor and you've tried to learn as much as possible about asthma. With all the new treatments, James should be able to attend school regularly and stay healthy and active. But it'll require frequent contact and cooperation among you, James' parents, and Head Start.

Some things you want to share at the meeting:

- You've been using a form called "Special Care Plan For A Child With Asthma" with many of your patients—you've found it helps share information and coordinate a plan between home and school.

- Together with James' parents, you completed the "Special Care Plan For A Child With Asthma" for James. *(Give a copy of Handout X to the other group members and review the key points.)*

For use with Activity 2

Handout X: Special Care Plan For A Child With Asthma—James

Child's Name: James Jefferys **Date of Birth:** 6 / 24 / 94

Parent(s) or Guardian(s) Name: Clark and Kelly Jefferys

Emergency phone numbers: Mother 292-1249 Father 292-1249

(see emergency contact information for alternate contacts if parents are unavailable)

Primary Health Care Provider: Maria Martinez, MD **Emergency Phone #:** 534-5929

Asthma Specialist's (if any): ________ **Emergency Phone #:** ________

Known triggers for this child's asthma (circle all that apply):

- [✓ colds]
- mold
- [✓ exercise]
- [✓ tree pollens]
- house dust
- strong odors
- [✓ grass]
- excitement
- [✓ flowers]
- weather changes
- [✓ animals]
- smoke
- room deodorizers

foods (specify): ________

other (specify): cold air

Activities for which this child has needed special attention in the past (circle all that apply):

outdoors

- [✓ field trip to see animals]
- [✓ running hard]
- [✓ gardening]
- [✓ jumping in leaves]
- [✓ outdoors on cold or windy days]
- [✓ playing in freshly cut grass]

indoors

- kerosene/wood stove heated rooms
- art projects with chalk, glues, fumes
- sitting on carpets
- [✓ pet care]
- recent pesticides application in facility
- painting or renovation in facility

other (specify): ________

Can this child use a **flowmeter** to monitor need for medication in child care? [✓ NO] YES

personal best reading: ________

reading to give extra dose of medicine: ________

reading to get medical help: ________

How often has this child needed urgent care from a doctor for an attack of asthma:

in the past 12 months? 6

in the past 3 months? 3

Typical signs and symptoms of the child's asthma episodes (circle all that apply):

- [✓ fatigue]
- face red, pale or swollen
- grunting
- [✓ flaring nostrils, mouth open (panting)]
- [✓ difficulty playing, eating, drinking, talking]
- [✓ breathing faster]
- [✓ wheezing]
- [✓ sucking in chest/neck]
- restlessness, agitation
- dark circles under eyes
- complaints of chest pain/tightness
- gray or blue lips or fingernails
- [✓ persistent coughing]

Reminders:

1. *Notify parents immediately if emergency medication is required.*
2. *Get **emergency medical help** if:*
   - the child does not improve 15 minutes after treatment and family cannot be reached
   - after receiving treatment for wheezing, the child:
     - is working hard to breathe or is grunting
     - is breathing fast at rest (> 50/min)
     - has trouble walking or talking
     - has sucking in of skin (chest or neck) with breathing
     - is extremely agitated or sleepy
     - has gray or blue lips or fingernails
     - has nostrils open wider than usual
     - won't play
     - cries more softly & briefly
     - is hunched over to breathe
3. *Child's doctor & child care facility should keep a current copy of this form in child's record.*

For use with Activity 2

Handout X: Special Care Plan For A Child With Asthma *(continued)*

Medications for routine and emergency treatment for asthma for: James Jefferys
(Child's Name)

Date of Birth: 6 / 24 / 94

Name of Medication	Cromolyn	Albuterol		
When to use (e.g., symptoms, time of day, frequency, etc.)	every 4 hours [✓ routine] or emergency	frequent cough, wheezing, rapid breathing, sucking in at neck, ribs routine or [✓ emergency]	routine or emergency	routine or emergency
How to use (e.g., by mouth, by inhaler, with or without spacing device, in nebulizer, with or without dilution, diluting formula, etc.)	inhaler with spacer	inhaler with spacer		
Amount (dose) of medication	2 puffs	2 puffs		
How soon treatment should start to work		within 20 minutes		
Expected benifit for the child	easier breathing	easier breathing		
Possible side effects, if any	cough	cough		
Date instructions were last updated by the child's doctor	Date: 6 98 Name of Doctor (print): M. Martinez Signature: MMartinez, MD			
Parent's or Guardian's permission to follow this medication plan	Date: 6 98 Parent's or Guardian's Signature: Clark Jefferys			

Handout Y: What Would You Do?

It's a cold and windy spring morning and there's lots of pollen in the air. It's outdoor play time. James has been anxious to go play outdoors. He and his friends have been talking about setting up a running race. ***What would you do?***

When James' Mom drops him off this morning, she explains that she's running late for work and didn't have time to give James his Cromolyn. ***What would you do?***

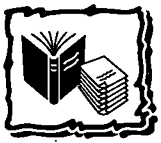
For use with Activity 3

Handout Y: What Would You Do? *(continued)*

Many children have had runny noses and coughs over the past few weeks. This morning when James' dad dropped him off, he mentioned that it looks like James might be coming down with a cold. ***What would you do?***

You're on a field trip at a local farm and you notice that James is sitting down on the grass, hunched over and coughing repeatedly. ***What would you do?***

Continuing Professional Development



1. ***Develop a Series of Workshops on Caring for Children with Chronic Conditions***

   Develop a series of workshops on caring for children with chronic conditions for Head Start staff, parents, and interested community members. Invite a panel of presenters including a parent of a child with chronic conditions, a health professional, and a teacher of a child with chronic conditions.

   Encourage panelists to share their feelings and experiences, provide general information about the condition, and make recommendations for improving in the care of children with chronic conditions.

2. ***Take Time to Discuss Challenges Faced by Staff***

   Periodically reserve time during staff meetings to discuss challenges in caring for children with chronic conditions. For example:

   - Has communication with parents or health professionals been difficult?
   - Is the timing of procedures or staffing problematic?
   - Do you need some tips in helping the child to cooperate with taking medication?

   Work with colleagues to share strategies to address the challenges.

3. ***Investigate Other Head Start Programs***

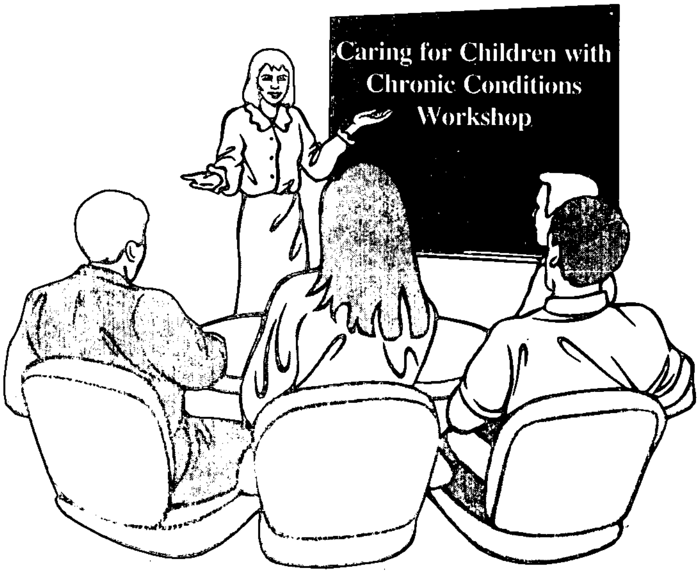
   Investigate other Head Start programs that are successfully caring for children with chronic conditions. Visit the programs and observe procedures, review their policies, and share strategies.

4. ***Join Organizations that Advocate for Children***

   Many organizations advocate for children with special needs—join one or two. Read the publications to become informed about current issues. Advocate for improved services for children with chronic conditions and their families in your community.

5. *Attend Workshops on Caring for Children with Chronic Conditions*

Attend classes, workshops, and conferences on caring for children with chronic conditions. Courses may be available through the local community college, child care resource and referral agency, hospitals, and other community organizations.



Publications

Beckman, Paula J., and Beckman Boyes, Gayle. *Deciphering the System: A Guide for Families of Young Children with Disabilities.* Cambridge, MA: Brookline Books, 1993.

A book written by the mother and aunt of a child with a disability to provide readers with basic information about the early intervention and educational service delivery system.

Bradway, Lauren, and Block, Lawrence A. *Children With Special Needs.* Durant, OK: Essential Medical Information Systems, Inc., 1990.

This quick reference book offers concise information about many common diagnoses, as well as brief recommendations for classroom management and sources for more resource information. Some may object to the authors generalizations about cultural and social subgroups

Hobbs, Nicholas, Perrin, James M., and Ireys, Henry T. *Chronically Ill Children and Their Families.* San Francisco, CA: Jossey-Bass Publishers, 1985.

This book provides a good overview of the psychosocial and educational needs of children and families living with chronic illness.

Kendrick, A.S., R. Kaufman, and K.P. Messenger, eds. *Healthy Young Children: A Manual for Programs.* Washington, DC: National Association for the Education of Young Children, 1995.

A comprehensive resource for designing health policies and practice for child care programs, including Head Start. Contains a section on the care of children with chronic conditions.

Rosenfeld, Lynn Robinson. *Your Child and Health Care: A "Dollars & Sense" Guide for Families with Special Needs.* Baltimore, MD: Paul H. Brookes Publishing Co., 1994.

This book is a financial primer for family advocates and parents. It is designed to help with the business aspects of caring for a child with a chronic illness or disability. While specifics about the programs discussed are likely to change over time, for example the book was written prior to the dismantling of AFDC, the basic approach of advocacy and problem-solving will always be valuable.

Urbano, Mary Theresa. *Preschool Children with Special Health Care Needs.* San Diego, CA: Singular Publishing Group, Inc., 1992.

A text designed to be a practical guide to professionals working in preschool settings. It addresses the continuum from basic preventive health care practices to management of complex medical conditions. The major focus is on the process of early identification and practical management of special health care needs of preschool age children.

Manuals and Guides

Bailey, William C., and Manzella, Bryn A. *Learn Asthma Control in Seven Days*. Birmingham, AL: University of Alabama, 1989.

A patient education curriculum for adults with asthma or adults caring for a child with asthma. The focus is on daily skills for preventing asthma episodes, a discussion of medication options, and simple definitions of what asthma is.

Child Care Law Center. (1994). *Caring for Children with HIV or AIDS in Child Care*. San Francisco, CA: Child Care Law Center

This report offers information regarding legal issues faced by child care providers who take care of children with HIV or AIDS.

Child Care Law Center (1994). *Legal Aspects of Caring for Sick and Injured Children*. San Francisco, CA: Child Care Law Center.

This report covers the legal aspects involved in taking care of sick or injured children.

Child Care Law Center (1993). *Caring for Children with Special Needs: The Americans with Disabilities Act and Child Care*. San Francisco, CA: Child Care Law Center

This report explains the implications of ADA for early child care programs.

Edelman, Larry, ed., *Getting on Board: Training Activities to Promote the Practice of Family-Centered Care.* Bethesda, MD: Association for the Care of Children's Health, 1995.

A training curriculum to help staff understand the new roles and skills required to deliver services in a family-centered way.

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A guide written to bridge the gap between service providers' past training and experience and new expectations of collaboration and partnership with families.

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A practical handbook for the formation and maintenance of parent support groups. Includes samples of documents such as workshop announcements, group by-laws, public service announcements etc.

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A guide for persons planning or conducting community-based programs that enroll children with HIV infection.

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