



316/936 Meeting the Needs of Medically Complex Children

A Training Curriculum

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**For the
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**University of Pittsburgh
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316 & 936: Meeting the Needs of Medically Complex Children

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316 & 936: Meeting the Needs of Medically Complex Children

An Overview of the Curriculum

Rationale

To provide child welfare workers, foster caregivers, adoptive parents, and family preservation workers a better understanding of the unique needs of medically complex children. By improving the knowledge level related to specific medical/disease conditions, these caregivers will be more prepared to personally participate in the involved child's care. By increasing the caregiver's knowledge base and awareness of available community resources, a more comprehensive approach to the care of these vulnerable children will be seen.

Learning Objectives

Upon completion of the training session, participants will be able to:

- Identify developmental and medical conditions which can affect the well being of children and their families.
- Identify the medical, developmental, and psychosocial needs of medically complex children.
- Access services and resources for medically complex children and their families.
- Identify how to meet the needs of medically complex children.
- Employ cultural considerations for provision of healthcare.

Competencies to be Addressed in Curriculum for Child Welfare and Family Preservation Staff

- The worker knows developmental and medical conditions which can affect the well-being of children and families or which can contribute to or result from abusive or neglectful caretaking. These include: failure to thrive, prematurity, AIDS, Sudden Infant Death Syndrome, cerebral palsy, fetal alcohol syndrome, and other conditions.
- The worker is aware of and can coordinate appropriate treatment and supportive services for families and children with developmental and medical conditions.

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An Overview of the Curriculum (continued)

Competencies to be Addressed in Curriculum for Foster Care Provider

- The foster care provider knows developmental and medical conditions, which can affect the well-being of children and families. These include: failure to thrive, prematurity, AIDS, Sudden Infant Death Syndrome, cerebral palsy, fetal alcohol syndrome, and other conditions.
- The foster care provider is aware of appropriate treatment and supportive services to families and children with developmental and medical conditions.

Competencies to be Addressed in Curriculum for Adoptive Parents

- The adoptive parent knows developmental and medical conditions, which can affect the well-being of children and families. These include: failure to thrive, prematurity, AIDS, Sudden Infant Death Syndrome, cerebral palsy, fetal alcohol syndrome, and other conditions.
- The adoptive parent is aware of appropriate treatment and supportive services to families and children with developmental and medical conditions.

Workshop Training Time

6 hours

Target Audiences

Child Welfare Professionals, Family Preservation Workers, Foster Caregivers, and Adoptive Parents.

Expectations of Trainer

This curriculum has been developed to be delivered by a team of three trainers. The training team should be knowledgeable in the medical, developmental, and psychosocial needs of the medically complex pediatric population, have an awareness of community resources available for meeting the unique needs of these medically complex children, and have experience with disease management in the home setting. At least two members should have strong medical background and have a minimum of a bachelor's degree in a medical major such as nursing, physical therapy, etc. A medical background will insure that the training team has the flexibility to adjust the curriculum to specific medical issues and disease management concerns that may result from specific audience composition or questions.

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An Overview of the Curriculum (continued)

Expectations of Trainer (continued)

The third trainer should have knowledge in child welfare practice, specifically in direct services to children and families. All trainers should have considerable experience in training workshops and should have excellent group facilitation skills. Trainers must possess knowledge and experience in diversity awareness so that special attention can be afforded to the provision of culturally congruent health care. If only one trainer is available, a trainer with medical background would be preferred due to the nature of the curriculum.

Equipment Needed

Specific materials needed to conduct the training are listed for each section of the curriculum. All sections require overhead projector or computer projector and screen.

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MEETING THE NEEDS OF MEDICALLY COMPLEX CHILDREN

Content & Schedule of Activities for One Day Curriculum

0.25 Hours INTRODUCTION AND OPENING ACTIVITIES

Section I THE INFANT AT RISK

1.5 Hours

- A. Prematurity
- B. Physical Disorders
- C. Complications of Birth
- D. Failure to Thrive

Section II EFFECTS OF SUBSTANCE ABUSE

1.0 Hours

- A. Fetal alcohol syndrome
- B. Fetal alcohol effects
- C. Narcotic abstinence syndrome
- D. Cocaine
- E. Fetal tobacco syndrome

Section III PEDIATRIC CHRONIC ILLNESSES & SUDDEN INFANT DEATH SYNDROME

2.0 Hours

- A. Cerebral Palsy
 - Care delivery
- B. HIV/Pediatric AIDS
 - Transmission as related to home care
 - Manifestation
 - Managing care and treatment
- C. Sudden Infant Death Syndrome
 - Potential causes
 - Prevention
 - Implications for family

Section IV CULTURAL CONSIDERATIONS FOR PROVISION OF HEALTH CARE TO MEDICALLY COMPLEX CHILDREN

0.5 Hours

Section V ACCESSING SERVICES AND RESOURCES FOR MEDICALLY COMPLEX CHILDREN AND FAMILIES

0.5 Hours

0.25 Hours EVALUATION AND CLOSURE

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Dear Trainer –

Pennsylvania's most vulnerable population is that of the medically complex children. The caseworkers, family preservation workers, foster parents, and adoptive parents have been entrusted with the challenging role of caregiver for this special group. Their ability to meet this challenge effectively can be one of our Commonwealth's strongest resources. It is our hope that this curriculum will assist in the provision of knowledge required to meet that challenge.

Best wishes as you teach "Meeting the Needs of Medically Complex Children".

David Hoffman

Donna Jenkins

Maureen Conlon-Krepps

Joan Mosier

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PREFACE

Meeting the needs of a medically complex child cannot be accomplished by one individual. The philosophy of collaboration and teamwork must be emphasized throughout all aspects of teaching this curriculum. Coordinated services for medically complex children and their families can eliminate the fragmentation of care in the community.

This curriculum was designed as a basic orientation to provide information on specific pediatric medical conditions and best practices of care. It must be understood that as research and medicine evolves, so do the basics of education and care practices. Be advised that any medical treatments reviewed are subject to change with the advancement of technology. Workers and parents should continue to stay updated on new information to assist in case planning for children and families.

Medically complex children need more than medical care to thrive in the community. Each child is unique and has unique needs. Individualized Family Service Planning (IFSP) for families and their children provides a mechanism to respond to and document the process for meeting these unique needs. Referrals to the local county early intervention center are paramount to initiating the collaborative process. The actual components regarding early intervention programming may vary somewhat from county to county and may change as new legislation is passed. Workers and parents are encouraged to keep current with their local county MHMR office in order to have the most accurate information available for case planning.

It is equally important to remember that beneath the complex medical language, the high technology, the signs and symptoms, the interdisciplinary, and the collaborations of this curriculum is a small child. A child who needs to play, go to school, be disciplined, and be loved in order to take his or her place in the family structure. The trainer must not lose sight of this child as the curriculum is taught.

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INTRODUCTION AND OPENING ACTIVITIES

Rationale	Participants interaction and group trust promote a positive environment for learning. Because each training audience may contain a blend of caseworkers, family preservation workers, adoptive parents, and foster parents, it is important for the trainer to provide an opening activity that will reduce stress caused by this diversity in participants and to encourage active involvement in the training experience.
Learning Objectives	Participants will be able to: <ul style="list-style-type: none">-Introduce themselves to other participants.-Identify their training needs.-Describe the course and details of the competencies.
Time	0.25 Hours
Methods	Presentation by trainer. Group discussion.
Materials	Name tents (large index cards or heavy stock paper), markers, 3x5 index cards Handout #1 – Participant Manual – Pages 1 & 2 Handout #2 – “Benign” Bingo Overhead #1 – Agenda Overhead #2 – Competencies
Activities	Activity #1 – Name Tents Activity # 2 – “Benign” Bingo Trainer Note: Refer to “Benign” Bingo Response Guide

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INTRODUCTION AND OPENING ACTIVITIES

Trainer Note:

Handout #1 (Participant's Manual), name tent materials, and 3x5 index cards may be given to participants when they arrive or placed on the participants' tables prior to the start of training. "Benign" Bingo handouts should be distributed as participants arrive.

- ◆ Introduction of the trainer and welcome participants to the training.
- ◆ Review specific of Competency-Based Training:
 - 15-minute rule
 - Sign-in sheet
 - Evaluation form completion and submission
 - Availability of continuing education units
 - Review "Housekeeping Rules" pertaining to specific training sites
- ◆ Review Agenda
 - Overhead #1
- ◆ Review Competencies
 - Overhead #2

Activity #1 – Name Tents and Question Cards

- Step 1 -- Instruct participants to write their name in the center of their paper name tent with a marker. They should also note if they are caseworker, foster parent, or adoptive parent.
- Step 2 -- Trainer should go around the room and have each participant give their name and why they are attending the training session (i.e. foster parent of child with cerebral palsy, caseworker for child with failure to thrive, ect.)
- Step 3 -- Trainer should explain that the 3x5 index cards are for writing questions participants may have. These questions will be addressed throughout the training as time permits.

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Activity #2 – “Benign” Bingo (Benign is a medical term for harmless)

Trainer Note: This activity can be very time consuming. Distribute game sheets as participants arrive. Instruct participants to play before the session begins, during breaks, and during lunch. The trainer will ask for winners immediately after lunch.

- Step 1 -- Distribute copy of Handout #2, “Benign” Bingo, to each participant. Explain that the purpose of the game is to talk with other participants to get responses on the handout blocks as in Bingo. The other participants must initial the block to which they responded. However, the same person can complete no more than one block on each sheet.
- Step 2 -- Participants can begin playing Bingo as they await the start of training. They may continue during break and lunch.
- Step 3 -- The trainer will end the game following lunch and before the afternoon session begins. The person with “Bingo” or the greatest number of completed blocks may be given a small prize related to the training topic, i.e. magnets, mugs, often available as marketing items from local hospitals, home health agencies, or medical equipment vendors.

The trainer should quickly review the blocks, soliciting responses from the participants. Answers are available to the trainer on “Benign” Bingo Response Guide. Allow only 5-10 minutes for the Bingo closure.

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“BENIGN” BINGO (*It Should Be Harmless)



Who has worn latex gloves?	Who has seen an apnea monitor?	Who has spent the night in a hospital?	Who has stayed awake all night caring for a sick child?	Who has taken a temperature?
Who gets an Apgar score?	Who has cared for a medically complex child?	Who has ever been in a wheelchair?	Who has gone to a support group meeting?	Who knows what “CP” means?
Who can name a “shot” babies must get?	Who has used the Internet?	Free space! <hr/> Write name here	Who has given an injection?	Who remembers liquid pink penicillin?
Who has changed a diaper?	Who has been in a cast of any kind?	Who can give a “folk remedy” for sickness?	Who has heard a heartbeat?	Who knows a superstitious cause for an illness?
Who knows what a physical therapist does?	Who knows what NICU means?	Who can name an infant formula?	Who knows a visiting nurse?	Who knows anyone who uses American sign language?

Directions: Playing “Benign” Bingo will assist you in meeting some of the other training attendees. Talk with other participants to see who can answer the various blocks. Have the other participant initial the block that he or she answered. However, the same person can initial no more than one block on your sheet. Bingo can be played prior to training, during break, and lunch. Bingo can be obtained across, down, or diagonal – sorry, no four corners! The trainers will ask for Bingo winners immediately following lunch. Good Luck!

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“BENIGN” BINGO RESPONSE GUIDE

Apgar Score – An evaluation method used on newborns immediately following delivery to assess heart rate, respirations, muscle tone, reflex, and color.

CP – Cerebral Palsy

“Shots” or Infant Immunization – Include but are not limited to: Diphtheria, Pertussis, Tetanus, Rubella, Mumps, Measles, Hepatitis.

Sample Folk Remedies – Rub potato on wart and then bury it to remove the wart; Copper bracelet for arthritis.

Sample Superstitious Causes for Illness – Cutting Baby’s hair before one year of age results in major illness; touching a toad causes warts.

Physical Therapist – Licensed health care professional who provides therapeutic exercise programs to increase mobility and range of motion.

NICU – Neonatal Intensive Care Unit

Infant Formulas – Similac, Enfamil

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SECTION I THE INFANT AT RISK

Rationale	Child welfare professionals, family preservation staff, foster care providers, and adoptive parents must have a better knowledge level of the infant at risk in order to better understand the unique needs of medically complex children. These caregivers will be more prepared to personally participate in the involved child's care and to assist in the delivery of services which meet the child's needs.
Learning Objectives	Participants will be able to: ◆ Identify the infant at risk and medical conditions which can affect the well-being of children and families.
Time	1.5 Hours
Methods	Presentation by trainer. Group discussion. Critical thinking exercises.
Materials	Handout #1 – Participant Manual – Pages 1A thru 13A Overheads # 1A thru 26A 3x5 Index Cards
Activities	Critical Thinking Exercise: Nonorganic Failure to Thrive Critical Thinking Exercise: Culture and Diet <u>Trainer Note:</u> Conclusion of Section I may be a suitable time for a 15-minute break.

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Trainer Notes

Section 1

Trainer Note: You may want to explain that you are purposely using both medical and non-medical terminology in order to familiarize participants with verbiage they may see on the child's medical record. Also alert them that there will be a medical glossary included in the handouts.

The at-risk infant is an infant who has the increased possibility of suffering harm, damage, loss, or death. Within the last 20 years, the field of neonatology has expanded greatly. Many levels of nursery care have evolved in response to increasing knowledge about the neonate: Special care; transitional care; and low, medium, and high risk care. In addition to the availability of high level neonatal care, other factors influence the outcome for these at-risk infants.

These factors include: Birth rate, gestational age, types and length of neonatal illness, environmental and maternal factors.

An at-risk infant is one who is susceptible to illness (morbidity) or even death (mortality) because of prematurity, physical disorders, or complications of birth.

Trainer Note: Overhead 1 has been created to provide talking points for the next section.

In most cases, the high at-risk infant is the product of a pregnancy involving one or more predictable risk factors. These include:

- Low socioeconomic level of the mother.
- Exposure to environmental dangers such as toxic chemicals.
- Pre-existing maternal conditions such as heart disease, high blood pressure, or diabetes.
- Maternal infection or substance abuse.
- Obstetric complications such as placenta problems at the time of delivery.

Because these factors and the perinatal risk associated with them are known, the birth of many at-risk newborns can often be anticipated and prepared for through adequate prenatal care.

Let's take a closer look at the at-risk, premature infant. A pre-term infant is any infant born before 37 weeks gestation. The length of gestation and, thus the level of maturity, vary even in the "premature" population.

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Trainer Notes

The major problem of the premature infant is variable immaturity of all systems. These systems include, but are not limited to: respiratory, temperature regulating, digestive, kidney, liver, immune, and central nervous systems.

Problems identified in a specific system will need further evaluation and treatment by the child's primary health care provider.

An important point to consider with the premature infant is the corrected age of the newborn. An infant born at 32 weeks gestation who is now 5 weeks old cannot be considered or compared to a full-term 5 week old both in terms of physical or neurobehavioral development. As case workers, foster care parents, and adoptive parents, this 5 week lag needs to be considered with the premature infant. Corrected age is generally used until the infant is 6 months old.

An example of the at-risk infant with a physical disorder will be discussed later in Section III.

Trainer Note: Overhead 2 has been created to provide talking points for the next section.

The at-risk infant suffering from complications of birth include the infant who has experienced perinatal birth asphyxia or decreased oxygen during delivery. The Apgar Score, a valuable tool in identifying the at-risk neonate, is performed at one minute and at five minutes of life. This scoring system assesses five categories: heart rate, respiratory effort, muscle tone, reflex irritability, and color. The lower the Apgar score after birth, the higher the percentage of neurologic abnormalities seen after and up to one year.

In addition to perinatal asphyxia, other factors leading to birth complications include:

- the large birth weight infant often seen in the diabetic mother, causing birth trauma;
- bleeding problems occurring at or during the time of birth leading to anemia in the newborn.

If a history of complications is known with regard to the infant in question, further evaluation must be done by a competent health care provider.

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Most of the aspects concerning high risk neonates are related to the incidence of prematurity. However, the actual cause of prematurity is not known in most instances. The incidence of prematurity is lowest in the middle to high socioeconomic classes in which pregnant women are generally in good health, are well nourished, and receive prompt and comprehensive prenatal care. The incidence is highest in the low socioeconomic class in which a combination of negative circumstances, such as poor diet and poor medical follow up, are present.

Other factors such as multiple pregnancies (twins, triplets, etc.), high blood pressure during pregnancy, and placental problems that interrupt the normal course of the pregnancy prior to completion of fetal development are responsible for a large number of premature births.

The outlook for premature infants is largely, but not entirely, related to the state of immaturity of the various organs and systems at the time of birth. Infants at term have advanced to a state of maturity sufficient to allow a successful transition to the extrauterine environment that we talked about earlier. Infants born prematurely, however, must make the same adjustments but with not fully developed organs and systems. The degree to which the infants are prepared for extrauterine life can be predicted to some extent by weight and the estimated gestational age.

Anticipation of Problems: Factors that influence neonatal outcome during this vulnerable period may occur simultaneously. For example, infants born prematurely may suffer from breathing problems surrounding the events at birth and develop respiratory distress syndrome. Other increased risk factors include problems with temperature regulation, infection, hydration, nutrition, and energy conservation. In addition, difficulties in the ability of the mother to properly care for the child or disturbances in the mother/child relationship can have serious consequences, both immediate and long-term, for the infant. These difficulties may be caused by disorders that impair the mother's ability to physically care for her infant or by psychological illnesses that interfere with the mother's emotional ability to provide proper care for the child.

Trainer Note: More specific examples of the above factors include: temperature regulation (where the child has a hard time maintaining his/her temperature within normal range), energy conservation (performing ADL's such as feeding, bathing, playing in such a way to allow for rest periods, hence conserving energy).

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Trainer Notes

Often professional health workers are so absorbed in the life-saving physical aspects of care that the emotional needs of infants and their families are ignored. The significance and need of early parent-child interaction and infant stimulation has been documented by reliable research.

Case workers, foster parents, as well as adoptive parents, need to become aware of these infant and family needs and incorporate activities that facilitate family interaction into their plan of care. Encourage father, sibling, and extended family involvement.

The birth of a premature infant can be a very unexpected and stressful event for which families are emotionally unprepared. They find themselves simultaneously coping with their own needs, the needs of their infant, and the needs of their families, especially when there are other children. To compound the situation, the very nature of the infant's condition, which many times is very fragile, engenders an atmosphere of apprehension and uncertainty. Families are faced with multiple crises and overwhelming feelings of responsibility, expense, and frustration.

Parents need to feel that they are not alone. Parent support groups have been of immeasurable value to families of infants in the Neonatal Intensive Care Unit or NICU. Some groups consist of parents who have had infants in the hospitals who share the same anxieties and concerns. Other groups include parents who have had infants in the NICU and have dealt with the crisis effectively. These groups are usually under the leadership of a staff person, involved physicians, nurses, and social workers. But, it is the parents who can offer other parents something that no one else can provide.

A relatively new national organization evolved from a local parent's group. Parent Care, Inc. provides information, referrals, and support to parents and professionals concerned with the care of high risk infants. It also publishes a national newsletter and resource directory that provides information to parents on items such as "premie" clothing, and hosts national and local conferences.

The Family Resource Coalition is a North American network of family support programs designed to help families of preterm infants. The Family Resource Coalition is distributed by Shinn & Associates.

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Trainer Note: Before moving on, are there any remaining issues? If so, please write your questions/concerns on the 3x5 card provided. The cards will be read and discussed as time permits.

Trainer Notes

Parents become very apprehensive and excited as the time for discharge approaches. Many times, they have concerns and insecurities regarding the care of this high risk and usually very tiny infant. They fear the child may still be in danger, that they will be unable to recognize signs of distress or illness in their infant, and that the infant may not yet be ready for discharge.

Trainer Note: Overhead 3 has been created to provide talking points for the next section.

The term “vulnerable child syndrome” is applied to a physically healthy child who is perceived by their parents to be at high risk for medical or developmental problems. The syndrome has been observed in parents of children who have had an earlier illness or injury from which they had not been expected to recover. The family continues to perceive the child as fragile, vulnerable, different, and having needs that warrant special status in the family, which adversely affects the child and family’s behavior. The parents may lack confidence in their parenting ability, persisting beyond the illness. The parents may also become overly indulgent and have difficulty setting limits, resulting in interference with normal development. Consequently, the child becomes dependent, demanding, and out of control. Over protection and frequent visits to health care providers are characteristics.

Problems that may arise in the high risk newborn include overfeeding, underfeeding, and difficulty separating the child from the parent. To help parents deal with the stress of home care for the infant, social workers and family/child preservation workers can help families discuss their fears and anxieties, which are exaggerated in parents of premature infants, and encourage the families to create a normal routine in caring for the infant. Parents need to learn the normal developmental delays expected of premature infants and the importance of setting disciplinary limits and schedules. Continued explanations and clarifications of the infant’s true health status and ongoing support of the parents’ efforts are important aspects of follow up care.

Failure to thrive (FTT) is a state of inadequate growth resulting from inability to obtain and/or use calories required for growth. FTT has really no universal definition, although one of the most common

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parameters is weight, and sometimes height, that falls below the 5th percentile for the child's age.

Trainer Notes

Growth measurements alone are not used to diagnose children with FTT. Rather, the findings of a persistent deviation from an established growth curve is cause for concern.

There are two common categories of Failure to Thrive:

Organic Failure to Thrive (OFTT) results from a true physical cause such as congenital heart defects, neurological lesions, or brain problems such as microcephaly, chronic urinary tract infections, gastroesophageal reflux, kidney problems, inability to absorb food, or endocrine or metabolic dysfunctions, as well as the cystic fibrosis or AIDS. OFTT results from a physical cause.

Nonorganic Failure to Thrive (NFTT) has a definable cause that is unrelated to disease. NFTT is most often the result of psychological factors such as inadequate nutritional information by the parent, deficiency in maternal care, disturbance in maternal/child bonding, or disturbance in the child's ability to separate from the parent leading to food refusal to maintain attention. NFTT has been described under a variety of less acceptable names including Maternal Deprivation or Environmental Deprivation.

Traditionally, the category of Nonorganic Failure to Thrive has implied a disturbance in the parent/child interaction. However, this is not always the case. Many other factors can lead to inadequate feeding of the infant such as the following:

Poverty -- Lack of funds to buy sufficient food. Many times families may dilute formula to extend available supply.

Health Beliefs -- Use of fad diets often from excessive concern with preventing conditions such as obesity, hypercholesterolemia (high cholesterol levels), or dental cavities. May involve use of skim milk, diluted formula, or excessive use of fruit juice.

Religious Beliefs -- Strict feeding schedules aid in development of church values.

Inadequate Nutritional Knowledge -- Lack of interest or poor parenting skills, as well as parents with cognitive impairment.

Family Stress -- Overwhelming involvement with another ill child. Any number of other stressors including financial stress, marital stress, excessive parenting, employment responsibilities, depression, substance abuse, or acute grief.

Feeding Resistance -- Results of non-oral nutritional therapy early in life.

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Insufficient Breast Milk -- Result of a number of different causes such as maternal fatigue, maternal illness, poor release of milk, insufficient glandular tissue, or lack of confidence on the part of the mother.

In these instances, parent education and provision of necessary supports, whether they be financial or psychosocial, are generally successful in correcting the reason for the malnutrition.

Dealing with families in which a child has Nonorganic Failure to Thrive because of a parent/child disturbance is much more difficult. Diagnosis is initially made from evidence of growth retardation. If Failure to Thrive is recent, the weight, but not the height, is below accepted standards, usually the 5th percentile. If FTT is long-standing, both weight and height are depressed indicating chronic malnutrition.

Regardless of the cause of FTT, the treatment is directed at reversing the malnutrition. The goal is to provide sufficient calories to support catch-up growth, a rate of growth greater than the expected rate for age. Also, any co-existing medical problems are treated. In most cases a multi-disciplinary team of physicians, nurses, dieticians, child life specialists, social workers, and mental health professionals, as well as the family is needed to deal with the multiple psychological problems. Efforts are made to relieve any additional stresses on the families, such as referrals to welfare agencies or supplemental food programs. Involvement of child protective services may be necessary in severe cases.

Home health involvement can be beneficial since the visiting nurses are able to observe the child feeding and family dynamics in the home setting at various times.

The prognosis for Nonorganic Failure to Thrive is related to the cause. If the parents have simply been ignorant of the infant's needs, teaching may remedy the child's limited caloric intake and permanently reverse the growth failure. Inadequate or decreased feeding periods by the infant's primary caregiver are often observed as the cause of NFTT in conjunction with family disorganization. When the family dysfunction is extensive, the prognosis is uncertain. Factors related to poor prognosis are severe feeding resistance, lack of awareness in and cooperation from the parents, low family income, low maternal educational level, and early onset of NFTT.

Trainer Note: Overhead 4 has been created to provide talking points for the next section.

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Many of these children are below normal in intellectual development, have poor language development, are less well-developed in reading skills, attain lower social maturity, and have a higher incidence of behavior disturbances.

Caring for the child with Nonorganic Failure to Thrive presents many challenges, whether treatment takes place in the hospital, clinic, or home. Providing a positive feeding environment, teaching the parents successful feeding strategies, and supporting the child and family are essential components of care. The feeding behavior of the child is documented, as well as the parent/child interactions during feeding, other caregiving activities, and play.

Trainer Note: Overhead 5 has been created to provide talking points for the next section.

Besides the obvious signs of malnutrition and delayed development, children with NFFT may interact differently from children with OFTT. They may display intense interest in inanimate objects, such as a toy, but are much less interested in social interactions. They are often vigilant of people at a distance, but become increasingly distressed if they would become closer. They dislike being touched or held and avoid face-to-face contact. However, when held, they protest briefly on being put down and are apathetic when left alone.

The children may also demonstrate reflux or gastroesophageal reflux known as GER. This is best defined as the passive transfer of gastric contents into the esophagus. The most common sign of GER is emesis after feeding. Other less common symptoms include: poor weight gain, blood in the stools, anemia, irritability, heartburn, or a gagging or choking noted after feedings.

Recurrent apnea and pneumonia may also be seen in children with GER. A diagnosis of GER and other possible respiratory problems should be discussed with your primary health provider.

Trainer Note: Overhead 6 has been created to provide talking points for the next section.

Frequently, there is a history of difficulty feeding, vomiting, sleep disturbance, and excessive irritability. Habit patterns such as crying during feedings, vomiting, hoarding food in the mouth, constant chewing after feeding, refusal to switch from liquids to solids, and aversion behavior such as turning from food or spitting food become attention-seeking mechanisms to prolong the

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attention received at meal time. In addition, chronic reduction in calories can lead to appetite depression, which compounds the problem.

A feature of many children with NFFT is their irregularity in activities of daily living. Some of these children typify the difficult temperament pattern. However, another type is the passive, sleepy, lethargic infant who does not wake up for feedings. Parents who have been advised of demand-feeding schedules may be unsure of whether to wake the child or let the child sleep. Because of their inexperience and lack of guidance, parents may develop a pattern of infrequent feedings that is inadequate to meet the infant's nutritional needs. Such a pattern is a major concern with breast feeding infants with whom frequent nursing is essential to an adequate milk supply. Such characteristics in a child do not necessarily result in NFFT. Rather, a complex set of variables is significant, such as the degree of fit between the child's temperament and that of the parents. Since the personalities of infants can have definite effects on the parent/child attachment process, identifying such situations of disharmony may be one approach.

Some parents are at increased risk for attachment problems because of:

1. Isolation and social crisis,
2. Inadequate support systems, and
3. Poor parenting as a child.

Other factors that should be considered are lack of education, physical and mental health problems such as retardation, depression, drug dependence, immaturity (especially noted in adolescent parents), and lack of commitment to parenting such as giving higher priority to career goals. Frequently, these parents and their families are under stress and in multiple chronic, emotional, social, and financial crisis.

Planning needs to begin as soon as the problem is identified, whether it is on an outpatient basis or hospitalization is required. The priority goal or main goal is to provide the infant with sufficient nutrients for growth. More specific care will depend on the identified cause of Failure to Thrive. If an organic etiology is confirmed, care is related primarily to management of the disorder. If the problem is one of inadequate knowledge regarding feeding the child, parental education is required. When serious psychosocial factors are involved, hospitalization may be needed and additional interventions are required to meet the needs of both the child and the family.

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Feeding guidelines for children with Nonorganic Failure to Thrive include:

****Providing a primary person to feed the infant.** The same person should be able to learn the child's cues and respond consistently.

****Provide a quiet, unstimulating atmosphere.** A number of these children are very distractable, and their attention is diverted with minimal stimuli. Older children do well at a feeding table, and younger children should always be held.

****Maintain a calm even temperament throughout the meal.**

Negative outbursts may be commonplace in this child's habit formation, therefore, limits on eating behavior definitely need to be provided. They should be stated in a firm, calm tone. If the primary person feeding the infant is hurried or anxious, the feeding process will not be positive.

****Talk to the child by giving directions about eating.** Examples of this would include "Take a bite, Lisa." This is appropriate and directive. The more distractable the child, the more directives the primary person feeding the child should use to refocus attention on feeding. Positive comments about feeding are actively given.

****Be persistent.** This is perhaps one of the most important guidelines. Parents often give up when the child begins negative feeding behavior. Calm perseverance through 10-15 minutes of food refusal will eventually diminish negative behavior. Although forced feeding is avoided, strictly encouraged feeding is essential.

****Maintain a face-to-face posture with the child when possible.** Encourage eye contact and remain with the child throughout the meal.

****Introduce new foods slowly.** Often these children have been exclusively bottle fed. If acceptance of solids is a problem, begin with pureed food and, once accepted, advance to junior and regular solid foods.

****Follow the child's rhythm of feeding.** The child will set a rhythm when the previous conditions are met.

****Develop a structured routine.** Disruption in other activities of daily living has a great impact on feeding responses. So, bathing, sleeping, dressing, and playing, as well as feeding, all need to be structured. The lengths of the feedings should also be established, usually 30 minutes.

Teaching infant care techniques to the parents is begun through example and demonstration, not by lecturing. As you perceive the infant cues, these should be emphasized to the parent. For example, during a feeding you might comment that the infant is still hungry because the child sucks vigorously and looks at the parent. When the infant is satisfied, one could point out that the infant is signaling this by releasing the strong suck, closing the eyes, and

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breathing more slowly and deeply. Parents should be given opportunities to care for the infant without having demands made on them. Whenever the parent has successfully demonstrated one of the above named feeding guidelines, they should be praised.

Teaching Strategies

Trainer Note: Critical Thinking Exercise. In a large group, the following critical thinking exercise should be discussed:

Discuss why caring for the child with NFFT is a challenge. What factors might cause one to become judgmental when caring for a family with a child with NFFT. Encourage discussion from perspective of foster parent, adoptive parent, and caseworker. Discussion should not exceed 10-15 minutes.

Trainer Note: Key points that need to be met with the above critical thinking exercise include:

Caring for a child with NFFT is a challenge because not only are you trying to meet the growth needs, you are also trying to meet the developmental needs, as well as the psychosocial needs of the child. You are also not just dealing with the child, you are dealing with the family, as well as the environment in which the child is living, which may pose a challenge. You must consider the activities of play, discipline, and school.

Factors that may cause one to become judgmental when caring for a family with a child with NFFT: Consider the fact that many times these families are of lower socioeconomic status, lack education, and present a passive attitude towards parenting.

Teaching Strategies

Trainer Note: Critical Thinking Exercise. In a large group, discuss the following critical thinking exercise:

What if any, does the role of culture play in a child's diet? (Discussion should be limited to 10-15 minutes.)

Trainer Note: Key points to include are that many children of cultural backgrounds do not have access to all types of foods and the four basic food groups. Many people avoid certain foods because of their culture or religious backgrounds.

How can the (Child Welfare/Family Preservation Staff, Foster Care Provider, or Adoptive Parent) incorporate cultural awareness into anticipatory guidance for the nutritional needs of the infant?

Trainer Note: Key points to include are parental education. Teaching parents of different cultural background about comparative shopping. Helping them to understand English and

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read English so they are able to go to the grocery store to read and understand labels, to understand what the caloric value on the labels mean. Educate how to substitute certain foods in American culture for foods that might be more accepting in their culture, such as using rice for carbohydrate intake if rice is an important staple in their diet. If a cultural or religious background prohibits meats in their diet, you may want to teach certain foods that are high in protein such as beans, peas, or lentils.

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SECTION II EFFECTS OF SUBSTANCE ABUSE

Rationale	Child welfare workers, family preservation staff, foster care providers, and adoptive parents must have an understanding of the effects of substance abuse as it relates to the medical and developmental need of children.
Learning Objectives	Participants will be able to: ◆List medical, developmental, and psychosocial needs of those infants affected by substance abuse.
Time	1.0 Hour
Methods	Presentation by trainer. Group discussion. Critical thinking exercises.
Materials	Handout #1 – Participant Manual – Pages 1B thru 10B Overheads # 1B thru 19B
Activities	Case Study: Fetal Alcohol Syndrome/Effects Case Study: Mrs. Williams

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Section 2

The incidence of Fetal Alcohol Syndrome (FAS) is on the rise in the United States despite public warnings, including the late 1980's US Surgeon General's warning that consumption of alcohol during pregnancy may cause mental retardation and other defects. In 1994, the number of reported cases was 4.7 per 10,000 births, as compared with 1979 when the number of reported cases was 1.0 per 10,000 live births.

Infants and children with FAS have characteristic facial and associated physical features attributed to excessive ingestion of alcohol by the mother during pregnancy. Behavioral problems, problem solving impairment, and emotional deficits have also been recognized as originating from alcohol ingestion by the pregnant mother. A number of children and adults who demonstrate cognitive, behavioral, and emotional problems without the facial abnormalities) and growth retardation are referred to as having Fetal Alcohol Effects (FAE)

Fetal Alcohol Syndrome is recognized as the leading cause of mental retardation, outranking Down's Syndrome and Spina Bifida.

Let's take a look at the major features of fetal alcohol syndrome or FAS:

Trainer Note: Overhead 7 has been created to provide talking points for the next section.

Facial features include a short box-like forehead, palpebral fissures, causing the eyes to look close to one another, vertical ridge in the upper lip, thinned upper lip, short, up-turned nose, and a small chin.

Neurologically these children may have varying degrees of mental retardation and motor retardation. They will have a smaller head and demonstrate poor coordination, poor muscle tone, and have hearing as well as visual disorders.

Behavioral features include an irritability present from infancy which can lead to poor mother-infant bonding; as a child, a hyperactivity will be seen.

Growth is retarded prenatally and these children demonstrate a persistent postnatal growth lag, especially seen in boys. Alcohol interferes with normal pregnancy; the effects on the fetus are permanent; and even moderate use of alcohol during

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pregnancy may cause long-term postnatal difficulties, impaired maternal-infant attachment.

Since there is no known safe level of alcohol consumption in pregnancy, women who plan to become pregnant should stop consuming alcohol at least three months before they plan to conceive.

It is not the degree of alcohol intake in the mother that is related to the presence of abnormalities in the fetus; rather, it is the amount consumed in excess of the liver's ability to detoxify. The liver's ability to detoxify is limited and inflexible - when the liver receives more alcohol than it is able to handle, the excess is continually recirculated until the organ is able to reduce it to carbon dioxide and water. This circulating alcohol is attracted to the brain tissue in the fetus.

Poor nutritional state, smoking, polydrug intake, and poor prenatal care may further compound the problem when alcohol abuse is observed.

From birth, infants born to mothers who have abused alcohol have a difficult time establishing respirations, are irritable, lethargic, demonstrate seizure activity and have poorly developed suck reflex. This behavior by the infant is a leading cause of Failure to Thrive. Affected infants frequently develop metabolic problems and have a variety of other birth defects. These include: cardiac defects, eye and ear malformations, and spinal cord abnormalities.

Care of an infant with FAS involves many of the same considerations when dealing with an infant with Failure to Thrive, especially in terms of the feeding schedule. Special emphasis is placed on monitoring weight gain, analyzing feeding behaviors, and devising strategies to promote nutritional intake.

The effects of alcohol or FAE tend to be more easily identified in adolescents and young adults, primarily in relation to growth deficiencies, delayed motor development, and cognitive impairment. Facial characteristics tend to be more subtle than in infants and children.

The dangers of heavy drinking are known, and women with a history of excessive alcohol ingestion should be counseled regarding the risks to the fetus. It should be emphasized to all women that there is no known "safe" amount of alcohol intake during pregnancy that will preclude either FAS or FAE.

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Furthermore, FAS & FAE is a totally preventable birth defect. A change in drinking habits even as late as the third trimester (when brain growth in the fetus is greatest) is associated with improved fetal outcome.

Trainer Note: Remind audience that video resources on fetal alcohol syndrome are available at the regional training centers.

Trainer Note: Critical Thinking Exercise. In a large group, discuss the following:

How can your moral beliefs or past experience with alcohol consumption affect your care of the family of a child with Fetal Alcohol Syndrome?

Trainer Note: Key points include the fact that if you have consumed alcohol yourself in the past and were pregnant, there may be some guilt feelings which are going to influence or affect your care of a family with a child with FAS. You may be reluctant to report this to appropriate authorities. You may be uncomfortable with the issue of abusing or using alcohol that you may not want to bring up the topic with a pregnant woman.

Trainer Note: Critical Thinking Exercise - Case Study:

Divide the audience into three groups. Each group should be assigned one of the following roles: caseworker, foster care parent, adoptive parent. Give each group an index card with the title of their assigned group. The following information should be written on each group index card:

CASEWORKER: The Williams family is currently on your caseload. You are providing in-home services. What steps would you take after the home visit?

FOSTER CARE PARENT: Nathan and Jessica are foster children in your home. You have just facilitated the described family visit. What steps would you take after the family visit?

ADOPTIVE FAMILY: Nathan and Jessica are your newly adopted children. You have been provided with information from the case study. What steps would you take upon adoption of the children?

Trainer Note: Overhead 8 has been created to assist with this activity. The case study can remain on the screen while participants complete the activity.

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Instruct the groups to read the Williams case study . Instruct each group to discuss interventions from the perspective of caseworker, one from the perspective of foster parent, and one from the perspective of adoptive parent, based on their assigned role. Allow 10 minutes for small group discussion. Each group should report to the large group on their approach for intervention.

CASE STUDY - Mrs. Williams

Recently you have observed that the behavior of 7-year-old, Nathan, and his 5-year-old sister, Jessica, is out of control. You detect alcohol on the breath of their mother, Mrs. Williams, who is in her second trimester of pregnancy. She complains that “the kids are driving me crazy, and Nathan is having lots of trouble with his school work.” You question Mrs. Williams about her current alcohol use, and she responds defensively. “I drank sometimes with these kids, and there’s nothing wrong with them.” After discussing the potential effects of alcohol use during pregnancy, what would be the most appropriate intervention on your part?

Continued . . . Case Study -- Mrs. Williams

Key points for the trainer include in the discussion:

Caseworker Examples:

1. Refer Mrs. Williams, Nathan, and Jessica to a genetic service for prenatal counseling for Mrs. Williams and evaluation of Fetal Alcohol Syndrome/Fetal Alcohol Effects for Nathan and Jessica.
2. Report the case to the Child Welfare authorities to investigate for abuse/neglect.
3. Refer Mrs. Williams to an alcohol treatment center.
4. Refer Nathan and Jessica to a child development specialist for behavior modification therapy and tutoring.
5. Other

Caseworker Perspective -- The most appropriate initial medical referral for Mrs. Williams needs to be genetic counseling and evaluation regarding the fetal exposure to alcohol and appropriate interventions to reduce or cease the exposure. The children are showing behavioral manifestations of FAE and need to be evaluated to be appropriately managed. Although Mrs. Williams’ parenting skills may be lacking at present, there is no evidence of abuse or neglect at this time. Options 3 & 4 may be appropriate after more evaluation is completed and need is determined.

Foster Parent Examples:

1. One of your foster children exhibits behavior similar to Nathan and Jessica. You wonder if they may have Fetal Alcohol Syndrome or Fetal Alcohol Effects.

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2. You contact your caseworker to discuss and to arrange testing with primary care physician.

3. You request additional information on Fetal Alcohol Effects/Syndrome from the library, regional training center, etc.

Adoptive Parent Examples:

1. You discuss your concerns with your child's pediatrician and request testing.

2. You contact the adoption agency in an effort to obtain a maternal history during pregnancy.

Foster Parent/Adoptive Parent Perspective -- Feelings most likely exhibited by both would be fear that their foster or adoptive child had Fetal Alcohol Effects or Syndrome. They should be encouraged to discuss concerns with primary care physician and request testing. Additional education and research on child's mother may be helpful to both.

Narcotics readily cross the placental membrane and enter the fetal system. When the mother is a habitual user of narcotics, especially heroin or methadone, the unborn child also becomes passively addicted to the drug, which places such infants at risk during the early neonatal period.

Narcotic abstinence syndrome (NAS) is the term used by many to describe the set of behaviors exhibited by the infant exposed to substances in-utero causing a withdrawal effect.

Most passively addicted infants of drug-dependent mothers appear normal at birth but begin to exhibit signs of withdrawal within 12 to 24 hours if the mother has been taking heroin by itself. If mothers have been taking methadone, the signs appear somewhat later, anywhere from 1 to 2 days to 2 to 3 weeks or more after birth. The manifestations may last up to 8 weeks, depending on the severity of the withdrawal.

Trainer Note: Overhead 9 has been created to provide talking points for the next section.

The clinical manifestations of withdrawal in neonates include:

- Hyperirritability (this may persist for 3 or 4 months)
- Tremors
- Restlessness
- Hyperactive reflexes
- Increased muscle tone
- Sneezing (normal newborns do not sneeze)

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- Rapid respirations
- High-pitched, shrill cry

Although these infants suck avidly on fists and display exaggerated rooting reflex, they are poor feeders with uncoordinated and poor sucking and swallowing reflexes. Regurgitation and vomiting after feedings are common, and diarrhea is a later symptom.

An observation in a large percentage of these infants is generalized sweating, the incidence of which is unusual in healthy newborn infants.

Not all infants of heroin-addicted mothers will show signs of withdrawal. Because the mother may have irregular and varying degrees of drug use, quality of drug, and mixed drug usage by the mother, some infants display mild to variable manifestations. Therefore, many times infant withdrawal is missed in the hospital setting since the manifestations are so vague, and nonspecific.

Breast feeding by a narcotic addicted mother should be discouraged since drugs are passed to the infant in the breast milk.

The treatment of passively addicted infant initially consists of controlling the environment to decrease external stimuli. Drug therapy may be instituted and would consist of such drugs as: phenobarbital, chlorpromazine, diazepam, or paregoric.

Methadone treatment does not prevent withdrawal reaction in neonates, but the clinical course of treatment for these infants may be modified. Many women enrolled in a methadone treatment program have a psychologic need for pregnancy and to have an infant. Experience has indicated that these mothers are usually anxious and depressed, lack

confidence, have poor self-images, and have difficulty with interpersonal relationships.

These women need long-term follow-up care to evaluate the status of the infant and the family environment. Sudden infant death syndrome (SIDS) and AIDS are observed more frequently in infants born to users of heroin and methadone.

There are many problems in relation to the placement of infants of drug-dependent mothers. Those who advocate separation of

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mothers and children argue that the mothers are not capable of assuming responsibility for their infant's care, that the child care is frustrating to them and that their existence is too disorganized and chaotic. Others encourage the maternal-child bond and recommend a protective environment such as a therapeutic community, a halfway house, or continuous on-going supportive services in the home setting.

Cocaine, the number one illicit drug used in the United States, has multiple modes of use. However, use of the relatively inexpensive and easily administered "crack" form is increasing alarmingly, especially among women. Because crack vaporizes at relatively low temperatures, it is smoked and absorbed in large quantities through the pulmonary (lung) system. The drug readily crosses the placenta, placing the fetus at risk.

Cocaine is a central nervous system stimulant and has the ability to increase blood pressure and heart rate while at the same time decreases blood flow to vital organs. In the case of a pregnant woman, cocaine use decreases uterine blood flow. Consequently, the fetus suffers decreased blood flow and oxygenation because the uterus and placenta which supplies all nutrients to the infant is constricted.

Many times the problem of cocaine usage is compounded when the mother is taking the drug in conjunction with other illicit drugs. Also, prenatal exposure to cocaine has been implicated as a risk for SIDS in infancy.

Additional findings in infants with prenatal cocaine exposure include cerebral infarcts or brain hemorrhages, renal defects, cardiac abnormalities, mild facial deformities, lower birth weight and length, decreased head circumference, and inflammation of the colon resulting in necrosis.

A second and different behavior often seen with prenatal cocaine exposure is the infant who is lethargic, feeds poorly, is hypotonic or has poor muscle tone, and is difficult to arouse. As with the narcotic addicted mother, breast feeding by a mother with known cocaine abuse should be discouraged since the drug will be passed to the infant in breast milk.

Trainer Note: Overhead 10 has been created to provide talking points for the next section.

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Treatment for the cocaine exposed infant is similar to that for the NAS infants - reduction of external stimuli, supportive treatment aimed at alleviating symptoms, and at times, sedation.

Swaddling of the cocaine exposed infant is a more accepted form of comfort since these infants have decreased flexor tone, meaning they tend to have little or no control over their extremities. Wrapping tightly in a semi-flexed position will help to console these infants.

Trainer Note: Cocaine videos are available through PA Child Welfare Competency-Based Training and Certification Program at the regional training centers.

Cigarette smoking during pregnancy is clearly associated with significant birth weight deficits up to one pound. In full-term newborns, there is a definitive relationship between the number of cigarettes smoked by the mother and these deficits. The amount of cigarettes smoked per day, also affects the infant's Apgar score. The Apgar score is a classification system that is done on the newborn at one minute of life and again at 5 minutes of life after birth in which a score has been assigned to the newborn in terms of respiratory effort, heart rate, color, muscle activity, and grimace. The number of infants with low Apgar scores (whose mothers smoked three packs per day) is nearly four times that of infants whose mothers smoked none or only one pack per day. Studies have also indicated that 40% of the incidence of low birth weight is attributable to maternal cigarette smoking.

The rate of preterm births is increased in mothers who smoke, but the infants are smaller at ALL stages of gestation. There is fetal growth retardation in weight, length, and head circumference. These deficits are not related to maternal appetite or weight gain.

The most active substance in cigarettes, nicotine, has been found to be higher in the newborn than in their mothers. In addition, nicotine is secreted in breast milk and remains in the system for up to 80 minutes.

The overwhelming evidence of the negative effects of maternal cigarette smoking on newborns has led some investigators to suggest the diagnostic term of fetal tobacco syndrome. Key features of fetal tobacco syndrome include:

- the mother smoked 5 or more cigarettes a day throughout pregnancy

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- the mother had no underlying evidence of hypertension during pregnancy
- growth retardation was evident in the newborn at the time of birth
- there was no other evidence of contributing intrauterine growth retardation

There has been some research conducted regarding effects of passive smoke inhalation during pregnancy and possible negative impact on the fetus. The father or other close companions to the pregnant woman should also be discouraged from smoking while in the mother's presence.

Numerous researchers have investigated the effects of environmental pollution on children's health and have determined that the worst pollutant is parental smoking, especially maternal smoking. Children exposed to environmental tobacco smoke have an increased number of respiratory illnesses, such as bronchitis, pneumonia, asthma, and otitis media or ear infections as compared with children of nonsmoking parents.

Maternal smoking has also been linked to increased risk of miscarriages, preterm births, and stillbirths. Recent evidence is showing a correlation between passive smoking and SIDS.

The American Academy of Pediatrics has renewed its statement on hazards of passive smoking and stated in 1995, "The danger to children of both active and passive tobacco exposure, including smokeless forms, are so well established that pediatricians should make the elimination of this threat a major issue as they pursue the goal of a tobacco-free generation by the year 2000."

Passive smoking during childhood may well be the most important precursor or cause of chronic lung disease in the adult. Both father and mother should be encouraged to stop smoking.

In families where smokers refuse to quit, house rules should be established for reducing smoke in the child's environment.

Trainer Note: Before moving on, are there any remaining issues?

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SECTION III PEDIATRIC CHRONIC ILLNESSES AND SUDDEN INFANT DEATH SYNDROME

Rationale	Child welfare workers, family preservation staff, foster care providers, and adoptive parents require basic knowledge of the most common pediatric chronic illnesses in order to better meet the needs of the children and families to which they provide care.
Learning Objectives	Participants will be able to: <ul style="list-style-type: none">◆ Recognize the more common pediatric chronic illnesses.◆ List caretaking techniques for these illnesses..
Time	2.0 Hour
Methods	Presentation by trainer. Group discussion. Group activities.
Materials	Handout #1 – Participant Manual – Pages 1C thru 20C Overheads # 1C thru 39C Cellophane or masking tape. Apnea monitor (optional) may be borrowed from a local durable medical equipment company in presentation location. Suggest calling several weeks in advance to arrange. <i>Trainer Note:</i> At the completion of the cerebral palsy section, a lunch break would be appropriate.
Activities	Cerebral Palsy Clinical Simulation Demonstration of Apnea Monitor (optional) Participant Exercise: Caring for Child with Terminal Illness

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Section 3

In this section, we will talk about a number of different chronic illnesses. A chronic illness is a long-term disorder which usually becomes progressively more debilitating. This is different than an acute illness such as appendicitis, fractured leg, or trauma. These types of illnesses occur suddenly without warning and may be resolved within a short period of time. Chronic illness requires ongoing treatment and care.

Cerebral palsy is a nonspecific term applied to disorders characterized by impaired movement and posture, usually at an early onset. It is usually nonprogressive and may be accompanied by language and intellectual impairment. Each case is different but the primary disturbance to a child is abnormal muscle tone and coordination. Cerebral palsy is the most common permanent disability of childhood. Since 1960 the prevalence of CP has risen about 20%. This is probably due to the improved survivability of low birth-weight infants.

There are a variety of factors which can contribute to CP. These factors can present themselves in the prenatal, perinatal, or postnatal period. It used to be believed that CP was caused by birth asphyxia; it is now known that CP more routinely results from a pre-existing brain abnormality. Premature delivery is still the single most important event that causes CP. Other causes include post natal trauma, domestic violence during pregnancy, and Shaken Baby Syndrome. However, in about 24% of the cases, no identifiable cause is found.

Trainer Note: Overhead 11 has been created to provide talking points for the next section.

There have been numerous methods used to classify the different types of CP. Most agree that there are four general categories of CP.

1. Spastic - This is the most common type of CP. It may involve one or both sides of the body. It is characterized by increased muscle tone combined with poor control of balance and posture, also decreased coordination. Fine and gross motor skills are impaired.
2. Dyskinetic - This is characterized by abnormal involuntary movement. Some may have slow worm-like movements of the extremities, trunk, or face and tongue. This may cause drooling and speech difficulties. Others may have involuntary jerking movements that increase with intensity under stress.

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3. Ataxic - This type of CP involves the child using a wide based gait when standing or walking. They may have repetitive movements of the extremities which are performed poorly.
4. Mixed-type - This is usually a combination of spastic movements and dyskinesic movements. They can appear in any combination.

Although children demonstrate the effects of CP differently, the caregiver should be aware of some of the more common characteristics which appear as the child grows and develops.

1. Delayed gross motor development - This is the universal sign of CP. The infant will show a delay in use and movement of the arms and legs. When they do sit up they may need their arms to balance them.

2. Abnormal motor performance - One of the earliest signs preferential use of one hand. Hand dominance does not usually develop till the pre-school years but children with CP may develop this tendency at 6 months.

Some children may develop an abnormal crawl. Some may pull themselves with their upper extremities only, while others may use only one side of the body.

Due to increased muscle tone some children may learn to stand and walk only on their tip toes.

Some children may develop involuntary jerking movements we talked about while others will show the slow worm-like movements of the extremities we discussed.

These infants may have difficulty sucking and later have difficulty chewing and swallowing food and liquids.

3. Alteration in muscle tone - These infants may be rigid like a board with an arched back or they may have poor muscle tone and resemble a rag doll.

4. Abnormal postures - Children with spastic CP assume abnormal postures when they are at rest. From an early age a child lying on their stomach will keep their hips higher than their torso with the legs and arms flexed and drawn under the torso.

When placed on their back these children cross their legs, make them stiff and point their toes down.

If an infant does not vary their resting position, for example, if the infant continuously crosses his arms and tucks them to his chest for four or five months, it may indicate CP.

5. Reflex abnormalities - normally developing infants have many primitive reflexes which diminish as they grow. Infants with CP may

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keep these reflexes. Some of the more common reflexes are the plantar, Moro, and grasp reflex.

6. Behavior Problems - Extreme irritability, failure to smile by three months, feeding difficulties such as persistent gagging or choking when fed or after 6 months of age, tongue pushes soft food out of mouth.

There are many problems associated with CP. Listed below are some of the most common.

Trainer Note: Overhead 12 has been created to provide talking points for the next section.

1. Mental Retardation – Approximately 70% of affected children have intelligence within normal limits. We may assume many children with CP are mentally retarded because they have speech difficulties due to their CP. It is also difficult to test the intelligence of a child with CP because of their motor and sensory deficits. Many people with severely limiting CP actually have the least intellectual impairment. Generally those children with the slow worm-like movements and those with repetitive involuntary movements are intellectually superior to those with other types of CP. Profound retardation is highest in those children who are rigid and not moving.
2. Sensory impairment – Some infants may have loss of vision or spasmodic involuntary movements of the eyeball which may require corrective surgery. Hearing loss is common however, many affected infants may spend their time lying flat which can contribute to ear infections which can in turn cause hearing loss.
3. Drooling – Drooling may occur in some children and contribute to skin irritation and wet clothing.
4. Constipation – A variety of factors contribute to constipation. Difficulty in eating bulky foods because of uncoordinated chewing and swallowing is probably the most likely cause. Other factors are toileting difficulties and decreased mobility. Stool softeners and laxatives may need to be used.
5. Respiratory problems – Coughing and choking, especially while eating, may contribute to aspirating debris into the lung fields. Movements of the respiratory muscles may be weak and uncoordinated causing decreased gas exchange and low oxygen levels.

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6. Orthopedic complications – Children with CP who don't walk have an increased risk for developing hip dislocations, curvature of the spine, and joint contractures.
7. Dental problems – Children with CP have a high incidence of cavities. This is due to a number of reasons: a) improper dental hygiene, b) congenital enamel defects, c) eating a high carbohydrate diet, d) poor nutrition, e) inadequate fluoride, f) difficulty in mouth closure. Spastic movements can also cause biting and grinding of teeth.
8. Seizures – Seizure activity is not commonly seen in children with CP. However, when these children do have seizures they are generally the grand mal or tonic – clonic type seizures. The child will generally lose consciousness, and experience severe convulsions. The peak incidence of seizures is between 1 and 6 years of age.
9. Attention deficit-hyperactivity disorder – The primary presenting symptoms are poor attention span, marked distractibility, and hyperactive behavior.

Many caregivers may suspect their child has some type of delayed motor development and would like it diagnosed and treated as soon as possible. Unfortunately there are no laboratory tests or diagnostic procedures to determine the presence of CP. Infants who are at risk warrant careful assessment during infancy to identify signs of muscular dysfunction as early as possible. Careful assessment and observation should be made of low birth weight and pre-term infants.

Because much purposeful movement in infants does not occur until 2 to 4 months of age, early diagnosis is difficult.

Mildly affected infants may be overlooked until they exhibit a delay of some advanced motor skills such as standing or walking.

The neurological examination and history are the primary tools used by the physician to make a diagnosis of CP.

Supplemental tests may be used to rule out other abnormalities such as slow growing brain tumors. CP is a permanent disorder and all care is chiefly symptomatic and preventative. For care to be effective it requires an organized team of health professionals and family. The team must be familiar with the nature of the disability, the defects associated with the disorder and the personal and social influence encountered by the child and caregivers.

The benefits of caring for a child with CP are based on early diagnosis and early intervention. Parents or caregivers are

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essential to the program. With early diagnoses caregivers can begin to provide sensorimotor experiences essential for development.

Trainer Note: Overhead 13 has been created to provide talking points for the next section.

The broad goals of care are:

1. Establish locomotion, communication, and self help.
2. Gain optimum appearance and integration of motor function.
3. Correct defects as early as possible.
4. Provide educational opportunities adapted to the needs and capabilities of the individual child.
5. Promote socialization experiences with other affected and unaffected children.
6. Parents/caregivers must be taught all of the caregiver skills required to care for the child with CP.

There is no medication that will cure or relieve all of the symptoms related to CP. There are several types of drugs that may decrease the severity of symptoms related to CP.

1. Antianxiety agents – have been used to some extent to relieve excess motion and tension.
2. Muscle relaxants – such as Dantrium and Robaxin may be used on a short term basis for older children and adolescents. Valium is frequently used but should be restricted to older children and adolescents. These drugs have been used in relieving stiffness and facilitating the ease of motion.
3. Antiepileptics – are routinely used for children who have seizures. Phenobarbital and Dilantin are the most commonly prescribed antiepileptics.
4. Local nerve block – injected to the motor points of a muscle will temporarily reduce spasticity, this is not routinely done.

Surgery is usually reserved for the child who does not respond to more conservative measures, but it is also indicated for the child whose spasticity causes progressive deformities. Surgery is used to improve function rather than cosmetics. Children with spastic SP are most likely to improve from surgery. The most common type of surgery is orthopedic. The goal of orthopedic surgery is to: 1) correct deformities, 2) provide stability to an uncontrollable joint, 3) to provide balanced muscle power. The most common types of surgery are tendon lengthening. This is most often done by cutting the tendons of young children to relieve contractures. Especially in the heel cord and wrist, this is done to improve mobility and relieve contractures.

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A number of assistive devices may be used by children with CP to help promote mobility.

AFO's are ankle foot orthoses or braces worn by many children with CP.

AFO's are molded to fit the feet and worn inside the shoes. AFO's are used to help prevent deformity and provide stabilization.

Wheeled scooter boards – allow children to propel themselves while the abdomen or total body is supported and the legs are positioned with wedges to help prevent scissoring.

Wheeled go-carts – provide good sitting balance and serve as an early wheelchair experience for young children.

Strollers – can be equipped with custom seats for mobilization.

Wheelchairs – Wheelchairs and/or motorized wheelchairs can be customized to meet the needs and preferences of older children.

Physical therapy is one of the most frequently used treatment modalities for CP. No physical therapy is able to produce spectacular changes in the ultimate outcome of the motor disability. But early intervention and a practical approach individualized for each child is recommended.

Physical therapists will generally employ a range of motion exercises, stretching and elongation exercises that can be taught to the caregivers. These exercises are valuable at any age even if the child is not able to cooperate.

Prevention of contracture deformity is the primary function of physical therapy.

Training in manual skills and activities of daily living should proceed along developmental lines and according to the child's functional level.

Sitting, crawling, and walking are encouraged at the appropriate age with assist devices and protection if needed.

Hand exercises and use of the extremities should begin at an early level. Objects and toys should be used sensory input. A variety of colors, textures, shapes and sizes should be used.

Play is a valuable tool in a therapy program to keep the child's interest and ability.

Speech therapy should begin early before the child learns poor habits of communication. Caregivers can help by talking to the child slowly and using pictures or objects about which the adult is speaking. If the child's disability prevents speech, nonverbal communication techniques should be used. Possibilities include sign language, communication boards, and computers.

Other healthcare professionals your primary care provider may refer you to include a neurologist, psychologist, neurosurgeon,

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psychiatrist orthopedist, and nutritionist to name a few. The goal of care is to attain the highest possible level of function and independence, a team of specialists may be consulted.

Care of they eyes and ears is important and may require the attention of a specialist. Dental care is important for children with CP and should not be overlooked. Regular brushing, flossing and dental exams are important.

Educational requirements should be based on the needs of the individual and their potential. Children with mild to moderate involvement may be able to participate for varying amounts of time in a class room setting. Public schools are required to provide comparable education for all special needs students. Integration of these children into the classroom should be the initial goal.

Children with CP should be encouraged to participate in athletic and other peer activities. Some can compete in athletic and artistic events, there are many other activities and games that can be suited to their capabilities. Adaptive physical education classes are mandated by law in many school systems.

Children with CP should be encouraged to participate with their peers to the best of their ability.

Parents can find help and solace from parent groups with whom they can share problems and concerns. Support groups are helpful in sharing experiences and accomplishments. Parents can understand from others what it is like to have a child with CP, which is generally not possible from professionals. The United Cerebral Palsy has branches in most communities. The association provides a variety of services for children and families. There are also a number of excellent books available to serve as guides for parents and nurses who work with the child with CP.

Trainer Note: CP is not only a debilitating but frustrating disease as well. To demonstrate the effects of CP, have participants tape the three middle fingers of their non-dominant hand together and attempt to: pick up small coins, unbutton their shirt, write their signature, dial a phone.

Discuss how the participants felt trying to complete this exercise. This should have generated feelings of: frustration, awkwardness, embarrassment, inadequacy.

CHILDREN WITH HIV/AIDS

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Children with HIV/AIDS need what other children need: love, nurturing, protection, and support. They need a loving, stable support family in which they can lead a full life.

Although a cure for HIV has not been found, children with HIV are living longer. Loving care within a family improves the quality of children's lives. Providing that care can be demanding, stressful and overwhelming at times. It can also be very rewarding because the child's caregiver can really make a difference.

Once infected the HIV (human immunodeficiency virus) attacks the ver system which protects us from all disease: the immune system. AIDS stands for acquired immune deficiency syndrome. AIDS is the final stage of HIV infection. AIDS develops when an individual develops one of the opportunistic infections the Center for Disease Control uses to diagnose this condition.

Some of the more common opportunistic infection in children include:

Pneumocystis Carinii Pneumonia (PCP) – a disease of the lung caused by a parasite.

Lymphoid Interstitial Pneumonia – an acute inflammation of the lung. This condition is common in children diagnosed with AIDS.

Chronic Candidiasis – a yeast infection of the mouth, esophagus, and lungs.

Chronic Cytomegalovirus – a disease of the brain caused by one of the herpes viruses.

Chronic Herpes Simplex – shingles and/or ulcers in the anus and mouth caused by the herpes simplex virus.

Cryptosporidiosis – severe and persistent diarrhea caused by a protozoa.

HIV is spread when a person has direct contact with an infected person's blood, semen, vaginal secretions, or breast milk. HIV has been spread by all these body fluids. It has also been found in other body fluids but not in sufficient quantities to transmit the virus. Here are some way HIV can get into the bloodstream.

Trainer Note: Overhead 14 has been created to provide talking points for the next section.

Sharing needles – When an injecting drug user, infected with HIV uses a needle to inject a drug, some of the user's blood may be drawn up into the needle or the syringe. When a non-infected person uses the same needle, he or she injects the blood contaminated with HIV directly into their blood stream.

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Sexual activity – HIV can be spread through oral, anal, or vaginal sex. During sex the virus can pass through the lining of the rectum, vagina, or mouth into the blood of the non-infected person.

Blood transfusion – All blood donated since 1985 is tested for HIV. The CDC estimates that only one out of 100,000 pints of blood may be contaminated with HIV.

Breast feeding – HIV is not easily spread this way because breast milk contains few white blood cells but, breast milk can transmit HIV.

Perinatal transmission – HIV can be spread from an infected mother to her baby during pregnancy or delivery. This is the most common methods for children below the age of thirteen become infected with HIV. About 30% of infants born to HIV infected mothers will have HIV infection.

Other body fluids – HIV is not spread in urine, feces, sweat, or saliva unless these fluids contain blood. HIV infection can be prevented if people learn how the virus is transmitted. Then they can take certain precautions so that the virus cannot be spread from one person to another.

Trainer Note: Overhead 15 has been created to provide talking points for the next section.

Blood – Anyone who may come in contact with blood should wear latex gloves. Latex provides a barrier that HIV cannot pass through. If blood gets on you skin you should wash with soap and water. Blood spilled on floors or furniture should be cleansed with a solution of chlorine bleach and water. (1/4 cup bleach to 1 gallon water).

Needles – Injecting drug users should stop that practice if possible. If they continue, they should never share needles. Disposable needles should be used of the “works” should be cleaned in between use with a chlorine bleach solution.

Sexual activity – People who are sexually active with partners of unknown HIV status should use condoms, spermicidal gel, and a dental dam. Testing is advised every six months for people who continue to have sexual partners of unknown HIV status. Only those partners free of HIV who remain in monogamous relationships can be certain they are free of HIV.

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Breast milk – It is recommended that women infected with HIV not breast feed her baby. Instead, formula should be used.

30% of all children born to HIV + mothers will become HIV+ also. Some infants will test negative at birth but later convert to positive. Once an infant converts to HIV positive they will almost always be positive for life.

Remember it will take parental consent and/or a court order to get HIV testing for an adoptive/foster child.

Infants who are HIV positive can show symptoms similar to symptoms of other childhood problems such as failure to thrive. Other symptoms include chronic diarrhea, ear infections, thrush, apathy, lethargy, shortness of breath, respiratory infections, or delays in walking or talking.

Remember though, just the presence of these symptoms does not mean the child has HIV. However, if you see these symptoms in a child who has an HIV positive mother or HIV antibodies, you should bring the child to medical care for further HIV testing.

Remember these symptoms are also found in infants born from mothers who used drugs or alcohol during pregnancy or from a poor diet and lack of medical care during infancy.

Trainer Note: Participants with additional questions regarding confidentiality and HIV testing should be referred to the “Confidentiality of HIV related Information Act” Act 148 or 1990.

Every year many older children and teens will become infected with HIV. Transmission takes place primarily through sexual activity and the sharing of unclean needles during injectable drug use. Children who are the victims of sexual abuse may also be at risk for HIV transmission.

Symptoms of HIV infection in older children and teens.

- Swollen glands of the neck, armpit, or groin
- Persistent fever
- Night sweats
- Unexplained weight loss
- Persistent diarrhea
- Extreme tiredness
- Forgetfulness, confusion, or disorientation
- poor appetite

*These symptoms may be due to other medical problems besides HIV infection. Any older child or teen who has these symptoms should be seen by a doctor.

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All children need medical care. Medical care is extremely important for children with HIV. Helping children get routine medical care is one of the most important things you can do as a caregiver. While there is no cure for HIV, early medical treatment can help children with HIV stay well for longer periods of time. Children with HIV infection (or who are suspected of having HIV infection) need to be seen, when possible, by a doctor experienced in treating children with HIV. Illnesses may be different in these children than it is in other children. HIV can also affect children differently from the way it affects adults.

Your child should be receiving regular dental care. When possible, find a dentist experienced in treating children with HIV.

There are currently drugs available called anti-virals that try to stop HIV from reproducing in your child's body. There are three commonly prescribed drugs that delay the reproduction of HIV in the body; AZT, ddI, and ddC. These are powerful drugs which are sometimes hard to take because of the adverse side effects. Your doctor may want to observe your child carefully when these drugs are being taken. Doctors give healthy babies and young children immunizations to protect them from childhood diseases. Some of these vaccines contain live viruses which may not be suitable for children with HIV. No children in the household of an HIV infected child should receive the live polio vaccine. This can be harmful to a child with HIV. An alternative synthetic vaccine should be considered.

Nutrition is important to all children for good growth and healthy development. It is especially important for children with HIV. At some point your child may need a special diet or supplement to keep healthy. Your doctor should refer you to a nutritionist for this. If a supplement is not needed your child should have a healthy well balanced diet. A healthy diet should include fruits and vegetables, meats/protein, grains, and dairy products. When preparing foods for a child with HIV it is important to avoid bacteria and molds which may make them ill. Use only pasteurized dairy products, wash and peel all fruits and vegetables, and cook all foods completely.

There may be times when your child may be ill and eating will be difficult. It is important to let your doctor know about any changes in your child's eating habits.

Good hygiene is important to help protect everyone's health. If you are caring for a child with HIV, keeping a clean home is even more important. Ways you can promote good hygiene include: wash

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hands frequently throughout the day, especially after toileting, changing diapers, or handling food. Minimize contact with blood and body fluids. If contact cannot be avoided, wear latex gloves. Keep bathroom and kitchen areas clean. Clean up all spills quickly. Use disposable paper towels and a chlorine solution to clean up blood and body fluids. Do not share personal items such as toothbrushes, razors, etc.

Pets should be well groomed and HIV infected children should not be expected to clean dog or cat excrement since it may contain bacteria.

HIV infection has a powerful effect on families. Each family member will react differently, how individuals share feelings in a family is very important. When they first find out about a child's illness, most families feel shock and disbelief. Some families will go through denial and not admit that a child has HIV. The most common feeling which usually follows is fear. Families worry about how long their child will live and how sick they may become.

Families will worry that someone outside the family will find out about the child's illness and what their reaction might be.

Caregivers may feel angry or guilty that they cannot do more for the child or that they could not prevent the illness. Many caregivers fear that the child will give the illness to others in the family. Some caregivers may feel helpless. This is especially true when you feel you don't have control over the child's illness. These are normal feelings when we are faced with something we can't control.

Medicine can also be very complicated and confusing; talking this over with the doctor can decrease confusion and anxiety.

Caregivers live with a lot of uncertainty about the child's illness. It is hard to plan an orderly life when a family member has an unpredictable illness. Caregivers can help one another by talking through these issues. By sharing, they can see how planning can be effective at gaining some control they may have lost.

All children have a right to be loved and respected. They need comfort in times of pain and they need to feel good about themselves. Children with HIV infection are no different, they need the same things. Children with HIV need to lead a normal life as possible.

Play is important for any child, how much you child can play and what activities they can participate in depend on their health. During periods of sickness, quiet play is best. Reading, drawing, and video games are suggestions. More active play such as running, baseball, soccer, and basketball are suitable when the child is feeling well. Children with HIV also need to play with other

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children. Contact with other children can be done without fear of spreading HIV. It's okay to share toys and play areas like swings and sandboxes. Caregivers worry about children with HIV biting another child or being bitten. Remember HIV is not spread through saliva. If your child's playmates become ill with measles, mumps, or chicken pox, the child with HIV should avoid contact until they are well. These diseases are highly contagious and can be deadly to children with HIV. Children should attend school and day care as their health will allow.

Children with HIV need to lead a normal life as possible, part of a normal life includes discipline. Children do not need physical or verbal abuse for inappropriate behavior, but need to be guided toward acceptable behavior. When you take care of a child with HIV, it is natural at times to feel stressed out. The many challenges you face will not only cause stress for you but for the family as well. Some stress is helpful but too much stress can lead to physical and psychological problems. Stress affects each of us differently. You need to know how stress affects you so you can deal with it. Stress tends to get worse, not better if it is not dealt with. Here are some methods to reduce your stress:

Trainer Note: Overhead 16 has been created to provide talking points for the next section.

- Take a break – sometimes a change of pace or a short break can give you a different way of looking at things. On one of those days when you are really busy, take a break for yourself.
- Exercise – choose a physical activity you like and participate regularly. Exercise not only relaxes your body, but also your mind.
- Get enough sleep – sleep is important and helps us handle every day challenges better. Most people need seven to eight hours of sleep each night.
- Learn to relax – there are many simple, inexpensive things you can do to relax. Try taking a hot bath, read a good book or magazine, or watch a favorite TV show or rent a favorite movie.
- Keep in touch – visit a good friend or relative or someone you enjoy being with. Plan to see a movie or go shopping. Arrange for someone else to be with your HIV infected child for a day or two so you can have time by yourself or with your spouse or friend.

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There are community AIDS programs that give many HIV related services at no cost. Some services include: support groups, education, buddy programs, and advocacy. Call the 800 number to find out what programs and services are available in your area.

Trainer Note: Overhead 17 has been created to provide talking points for the next section.

Trainer note: This is an important exercise for all participants. Ask participants to imagine what it would be like to care for a child who they knew had a terminal illness. Discuss the feelings associated with the care and eventual loss of a child with a terminal illness.

- How would they feel about the transmittability of a disease such as HIV?
- Would they fear for other family members?
- Are there guilty feelings?
- How do they feel about the eventual loss of a child?

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SUDDEN INFANT DEATH SYNDROME

There are a number of disorders which occur during childhood in which the cause is unknown. SIDS is one of those disorders. It occurs exclusively in infants and generates a tremendous amount of stress for the family and all involved. The family must cope with the loss of the infant. Competent and sensitive care is crucial for the family. Sudden infant death syndrome (SIDS), also known as crib death, is defined as the sudden death of an infant under 1 year of age that remains unexplained after a complete postmortem examination, including an investigation of the death scene and review of the case history. It is the leading cause of death in children between the ages of 1 month and 1 year. SIDS claims 7000 lives each year.

SIDS occurs in 2 out of every 1000 live births. The peak age is 2 to 4 months with 90% of all SIDS cases occurring before 6 months of age.

A higher percentage of males are affected.

The time of death is during sleep with a peak incidence in the winter months.

There is a greater incidence of SIDS in Native Americans and African Americans, followed by Caucasians.

There is an increased incidence in the lower socioeconomic class.

There is a higher incidence in premature infants, especially low birth weight.

There is also a higher incidence in multiple births and infants with low Apgar scores.

Breast feeding does not prevent SIDS.

There is a higher incidence to mothers who are younger, smoke cigarettes, and addicted to opioids and cocaine.

Trainer Note: Overhead 18 has been created to provide talking points for the next section.

Numerous theories have been developed regarding the cause of SIDS, however the cause is still unknown. The most promising theory is that SIDS is related to a brainstem abnormality which causes problems with cardio-respiratory control. The abnormality causes prolonged periods of sleep apnea, pauses on respiration, and a build up of carbon dioxide and a decrease in oxygen levels. However, it should be noted that not all infants with apnea die from SIDS, and only a small minority of SIDS children have previously documented episodes of sleep apnea. A theory that has proven to be false linked SIDS with diphtheria, tetanus, and pertussis vaccines. Although the cause of SIDS remains unknown, the diagnoses is

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confirmed on autopsy. All suspected SIDS children should have an autopsy to confirm the cause of death.

Trainer Note: Overhead 19 has been created to provide talking points for the next section.

The most important intervention in preventing SIDS is **identifying those at risk**. We already discussed those children who have a higher than normal risk of SIDS. There is no diagnostic test available to predict who will develop SIDS. Those with known risk factors can be treated with **respiratory stimulants**. There are certain types of medications which stimulate the breathing center in the brain and decrease sleep apnea. The use of respiratory stimulants is not a common practice at this time. As a preventative measure for SIDS, it is recommended to **place high risk infants on their back or side for sleeping**. Pillows should not be used in the infant's crib. A more acceptable intervention is the home **apnea monitor**. This is a small battery powered device which includes two electrodes which are placed on the infant's chest. The settings are adjustable, but an alarm will sound if the infant has a lengthy period of apnea.

Optional activity: Apnea monitor. Allow participants to see an apnea monitor and hear alarm. Demonstrate electrode connection. Apnea monitor can be obtained from medical equipment supplier in presentation location.

The best strategy at the current time to prevent SIDS is decrease known risk factors. Families/caregivers should seek adequate prenatal care and avoid cigarette smoking and drug use both before and after the child's birth.

Usually it is a parent who finds the infant dead in the crib. Typically the child is disheveled in bed and huddled into a corner. Frothy, blood tinged fluids fills the mouth and nose, the infant may be lying face down in secretions, suggesting that her or she bled to death. The diaper is wet and full of stool suggesting a cataclysmic type of death. The hands may be clutching the sheets as if the child was in distress before death. The initial appearance of the child combined with the shock of such an experience adds to the horror that the family members must face. Usually the first people to arrive on the scene are police or paramedics. A compassionate sensitive approach should be used during this traumatic time. The infant should then be transported to the local emergency department where a physician can pronounce death and order an autopsy.

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One important issue for the parents which is sometimes overlooked is allowing them quiet time with the infant to say good-bye. Before the parents return home they should be allowed to have some quiet uninterrupted time with the baby. These will be the last moments with their child and they should be as meaningful as possible.

When the parents return home they should be visited by a nurse or a competent qualified professional as soon after death as possible. A referral to the local SIDS foundation should also be made. A complete explanation of SIDS should be provided, all questions the parents have should be answered, and any feelings of guilt they have should be allayed.

During the second visit with the parents the goal is to help the parents bring their feelings out into the open. During this session the parents are asked to explore their coping mechanisms, if they are not effective, explore new ones. This is not a time for the parents to make rash decisions about never having children again.

The needs of siblings in the family must be considered also. Although they may initially appear accepting of the explanation and well adjusted, subsequent problems may exist or develop later and be addressed.

- Changes in the parent – child interaction – children have anger toward the parents for the loss of a sibling. Discipline problems may result.
- Altered sleep patterns – children may become frightened to go to sleep. They may fear not waking up, and resist going to bed for refuse to sleep alone.
- Changes in social patterns – children may change from withdrawn to aggressive.

Children need the opportunity to talk about their perception of death. With young children, the use of stories about death or drawings, or play is recommended. Even if they express no concerns, their safety and the inability to have predicted or prevented the death must be emphasized. Parents should be aware that sibling grief often lasts as long as adult grief – typically longer than a year.

Trainer Note: Overhead 20 contains the number for the Nation Sudden Infant Death Syndrome Foundation and can be used here.

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The national sudden infant death syndrome foundation has a 24 hours toll free number. They can provide information on SIDS, support groups, and other helpful information for parents and caregivers.

**SECTION IV
CULTURAL CONSIDERATIONS FOR PROVISION OF HEALTH CARE
TO MEDICALLY COMPLEX CHILDREN**

Rationale As cultures vary, so do notions of what the human body symbolizes, how it should appear, how it functions most appropriately and why, when and how it should be treated. There are cultural and situational influences which, if ignored, may from the outset, doom to failure even the best intentioned services for culturally diverse children and their families. This section is designed to assist participants to effectively serve families with children with disabilities within the families' own cultural frameworks and individual lifestyles.

Learning Objectives Participants will be able to:

- ◆Employ cultural considerations for provision of health care.

Time 0.5 Hours

Methods Presentation by trainer. Large group discussion.

Materials Handout #1 – Participant Manual – Pages 1D thru 5D
Overheads # 1D thru 9D

Activities Group discussion: Health care practices of culture groups.

Trainer Note: Conclusion of Section IV may be an appropriate time for a 15-minute break. If trainer is going to use the optional “Special Kids Network” activity, he/she should select a participant to be the caller at this time since the call is to be made during break.

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Trainer Note: Overhead 21 has been created to provide talking points for the next section.

Culture is an important consideration in the provision of health care. The Competency-Based Training System utilizes a definition of culture developed by Wade Nobles, an African American psychologist. Nobles states that “culture represents the vast structure of behaviors, ideas, attitudes, values, habits, beliefs, customs, language, rituals, ceremonies, and practices “peculiar” to a particular group of people. Culture provides them with (1) a general design for living, and (2) patterns for interpreting reality.” Culture determines how we see the world, and the way we see the world is reflected in our behavior.

Cultures vary significantly in their health beliefs and practices. These differences include beliefs about the causes of illness and what types of treatment are effective, actions that individuals take to maintain health or treat themselves, nutritional practices, and the use of healers or healing systems.

Families who are from cultures different from that of their physician and other caregivers may view health in a very different way. To understand culturally competent care, it is therefore necessary to try to understand health problems and behaviors from the perspective of the family.

A first step in assessing cultural factors is to determine the family’s degree of identification with a particular cultural group. This can provide initial clues about their beliefs and practices. Information such as the family’s ethnic origin, religious affiliation, and country of origin can assist in the assessment.

Socioeconomic factors also influence a family’s perceptions of health, their health behaviors, their use of health care, and their ability to comply with a treatment plan. Two powerful factors that predispose children to a wide variety of health problems are poverty and a lack of health insurance. Cultural competence demands that health care providers work with families to understand barriers to health-promoting behaviors and to develop strategies for dealing with health problems that take into account socioeconomic factors.

The Pennsylvania Child Protective Services Law notes that no child shall be considered abused or neglected based solely on

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environmental factors that are beyond the control of the parent. These factors include inadequate housing, furnishings, income, clothing, and medical care.

Trainer Note: In a large group discussion, ask participants for specific examples of the health care practices of cultural groups with which they have had contact.

It is important to assess each individual family to determine their particular health beliefs and practices and whether they subscribe to a particular culture's beliefs and practices. Information about particular groups can be helpful in understanding beliefs and practices that may exist for particular families. The following brief portraits provide an introduction to common cultural elements for four major ethnic groups in the United States. They are noted to provide an appreciation of the diversity between groups and the types of beliefs and practices that health providers may encounter.

African Americans' places of origin significantly influence their cultural patterns and shape their attitudes toward health behavior. For example, many Haitian Americans believe that blood is the medium of bodily and spiritual disease. Since most dangerous illnesses are believed to be caused by irregularities in the blood, Haitians may be reluctant to receive transfusions or to have their own blood drawn.

Strong religious beliefs that events happen because of the will of God and "what will be, will be" are intertwined in the lifestyle pattern of some African Americans. Religious beliefs provide a strong emotional basis for enduring stress. However, they may contribute to fatalistic outlooks that discourage taking steps to protect one's health, such as wearing a seat belt. For some, such as Haitians, religion may include spiritual beliefs that illness has supernatural causes such as evil spirits or witchcraft.

Some African Americans show distrust of traditional medicine and providers because of previous experiences with the health care system or a belief that the dominant society engages in subtle attempts to limit or decrease the African American population.

A well-known example of racial bias in medical research is a syphilis study called the "Tuskegee Experiment" which ran from 1932-1972. It was conducted by the U.S. Public Health Service. Researchers studied African American men with syphilis. Even after penicillin was proven a cure, the researcher withheld

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treatment, causing unnecessary death or disability of many of the men.

There are still problems with the medical attention African Americans receive. Overall, African Americans die an average of six years younger than Caucasians. African American infant mortality is twice as high as that for Caucasians. In 1950, an African American infant was 1.6 times as likely to die as a Caucasian infant. By 1988, African American infants were 2.1 times as likely to die as Caucasians.

The lack of trust in medical providers and institutions can interfere with compliance in the prescribed use of medication and therapy. Some African American self-treat and medicate themselves by means of long-standing home remedies. Those from low income families may delay seeking medical attention because of lack of health insurance or money, inadequate health education, or inaccessibility of medical services. Therefore, health problems may be more severe when care is sought.

Some major cultural differences exist between Eastern and Western medicine. Eastern forms of medicine are based on the philosophy of “Yin and Yang” forces that keep the universe in balance. Illness is the result of imbalances between the body and events occurring in the universe. The goal of Eastern medicine is to restore balance and bring the parts of the body into a harmonious state.

Some Asian Americans follow the hot-cold theory of disease, which dictates that some foods or medications are hot or cold and, therefore, need to be balanced when treating an illness. For example, in a Vietnamese family that perceives Western medicine as “hot”, a child taking antibiotics may also roll a hard boiled egg over his or her body to “take up the hot”.

Noncompliance with prescribed Western medicine may occur if dietary recommendations of the health provider conflict with the hot-cold theory. Parents might also fail to give full doses of medications to their children if the full amount is considered “too strong” or “too hot”. Thus, caring for Asian American children requires good communication with their parents, careful explanation of medications and their benefits, and negotiation of flexible treatment plans that allow families to maintain cultural beliefs and practices.

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Beliefs about the body vary among Southeast Asians in ways that may affect health care. The head is considered by many to be the seat of life and is therefore vulnerable, honorable, and untouchable except by close intimates. Thus, procedures that invade the surface or an orifice of the head, even touching, are usually frightening to Southeast Asians.

Other cultural beliefs pertaining to health include inhibitions regarding discussing sex and childbearing openly, having a physician of the opposite sex, undergoing a pelvic examination, and going to the hospital for childbirth. In addition, birth defects and other disabilities may be considered punishments for sins committed by parents as well as previous generations. Respect is an important element of communication among Asian and Pacific Islander Americans. They often consider it impolite to question authority figures, such as medical personnel. Although there may not be full understanding of instructions or questions posed by physicians or nurses, Asian and Pacific Islander Americans may indicate they agree or comprehend.

Many Asian Americans show a preference for using physician-prescribed treatments simultaneously with herbal medicine or other traditional treatments. These practices may include the intake of herbal teas or coin rubbing, which involve rubbing the skin with a coin to expel the invading illness. The bruises made from the coin rubbing may be interpreted as physical abuse.

One common belief of Latino families is often referred to as an external locus of control -- that events in one's life result from luck, fate, or other powers beyond the individual's control. This may be helpful in some cases, for example, when a family views a child with a chronic disability as not being responsible for his or her condition. However, it may lead to more passive participation in treatment or healing.

Some Latinos may also believe in the hot-cold theory of disease and treatment as described in the discussion on Asians and Pacific Islanders.

Two important cultural values guide communications among many Latinos.

Respeto, or respect, refers to appropriate deferential behavior toward others on the basis of age, sex, social position, economic status, and position of authority. Health providers are seen as authority figures and are awarded *respeto*. Adults expect reciprocal

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respeto to be accorded them by the provider, especially if the provider is younger than the parent.

A second value that guides interpersonal relations is that of *personalismo*, which stresses warm, personal relationships. This value dictates that the relationship with the provider is more important than the institution where care is provided. Therefore, when a provider leaves a practice setting, Latinos may follow the provider to a new medical setting or stop treatment unless the provider helps to make a transition to a new provider.

Some Latinos may use folk or spiritual healers instead of or in addition to traditional medical care. Also, persons may consult a *yerbero*, a person who heals with herbs, or a *botanica*, an herb shop.

Native Americans are the most diverse of all ethnic groups in the United States. More than half of this population live in or near urban areas.

Religion is holistic and pervades every aspect of life. The person, nature, and spirituality are considered inseparable. Therefore, individual wellness depends on physical health as well as on the balance of harmony of the mind, body, spirit, emotions, and surrounding environment. Emphasis on harmony with nature and the need to endure all natural happenings contributes to great resilience in the face of adversity.

Illness is conceived as an imbalance in the natural order of things. Healing may involve restoring personal relationships affected by one's illness or making an offering to restore the balance of nature. Each person is responsible for his or her own wellness.

In traditional families, childbearing and discipline are shared by members of the family, clan, and tribe with several adults taking responsibility for teaching and disciplining the child. This provides a strong nurturing environment for the child and allows parents frequent opportunities for nondisciplinary interactions with their children.

Children are given great freedoms and encouraged to explore and be independent early in life. Physical punishment is rarely used in traditional families. The preference is for allowing children to learn from the natural consequences of their behavior rather than through direct criticism or correction.

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Traditional healing practices frequently include family, kin, and friends joining together to help with a problem. Medicine men or other cultural healers may be consulted regarding illnesses. These persons hold positions of considerable power and wisdom and are regarded as religious leaders as well. A dual system of care exists in most American Indian and Alaskan native communities, with people consulting both cultural healers and modern medical providers.

In addition to ethnicity, various health and healing beliefs and practices are based in religion. For example, most members of the Jehovah's Witness faith believe that prohibitions against blood transfusions are contained in the Bible. Committees serve as a liaison between hospitals and Jehovah's Witnesses. To adhere to the religion's rules, committees encourage doctors to use alternative, bloodless methods of care when treating congregants. As another example, the Faith Tabernacle Congregation holds medical care as an affront to God.

The Pennsylvania Child Protective Services Law lists religious beliefs among its exclusions to child abuse. The exclusion only pertains to cases of physical or mental injury. It involves situations in which a child has not been provided needed medical or surgical care because of seriously held religious beliefs of the child's parents, guardian, or person responsible for the child's welfare. The beliefs must be consistent with a bona fide religion. When these situations arise, the children and youth agency must closely monitor the child and seek court-ordered medical intervention when the lack of care threatens the child's life or long-term health. The family is referred to general protective services, if appropriate.

Again, it must be stressed that it can never be assumed that a family will subscribe to the beliefs and practices common to their culture. Assessments must be individualized for every family.

Trainer Note: Overhead 22 has been created to provide talking points for the next section.

Various efforts will assist in interacting effectively with families in the context of cultural differences.

*Establish positive relationships. Cultural differences between providers and families may contribute to feelings of discomfort or mistrust. An important part of cultural competence is to establish a relationship that will overcome these barriers. This can be done by establishing trust and rapport, accommodating cultural differences

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in communication patterns, and addressing cultural misunderstandings.

*Assess cultural factors. Families' cultural backgrounds can be integrated into the assessment and history taking in a way that will help providers understand how cultural factors may influence particular health problems and behaviors.

*Modify plans. Whenever possible, aspects of the family's cultural beliefs and practices should be used and respected by being integrated into plans for the family.

*Recognize the person underneath a disability. People with disabilities, like children and women, often find their personal space violated with no warning. If you determine help might be useful to a person with a disability, observe a moment, then ask if they would like help. The answer may be no, but there is usually appreciation for your having the courtesy to ask.

*Avoid demeaning terms when writing and speaking about disability. Advocates do not always agree on the best terms to use in describing disability issues since we are in the early days of the disability movement. However, some guidelines are available.

The term "handicapped" has gone out of favor because of negative associations with beggars asking for charity with "cap in hand". Most people accept the terms "disability" or "disabled" as the terms of choice. Some people prefer "person with a disability" because they want the emphasis on the person, not on the disability. Never hesitate to ask persons with disabilities which terms they prefer.

Disability issues should be described in neutral, unsentimental, and nonjudgmental language. Avoid sensationalized words and phrases like "victim", "suffers from", "afflicted with", or any words that suggest tragedy. These terms do not reflect accurately the real problems that people with disabilities face in our society. They suggest that it is up to the individual to "overcome" a disability. They ignore society's responsibility to remove the real barriers of inaccessibility and prejudice.

Finally, when referring to an individual with a disability, remember that the disability is only one aspect of that person -- only one aspect among a full range of human needs and talents. It is not necessary to mention a person's disability unless it is relevant to the matter being discussed. If the disability is relevant, it should

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be discussed within the context of the person's other unique needs and talents.

The effectiveness of services for multicultural populations of children with disabilities and their families rests heavily upon the sensitivity, understanding, and respect paid to the specific cultural, familial, and individual diversity involved. Thus, if comprehensive family-centered community-based services for all children with disabilities are to be achieved, cultural awareness and sensitivity must be stated as a priority at the outset. Good intentions alone will not achieve culturally appropriate services for diverse children and their families; commitment, creativity, openness to new ideas, and resources are needed to make such a vision a reality.

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SECTION V ACCESSING SERVICES AND RESOURCES FOR MEDICALLY COMPLEX CHILDREN AND FAMILIES

Rationale	Child welfare workers, family preservation staff, foster care providers, and adoptive parents should be aware of appropriate treatment and supportive services available to assist them in the provision of care to medically complex children.
Learning Objectives	Participants will be able to: <ul style="list-style-type: none">◆ Access supportive services for medically complex children.
Time	0.5 Hours
Methods	Presentation by trainer. Large group discussion/activity.
Materials	Handout #1 – Participant Manual – Pages 1E thru 7E Handout #3 – Accessing Services Directory Overheads # 1E thru 13E Access to telephone (optional) Spinoza™ bear (optional) – Available for purchase at 1-800-CUB-BEAR or for loan from home health agency or hospital in presentation area. Call several weeks in advance to arrange Spinoza™ and tape “Everybody Needs a Little Tenderness” (<i>Trainer Note:</i> If presentation room is large, trainer may want to use higher volume tape recorder rather than recorder in Spinoza™ for better audibility.) VCR equipment Video – “You Are Not Alone” (optional)
Activities	Special Kids Network demonstration call. Spinoza™ demonstration. Video segment

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Definition of SUPPORT -- to encourage, to enable, to continue, to bear the weight or stress of; to keep from sinking or falling.

The single most important element of success in the care of a medically complex child is a supportive family unit.

Caseworkers and family preservation workers can support the foster caregiver, adoptive parents, and each other.

In order to do this, they must . . .

1. Learn how to access and use all community resources.
2. Be able to recognize signs of caregiver stress and burnout and provide suggestions for stress relief.
3. Celebrate the incredible things that staff and foster/adoptive parents do.

The available information resources are nearly endless and can be accessed by phone, mail, Internet, e-mail, or in person.

Optional Activity: Show a brief clip of video; suggest last 5-10 minutes of "You Are Not Alone". Video is centered around developing resources and learning to become a skilled advocate for adopted or foster children with special needs. This activity should not be considered if time is limited. Trainer may note that a copy of this film is available at the regional training centers for individual viewing.

ISBN 1-57295-209-5; 27 minutes; #CM-4CW
Fanlight Productions
47 Halifax Street
Boston, MA 02130

Here in Pennsylvania, there is a quick and easy way to access a broad range of services and resources for children with complex medical needs -- The Special Kids Network.

The Special Kids Network was developed to help coordinate, link, and make sense of the wide variety of services and systems that already exist in the commonwealth.

Incoming calls are automatically referred to one of six regional offices. Each regional office is staffed by phone counselors who utilize a computer based resource directory of both local and statewide services for children with special health care needs and their families.

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Trainer Note: Overhead 23 & 24 have been created to provide talking points for the next section.

The system enables The Special Kids Network to:

1. Provide information, referral, and support to families and service providers.
2. Facilitate cross-system coordination and collaboration on behalf of families and service providers.
3. Identify unmet needs of children, families, and service providers for use in program development.

Services include, but are not limited to:

1. Counseling -- bereavement, behavior modification, adolescent group counseling.
2. Support Group -- parent, disease specific.
3. Advocacy -- special education advocacy, education law center.
4. Therapy -- outpatient, home therapy
5. Recreation and Leisure -- special needs camps, therapeutic riding, parks and accessibility options.
6. Education -- day care, special schools/classes
7. Health Care Products/Services -- home health, hospitals, physicians/specialists, durable medical equipment, adaptive devices, disease-specific information, disease-specific organizations, respite care, Medical Assistance coverage

The Special Kids Network is managed by the Division of Special Health Care Needs, part of the state's Bureau of Maternal and Child Health (MCH) 1-800-986-4550

Optional Activity: Trainer may have a participant in the group call The Special Kids Network during afternoon break and ask for specific information. During this session, the caller should report back to the group. How was the call handled? Did you get help/information?

Early Intervention is a statewide system of services and supports for infants and toddlers with disabilities or delayed development, ages birth through three years, and their families. Screening and a Multi-disciplinary Team Evaluation (MTE) are necessary for eligibility determination.

The Individualized Family Service Plan (IFSP) is a required component of the Early Intervention system. The Individualized Family Service Plan (IFSP) is the cornerstone of family-centered

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Early Intervention services. Family members and professionals work together and share information in an effort to achieve desired outcomes. Annual meetings occur as long as the child is eligible for Early Intervention services. Periodic progress reviews occur when requested by families but at a minimum of 6 month intervals following the development of the initial IFSP.

Call your local county Mental Health Mental Retardation Office or Special Kids Network for additional information.

The attached directory has been included as a resource guide for support groups, disease-specific information, equipment, and a wide variety of other related information. It includes phone numbers to call, address to write, or Internet locations to access. To find more specific information, don't forget the yellow pages of the telephone book.

Trainer Note: Distribute Handout #3, "Accessing Services Directory". Discuss some of the entries with participants. You may wish to select those specific to the audience or perhaps the more common or more unusual. Be sure to note that some resources are Internet, telephone, or mail accessible. Also alert participants to the glossary of medical terms located at the end of the directory.

The caregiver often needs emotional support or respite to allow them to continue their care provision for the medically complex population.

Family Consultants are parents of children with special health care needs who work directly with families in the hospital to provide peer counseling and support. Who better than a parent of a child with a similar medical need to offer another parent emotional support and understanding.

Family Consultants are available at Hershey Medical Center, Children's Hospital of Pittsburgh, Children's Hospital of Philadelphia, and St. Christopher's Hospital in Philadelphia.

Parent-to-Parent is a unique Pennsylvania program that matches parents, foster parents, and adoptive parents of children with special needs to parents in a similar situation. They are able to share experiences and offer practical information and/or advice. This network can help parents locate a support group, provide technical assistance to local support and mentor groups, and assist and encourage the establishment of new local support or mentor groups.

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Support can be creative and unique. It can soothe, relax, and celebrate!

You do wonderful things for others -- reward yourself by meeting your own personal support needs.

In addition to formal support networks and services, there are those times when a more personal support is needed. People like to help other people, and people need other people -- all of you -- caseworkers, family preservation workers, foster caregivers, and adoptive parents. Build a personal support list -- a list that helps you remember people in your life who can be a potential source of assistance to you now or at some later time.

Take a sheet of paper and divide it in two columns. On top left, write "places I go." On top right, write "people I meet." List everywhere you go (work, church, social groups, friends house, relatives house). Then, list who you see there. Give participants 5 minutes to complete this task.

On a new sheet of paper, write only those names who meet specific criteria: (Allow 2-3 minutes to complete this task.)

- Good listener
- Understanding and compassionate
- Enjoys helping others
- Easy to be with
- Makes you laugh
- Offered you help if you ever needed it
- Similar circumstances
- Similar work

Put a star by those names you would feel comfortable sharing or asking for help. Allow 3 minutes to complete this task. You've just listed your "first string" support team.

Call these people when you need someone to talk to, invite them to visit, go to lunch or movie -- be creative. There are times when an informal support system may be more helpful than a more structured network or service.

Support can be a bear. Support can be SPINOZA (R) . . . The bear who speaks from the heart. (TM)

Available for purchase or loan from local hospitals, home health agencies, or hospices, SPINOZA is a therapeutic relaxation tool. Tucked inside his super soft body is a cassette player and speaker. Spinoza comes with a selection of tapes for education, grief and

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bereavement, relaxation and stress reduction. He can be used by patients and caregivers of all ages in a variety of settings.

- *Giving respite to an anxious parent of a challenging child.
- *Comforting children with separation anxiety.
- *Empowering a student with disabilities to accept him/herself and understand that “you are all you need to be”.
- *Provide stress relief for staff and parents by helping them acknowledge themselves for what they give to others.
- *Provide relaxation techniques.

Optional Activity: (10-15 minutes based on number of participants.)

Equipment Required: Spinoza bear

Tape: “Everybody Needs a Little Tenderness”

Trainer Note: If presentation room is large, you may want to use a higher volume tape recorder to improve audibility.

Stress management is extremely important to the staff. Our stress is minimized when we take the time to acknowledge and take responsibility for our accomplishments, however small or large, and give ourselves or receive the praise we deserve. By taking just a few minutes to listen to “Everybody Needs a Little Tenderness”, we can refresh ourselves for whatever is next.

Listen to the tape “Everybody Needs a Little Tenderness”. Do the deep breathing and relaxation exercises along with Spinoza. If desired, have the participants form a circle and share what they feel proud about today or acknowledge something about the person next to them.

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EVALUATION AND CLOSURE

Rationale	Participants may be feeling overwhelmed at the end of training since they have been exposed to much medical and technological information. This section is designed to assist participants in evaluating presentation and providing a closure celebration to acknowledge their commitment to the medically complex child.
Learning Objectives	Participants will: <ul style="list-style-type: none">◆ Complete and submit the program evaluation form.◆ Receive positive reinforcement for their commitment to the medically complex child.
Time	0.25 Hours
Methods	Group activity. Presentation by trainer.
Materials	Evaluation Form Handout #1 – Participant Manual – Pages 1F thru 3F Handout #4 – “I Am The Child” (Reprinted from the Ohio Coalition for the Education of Handicapped Children; dedicated to Daryl Hayes, Jr., The Little Boy Who Cannot Talk; reprinted from “Education Update”, Vol. 14. No. 2) Overheads # 1F thru 6F
Activities	Completion of Evaluation Forms. Reading by Trainer.

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Trainer Notes:

Before closing the training sessions, all participants must complete the evaluation forms and return to assist in future curriculum planning.

Trainer Note: Allow approximately 5-10 minutes for participants to complete the evaluation.

In closing, I/we want to celebrate with you -- the caseworkers, the family preservation workers, the foster parents, and the adoptive parents -- the exceptional things you do for Pennsylvania's most vulnerable population. Thank you for being a special person by caring for a special child.

Trainer Note: Narrate the following selection for participants. If the curriculum is being team trained, the reading can be broken into sections with each trainer doing a piece. Handout #3 includes the entire text of "I Am The Child". Distribute handout as participants exit the training.

I am the child who cannot talk. You often pity me. I see it in your eyes. You wonder how much I am aware of. I see that as well. I am aware of much. Whether you are happy, or sad or fearful, patient or impatient, full of love and desire, or if you are just doing your duty by me. I marvel at your frustration, knowing mine to be far greater, for I cannot express myself nor my needs as you do. You cannot conceive my isolation, so complete it is at times. I do not gift you with clever conversation, cute remarks to be laughed over and repeated. I do not give you answers to your every day questions, response over my well being, sharing my needs, or comments about the world around me. I do not give you rewards as defined by the world's standards . . . Great strides in development that you can credit yourself; I do not give you understanding as you know it.

What I give you is so much more valuable. . . I give you instead opportunities. Opportunities to discover the depth of your character, not mine. The depth of your love, your commitment, your patience, your abilities; the opportunity to explore your spirit more deeply than you imagined possible. I drive you further than you would ever go on your own, working harder, seeking answers to your many questions, creating questions with no answers. I am the child who cannot talk.

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I am the child who cannot walk. The world sometimes seems to pass me by. You see the longing in my eyes to get out of this chair to run and play like other children. There is much you take for granted. I want the toys on the shelf. I need to go to the bathroom. Oh, I've dropped my fork again. I am dependent on you in these ways.

My gift to you is to make you aware of your great fortune, your healthy back and legs, your ability to do for yourself. Sometimes people appear not to notice me; I always notice them. I feel not so much envy as desire, desire to stand upright, to put one foot in front of the other, to be independent. I give you awareness. I am the child who cannot walk.

I am the child who is mentally impaired. I don't learn easily, if you judge me by the world's measuring stick. What I do know is infinite joy in the simple things. I am not burdened as you are with the strifes and conflicts of a more complicated life.

My gift to you is to grant you the freedom to enjoy things as a child, to teach you how much your arms around me mean, to give you love. I give you the gift of simplicity. I am the child who is mentally impaired.

I am the special child. I am your teacher. If you allow me, I will teach you what is really important in life. I will give you and teach you unconditional love. I gift you with my innocent trust, my dependency upon you. I teach you respect for others and their uniqueness. I teach you about the sanctity of life. I teach you about how very precious this life is and about not taking things for granted. I teach you about forgetting your own needs and desires and dreams. I teach you giving. Of all, I teach you hope and faith. I am the special child.

Reprinted from the Ohio Coalition for the Education of Handicapped Children; dedicated to Daryl Hayes, Jr., The Little Boy Who Cannot Talk; reprinted from "Education Update", Vol. 14, No. 2.

Good Bye and thank you for choosing to care for Pennsylvania's children!

Trainer Note: As participants are doing their evaluations put Overhead 25 on the screen for them to see.

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