

Chapter 7

Medical, Developmental, and Mental Health Considerations

Knowledge of the medical, developmental, and mental health issues that should be considered by individuals and couples planning the creation of a family through adoption is critical to informed decision making. These concerns are no more pertinent for children in adoptive families than they are for children in families formed by birth. This chapter covers a variety of issues related to the medical, developmental, and mental health considerations for parenting children who were adopted.

Adoption in Cases of Fetal Anomaly and Genetic Risks

Adoption is typically considered by expectant parents in cases of unplanned pregnancies and by individuals and couples who experience fertility issues. However, with ongoing advancements in prenatal technology and the recent completion of the Human Genome Project, it is becoming increasingly important that adoption be considered a viable option in additional situations.

Each year in the United States, approximately 3 percent of all pregnancies result in the birth of a child with significant birth defects (Centers for Disease Control and Prevention, 2007). Anomalies may result from prenatal substance abuse on the part of the mother, advanced maternal age at conception, and/or environmental or genetic causes. Most often, anomalies result from a combination of two or more of these factors.

Recent improvements in ultrasound technology and prenatal testing have made it possible to detect many of these abnormalities in the developing fetus. As a result, expectant parents and their health care providers are better equipped to prepare for the birth of children with special needs. However, this information also requires expectant parents to make a difficult decision regarding whether they should terminate the pregnancy, continue the pregnancy and parent the child, or continue the pregnancy and make an adoption plan. Individuals and couples who must make this decision may experience conflicting emotions not limited to grief, guilt, denial, detachment, and anger.

Because many pregnancies in which a fetal anomaly is detected are planned or accepted pregnancies, expectant parents may feel that termination is not an option for them. However, they may also feel overwhelmed and physically, emotionally, or financially unable to parent a child with a

76 Adoption in the United States

disability. It is important for expectant parents and health professionals to understand that there are families and individuals who are waiting to adopt infants and children with special needs. Prospective adoptive parents may choose to adopt a child with special needs for a variety of reasons. These individuals often have previous experience with certain disabilities and may feel better prepared to parent children with these conditions. Some individuals may have a wealth of knowledge regarding a particular disorder and may feel that they are in a position to care for a child affected by that disorder. Others may have personal experience, such as another child with a certain condition. Expectant parents should understand that while some families may be able to care for children with disabilities, other families may find this too difficult.

Genetic counselors and other health professionals such as obstetricians, midwives, and health center social workers are often the first resource that expectant parents encounter after a fetal diagnosis. The response of health care professionals can have a significant impact on parents' reactions and decisions. Because knowing one's options can diminish feelings of helplessness, health professionals can help minimize these feelings by offering unbiased information regarding options, support, and referrals. It is critical for health professionals faced with these situations to be familiar with adoption-sensitive language, as well as policies, laws, and resources. It is equally important that this information be conveyed in a non-directive manner in order to ensure that the most appropriate decision for the patient is reached.

Advancements in the identification of genes responsible for certain genetic conditions have resulted in increased pre-conception counseling and discussion of options. Genetic counselors and other health professionals are often faced with patients who either carry an identified genetic mutation or have a family history of a genetic condition. These patients may be interested in expanding their families but often do not want to risk passing the gene on to their children. In such cases, health professionals must be prepared with information regarding the options of domestic and intercountry adoption, as well as adoption from foster care.

Adopting a Child with a Developmental or Chronic Disability

It has been estimated that between 30 and 50 percent of children awaiting adoption have a developmental disability (Glidden, 2000). These disabilities may be emotional, mental, or physical disorders and vary in severity. Children may be afflicted with differing degrees of cerebral palsy or autism, physical malformations such as cleft lip and palate (which, in some cases, can be indicative of a larger disorder), genetic conditions such as cystic fibrosis, disorders resulting from prenatal maternal substance abuse (e.g., fetal alcohol syndrome), learning disabilities or mental retardation varying in basis, or

Medical, Developmental, and Mental Health Considerations 77

genetic/environmental conditions such as epilepsy. One well-known disorder affecting multiple children awaiting adoption is Down syndrome. Down syndrome occurs in approximately one in eight hundred live births and is caused by the presence of an extra copy of chromosome 21 in the child's cells. As in other cases of genetic anomaly, individuals affected with Down syndrome exhibit varying levels of functionality. Some children born with Down syndrome have no sign of the disorder aside from some level of mental retardation and characteristic features such as upward slanting eyes and epicanthal folds (i.e., folds of skin at the inner corner of the eyes), a flattened nasal bridge, short broad hands, and a single deep crease in the palms. Others also possess heart abnormalities or vision and hearing impairments and may require extensive medical treatment throughout their lives. Ultrasound examination and maternal blood tests can indicate the risk of Down syndrome in the developing fetus; however, a definite prenatal diagnosis of this condition must be done through amniocentesis.

As with all children, those awaiting adoption may be afflicted with several other disabilities of varying natures. These conditions may have a genetic or non-genetic basis, and some may be identified through prenatal testing, while others may only manifest after birth. Cerebral palsy results when brain damage occurs, often as a result of the failure of oxygen to reach the brain near the time of birth. Muscle control is often difficult or unattainable for children with cerebral palsy. Cystic fibrosis, another chronic condition that may be present in children awaiting adoption, is a genetic condition that affects the lungs and digestive system. The body produces thick, sticky mucus that clogs the lungs and obstructs the pancreas, leading to lung infections and poor food absorption (Cystic Fibrosis Foundation, 2007). Some children in care may also show signs of autism, a developmental disorder affecting the areas of the brain responsible for abstract thought, language, and social skills. Children with autism can have both physical and behavioral disabilities. Epilepsy is another condition found in some children. This disorder is characterized by seizures and can result from genetic or environmental causes. Seizures can occur in the form of muscle convulsions, loss of consciousness, or other mental or physical anomalies. Spina bifida, a condition that may be present in some children and is often detected prenatally, is a birth disorder that affects the spinal cord. Vertebrae do not develop completely, which results in varying levels of difficulty with leg movement, sensation, and bowel/bladder control. The most common disorders affecting children awaiting adoption, however, are fetal alcohol syndrome and alcohol-related neurodevelopmental disorders. These conditions may be characterized by physical and/or mental challenges resulting from maternal usage of alcohol or other controlled substances during pregnancy. Possible manifestations of the disability include behavioral issues, characteristic facial features, and some level of mental retardation (Centers for Disease Control and Prevention, 2006).

78 Adoption in the United States

Required medical services and other treatments are dependent upon each individual child's needs. Treatment may include physical, speech, and/or occupational therapy in addition to medical intervention. Prospective adoptive parents who wish to adopt a child with a disability must demonstrate the ability to care for a child with the disorder in question and should live near any required medical or related services.

Individuals and couples wishing to adopt a child with a disability may choose to contact their health provider for more information. Therefore, health professionals must be aware of adoption agencies that place children with disabilities and adoption-related resources that can support these individuals in making a decision. A variety of resources are available for birth parents and prospective adoptive parents of children with disabilities. Web sites focusing on children with specific special needs attempt to match waiting children with prospective adoptive parents through photolistings. In addition, organizations such as AKIDS Exchange, which matches children with Down syndrome to prospective adoptive parents, also work to recruit individuals and families willing to care for children with disabilities.

Adopting a Special-Needs or High-Risk Child through Domestic Adoption

Over the past several decades, the placement of special-needs and high-risk youngsters through domestic adoptions has increased. These tend to be older children with medical conditions, physical and developmental disabilities, and known emotional and behavioral problems, and those who have experienced significant abuse or neglect, or multiple placements. These children often have genetic predispositions to cognitive and learning problems, as well as to certain socio-emotional problems such as bipolar disorder, attention-deficit/hyperactivity disorder, and autism (Brodzinsky et al., 1998; Peters, Atkins, & McKay, 1999). The majority of these adoptions are successful (Rosenthal, 1993). However, these children can sometimes pose significant and often long-term challenges to caretakers. Parents and families need to carefully assess their ability to help these children deal with their medical, educational, and/or socio-emotional difficulties. Adoptive families that have successfully integrated children with more severe difficulties are generally cohesive, have experience raising children and realistic expectations of the child, exercise flexibility when making decisions, and are tolerant of differences between the child and other family members (Barth & Berry, 1988; Groze, 1994; Keck & Kupecky, 1995).

The types of behavioral health issues that can be seen in domestic adoptions range from relatively benign adjustment issues to more significant psychopathology such as bipolar disorder, attention-deficit/hyperactivity disorder, and post-traumatic stress disorder, as well as difficulties associated with cognitive and academic performance, such as various learning disabilities.

Medical, Developmental, and Mental Health Considerations 79

In general, none of these disorders are unique to children who were adopted, and there is very little evidence that suggests the majority of them appear more often in this population. However, possible exceptions do include several disorders whose development is heavily influenced by environmental events that may be part of the child's pre-adoption history, such as post-traumatic stress disorder resulting from physical and/or sexual abuse and reactive attachment disorder (RAD), which results from the disruption of early attachments to primary caregivers. A detailed discussion of specific mental health disorders is beyond the scope of this book; however, the Suggested Readings at the end of this book lists texts with more detailed descriptions of these problem areas.

If a child is having behavioral problems, discussion with a pediatrician who can make an appropriate referral for further assessment and possible intervention is important. Learning problems are generally assessed and remediated within educational settings. Behavioral and socio-emotional issues may be assessed by mental health professionals such as psychiatrists, psychiatric nurses, clinical psychologists, and clinical social workers, all of whom are trained to deal with these issues. Many adoption agencies offer post-adoption services or can make referrals to appropriate professionals; adoption support groups and associations are also good sources for referrals.

The first step should be a careful assessment of the child and the circumstances, including pre- and post-adoption history. This can be difficult if little is known about the child's early life. Exactly what is the concern? Whose concern is it? Is the concern one that is best construed as a normal developmental bump in the child's adjustment, or does it represent something more serious? Most professionals stress the importance of addressing these questions, as there is danger in overestimating difficulties, which can actually make matters worse (Nickman & Lewis, 1994). For example, children understand what it means to be adopted very differently at age seven than at age four. They may ask more questions about their biological heritage, which may reflect these changes in their level of understanding. This is not an indication of more significant psychological problems regarding their adopted status. Families, too, are subject to life cycle changes that may or may not be out of the ordinary as they face the challenges of dealing with adoption-related tasks (Brodzinsky, 1987). Attempts to help the child and family may not only prove futile but also frustrate them, adding stress to an already tense situation.

When an intervention seems necessary, the parents are often directly involved in treatment—this is generally true for child therapy. Treatment may take the form of parent management, education about the child's problems, or more structured family therapy sessions involving all family members. This is not necessarily an indication that the parents or family members have done something wrong but instead may reflect the belief held by many mental health professionals that children are very dependent on their parents

80 Adoption in the United States

and reactive to their environments, and that parents are usually the best source of help for their children. In addition to family counseling, treatment plans can also include individual counseling with the child. Use of medications has increased for a variety of child and adolescent problems ranging from attention-deficit/hyperactivity disorder to mood disorders. It is not uncommon for multiple interventions to be utilized.

In some instances, specialized treatments may be considered. For example, children who are suffering from a pervasive developmental disorder such as autism may profit from more intensive targeted interventions such as applied behavior analysis and sensory integration therapy (Bundy, Lane, Fisher, & Murray, 2002; Maurice, 1993). These therapies can be controversial, as professionals do not always agree upon their effectiveness. Researchers still are not able to predict which children will profit from which intervention. One of the more controversial treatments for children with severe attachment problems is holding therapy, which involves very lengthy and emotionally intense sessions with the child and the parents (Cline, 1990). Unfortunately, there is really no research evidence that it is effective, and it remains an experimental treatment.

Ancillary support services such as respite care can prove beneficial in helping families cope with difficult situations such as severe child behavior problems. Short-term hospital stays are mainly used to assess medication needs when this is not possible on an outpatient basis, and to stabilize behavior in acute crisis situations such as suicide attempts. Partial hospitalization programs and day treatment programs can offer a structured monitored environment on a short-term basis when needed. An alternative to these outpatient interventions is residential treatment, which can provide comprehensive educational and psychotherapeutic interventions for children who are unable to tolerate the intimacy of family life. The challenge in these cases is integrating the child back into the family once the child's individual issues are resolved.

General Guidelines for Working with Pediatricians

Prospective adoptive parents should screen potential pediatricians for their child. In addition to asking standard questions about their pediatric practice and philosophy, parents should ask pediatricians about their experience reviewing prenatal and birth histories for adoption-related cases to assess their understanding of health care considerations and practices for children who were adopted, and their willingness to learn about caring for children who were adopted. The American Academy of Pediatrics Committee on Early Childhood, Adoption and Dependent Care (1991) has issued recommended guidelines for pediatricians' practices around caring for children who were adopted and working with their families. Pediatricians should be able to provide comprehensive medical, developmental, and psychological evaluations

Medical, Developmental, and Mental Health Considerations 81

of the child; help adoptive parents evaluate any information they have received about the birth parents and the birth history; evaluate any behavioral or emotional concerns and offer referrals to trained professionals; and distinguish between adoption-related issues and typical issues of development. In addition, they should understand the issues related to adoption that may arise and should have information about how to access professional and community resources for adoption-related issues, including information about parent support groups and mental health professionals. Finally, they should use appropriate language to describe adoption and related issues and demonstrate sensitivity regarding issues related to loss for all members of the adoption triad (children, birth parents, and adoptive parents).

Research Spotlight: Adoption and Overall Adjustment

Many questions have been raised by professionals over the past fifty years in regard to adjustment issues of adopted children relative to children who were not adopted. Studies have pointed out that children and adolescents who were adopted are overrepresented in both outpatient and inpatient mental health services (Brodzinsky, 1993; Wierzbicki, 1993). While this finding has been sustained over time, there is some controversy over what it means. Do children who were adopted indeed have more problems than those who were not, or are there alternative explanations for this phenomenon? For example, researchers have raised the possibility that this could be influenced by a differential referral bias for adoptive families. That is, families who adopt appear to be more sensitive and tuned in to their child's difficulties and are more apt to seek help for them, which may contribute to their greater presence in mental health services (Warren, 1992). However, studies of children in the general population have also found a modest but still significant presence of cognitive, behavioral, and emotional difficulties among adopted children in middle childhood and adolescence compared to children in the same age groups who were not adopted (Brodzinsky, 1993). Taken as a whole, the literature generally supports the idea that these youths are at an increased risk of developing various psychological, behavioral, and academic problems compared to non-adopted individuals.

However, research has also shown that the overwhelming majority of adopted youngsters are well within the normal range of adjustment, and adults who were adopted as children show no increased prevalence in receipt of mental health services (Bohman & Sigvardsson, 1990; Brodzinsky, Smith, & Brodzinsky, 1998). This research suggests that a developmental component may be involved. Furthermore, most studies that support the belief that children who were adopted are at increased risk for the development of problems do not differentiate the populations studied regarding what would appear to be important variables, such as type of adoption, age of the child at adoptive placement, reasons for placement, and pre-adoptive

82 Adoption in the United States

history (e.g., experiences of abuse and neglect, multiple placements). Some of these variables have been found to affect the risk that a child will develop problems in the adoptive placement, which makes it difficult to interpret the research findings. Finally, there is much evidence that a loving, supportive, and secure environment goes a long way toward alleviating the impact of adverse factors (Brodzinsky et al., 1998). The adoptive family's strengths have also been shown to have an effect on their potential for change when they are engaged in mental health treatment (Cohen, Coyne, & Duvall, 1993). Regardless of the risks, however, adoption remains the best alternative for children whose birth families are not able to care for them (Brodzinsky et al., 1998; Cohen et al., 1993).

Health Considerations for Children Adopted from Foster Care

People considering adoption of children from foster care are often concerned about the physical, emotional, and developmental consequences experienced by these children, who may have been abused or neglected prior to their foster placement. Children who have lived in foster care have a number of risk factors for poor health and disordered development. Prospective adoptive parents who are interested in adopting children from foster care should be aware of the health issues associated with the experience of foster care. Understanding the needs of these children can help parents address their needs promptly, provide them with stable and nurturing homes, and have a positive impact on their child's development. In addition to lack of access to appropriate medical care, issues that must be taken into consideration for children who have lived in foster care include their prenatal histories, chronic health problems, and various developmental and mental health issues.

Ideally, children's positive experiences in foster or adoptive care with secure and loving caregivers can counteract prior negative experiences and promote healing (Pearce & Pezzot-Pearce, 2001). Several studies have demonstrated the reversal of physical health conditions (e.g., elevated lead levels, growth delay) afflicting children in foster care once they are placed in a permanent and stable family (Chung, Webb, Clampet-Lundquist, & Campbell, 2001; Wyatt, Simms, & Horwitz, 1997). Other research has demonstrated that a child's foster care or subsequent adoptive experience itself can serve as a compensatory factor in developmental delays (Horwitz, Simms, & Farrington, 1994; Newton, Litrownik, & Landsverk, 2000). The hope and expectation is that once a child is placed in a loving and nurturing home, his or her health status will improve.

More than good intentions are usually needed to care for these children. Reports from health professionals who were involved in the foster care system during their youth suggest that health and child welfare professionals, while attempting to intervene to benefit the child, may actually unwittingly

Medical, Developmental, and Mental Health Considerations 83

contribute to the trauma the child experiences (Cournos, 1999). Writing about her own perspective as a child placed into foster care after the death of her parents, Cournos described the experience as a series of inexplicable and mysterious events that made her feel threatened and humiliated. If foster or adoptive parents are poorly matched to the child or unprepared for the demands of the child's health issues, they may exacerbate the child's psychopathology. Adoptive and foster parents who must constantly deal with a child's difficult behavior and receive little support from agency or health professionals may become frustrated and unintentionally make the situation worse. Unfortunately, as a result, parents and other caretakers may personalize the child's behavior, blame the child, react in anger, or even further abuse the child. This can reinforce the child's perception of him- or herself as unlovable, and of others as dangerous and untrustworthy. In turn, these responses make future placements even more difficult. Well-trained professionals can help parents prepare to nurture a child who has experienced trauma and poor caregiving. Understanding common health problems and the consequences of different experiences increases the likelihood that parents will be able to help their children heal.

Health problems among children in foster care are the consequence of a number of factors. Inadequate prenatal care, along with prenatal exposure to drugs and alcohol, may lead to premature birth and/or low birth weight. Chronic maternal ill health and serious infections such as HIV and hepatitis C may affect the health of newborns. Poor nutrition, exposure to high levels of violence, chaotic and inconsistent parenting, parental unemployment and lack of education, mental illness, and homelessness are common factors that are detrimental to the early growth of children who enter foster care (Simms, Dubowitz, & Szilagyi, 2000). These children are more likely to have been exposed to toxins in the environment, particularly lead (Chung et al., 2001), and less likely to have received routine preventive health care prior to entering foster care (Combs-Orme, Chernoff, & Kager, 1991). They are less likely to have developed a consistent relationship with a health care provider. Instead, they are often brought to hospital-based clinics and emergency rooms, where record keeping and information sharing are inconsistent (Combes-Orme et al., 1991). To improve children's overall well-being, social workers and foster and adoptive parents should work together to ensure that children receive routine health care and have accurate medical records.

Obtaining Medical Information for Children in Foster Care

A number of best practices concerning health care for children who have been in foster care have been established. Adoptive parents should be aware of and understand the medical issues and barriers encountered by these children so that they can help them obtain the best health care.

84 Adoption in the United States

Although acquiring medical information from scattered sources may be challenging, it is worth the time and energy to get a comprehensive picture of a child's health. The starting point for this undertaking is usually a discussion with the child's social worker. If the social worker has little health information about the child, he or she may be able to identify the child's most recent health care provider and help parents access the information that is available. The following medical information is very useful:

- health histories for birth parents, birth siblings, and birth relatives (as available), including diagnosed medical concerns, developmental or cognitive delays, mental health problems, smoking, alcohol and/or drug abuse, and genetic conditions, as well as medications prescribed and taken
- birth history, including problems with pregnancy, labor, or delivery; quality of prenatal care; gestational age (full term or premature birth); birth weight; information regarding issues such as withdrawal from opiates, infection, or jaundice; and any feeding difficulties
- past medical history, including hospitalizations, operations, immunizations, laboratory evaluations, and diagnoses of chronic illness
- records of developmental milestones and any treatment for developmental delays
- behavioral/mental health evaluations and treatment protocols prescribed
- allergies to medications and foods
- current medical problems
- current medications

When parents find a pediatrician to care for their child, they should request that their child's developmental assessment include the evaluation of gross and fine motor skills, cognition, speech and language function, self-help abilities, emotional well-being, coping skills, and relationships with others (American Academy of Pediatrics Committee on Early Childhood, Adoption and Dependent Care, 2000). It is important to identify a local pediatrician who is trained and willing to care for children who have lived in foster care. Parents should seek a primary health care provider who can give attention to the mental health needs of the child. When interviewing pediatricians, parents can ask a few specific questions:

- Have you ever cared for any children who have lived in foster care?
- Are you familiar with the American Academy of Pediatrics' guidelines for assessments of children who have lived in foster care?
- Can your office help me locate and acquire my child's health records?
- Do you perform developmental assessments at each visit and provide recommendations for follow-up?

Medical, Developmental, and Mental Health Considerations 85

- Are you familiar with the effects of trauma on child development?
- Will you make referrals to specialists who can address my child's physical, developmental, or mental health needs?

Developmental and Mental Health Considerations

It is critical for children in foster care to get routine developmental screenings and any necessary follow-up. Routine pediatric visits include developmental check-ups, but children may not be seen regularly by a pediatrician while living in foster care. A child's physical and mental functioning may improve if problems are recognized during routine developmental screenings and necessary treatment is provided.

Given that the life of a child in foster care is often filled with separation and loss, it is not surprising that behavioral and psychiatric issues are common in these children. While preschoolers in the general population are diagnosed with behavioral problems at a rate of 3–6 percent, 20–40 percent of young children in foster care have similar diagnoses (Hochstadt, Jaudes, Zimo, & Schachter, 1987; Leslie, Gordon, Lambros, Premji, Peoples, & Gist, 2005). Disproportionate rates of mental health problems persist for these children as they age. For instance, children in foster care are sixteen times more likely to receive psychiatric diagnoses and eight times more likely than their peers to take psychotropic medications (Racusin, Maerlender, Sengupta, Isquith, & Straus, 2005). Mental health issues for children in foster care can be exacerbated by lack of access to up-to-date screening and treatment methods. Professionals who work with this population can help children and caregivers understand the consequences of negative experiences on emotional and behavioral health.

Early interruption or poor quality of attachment often underlies many of the behavioral problems of children in foster care. Attachment is the ability of a child to form an emotional bond with a primary caregiver. Secure attachment allows children to explore their environment, develop relationships, and form a positive self-image. When this bond is disrupted or formed in a disordered way, a number of mental health problems result. Children with attachment disorders may show overly vigilant or overly compliant behaviors or display indiscriminate connections to every adult, or they may not demonstrate attachment to any adult. These disordered or disorganized attachments can lead to other adverse outcomes that, left untreated, can persist into adulthood (Harden, 2004; Leslie et al., 2005).

Attachment disorders can result from poor parenting; abuse; neglect; and insecure, interrupted, or poor foster placements. Maltreatment itself is associated with insecure attachment organization, poor emotional and behavioral self-regulation, and problems in development of the autonomous self and self-esteem. Toxic and traumatic events directly affect neural and

86 Adoption in the United States

brain development, as neuronal connections do not form well when stress hormone levels are high. These traumas also result in problems such as post-traumatic stress disorder (Leslie et al., 2005; Pearce & Pezzot-Pearce, 2001; Perry, 2001).

It is important to note that young children who are well attached to their birth parent or other caregiver in foster care go through significant stages of grieving when they are separated from these caregivers. Bowlby (1969) describes the stages of grieving as protest (crying and attempts to recover the attachment object), despair (appearing preoccupied and depressed, yet watchful), and, finally, emotional detachment with loss of interest in caretakers. It is important to recognize the difference between separation problems and attachment problems (Fahlberg, 1991). While they may lead to similar behaviors, treatment for separation issues may have a better prognosis than treatment for a true lack of attachment. Facilitation of the grieving process can help children become more open to the benefits of new attachments. To help a child through these issues, parents can seek assistance from professionals who specialize in treating children with traumatic histories. They can help parents understand the impact of these experiences on children's development and offer practical parenting strategies to foster healthy development for the child and family.

Beyond abuse and neglect, other conditions that result in foster placement present additional risk factors. Parental psychiatric illness has been documented in 46 percent of children in state custody; 60 percent of those birth parents were noted to be alcoholics, and 32–54 percent were reported to have problems with substance abuse (Pearce & Pezzot-Pearce, 2001). The effects of these problems include genetic predisposition to substance or alcohol abuse; prenatal exposure to teratogens; and especially dysfunctional parenting, including neglect and time spent living in impoverished environments. Poor supervision, inconsistent discipline, and lack of modeling or positive reinforcement have been found to be factors that contribute to developmental and emotional delays in children.

As children in foster care age, lack of recognition of the need for adequate mental health treatment may lead to further psychopathology. These disordered behaviors can be separated into two types: internalizing disorders (including depression and anxiety) and externalizing disorders, which result in aggressive, destructive, or antisocial behaviors. Children in foster care often receive diagnoses of both types of disorders. The most common problems identified include relational and coping difficulties and school failure. Of the emotional and behavioral disturbances that cause moderate to severe impairment of the child's ability to function and engage with others, most common are conduct disorders, attention disorders such as attention deficit disorder and attention-deficit/hyperactivity disorder, aggressive behavior, and depression (Leslie, Landsverk, Ezzet-Lofstrom, Tschann, Slymen, & Garland, 2000). Specifically, adoptive parents may encounter

Medical, Developmental, and Mental Health Considerations 87

atypical eating behaviors such as food hoarding, rumination, swallowing problems, and failure to thrive. Children may also engage in primitive soothing behaviors such as rocking, head banging, scratching, and cutting. Inappropriate modeling or mimicking of adult behavior, even if it is abusive, is also common (Leslie et al., 2005; Perry, 2001).

It is essential that parents request assistance from professionals trained in the care of children who have experienced trauma. Children suffering from trauma do not ordinarily recover without treatment. One trauma specialist has pointed out that delaying treatment for trauma is the worst thing one can do, because over time the trauma becomes more deeply embedded in the psyche, and the person develops and employs less constructive defenses and coping strategies (Terr, 1991). According to Terr (1991), "If one could live a thousand years, one might completely work through a childhood trauma by playing out the terrifying scenario until it no longer terrified. The lifetime allotted to the ordinary person, however, does not appear to be enough" (p. 13). Therapy is vital if children are going to be able to live with foster families, be adopted, or be reunified with the birth parent. The impact of trauma evolves differently in each child. Child-specific diagnoses and treatments are critical. Adoptive parents can benefit from pre-placement preparation as well as post-placement support and training. By accessing resources from within the community, adoptive families can buttress their integration and strengthen their family development.

Fahlberg (1991) outlines strategies to support infants and young children in their transition from foster to adoptive homes. She notes that social workers and parents must pay close attention to the signals children send about their feelings. Initial contacts with adoptive families work well when they take place in the foster home, in the presence of foster parents, and when the pace is set by the child. It is also important that prior to placement, adoptive parents spend significant time visiting during different times of the day so they can become familiar with all aspects of the child's routines. Getting to know one another in the comfort of the child's current home setting can ease the process. Parents can provide children with a sense of history and belonging, which can help ease the transition to an adoptive home, by helping them create a life book, or memory book, a collection of photographs or mementos that document special memories, and by helping them maintain contact with siblings and peers.

Parenting Tools and Skills

Family stability is the first step toward developing the parenting tools and skills that help children who have experienced foster care learn to trust. These children need to reestablish their ability to trust nurturing adults. Trusting relationships help children achieve better self-control and cope with their many losses (Racusin et al., 2005). Family stability can be defined

88 Adoption in the United States

in many ways, but the family characteristics that most benefit children recovering from multiple losses include parental mental health, stable relationships between caregivers, and positive parenting (Harden, 2004). Parents and caregivers must be emotionally available. Home environments should be warm and stimulating, provide a sense of family cohesion, and be characterized by routine day-to-day activities. Caregivers primarily need to be constant and consistent and remain connected with the children (Harden, 2004; Leslie et al., 2005).

Once the child is in a stable situation, other ways to help include nurturing the child, trying to understand problematic behaviors before punishing, parenting based on the child's emotional age, being consistent and predictable, modeling and teaching appropriate social behaviors, relaxing and playing with the child, having realistic expectations of the child and of oneself, and caring for oneself and making wise use of support systems and resources.

Nurture the child. Children who have experienced foster care placement may not have previously had predictable, comforting, or loving relationships with adults. They may need to relearn what it means to be hugged, comforted, and touched in an appropriate way. Unfortunately, relearning love is much harder than learning it during infancy. Patience and persistence are required for children to develop healthy attachments.

Try to understand a problematic behavior before punishing. Understanding the consequences of attachment disorders allows parents and other caregivers to understand a child's behavior in context. A child who is hiding feces or hoarding food is displaying insecurity rather than being naughty. These disturbing behaviors are usually not improved by punishment but are indicators that parents must seek help from professionals to address the child's trauma.

Parent based on the child's emotional age. Children who have been maltreated have delayed coping skills. When stressed, angry, or fearful, they can regress further. While a child may be chronologically nine or ten years of age, emotionally he or she may only have the developmental skills of a two-year-old. If a child is behaving like a two-year-old (responding to stress with tantrums, crying, and demonstrating a loss of control), parents should treat him or her like a two-year-old during that episode. While verbal explanations are appropriate for children of that age in general, such advanced parenting strategies will not be helpful for a child who is not emotionally mature.

Be consistent and predictable. Neglected and maltreated children often have not had the security of routines and support during transitions. Children feel safe in a calm environment with scheduled routines. When

Medical, Developmental, and Mental Health Considerations 89

presented with changes in routine or new settings (like a party or trip), children can become overwhelmed and may need extra support to help them cope with those changes.

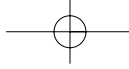
Be consistent and predictable. The fundamental problem with attachment disorders is that children do not learn how to interact appropriately with others. Experiencing consistency and love in daily life allows children to acquire the skills they need to behave appropriately. It helps for parents to identify their own behaviors, break those skills down into understandable components, and then explain them to the child. Physical contact can be challenging for children. Some may not know when to give a hug, how to break eye contact, or how close to stand to someone else. Others are indiscriminate with their affection and need to know where to set limits. The use of gentle modeling and redirection without embarrassing or drawing attention to the child can help him or her develop these skills.

Relax and play with the child. Children may find it easier to relax and share their feelings during quiet and unstructured moments. During these times children should be helped to understand that all feelings are okay to feel, and that there are healthy ways to express their feelings. When the child is clearly happy, mad, or sad, ask how he or she feels and help him or her express those feelings in words.

Have realistic expectations of the child and of oneself. Skills and abilities that are easily acquired soon after birth cannot be learned as easily when children are older. Progress is often slow, and parents have every reason to be frustrated by the task. Look for individual gains instead of comparing the child's progress with that of others. Rewarding small successes helps children develop confidence.

Care for oneself and make wise use of support systems and resources. No one can do this alone. It is important for adoptive parents to take care of themselves. If parents are stressed or frustrated, they will be unable to care adequately for their children. Professional resources can help and should be employed. Support groups for parents; respite care; and the cooperation of medical, psychological, and child welfare professionals are vital to successful parenting under special circumstances (Perry, 2001).

Finally, it is important to understand that separation and loss issues may continue to reappear throughout the child's lifetime. There are some predictable ages and stages of development during which the effects of earlier losses may resurface, leading to further grieving. More information on children's stages of development can be found in chapter 8. It is important to remember that early experiences, especially trauma, affect a person throughout his or her life span. Even adults may have feelings of separation and loss long after they have put those experiences behind them (for example, these



90 Adoption in the United States

feelings may surface when one's child reaches the age one was at the time the trauma or loss occurred).

Parenting children who have experienced foster care presents unique challenges and joys. Foster placement and adoption can be confusing, frightening, and traumatic on a number of levels. It is best if the transition in placement is well planned. It is critical that parents understand that the child's experience of neglect, violence, or loss prior to placement will affect how the child manages emotionally. Also, the emotional support offered to the child and family can have an impact on how he or she manages the experience (American Academy of Pediatrics Committee on Early Childhood, Adoption and Dependent Care, 2000, 2002; Simms et al., 2000). A child's successful transition from foster child to son or daughter through adoption requires the support of trained professionals, educators, and the community.

Recognizing the Medical Needs of Children in Foster Care

Finding the right doctor is critical for the adequate care of a child. There is ample evidence that even when children reach a medical professional, their needs are often under-recognized (O'Hara, Church, & Blatt, 1998). Formal medical and nursing education programs do not specifically address the medical needs of children in foster care, nor do ongoing educational opportunities provided to health care practitioners (Henry, Pollack, & Lazare, 2006; Simms et al., 2000). There is little communication among child welfare and health professionals, so information about a child's health is often not directed to the attention of those who can use or make sense of it. Despite the fact that children in foster care have significant unmet health care needs, untrained community providers are much less likely to refer young children entering foster care for evaluation and treatment of developmental and mental health problems than are foster care specialists.

The importance of communication and the need for the coordinated transfer of medical information among caregivers is vital. Foster and adoptive parents must be informed and involved in the evaluation of developmental and mental health problems. An accurate diagnosis is unlikely without their informed participation in the assessment, and treatment cannot be successful without their cooperation.

Research Spotlight: Physical, Developmental, and Mental Health Issues in Foster Care

Over 70 percent of children in state custody have a history of abuse and neglect (U.S. Department of Health and Human Services, 2003). As a result of circumstances surrounding their histories, these children are at risk for increased health problems that affect their overall well-being. The health problems of children in foster care exceed those of other high-risk groups, such as children living in poverty and children who are homeless. Multiple stud-

Medical, Developmental, and Mental Health Considerations 91

ies indicate that children in state care may experience growth delays, vision and hearing deficits, immunization deficiencies, dental caries, anemia, and obesity and may have communicable diseases (including sexually transmitted infections) and high lead levels. Developmental delays, as well as psychiatric and behavioral issues, are also more prevalent in this population.

Chernoff, Combs-Orme, Risley-Curtiss, and Heisler (1994) found that 92 percent of 1,407 children entering foster care in Baltimore, Maryland, over a two-year period had at least one problem noted on their physical exam. Ailments of the upper respiratory tract (66%), skin (61%), genitals (10%), eyes (8%), abdomen (7%), lungs (7%), and extremities (6%) were most common. In the same study, it was noted that one-quarter of these children failed the vision screen, while 15 percent failed the hearing screen. Growth delays and short stature were three times more prevalent for these children than for the general population. Half of the children had unmet dental needs.

Takayama, Wolfe, and Coulter (1998) found medical problems in 60 percent of 749 children entering foster care in San Francisco during a fifteen-month period. As was found in Baltimore, the most common problems experienced by the children were skin conditions and upper respiratory infections. In addition, one-third of the children had abnormal vision screens.

Flaherty and Weiss (1990) studied children in Chicago who were placed in protective custody during a twenty-two-month period. Nearly half had a health problem (44%), of which infections (otitis media, sexually transmitted infections) were the most common, followed by anemia and lead poisoning. It was particularly startling that seventeen of these children were found to have broken bones that had gone unnoticed.

Several studies indicate that there are health conditions that are ameliorated in foster care. Elevated lead levels in foster children in Philadelphia were found to drop significantly once the children were moved to a foster home (Chung et al., 2001). A Connecticut study found that children who were placed in foster care for the first time grew at an astonishing rate. Regardless of the child's height at the time of placement, nearly half of the preschool children studied experienced a large catch-up growth spurt during their first year in foster care (Wyatt et al., 1997).

Developmental delays are found in 30–60 percent of the foster care population, as opposed to only 4–10 percent in the general population. Specifically, problems that have been reported in this population include language delays (57%), cognitive problems (33%), gross motor delays (31%), and growth problems (10%) (Leslie et al., 2005).

Research Spotlight: Guidelines for and Barriers to Quality Health Care for Children in Foster Care

Guidelines that clarify what care is appropriate for this very special subset of children, in addition to routine well-child care, have been published based on what is known about the myriad health needs of children in foster care.

92 Adoption in the United States

The Child Welfare League of America (1988) developed a template for child welfare agencies to organize health and mental health services for children in their care. Similarly, the American Academy of Pediatrics Committee on Early Childhood, Adoption and Dependent Care (1994, 2002) has laid out components of health care services that should be made standard for children in foster care.

Both organizations stress that care should be comprehensive and continuous. They recommend a health screening exam within seven days of placement to rule out signs of abuse or neglect and to determine if there is any evidence of infection or chronic illness, or a need for medication or immediate medical intervention. Within thirty days of placement, a comprehensive health assessment should be performed by a medical professional who is skilled in identifying abuse and neglect, and knowledgeable of the health needs of children in foster care. Developmental, educational, and mental health evaluations must be part of the evaluation. An enhanced well-child visit schedule is recommended after the assessment period to identify issues that may change with time.

The American Academy of Pediatrics' most recent recommendations stress the neurobiology of development. Traumatic events experienced in the first two or three years of life may have a long-lasting negative impact on a child's subsequent development. The American Academy of Pediatrics Committee on Early Childhood, Adoption and Dependent Care (2000) specifies how comprehensive evaluation, treatment, placement, and caregiving must be approached in order to ameliorate those effects. Assessments should include the evaluation of "gross and fine motor skills, cognition, speech and language function, self-help abilities, emotional well-being, coping skills, relationship to persons, [and] adequacy of caregiver's parenting skills and behaviors" (American Academy of Pediatrics Committee on Early Childhood, Adoption and Dependent Care, 2000, p. 1147). Treatment through the primary health care provider's office, with attention to the mental health needs of the child, is emphasized. Early interventions and immersion in stimulating environments are identified as the best ways to combat the effects of deprivation and trauma.

There are, however, barriers that prevent foster children from receiving comprehensive, high-quality medical care. A national study on health care policies for children in out-of-home care showed that almost all the participating child welfare agencies noted that they fell short of meeting the Child Welfare League of America's standards (Risley-Curtiss & Kronenfeld, 2001). One significant obstacle is the lack of medical information available for foster children. Obtaining this information has not traditionally been a priority in the often chaotic and unplanned placement of children into foster care. Given their adversarial relationship with the state agency that is removing the child from their care, birth parents are often hostile or may be missing or uninformed. Thus, little information about a child's health history and

Medical, Developmental, and Mental Health Considerations 93

important health conditions is generally obtained at the time of removal. There may not be any place in child welfare records for medical information, and the transfer of medical information between foster agencies and foster homes is not well organized. It is not unusual for the new foster parent to receive no medical information for a medically complex foster child. Research has shown that the majority of foster parents do not have access to information on prior medical or mental health evaluations (Chernoff et al., 1994; Vig, Chinitz, & Shulman, 2005).

Other reasons for inadequate and inconsistent health care include lack of continuity of care because of foster home changes, limited access to health care providers, issues of consent and confidentiality, and poor communication about health care needs in a busy and overwhelmed child welfare system. In addition, a research study recently concluded that foster parents are not clear about what their role as a foster parent entails and do not receive either the quality or quantity of training, information, and support they need to address complex health issues (Pasztor, Hollinger, Inkelas, & Halfon, 2006). Poorly selected and multiple placements when a child is in care are also associated with poor health outcomes (Newton et al., 2000; Rubin, Alessandrini, Feudtner, Mandell, Localio, & Hadley, 2004). While foster parents are given the responsibility to see that the children in their homes receive physical and mental health care, they are rarely given any historical information, and they often cannot give legal consent for treatment. When anything beyond routine care is required, child welfare workers must find the birth parents to obtain their consent or obtain a court order for treatment. Separate consents may be required for developmental, educational, and mental health evaluations. At best, these requirements cause delays in care; at worst, they become insurmountable obstacles for a welfare system that is already stressed.

Though reimbursement issues are often cited to explain why children in foster care receive inadequate health care, most of these children are covered by Medicaid because they receive federal foster care or adoption assistance benefits or child welfare services (Centers for Medicare and Medicaid Services, 2008). Therefore they are eligible for the Early and Periodic Screening, Diagnosis, and Treatment Program, a federally mandated program developed to ensure that all children from birth to the age of twenty-one who are covered under Medicaid receive comprehensive well-child care, which includes the maintenance of health history records, physical examinations, developmental and mental health assessments, laboratory screenings, and immunizations. These standards are based on the American Academy of Pediatrics Committee on Psychosocial Aspects of Child and Family Health's (1997) Guidelines for Health Supervision II.

Most often, children in foster care do not receive these services. Most agencies responsible for foster children do not have formal policies or arrangements to provide health care. Foster parents rely on local or family

94 Adoption in the United States

physicians or clinics that accept Medicaid (Leslie, Hurlburt, Landsverk, Rolls, Wood, & Kelleher, 2003). They receive no training about accessing services for children with special needs. Social workers and case managers are similarly untrained regarding the medical services that foster children should receive and thus cannot effectively oversee their medical care needs. As a result, children with complex health needs are left in the hands of foster parents. Alone, the foster parent must navigate a complicated and confusing health system (Simms, Freundlich, Battistelli, & Kaufman, 1999).

Large caseloads and a high turnover rate among child welfare workers in many welfare agencies make it even less likely that children receive the health care services they need (Klee, Kronstadt, & Zlotnick, 1997). Assessment results may not be documented or communicated. As a result of overwhelming caseloads, a triage mentality is employed: only the most urgent cases receive attention. A U.S. General Accounting Office (2003) report outlining the state of U.S. child welfare agencies indicates that lack of staffing, high turnover among staff, and issues of worker safety have led to the assignment of much heavier caseloads than recommended. In addition, the report showed that services are often not provided in accord with best practice standards. A national survey of child welfare agencies revealed that fewer than 43 percent provide comprehensive physical, mental health, and developmental examinations for all children entering out-of-home care (Leslie et al., 2003).

Health Considerations for Intercountry Adoption

Adopting a child from a developing country can be a tremendously rewarding experience. Providing children who might otherwise grow up in poverty with a good home and a chance to maximize their potential can be a life-altering experience for the whole family. Since 1985, nearly a quarter of a million children have been adopted by families in America (U.S. Department of State, 2008). During the past ten years most of these children have come from China, Russia, South Korea, Ukraine, Kazakhstan, Romania, Vietnam, and Guatemala (U.S. Department of State, 2008). Children adopted from South Korea and Guatemala usually have been cared for in foster homes, where the risk of certain illnesses is lower. Children from China, Russia, Eastern Europe, and Southeast Asia are more likely to have been cared for in orphanages or baby homes, in which malnutrition, emotional and physical neglect, and infectious diseases are more common.

Choosing a Pediatrician

Individuals and couples interested in adopting a child from another country should identify a local pediatrician who can provide ongoing primary care for the child. Adoptive parents are encouraged to seek recom-

Medical, Developmental, and Mental Health Considerations 95

recommendations of pediatricians from other families that have adopted internationally. It is important to feel comfortable with the pediatrician one chooses, and to assess his or her experience with medical considerations related to intercountry adoption. Parents may opt to choose a pediatrician who has had little experience with children adopted from other countries but who is willing and eager to learn about the best practices for their care. The American Academy of Pediatrics has made recommendations about caring for children adopted internationally, and parents can direct interested pediatricians to the American Academy of Pediatrics for more information. During the interview process, parents should ask a series of questions to assess a health care provider's philosophy and experience with international adoption medicine. In addition to questions that are typically asked during the screening process, the following is a series of questions parents who are adopting internationally can ask while screening pediatricians.

Do you have any experience with children adopted from other countries? If so, from what countries? It is helpful if a pediatrician has had experience caring for children from a country similar to that of the child. Different countries pose different health risks, and working with a provider who understands those risks is an additional benefit.

How many children in your practice were internationally adopted? Pediatricians who have other children in their practice who were internationally adopted are more likely to be aware of the common medical concerns for children who were adopted and are often familiar with the latest research and recommendations for their care.

Do you have experience reviewing pre-adoption medical records and videos of children? If so, from what countries have you reviewed records? Do you have any concerns about reviewing records? When it is time to review the pre-adoption medical records during the child referral process, parents should use a health care professional who has extensive experience reading and understanding foreign medical records. Some foreign medical terms have no English translation. Practitioners who are familiar with country-specific records can determine the implications of certain findings. There are large research and university-based programs that specialize in reviewing pre-adoption records and can provide summaries and recommendations for a child's primary care physician since he or she will be responsible for providing ongoing primary care for the child. Similarly, prospective adoptive parents are advised to find a health care advisor who has experience reviewing videos of children. It is helpful for pediatricians to be aware of what the images of the child say about his or her state of health and development. Videos can help prospective adoptive parents and medical professionals assess a child's development, coordination, strength, and social interactions.

96 Adoption in the United States

Do you make recommendations to parents about whether they should accept a child referral? A pediatrician's role in reviewing medical records is to provide a current medical assessment of the child, and a prognosis for future care and development. Once parents have that information, they need to consider on their own whether they have the personal and financial resources to parent the child and meet his or her anticipated needs. A doctor cannot and should not make that decision for them.

Do you inform parents of their child's medical risk to the best of your professional abilities after reviewing the pre-adoption records? Parents must be able to seek the expertise of a health professional to determine the immediate and future needs of the child and decide whether they have the resources to meet those needs.

Are you familiar with the American Academy of Pediatrics' recommendations for screening tests and assessment of immunization status for children adopted internationally? Parents need a pediatrician who understands the immunization considerations for children adopted from other countries. Children are often under-immunized because of different practices or inefficient immunizations. It is important for children not to be over- or under-immunized. Parents should request blood tests to determine whether children exhibit the antigens for (i.e., protection from) specific diseases to determine which vaccines or immunizations they should receive and the appropriate schedule for those shots.

How soon after my child's arrival will you be able to see him or her? It is recommended that a child be seen within two weeks of arriving in the United States unless the child is sick, in which case he or she should be seen as soon as possible after arrival. If the child is healthy, it is a good idea to wait a week or so before seeing a physician to ease the significant transition into a new family, surroundings, and culture.

How soon after my child's arrival can laboratory work be conducted? It is recommended that children have a series of laboratory tests within a month of arrival. These tests can determine if your child needs additional immunizations or has any other medical issues that need attention.

Do you make referrals for vision, hearing, developmental, and mental health specialists? It is important for any pediatrician to be able to make quality referrals for vision, hearing, speech or language, and developmental or mental health practitioners.

How often during the first year do you see a child who was adopted internationally? Pediatricians should be willing to see the child as often as parents request. It is important during the first year after arrival that children

Medical, Developmental, and Mental Health Considerations 97

be seen often enough to assess catch-up growth and to monitor any other developmental issues that may arise.

Do you have any information on resources for multicultural families?

When adopting internationally, most families become multicultural. It is helpful if the child's primary care provider has information for families on multiculturalism as the child grows and experiences different social situations. Pediatricians often have information about community programs or support groups that families may find useful.

What is your opinion about late circumcisions? If for religious or other reasons parents would like to have their son circumcised, it is important to find a practitioner willing to perform the surgery after infancy.

At what age can a child no longer be seen by you? It is important for children to have continuity of care even as they age into adolescence and young adulthood. It is often important for children of college age to continue to be seen by the same pediatric practice that has been regularly caring for them, since health care can be fragmented without a primary provider. Once a child reaches adulthood, he or she can obtain an adult primary care physician.

Pre-adoption

Families planning to adopt a child from overseas should obtain as much information as possible about the adoption agency with which they plan to work. What kind of medical problems or developmental or behavioral issues have been reported in children adopted through the agency? Have the children usually been well cared for and well fed? Are any particular diseases common in the orphanages from which these children come? Adoption agencies provide families with medical information about the child to be adopted. Because many of these children have been abandoned at hospitals or orphanages, there is often little information about the ages and medical histories of the parents, problems during pregnancy, the child's birth history, or any medical issues the child experienced after birth. It is important for prospective adoptive parents to understand that there may have been problems during pregnancy, inadequate prenatal nutrition, or drug or alcohol use by the birth mother that might affect the child's later development. The child might have suffered emotional or physical abuse before being placed for adoption; such abuse could also affect later emotional development. Discussing these concerns with the agency is important.

Agencies provide a brief history and pictures or videos of the children to adoptive families. Videos can help prospective adoptive parents and medical professionals assess a child's development, coordination, strength, and social interactions. It is always reassuring to see a child who engages easily and

98 Adoption in the United States

smiles readily for visitors or for a caregiver. More consideration should be taken when children are indifferent to their surroundings. Pictures often show children bundled in several layers of clothes, propped in a seat or a walker, and may not provide extensive information about the child's overall condition. A series of pictures can provide useful information about a child's movements and interactions with his or her surroundings.

Based on these types of records, families are asked to make a decision as to whether or not they would like to adopt a particular child. Reviewing the information with a pediatrician or an adoption medicine specialist may help relieve concerns or raise questions. Careful examination of photographs may help rule out congenital malformations or problems such as fetal alcohol syndrome, limb anomalies, or cleft lip. If questions arise about the information provided in the referral, prospective adoptive parents should not hesitate to ask the agency for further information. Once the decision is made to adopt a particular child, the agency will provide periodic nutritional assessments, developmental assessments, and measurements of height, weight, and head circumferences for the adoptive family to review.

Russian medical records often contain dire-sounding terms such as "hypertension-hydrocephalic syndrome," "vegetovisceral dysfunction," and "perinatal encephalopathy." These terms do not have equivalents in Western medicine and do not necessarily mean that a child will have problems in the future. However, children who have a diagnosis of congenital syphilis or rickets should be carefully reevaluated once they arrive in the United States.

Travel Preparations

Traveling overseas increases the risk of medical problems such as malaria, hepatitis A, typhoid, and traveler's diarrhea. Families planning to travel overseas to adopt a child should discuss their upcoming trip with their primary care physician. They may also want to consult a travel medicine specialist to prepare for the trip and to decrease the risks of contracting travel-related illnesses. If young children will be accompanying the adoptive parents, they should be prepared for the trip as well; parents should make sure their routine immunizations are up to date and that any special medications or immunizations they need for the trip are provided in advance.

Before traveling, adoptive parents may want to meet with their chosen pediatrician to discuss how to manage possible illnesses while traveling with the child. It also would be beneficial to learn how to take temperatures. While orphanages usually have doctors who can help, and the U.S. embassy may be able to recommend local hospitals or doctors, once adoptive parents have embarked on the return trip to the United States, it may be helpful to have the pediatrician's phone number and/or an e-mail address.

During the past several years, several infectious diseases have complicated international adoptions. In 2003, outbreaks of SARS disrupted travel to China and Southeast Asia. In 2004, adoptions from China were temporarily

Medical, Developmental, and Mental Health Considerations 99

halted because of measles outbreaks. No one knows how bird flu will progress and spread over the next few years, but it will be important for international travelers to be prepared to deal with outbreaks of infectious diseases and to know about current medical threats in countries or regions they are visiting. The Centers for Disease Control and Prevention provides current information about outbreaks of disease around the world on their Web site.

Some adoption agencies suggest taking an extensive list of medical supplies on the trip. Before spending a lot of money on antibiotics, creams, lotions, cold medicines, or remedies for head lice and scabies, prospective adoptive parents should discuss with the agency the kinds of medical problems families have encountered in the past. If they frequently see scabies or head lice in the children, it is worth taking a treatment such as Elimite Cream or Nix Shampoo. Antibiotics are usually not necessary. Diapers, antibacterial wipes, medication for fever such as acetaminophen or ibuprofen, soothing body lotions, and a digital thermometer are the most useful items to have. In addition, parents may wish to bring diaper rash ointments, a stroller, hydrocortisone 1%, diarrhea medication, insect repellants, sunscreen, bottles or sippy cups, a first aid kit, saline nasal drops, antihistamines, a medicine dropper, powdered formula, and powdered electrolytes, as well as prescription and over-the-counter medications for themselves. Again, parents should plan ahead, since due to airline restrictions, it may be necessary to pack these items rather than bringing them in carry-on baggage. It might also be quite practical to correspond with one's travel group, if there is one, to make a plan to share responsibility for bringing supplies.

The Trip Home

It is a difficult experience for a person of any age to be removed from the familiar environment of the only home he or she knows, and brought to a totally different place, perhaps halfway around the world. Remember, the child's regular schedule will be off. Sleep disturbances both during the trip and for the first few days or weeks after the arrival home are common. Parents can help relieve ear discomfort during an airline flight by giving the child food to chew or liquids to drink; acetaminophen or ibuprofen may also help. Children may have never traveled in a motorized vehicle and may suffer from motion sickness. Other suggestions for traveling with children can be found at the Flying with Kids Web site (see Selected Resources). Also, appetite may suffer from the impact of the time change; to encourage eating, parents should include some foods that the child is used to eating when packing for the trip home. Having an adequate supply of diapers and wipes may help because changes in diet may result in diarrhea. Crying is one natural response to separation and sadness a child may express. Hugging, caressing, and, if possible, a familiar object or two may provide comfort. Adoptive parents should try to keep as many of the child's original belongings, particularly clothing, as possible; the familiarity of their own clothes

100 Adoption in the United States

can help comfort a child during the initial transition. Some adoptive families take the time to learn a few words of the child's language so the child can hear some things he or she understands. Hearing the names of common foods, and the words for "milk," "sleep," and "I love you" may comfort a child. Self-stimulating behaviors such as rocking or head banging are common in children who have spent time in large institutions; these behaviors may resolve with time.

Arrival Home

Arranging for a complete medical checkup for the internationally adopted child shortly after arriving home is important. It may even be worthwhile for adoptive parents to schedule the appointment before leaving on the trip to pick up the child. At this first evaluation, the pediatrician will want to review all the medical information available about the child, including immunization records. Some adoption agencies provide translations of medical information; these are very helpful for the medical care provider. During the initial medical checkup, the pediatrician should conduct a physical exam, take body measurements, and make an effort to detect major problems or illnesses and to gain a general sense of the child's developmental status.

The physical exam is important to assess growth and nutritional status, to document birthmarks such as Mongolian spots, to detect the presence of any congenital anomalies or acute infections, and to document the child's level of development. Minor skin rashes, bald spots on the back of a child's head, thinning of the hair, and muscle weakness are not uncommon. Scars from illnesses such as chickenpox, from the BCG vaccine for tuberculosis, or from any surgeries should be noted. Occasionally children have scars that have no explanation. Congenital anomalies such as extra fingers or toes or skin tags should also be noted. Children should be carefully examined for features of fetal alcohol syndrome. Later, a more comprehensive evaluation should include immunization titers, screening tests, and remeasurement to assess catch-up growth. This should also be an opportunity for parents to ask questions regarding the child's health, well-being, behavior, diet and eating patterns, sleeping (both at night and at nap time), and defecation and urination, as well as any unusual behaviors parents have noticed or about which they might be concerned.

Many children who come from large orphanages or group homes in which they have had minimal amounts of exercise, stimulation, and nurturing experience delays in their growth and development. Many of their developmental and growth delays correct rapidly in a loving, nurturing environment where they are provided with adequate nutrition and stimulation. It is important for the adoptive parents and their medical care provider to enlist the help of early intervention services for the child. Early intervention staff can evaluate the child, offer suggestions on how to stimulate all aspects of development, and follow the child as long as he or she needs help.

Medical, Developmental, and Mental Health Considerations 101

Immunizing children against vaccine-preventable diseases is a key part of routine well-child visits. Thus, it is very important to review a child's immunization record at the first visit. Developing countries usually immunize children against tetanus, diphtheria, pertussis (whooping cough), polio, measles, and hepatitis B. But most developing countries do not immunize against *Haemophilus influenzae* or *Streptococcus pneumoniae*, bacteria that can cause meningitis, blood infections, and pneumonia. Many countries do not immunize against mumps, rubella, or chickenpox either. In some developing countries, vaccines may not be manufactured or handled as carefully as they are in the United States. In addition, they may be improperly stored or improperly administered, so they may be less effective than vaccines given in the United States. Many adoption medicine experts recommend reviewing a child's immunization record and documenting his or her response to previous immunizations by blood tests. These immunization titers either document a response to vaccines or demonstrate that certain vaccines may need to be given again. The pediatrician should discuss with the parents any catch-up immunization schedule that may be necessary.

Screening for infectious diseases is an important aspect of the initial medical evaluation. Many countries do not have accurate information on the frequency of certain infectious diseases within their borders. In a number of countries, diseases such as HIV, tuberculosis, and hepatitis C are actually underreported. Although some children have been tested for HIV, hepatitis B, or hepatitis C in their birth country, it is not possible in many cases to verify the accuracy of these tests. Most adoption medicine experts recommend that testing be done in the United States for HIV, hepatitis B, hepatitis C, syphilis, and tuberculosis. It is also important to send stool tests for intestinal parasites. Other important laboratory tests that should be scheduled by the child's pediatrician include a complete blood count; a lead level assessment; neonatal metabolic screens for thyroid, hemoglobin, and metabolic abnormalities; PKU/TSH tests for phenylketonuria and congenital hypothyroidism; thyroid function tests if growth or development is delayed; vision and hearing screens; a G6PD assay; and urinalysis and culture testing.

Tuberculosis is a lung infection caused by a bacterium called *Mycobacterium tuberculosis*. Adults with active TB can very easily spread the infection to children, and an adult with active TB working in a crowded orphanage could infect many children. Developing countries have a much higher incidence of TB than does the United States. All children adopted from a developing country should have a TB skin test shortly after arrival home.

Because of the high incidence of TB infection, many developing countries give a vaccine for TB, called BCG, to infants. This vaccine is given as an injection in the upper arm and usually leaves a small scar that looks like a pock mark. The vaccine is not very effective in preventing pulmonary tuberculosis, but many countries use it because it does decrease the chance that the child will develop TB meningitis. Because it is not very effective, we do

102 Adoption in the United States

not use the BCG vaccine routinely in the United States; in addition, it can cause some significant side effects, and it may interfere with the TB skin test. In some situations, the BCG vaccine may cause the TB skin test to be falsely positive. Until recently, there has been no way to differentiate a skin test that tests positive because of TB infection from a skin test that tests positive because of the BCG vaccination. The Centers for Disease Control and Prevention and the American Academy of Pediatrics recommend that positive skin tests be treated as indicating TB infection regardless of whether or not the child has received the BCG vaccine. A new blood test called Quantiferon Gold may help differentiate positive test results caused by presence of the disease from positive test results caused by the BCG vaccine. A child's health care provider can discuss this with parents. If a child's test is negative, it is a good idea to repeat the test in six to twelve months in case the child was exposed to TB shortly before his or her arrival in the United States. Some findings from the first medical exam after the child's arrival in the United States may indicate a need for concern, or that more testing is warranted. These more serious findings include indifference, asymmetrical movements, fetal alcohol syndrome stigmata (alcohol is a neurotoxin and is one of the most common teratogens), indications of mental retardation, poor pre- and post-natal growth, fine motor dysfunction, and irritability or hyperactive behavior. It is also important to determine whether bruises are indeed bruises, or if they may be mongolian spots, which are harmless skin discolorations often found in children with dark skin.

The newly arrived child not only needs to be evaluated physically but should be evaluated developmentally as well. This involves an assessment of the child's functioning within the cognitive, motor, socio-emotional, and behavioral domains. In most cases, a skilled pediatrician is sufficient for this purpose. However, in cases of questionable delays, a more detailed examination by a developmental and behavioral pediatrician may be warranted. This may also involve more formal testing by a developmental psychologist as well as other professionals. It is important to identify any difficulties as early as possible, as there are effective interventions to help children develop appropriate functioning. For infants and children under the age of three years old, early intervention programs that work with both the child and parent are helpful. Public school systems are important sources of both evaluation and intervention for developmental and learning problems among preschool and school-aged children. Local school systems are mandated by law to provide the services necessary to evaluate and meet the children's special needs in these areas when requested by a parent. Interventions may include academic support in cases of learning disabilities, speech therapy, occupational therapy, and modified academic instruction.

If a child exhibits more emotional or adjustment difficulties, a pediatrician may consider a referral to a child psychiatrist or other mental health professional such as a clinical psychologist or clinical social worker. Problems such as attachment difficulties, conduct problems, fears and worries,

Medical, Developmental, and Mental Health Considerations 103

attention-deficit disorders, and peer problems, along with general behavior management concerns, are the types of issues that can be addressed by mental health professionals. Unfortunately, most mental health specialists have neither specific training nor extensive clinical experience in dealing with adoptive families. They may have problems assessing whether the issues families are experiencing are part of a normal adjustment process or if these need more intensive intervention. It is best to select a clinician who is familiar with these issues, especially if there is a large pool of professionals from which to choose. Seeking information about appropriate practitioners from adoptive support groups or other specialized services in the adoptive family's geographical area is a good starting strategy. Finding an appropriate mental health professional is especially critical for issues that are central to the adoption experience, for example, attachment difficulties.

Follow-Up

Children who have spent time in institutional settings are at risk for problems as they grow. Delays in development and socialization skills, in addition to slow growth, early puberty, dental problems, behavioral issues, and attachment disorders, may occur. Separation anxiety is normal at certain ages, as are temper tantrums, occasional stuttering, and picky eating. Thus, these may not actually indicate that a problem is developing.

The primary care provider should monitor the child carefully for these problems. It is important that parents recognize which of these problems are normal developmental issues and which are abnormal. Parents should be willing to share their concerns with health care providers and ask for help. It can also help to talk with other parents who have adopted children from overseas. Sometimes the necessary counseling or therapy may not be covered by insurance. While this is a potentially daunting aspect of caring for a child adopted internationally, at the same time, parents can take pride that the child has the opportunity for a new and better life than he or she might otherwise have had.

Behavioral Health Considerations

Intercountry adoptions, by definition, entail a cultural displacement that may have implications for the child's adjustment. This not only is true for the ultimate preservation of the child's native culture and heritage necessary for identification but is very obvious in simple day-to-day activities as the child transitions into the new household. For example, differences in language, routines, and customs associated with basic activities such as feeding and toilet training need to be addressed for the very young infant as well as for the older child. International adoptions may also involve multicultural considerations and require the adoptive family to deal with community values and prejudices.

104 Adoption in the United States

Many other factors that are not unique to international adoption play a role in the child's ability to adjust. These include the child's age, biological makeup, temperament, cognitive ability, and pre-adoption experiences, as well as the adoptive family's characteristics. Some children adopted through international adoptions have special needs. Some children are in poor health or have neurological and developmental disabilities that may be initially unknown or undisclosed. Some children may have experienced the prolonged privation of institutional care or, in the case of older children, may have lived on the street and had to depend upon themselves for everyday survival. These factors can have profound long-term implications for the child's behavior, attachment, and overall functioning.

Behavioral health professionals have spent a good deal of time in the last ten years looking at adjustment issues in international adoptions. This research was prompted and made possible by the relatively large influx of children adopted from Romanian orphanages in the early 1990s (Wilson, 2003). Interest has focused on the institutional care that these children and other internationally adopted children experienced and its impact on their development. While the negative impact of institutional care and deprivation on young children has been well documented historically (Tizard & Rees, 1975), these more recent adoption studies have attempted to look at the long-term outcomes once the child has been removed from the orphanage and adopted into a family.

Researchers have found that institutionalized children have significant difficulties in various domains of functioning, including attachment, as well as cognitive, behavioral, and emotional problems (Johnson, 2000). For example, institutionalized children have been shown to exhibit difficulty establishing selective attachments with caregivers and show a range of negative affect from sadness to excessive worry, autistic-like features such as self-stimulatory behavior, cognitive delays, inattention and hyperactivity, peer difficulties, and conduct problems (Chisholm, 1998; Gunnar, Bruce, & Grotevant, 2000). However, the majority of these children showed significant improvement in these domains when reexamined two years post-adoption (Rutter, 1998). As would be expected, the persistence of these difficulties correlated positively with the amount of time that the child had spent in institutional care. Institutionalization remains a significant risk factor for the persistence of a variety of socio-emotional problems, despite the fact that the majority of these children ultimately achieve normal functioning.

It should be stressed that the above remarks pertain to internationally adopted children who had spent time in an institution. Indeed, recent studies demonstrate that overall, internationally adopted children do not present with more significant behavioral health problems than children who were adopted domestically. There is actually some evidence to suggest that these children may have fewer problems than those adopted domestically (Juffer

& van IJzendoorn, 2005). This evidence needs to be understood within the context of studies looking at the general population of adopted children here in the United States, which do point to the fact that adopted children are overrepresented in both outpatient and inpatient mental health settings (Brodzinsky, 1993). However, studies looking at the differential rate of learning and socio-emotional problems in community samples of adopted and non-adopted children show only modest increases for the adopted population, suggesting more of a differential referral pattern for adopted children to mental health services (Warren, 1992).

Families who are considering adopting children from other countries should plan and prepare to seek treatment for the potential cognitive and mental health issues these children may have. While love and caring alone may not be able to erase the influences of adverse genetics and experiences, they do enable adoptive parents to be sensitive to a child's needs and prompt them to seek realistic ways to help the child. The alternative, denial and minimization of problems at the outset, can lead to strained family relations and stress if the child's initial problems do not abate with time (Cohen, 2005). What at first might be tolerated may in time take a negative toll on the entire family.

For families thinking about an international adoption, an important place to start is to explore the various countries that are potential sources of children who are free for adoption and then to develop a working knowledge of the various situations that have made those infants and children potential candidates for adoption. Are these children usually available for adoption because they have been abandoned or their parents have died, or have they been abused or neglected? What are the customary ways that the culture deals with such children? Are these children usually cared for by relatives or forced to live on the streets, or are they placed in institutions? Are there particular institutions in which most children are placed? What are the conditions and practices in these places? What is known and shared with prospective adoptive parents about a particular child's background and experience? Answers to these questions can give adoptive parents a better understanding of the risk factors that a child and family may face.

Once a particular country is identified, becoming familiar with attitudes and customs regarding child rearing can help adoptive parents plan their child's transition from one culture to another. It can help to obtain information about the child's usual diet, feeding practices or meal time customs, behavior management, and toilet training practices. Once a child is selected for adoption, learning as much as possible about the child's most recent environment and experiences can be helpful for developing routines in the home that will support a smooth transition. For example, rocking the child as part of a bedtime routine may be important to incorporate into the new routine if this was an important part of the child's caretaking experience in the native country.

106 Adoption in the United States

Intercountry Adoption Support Services and Resources

A number of organizations and resources offer information pertinent to health care issues that often arise in intercountry adoptions. The Immunization Action Coalition provides information on immunization issues specifically of interest to health care professionals working with families created through intercountry adoption. Another resource is Jane Aronson's Orphan Doctor Web site, which has helpful information about adoption and medical resources. Dr. Aronson is the director of International Pediatric Health Services and has helped thousands of parents with health evaluations of children adopted from abroad. ComeUnity's Web site on international adoption health and medicine provides information about the various ailments that may be found in children adopted from other countries, a directory of adoption medicine clinics, and information on health-related international travel issues. The Centers for Disease Control and Prevention is an excellent and reliable source of information on traveler's health issues that is particularly useful to parents planning a trip abroad to bring their child home. The American Academy of Pediatrics Section on Adoption and Foster Care is another useful Web site that provides information to improve the health outcomes of children who have been adopted and children in foster care. In addition to links to resources such as the American Academy of Pediatrics' recommendations for children's health care, it offers a directory of pediatricians who work with children in foster care, as well as a directory of pediatricians who work with children who were adopted. As its name suggests, Families with Children from China is a support network for families who have adopted children from China. Members share information they have learned on a variety of topics through efforts to strengthen their families. Their Web site provides links to information specifically about adoption from China, as well as some general adoption resources. Contact information for these organizations can be found in Selected Resources.

Conclusion

Adoption is a process, not an event. A family evolves and develops from the point of welcoming its newest member onward as the child matures into adulthood and independence. As children develop, their understanding of and feelings about their experiences change and evolve, becoming more complicated. What it might mean to be adopted at age three is different from it will be at age eight or thirteen or twenty. Family members' first impressions upon meeting and welcoming the child will surely evolve as they watch the child grow into adulthood. While problems can surely crop up at any point in this process, the joys are sure to be many and heartfelt. The reflections in the final chapter are intended as guidance throughout the entire journey, not just for the initial phase of adjustment.