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# Introduction

Children enter out-of-home care<sup>1</sup> for a variety of reasons. Some enter out-of-home care because of abuse or neglect. In other cases, families voluntarily place their children as a result of health, social, or economic stresses within the family, and sometimes children enter out-of-home care because their families are not able to cope with the children's behavioral or emotional issues. Each child in out-of-home care is entitled to quality services designed to ensure the child's safety and well-being. Public and private child welfare agencies assume responsibility for children's health and well-being when they are in out-of-home care.

Each year, approximately 800,000 children and youth spend some period of time in out-of-home care. Recent trends indicate that about one-third of children in out-of-home care are age 5 and younger, about one-fifth are between the ages of 6 and 10, and one-half are 11 and older. Children and youth in out-of-home care live with unrelated foster families (about one-half), with relatives (about one-quarter), and in residential and group settings (about one-fifth). Children and youth who reside in residential and group care settings receive care in residential treatment programs, emergency shelters, group homes, detention facilities, and other juvenile justice facilities (U.S. Department of Health and Human Services [HHS], 2005a).

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<sup>1</sup> "Children in out-of-home care" includes children residing in emergency shelters, with kin, in family foster homes, in group homes and residential centers, in independent-living programs, and in other settings in which children who are in the legal custody of a public child welfare agency or the agency's designee reside. In these standards, the terms *child* and *children* are used to describe children of all ages, including infants and youth. The term *youth* is used in those instances in which the standard or discussion applies specifically to adolescents.

Children in out-of-home care have unique health care needs.<sup>2</sup> Their experiences prior to entering out-of-home care and their experiences while in care place them at higher risk of poor physical and mental health and poor developmental outcomes. In response to the growing knowledge base regarding the pervasive health problems among children in out-of-home care, recent reports have highlighted the need for improved health services—including physical, dental, and mental health as well as developmental services—for these children (American Academy of Pediatrics, 2002a; McCarthy, 2002). These studies have outlined the challenges associated with providing quality health care services for children and youth in out-of-home care, including: children’s lack of health care services prior to entering out-of-home care; the placement of children with families or in facilities that are geographically distant from their previous health care providers, resulting in a loss of continuity of health care; difficulties in obtaining full health histories when children enter out-of-home care; locating and providing access to the range of health care services that children and youth in care need; lack of coordination among physical health, mental health, and developmental services; poor communication among health care providers, child welfare agencies, and caregivers; and limited health care resources in the communities in which children’s families live (McCarthy, 2002).

Considerable work has been done in identifying best practices in the provision of health care services for children and youth in out-of-home care. McCarthy (2002), for example, found that effective approaches include the inclusion of children in out-of-home care in universal health care programs, the development of effective collaborations among agencies, the employment of health care professionals in the child welfare system, the tracking of health care data, training, health care management, comprehensive health assessments, and centralized health centers.

The growing body of knowledge on providing quality health care services to children in out-of-home care has informed the development of the *CWLA Standards of Excellence for Health Care Services for Children in Out-of-Home Care*. These standards are

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<sup>2</sup> The term *health care* is used to broadly refer to physical, mental, and behavioral health, as well as dental and developmental or early intervention services.

based on an understanding of health care as defined by the Georgetown University Child Development Center (McCarthy, 2002): “Strategies and services for meeting the physical, dental, mental, emotional, and/or developmental health needs of children. It includes all health care: primary, tertiary, and specialty care” (p. 2). These standards are based on a recognition that the needs, strengths, and resources of children and families are the heart of how best practices are defined and implemented. These standards provide out-of-home-care providers and child welfare workers guidance on best practices in the provision of health care services to all children in out-of-home care.

## Federal Legislation Addressing the Health Care Needs of Children in Out-of-Home Care

### **Child Welfare Legislation**

The Child Abuse Prevention and Treatment Act of 1974, the Adoption Assistance and Child Welfare Act of 1980, the Adoption and Safe Families Act of 1997, and the John H. Chaffee Independence Program of 1999 address certain health care needs of children in out-of-home care.

In 1974, Congress enacted the Child Abuse Prevention and Treatment Act (CAPTA). This first federal effort was designed to ensure the safety of children and improve the responses of child protective service systems to the maltreatment of children. CAPTA has been amended on several occasions, making new programs and funding available to the states to strengthen their child protective services systems. Through recent amendments, CAPTA added requirements that child welfare agencies refer children younger than the age of 3 who are involved in substantiated reports of child abuse or neglect but who are determined not to be at risk of imminent harm to early intervention services funded under Part C of the Individuals with Disabilities Education Act. This provision has been viewed as one of the richest entitlements to services for children younger than 3 who have experienced abuse or neglect, and it is aimed at preventing and remediating developmental difficulties, delays, and disorders (Spiker & Silver, 1999). It requires referrals for children who otherwise may never have received these services because their parents are unaware of

these services or they lack a pediatrician who is closely following their developmental progress.

The Adoption Assistance and Child Welfare Act of 1980 (AACWA; P.L. 96-272), for the first time in federal law, recognized the goals of supporting and preserving families, required the implementation of permanency planning for all children in out-of-home care, and promoted adoption and other permanency alternatives when children could not be safely reunited with their families. AACWA established federal support for preventive and reunification services as well as support for services designed to ensure permanency for children who could not be reunified with their families. Although health care was not a focal point of AACWA, the act provides that all children eligible for federal foster care support are also eligible for Medicaid, thereby giving children access to the health care services covered by the program. It also created an adoption assistance program for children with special needs adopted from foster care, making all children eligible for this program also eligible for Medicaid. AACWA significantly changed child welfare practice. Many agencies that provided out-of-home care adapted their policies and practices to focus on permanency for children in out-of-home care, and many agencies shifted from a child-only focus to a family focus, from a single service to an array of services, and from working alone to working within a network of child and family service providers (Child Welfare League of America [CWLA], 1990).

In 1997, Congress amended AACWA through the passage of major federal legislation in the arena of out-of-home care: the Adoption and Safe Families Act (ASFA; P.L. 105-89). ASFA emphasizes three goals for children: safety, well-being, and permanency. ASFA specifically addresses health care services for children in foster care in three ways. First, ASFA extends health care coverage to all children with special needs adopted from out-of-home care, providing that they receive postadoption health care coverage through Medicaid or a state medical assistance program. Second, ASFA requires that states develop and implement standards to ensure that children in out-of-home care are provided with quality services “that protect the safety and health of the children.” Finally, ASFA requires HHS to regularly conduct an assessment of each state’s performance in serving children in out-of-home care. The assessment process developed by the HHS, the Child and Family Services Reviews (CFSRs), includes, as one

performance measure, how well each state has met the health care needs of children in out-of-home care. Following CFSR results that indicated that states generally were not successfully meeting the health care needs of children in out-of-home care, Congress, in the Child and Family Services Improvement Act of 2006, mandated that states ensure that physicians and other medical professionals are actively consulted and involved in health assessments and appropriate medical treatment for children in care.

The John H. Chaffee Foster Care Independence Program (P.L. 106-169), enacted in 1999, provides funds to states to assist children who are likely to remain in care to age 18 with services and supports designed to prepare them for life on their own after discharge from out-of-home care. These services and supports include training and employment preparation and personal support for youth as they prepare to leave care. The act allows services and supports to be provided to youth between the ages of 18 and 21, including offering states the option to extend Medicaid coverage to this population of youth.

## Health Care Legislation

Other federal legislation more specifically addresses the health care needs of vulnerable children, and, as a result, these statutes are relevant to the health care of children in out-of-home care.

Since the enactment of Title IX of the Social Security Act in 1965, Medicaid has been the primary health care coverage for low-income families and their children. Children in out-of-home care who meet the eligibility criteria of Title IV-E of the Social Security Act, as well as children who are adopted from out-of-home care and who receive Title IV-E adoption subsidies, receive health care coverage under Medicaid. States have the option of providing Medicaid coverage for other children in out-of-home care and for children adopted from foster care who do not meet the Title IV-E requirements.

Medicaid covers a range of services for children, including medical and dental services. Of particular importance is Early and Periodic Screening, Diagnostic and Treatment (EPSDT), a mandatory Medicaid service for children who are eligible for the program. EPSDT provides access to a comprehensive range of preventive, diagnostic, and treatment services for children eligible

for Medicaid. Targeted case management, an optional Medicaid service, provides for the coordination of rehabilitative, therapeutic, psychiatric, and other services for specific populations of children, including, in many states, children in out-of-home care. Recent changes in federal law, however, are likely to significantly affect the extent to which targeted case management will be available as a Medicaid-funded service for children in out-of-home care (Congressional Budget Office, 2006).

When the Social Security Act was passed in 1935, the federal government, through Title V, pledged its support of state efforts to extend and improve health and welfare services for mothers and children. Title V has been amended many times over the years to reflect the expansion of the national interest in maternal and child health. It was converted to a block grant program as part of the Omnibus Budget Reconciliation Act of 1981. States and jurisdictions use Title V funds to design and implement a wide range of maternal and child health programs that meet national and state needs. Although specific initiatives may vary, all programs focus on:

- reducing infant mortality and the incidence of disabling conditions among children;
- increasing the number of children appropriately immunized against disease;
- increasing the number of children in low-income households who receive assessments and follow-up diagnostic and treatment services;
- providing and ensuring access to comprehensive care, including long-term care services, for children with special health care needs;
- providing rehabilitation services for children who are blind or disabled, younger than 16 years of age, and eligible for Supplemental Security Income; and
- facilitating the development of comprehensive, family-centered, community-based, culturally competent, coordinated systems of care for children with special health care needs.

In 1997, the Individuals with Disabilities Education Act (IDEA) was restructured into four parts: Part A, General Provisions; Part B, Assistance for Education of All Children with Disabilities; Part C, Infants and Toddlers with Disabilities; and Part D, National

Activities to Improve Education of Children with Disabilities. Under Part B, every school district is legally required to identify, locate, and evaluate children with disabilities. After the evaluation, a child with disabilities may be provided with specific programs and services to address his or her special needs as they relate to the child's entitlement to a free and appropriate education. IDEA defines "children with disabilities" as individuals between the ages of 3 and 22 with one or more of the following conditions: mental retardation, hearing impairment (including deafness), speech or language impairment, visual impairment (including blindness), serious emotional disturbance, orthopedic impairment, autism, traumatic brain injury, specific learning disability, or other health impairment. An Individual Education Plan (IEP) is developed to guide the provision of services and support. Part C of IDEA provides early intervention and other services for infants and toddlers (from birth to age 3) with disabilities and their families. These early intervention and other services are provided in accordance with an Individual Family Service Plan (IFSP) developed in consultation with families of infants and toddlers with disabilities and the appropriate state agency. Part C also provides grants to states to support these programs. In 2004, IDEA was reauthorized. The law now requires that states, in their application for grants under Part C, provide satisfactory assurances that policies and procedures have been adopted to ensure the "meaningful involvement of underserved groups, including . . . children with disabilities who are wards of the state" in the planning and implementation of all requirements of Part C (Dicker & Gordon, 2006, §637[a] and [b]7).

In 1997, Congress, in the Balanced Budget Act, created a new title of the Social Security Act, Title XXI, the State Children's Health Insurance Program (SCHIP). This legislation expands medical coverage to families earning too much to qualify for Medicaid through a program jointly financed by the federal and state governments and administered by the states. Although states are permitted to develop different eligibility rules, in most states, uninsured children younger than 19 whose families have limited incomes are eligible for SCHIP. Within broad federal guidelines, each state determines the design of its program, eligibility groups, benefit packages, payment levels for coverage, and administrative and operating procedures. SCHIP in each state generally covers doctor visits, immunizations, hospitalizations, and emergency room visits.

The Children's Health Act of 2000 was designed to promote the health and well-being of children and youth throughout the United States. It established funding for new research and treatment services for diseases and conditions known to have a significant or disproportionate effect on children. The Healthy Start demonstration program was created to expand the accessibility of health care services for pregnant women and infants in targeted neighborhoods. The Day Care Health and Safety program, also created by the act, focuses on improving the health and safety of child-care centers through strengthening the enforcement of state health and safety standards for child-care centers and increasing training and education of providers. The act also addresses the quality of mental health treatment services for children, with specific provisions related to monitoring and regulating the safe use of seclusion and restraint in residential treatment programs. The act reauthorized the Substance Abuse and Mental Health Services Administration and provides resources to support youth substance abuse prevention and treatment programs.

Also relevant to the health care of children in out-of-home care is the Health Insurance Portability and Accountability Act of 1996 (HIPAA). Of importance in relation to health care services for children and youth in out-of-home care, HIPAA mandates greater privacy protections for individuals' personal information (including health care information), both in relation to agencies' handling of this information and in the transmission of such data among agencies.

## The Effect of Social and Economic Conditions on Child, Youth, and Family Health and Well-Being

Social and economic conditions have had a profound effect on the well-being of children and families. These conditions also have affected the delivery of child welfare and health care services to children and families served by child welfare agencies.

### **Poverty**

In 2001, 16.3% of the children in the United States lived in poverty. Although children comprise 25.6% of the total population of the United States, they represent 35.7% of the poor (Proctor &

Dalaker, 2002). Poverty can significantly undermine the ability of families to meet their children's basic needs, including adequate food and shelter, preventive and primary health care, dental care, and specialized health care services. Parents who face financial hardship and lack social supports may face particular difficulties in meeting their children's needs.<sup>3</sup>

Many families struggle to make ends meet even when one or more adults in the family are employed. According to the 1999 National Survey of America's Families, one in six non-elderly Americans lived in a "working poor" family in 1996 (Acs, Phillips, & McKenzie, 2000). The primary earners in these families held jobs that paid less, offered fewer benefits, and provided less job security than earners in non-poor families. Importantly, non-poor families (88.6%) were significantly more likely than working poor families (54.3%) to receive health insurance through employment. The working poor also face difficulties qualifying for government-sponsored benefits. Compared to the non-working poor, the working poor are less likely to receive Medicaid and food stamps (Acs et al., 2000).

When families struggle to meet basic needs, they often must prioritize the use of limited resources. Health care may be sacrificed as families strain to obtain housing and food and pay for heating. According to the National Center for Health Statistics of the Centers for Disease Control and Prevention (CDC, 2005), families' socioeconomic status, housing status, access to transportation and services, and social and environmental stressors play significant roles in promoting or undermining the health of children and adults. As a result of these factors, children and adults in families with incomes near or below the federal poverty level have consistently been found to be in worse health than individuals with higher incomes (CDC, 2005).

Because poverty may mean that children live in substandard housing, receive insufficient nourishment, and cannot see doctors for preventive and routine health care, children in poor families

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<sup>3</sup> The term *parent* as used in these standards refers to the child's birth-parent. The terms *foster parent* and *adoptive parent* are used to designate these types of parents. The term *caregiver* refers to a kin caregiver, foster parent, or group or residential staff member with a relationship with the child. The term *health care* is used to broadly refer to physical, mental, and behavioral health, as well as dental and early intervention or developmental services.

face significant risks to their health and well-being. Children who live in substandard housing, compared with children who live in adequate housing, suffer from more acute illnesses such as fever, ear infection, cough, stomach problems, and asthma. When these and other conditions escalate and demand emergency medical attention, treatment of acute illness is often delayed because families do not have health insurance or lack transportation. Even when families have health coverage, they may find it difficult to obtain quality care (Acker, Fierman, & Dreyer, 1987).

Nutritional deficits and food insecurity may further add to children's already existing physical health, mental health, and developmental problems. Families who are poor may reduce portion sizes and skip meals to extend the use of limited food supplies. A 2002 study by the Food Research and Action Center and the Center on Hunger and Poverty (Hamilton & Rossi, 2002) found that families facing economic strain purchase foods higher in fat, calories, and sugar more often than healthier alternatives such as fruits and vegetables because of the higher costs of these items. These practices may have long-term health effects for children. A 2004 report by the Children's Defense Fund indicated that compared with children in food-sufficient households, children who experience hunger and whose intake is so limited that they are considered malnourished are more likely to have a lower level of classroom success, increased behavior problems, and increased mental health problems. Many children who enter out-of-home care arrive with preexisting health conditions as a result of poverty, insufficient housing, and inadequate nourishment.

### **Race and Ethnicity**

Families of color are likely to face added challenges as a result of racial and ethnic discrimination (Hill, 1999; McAdoo, 1998; Padilla, 1997; Scannapieco & Jackson, 1996; Vega, 1995). Children of color are more likely to live in families who experience poverty. In 2001, 30% of black children and 28% of Hispanic children lived below the poverty level compared with 9% of non-Hispanic white children (Proctor & Dalaker, 2002).

Families of color often experience barriers when seeking needed services. Studies show that families of color face significant challenges in accessing needed health care services, often do not have adequate health insurance, receive inadequate health care, and

experience lengthy waits at publicly funded clinics (McAdoo, 1998; Padilla, 1997; San Miguel, Morrison, & Weissglass, 1998; Scannapieco & Jackson, 1996). With respect to health insurance coverage, data indicate that in 2003, 93% of non-Hispanic white children had insurance coverage, compared with 88% of Asian children, 86% of black children, and 79% of Hispanic children (Child Trends Data Bank, 2005).

Immigrant and refugee families may face additional challenges in accessing health care. These families and children, who represent the fastest growing portion of the U.S. population (U.S. Census Bureau, 2001), often experience financial pressures as a result of generally lower levels of educational and occupational status. They may struggle to cope with stresses associated with acculturation, a lack of English proficiency, and, in some cases, issues regarding their immigration status (Padilla, 1997; Vega, 1995). Recent studies suggest that immigrant and refugee families are at greater risk of involvement with public child welfare agencies as a result of these factors (Capps, Ku, & Fix, 2002; Elmelech, McCaskie, Lennon, & Lu, 2002; Legal Aid Society, 2002).

### **Adolescent Pregnancy**

Although rates of adolescent pregnancy have declined in recent years, adolescent parenting continues to pose significant challenges. Between 1991 and 2001, the birth rate for teenagers fell by one-quarter (26%) with declines among all ethnic groups (Martin et al., 2002). Children born to adolescent mothers face increased risks of a range of health problems as a result of greater probabilities of premature birth and low birthweight (Ventura, Martin, Curtin, Menacker, & Hamilton, 1999). Research indicates that these children are at greater risk for developmental problems. One study, for example, found that children of adolescent parents had poorer behavioral and academic outcomes than children born to older mothers (Black et al., 2002).

A study indicates that youth in foster care may be at particular risk of pregnancy as they often lack meaningful relationships and face increased pressure to engage in sexual activity (National Campaign to Prevent Teen Pregnancy and Uhlich Children's Advantage Network, 2006). The study found that although information about sex and pregnancy was offered to youth in foster care, it often was not offered in a timely manner. Furthermore, it

was found that many youth in care saw great benefit to having a child at an early age because it gave them an opportunity to prove that they can be better parents than their own parents had been to them (National Campaign to Prevent Teen Pregnancy, 2006).

### **Parental Mental Health and Substance Abuse Issues**

The prevalence of mental health and substance abuse issues that affect parenting ability has increased dramatically among parents whose children enter out-of-home care. An estimated 26.2% of adult Americans—about one in four adults, or 57.7 million adults in 2004—suffer from a diagnosable mental disorder in a given year (Kessler, Chiu, Demler, & Walters, 2005).

Children whose parents have mental illnesses are at greater risk of developing mental illnesses themselves. The risk further increases when both parents have a mental illness. The risk of the child developing mental health problems is particularly strong when a parent has bipolar disorder, an anxiety disorder, attention-deficit/hyperactivity disorder, schizophrenia, alcoholism or other drug abuse, or depression (American Academy of Child and Adolescent Psychiatry, 2004).

The spread of crack cocaine, methamphetamines, and other illegal drugs over the past two decades has combined with alcohol abuse to bring an increasing number of families to the attention of child welfare systems across the country. In 2001, an estimated 6 million children in the United States lived with at least one parent who abused or was dependent on alcohol or other drugs (Office of Applied Studies, 2003). Parental substance abuse can affect children in three ways: through prenatal exposure to drugs and alcohol, through the effect on children's physical and emotional well-being in the family, and through intergenerational patterns of substance abuse (Bierut et al., 1998; Center for the Future of Children, 1991; Matthias, 1998; Takayama, Wolfe, & Coulter, 1998).

### **Violence**

Societal violence creates an additional stressor for children and their families. Children are exposed to domestic violence in their homes, deliberate and random violence in their communities, and violence as depicted in the broadcast media and on the

Internet. The effect of a child's exposure to violence depends on the child's age, the frequency and type of violence exposure, neighborhood characteristics, community resources, support from caregivers or other adults, the experience of previous trauma, the proximity to the violent event, and familiarity with the victim or perpetrator (Osofsky, 1997). Exposure to violence creates an environment in which children's physical, emotional, and developmental well-being may be compromised. In some situations, children may be seriously traumatized as a result of exposure to violence.

Although domestic violence has received increased attention in the past 15 years, it remains an issue of concern. In 2001, almost 692,000 incidents of nonfatal violence against a current or former intimate partner occurred (Rennison, 2003). The majority of victims (85%) were women (Rennison, 2003). Between 1993 and 1998, almost 70% of intimate partner violence against both men and women occurred in the individual's home. Children younger than 12 years of age lived in 43% of the households where intimate partner violence occurred (Rennison & Welchans, 2000).

Domestic violence can significantly affect parental functioning. It also can play a role in child maltreatment and negatively affect the emotional well-being of children currently and in the future. Parents who are victims of domestic violence need sensitive and skilled support and assistance in addressing domestic violence issues and maintaining their children's safety. Families that have learned patterns of violence need assistance in developing new patterns of interaction. Families also can benefit from mutual support, including victim support groups and more generic parent and youth support groups; assistance in meeting housing, health, and other basic needs; and opportunities to participate in normalizing experiences such as recreation, meals, and social time.

### **The Health Status of Children in Out-of-Home Care**

Studies have documented that children and youth in out-of-home care experience higher rates of physical and emotional problems and that significant percentages of children in care have chronic medical conditions (Simms, Dubowitz, & Szilagy, 2000), developmental delays (Simms & Horowitz, 1996), and mental health problems (dosReis, Zito, Safer, & Soeken, 2001). One study, for example, found that approximately 60% of children in care had a chronic medical condition, and one-quarter

had three or more chronic health problems (Simms et al., 2000). Studies further suggest that up to 60% of preschoolers in out-of-home care have developmental delays (Halfon, Mendonca, & Berkowitz, 1995; Szilagyi, 1998). One study found that children younger than 6 in out-of-home care had higher rates of respiratory illnesses (27%), skin problems (21%), anemia (10%), and poor vision (9%) than the general population of young children (Takayama et al., 1998). In relation to mental health problems, it is estimated that between 54% and 80% of children in out-of-home care meet clinical criteria for behavioral problems or psychiatric diagnosis (Clausen, Landsverk, Ganger, Chadwick, & Litrownik, 1998; Halfon et al., 1995; Urquiza, Wirtz, Peterson, & Singer, 1994). In one study, researchers found that between 40% and 60% of children in out-of-home care had at least one psychiatric disorder and that this population of children used both inpatient and outpatient mental health services at a rate 15 to 20 times higher than the general pediatric population (dosReis et al., 2001). Children's experiences in out-of-home care can significantly affect their health and well-being. Separation from parents and in some cases from siblings, frequent changes in placements and caregivers, and a sense of impermanence and uncertainty about the future can undermine children's physical, emotional, and developmental well-being. Children often hold strong attachments to their birthparents even when they are in out-of-home care for long period periods of time (Poulin, 1985), and parent-child separation can result in children experiencing escalating emotional and behavioral problems. The negative emotional effects on children when they experience frequent changes in placements and caregivers have been well-documented (Annie E. Casey Foundation, n.d.). Children who enter foster care with few apparent health issues may, over time, develop physical, emotional, and behavioral problems that were not evident at the time they entered out-of-home care.

### **Emerging Issues in the Health Care of Children**

The federal initiative Healthy People 2010 was developed to increase quality years of healthy life and eliminate health disparities for all people, with goals to be achieved by 2010, as the initiative's title suggests. Healthy People 2010 identified a number of leading health issues that must be addressed to reach these

goals, some of which, as described in the following, are particularly relevant to the health care of children in out-of-home care. The American Academy of Pediatrics (AAP) also has examined a range of issues affecting the health of children in foster care. The AAP's publications, which include *Fostering Health: Health Care for Children and Adolescents in Foster Care* (2004), *Developmental Issues for Young Children in Foster Care* (2000a), *Health Care of Young Children in Foster Care* (2002a), and *Identification and Care of HIV-Exposed and HIV-Infected Infants, Children, and Adolescents in Foster Care* (2000b), provide essential information on emerging health issues for children in out-of-home care.

### **Infant, Child, and Adolescent Mental Health**

Increasing attention has been brought to infant development and mental health over the past several years (National Research Council and Institute of Medicine, 2000).<sup>4</sup> Over the past several decades, significant attention has focused on early childhood development. An explosion of research in the neurobiological, behavioral, and social sciences has led to major advances in understanding the conditions that influence children's starts in life. These scientific gains have led to a growing appreciation of the importance of early life experiences, as well as the inseparable and highly interactive influences of genetics and environment on the development of the brain and the unfolding of human behavior and the central role of early relationships (National Research Council and Institute of Medicine, 2000). These advances have focused growing attention on the promotion of infant development and mental health (Hawley, 1998; Lederman, Osofsky, & Katz, 2001; Tomlin & Viehweg, 2003).

Of increasing concern in relation to promoting the mental health of children in out-of-home care are the needs of very young children. About one-quarter of children in out-of-home care are younger than 12 months of age. Few, if any, mental health services have been made available to this group of children, largely because the understanding of the effects of maltreatment on very young children is limited (Lederman et al., 2001) and the warning signs of infant and toddler pathology are not well understood

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<sup>4</sup> The term *infant* as used in these standards refers to children younger than one year of age.

(Tomlin & Viehweg, 2003). It is clear from research that infants and toddlers require secure, stable, and nurturing bonds for healthy brain development (Hawley, 2000). This understanding has raised many concerns about the mental health of infants in out-of-home care because their early life experiences prior to out-of-home placement typically do not involve stable, nurturing, and secure relationships with caregivers. Infants and toddlers in out-of-home care may be at particular risk of emotional difficulties and developmental delays (Silver, Amster, & Hacker, 1999; HHS, 2005b).

Increasingly, the mental health needs of school-age children and youth have been the subject of research and professional examination. In the United States, the Surgeon General (2005) estimates that almost 21% of U.S. children ages 9 to 17 have a diagnosable mental or addictive disorder associated with at least minimum impairment. Youth suicide continues to be the third leading cause of death among U.S. youth ages 15 to 24. Yet between 75% and 80% of children and youth do not receive the mental health services that they need (HHS, 1999).

This situation is of particular concern for children in out-of-home care. The AAP (2002a) has estimated that more than 80% of children in care have developmental, emotional, or behavioral problems. The U.S. Surgeon General (U.S. Public Health Service, 2000), in his report on the 2000 Conference on Children's Mental Health and Development, reported that although children and youth in out-of-home care are at higher risk for negative emotional outcomes than the general population, they do not, in general, receive the mental health services that they need, and for some subgroups, mental health service utilization is particularly low. The report analyzed the use of mental health services for different groups of children in out-of-home care and found that children who entered care as a result of sexual abuse were three times more likely to receive mental health services than children entering care after allegations of physical abuse; children and youth who suffered neglect were least likely to receive mental health services; and in comparison to white children, black and Hispanic children and youth received fewer mental health services while in care. Research also has documented that children in out-of-home care need and use mental health services at higher rates than other comparable groups of children, such as children who receive medical assistance but who are not involved in the child welfare system (Simms et al., 2000).

## Use of Psychotropic Medications

The use of prescription psychotropic medications with children and adolescents has been steadily increasing over the past decade. Data indicate that children and adolescents were three times more likely to use prescription psychotropic medication in 1996 than in 1987, an increase found across all geographic regions as well as all age, race and ethnicity, gender, and insurance groups (Olson, Marcus, Weissman, & Jensen, 2002). Concerns have grown about the use of psychotropic medications with children, particularly given the paucity of studies documenting the effectiveness of these medications and the growing body of research that suggests that these drugs may have serious long- and short-term effects on children and youth. Because clinical trials have not been conducted, very few psychotropic medications have been approved by the Food and Drug Administration (FDA) for the treatment of mental health disorders in children (National Institute of Mental Health, 2005). Few studies, for example, have focused on drugs such as selective serotonin reuptake inhibitors (SSRIs) to treat depression and anxiety and other medications used to treat psychotic disorders in children.

In December of 2003, the Medicines and Healthcare Products Regulatory Agency, the British medical regulating body, issued an advisory that the broader class of SSRI medications should not be prescribed to children younger than 18 (Boseley, 2003). In February 2004, the United States initiated an intensive review of psychotropic medications commonly prescribed to children, including SSRI medications. These medications had generated particular concern following several reports of children's suicides while taking them. The FDA's review of cases of nearly 2,200 children being treated with SSRI medications found that none had committed suicide during the course of the treatment. When compared to the group administered a placebo, however, the children being treated with SSRI medications had a higher rate of suicidal thinking and behavior, including attempts (4% compared to 2%; Glass, 2004).

These developments have generated considerable debate regarding the use of psychotropic medications with children. There is agreement that in some situations, the severity of a child's condition justifies the use of psychotropic medications, but concerns continue to be expressed that psychotropic medications are being administered absent a thorough evaluation by a mental health professional

and without careful monitoring by all caregivers throughout the course of medication usage (Olfson et al., 2002). Psychiatrists specializing in the treatment of children advise that psychotropic medication should not be used as the sole treatment for children with mental health disorders (Olfson et al., 2002). It can be expected that the use of psychotropic medications with children will be the subject of ongoing examination (Olfson et al., 2002).

### **Eating Disorders and Nutritional Issues**

Children in out-of-home care may experience eating disorders that place them at serious health risk. Eating disorders affect adolescents with increasing frequency, and currently, they are the third most common chronic illness in adolescent women. Adolescent eating disorders may take one of two major forms: a restrictive form, in which food intake is severely limited (anorexia nervosa), and a bulimic form, in which binge eating episodes are followed by attempts to minimize the effects of overeating via vomiting, catharsis, exercise, or fasting (bulimia nervosa). Both forms can result in serious biological, psychological, and social problems. Eating disorders typically signal problems related to self-concept and self-esteem and problems associated with separation from the family, and they may co-exist with mental health issues (particularly depression and anxiety) and substance abuse (Canadian Paediatric Society, 2004). The treatment of eating disorders may require interdisciplinary approaches that can be time consuming, prolonged, and costly. When such treatment is not available, adolescents may experience increasingly severe physical, emotional, and social problems and, in some cases, even death (Canadian Paediatric Society, 2004).

Children may experience nutritional problems, ranging from undernutrition to being overweight and obesity. Undernutrition generally involves a deficiency primarily of calories (that is, overall food consumption) or protein, a condition that also is likely to include deficiencies of vitamins and minerals. Although in developed countries such as the United States, undernutrition is usually far less common than overnutrition, it does occur, and children in out-of-home care are at particular risk of entering care undernourished and with growth delays. Children whose families are poor, particularly children whose families are homeless, are most vulnerable. Undernutrition also can occur when chil-

dren are very ill and are unable to eat enough food because appetite is lost or their body's need for nutrients is greatly increased ("Undernutrition," 2005).

Being overweight and obesity are health challenges on the rise in all pediatric age groups (Surgeon General, 2006). The terms *overweight* and *obese* are labels for ranges of weight that are greater than what is generally considered healthy for a given height. Both are tied to "body mass index." The terms also identify ranges of weight that have been shown to increase the likelihood of certain diseases and other health problems (CDC, 2005). In 2002, more than 10% of children ages 2 to 5 years were considered overweight. Data from 1999–2000 indicate that 15% of children ages 6 to 11 and 15% of youth ages 12 to 19 were overweight (Ogden, Flegal, Carroll, & Johnson, 2002).

Obesity can be influenced by heredity and the combined effects of race and ethnicity, income, and fast-food restaurants in the communities where children and youth live (Block, Scribner, & DeSalvo, 2004). Obesity is also associated with a lack of physical activity. With regard to children's levels of physical activity, the HHS (2003) recently found that fewer than 40% of children ages 9 to 13 years participate in organized physical activity during non-school hours. Obesity places children at greater risk for health problems. It is associated with increased risks of developing Type 2 diabetes, heart disease, some types of cancer, arthritis, sleep apnea, and gout (Eckel & Krauss, 1998; Loke, 2002). The social discrimination that obese children may experience has mental health implications. Negative responses from peers and others whom the child encounters can significantly affect the child's social and psychological development.

## The Challenges in Meeting the Health Care Needs of Children in Out-of-Home Care

Children in out-of-home care require a range of health care services that promote their physical, emotional, and developmental well-being. The recent CFSR, which was conducted by the HHS and focused on each state's provision of child welfare services, found significant deficiencies in states' provision of health care services for children in out-of-home care.

Based on a review of 50 case records in each state over the period from 2000 to 2004, HHS rated states on a number of factors, including “Well-Being Outcome 3: Children receive services to meet their physical and mental health needs.” Only one state was found to be in substantial compliance with this standard. On average, states met this standard in only 69% of the cases reviewed (90% was required for a determination of substantial compliance). The review process also involved ratings of states in a number of areas as “strengths” or as “needs improvement.” Only half of the states were found to demonstrate a strength in the provision of health care services, with the great majority of those states demonstrating a strength in meeting children’s physical health care needs (20 states) and only four demonstrating a strength in meeting children’s mental health needs. States identified a number of challenges in effectively meeting children’s health care needs: an inadequate number of doctors or dentists willing to accept Medicaid, difficulties coordinating preventive care and conducting timely health assessments, a lack of mental health services for children, and variations in mental health assessments.

Workforce issues also affect the provision of timely and appropriate health care for children in out-of-home care. Many child welfare caseworkers are young, with limited life and professional experience. Workers often manage caseloads far exceeding recommended standards and maintain long hours to meet the needs of the children in their caseloads. Few incentives and high stress often culminate in early burnout for child welfare caseworkers, making retention a significant problem.

The medical and mental health care systems also have struggled to respond to the needs of children in out-of-home care. Health care providers often lack experience in treating the physical and mental health problems that children in out-of-home care experience. Children may arrive for services without medical records or information about their previous health care providers. Many may not have had a primary care physician. Health care professionals may face serious obstacles in obtaining accurate medical histories for children, including information about current and prior medications.

Many of the challenges associated with the provision of health care for children in out-of-home care relate to funding, specifically the constraints posed by the Medicaid program. In many states, providers report very low reimbursement rates and long

waits for payment. In some communities, providers have declined to continue to see patients who have Medicaid as their health care coverage. As the number of providers for children in out-of-home care decreases, access and choice diminish, waiting lists become commonplace, and services are delayed. At the same time, a number of states have mandated that children in out-of-home care shift from fee-for-service Medicaid to Medicaid managed care. These changes in the delivery and funding of health care services have led to concerns that services for children in out-of-home care will be rationed and that services that were already difficult to obtain under the fee-for-service model, particularly mental health services, will become even more difficult to access (AAP, 2002a).

Adding to the funding challenges are other barriers to the timely provision of quality services to children in out-of-home care: distance to providers and lack of transportation, placement changes while in out-of-home care, barriers to information sharing between the health care and child welfare systems, and failures to coordinate the child's health care and child welfare plans.

## Meeting the Health Care Needs of Children in Out-of-Home Care Through a Comprehensive, Community-Based Approach

A comprehensive, community-based approach to meeting the needs of children and families requires a partnership between the health care and child welfare system and effective collaboration and communication among health care providers, caseworkers, children, children's families, and children's caregivers. Children, youth, and families have significant strengths and should be actively engaged in health care planning and services when children and youth are in foster care. They are key partners in promoting positive health outcomes while children and youth are in care and after they leave care. In ensuring the health and well-being of children in out-of-home care, child welfare agencies must form partnerships with children's parents, extended families, and caregivers.

Health care services are essential to the prevention of child abuse and neglect, the identification of child maltreatment, and early intervention. Effective partnerships between child welfare systems and health care systems can promote children's safety and

reduce the risks of child maltreatment. The child welfare system and medical, mental health, and developmental service providers must act in partnership to offer coordinated, continuous, comprehensive, and culturally competent services that involve children's birthfamilies and foster families. Successful partnerships can be achieved through cross-system training and the development and implementation of efforts designed to improve communication and cooperation. Continuity in service is essential, with a focus on preventive and primary health care services, early assessment, and specialized health care services. Integrating the child's health care plan with the child's child welfare service plan (which includes the child's permanency plan), can provide a foundation for service continuity while a child is in out-of-home care. Service integration can help ensure continuity of care after the child leaves care through reunification, placement with relatives, or adoption, or when the child prepares for adulthood. Attention to the continuous provision of quality health care services can prevent the negative outcomes often associated with disrupted care when children must change placements.

In keeping with a broad definition of health care and the focus of these standards, health care for children in out-of-home care must be comprehensive, recognizing the physical, emotional, and developmental needs of each child. Services should incorporate the full range of prevention, early intervention, and treatment services needed to promote the physical and mental health and the developmental well-being of children. Services should be individualized for each child, based on the child's age, developmental level, and health condition. Age-specific services, for example, may include reproductive services for adolescents and early intervention developmental services for infants and toddlers. Care coordination should ensure that services are provided in such a way as to reduce the duplication of diagnostic, screening, and treatment services; ensure that all providers are aware of the child's needs, including the medications that have been prescribed for the child; avoid discomfort for the child; and eliminate unnecessary costs.

Culturally competent health care practices for children in out-of-home care are essential. Children from different racial and ethnic backgrounds and lesbian, gay, bisexual, or transgender (LGBT) youth may have different health care needs, and families who are served by the child welfare system may have different cultural

beliefs and practices that affect the delivery of health care services. Health care services and resources should be matched to children's needs while acknowledging and appreciating differences in customs and traditions in their families. It is essential that the role of family members and caregivers in the child's health care plan be acknowledged.

Several principles guide the provision of coordinated, continuous, comprehensive, and culturally competent health care services for children in out-of-home care:

- The timely assessment of a child's health care status on entry into out-of-home care
- Children's access to comprehensive health care services, including medical, vision and hearing, dental, mental health, and developmental services
- Strong partnerships with children's families and caregivers and with children and youth
- Well-organized and properly administered health care services
- Efficient coordination and communication among the agencies and individuals responsible for children's health and well-being
- Effective collaboration among child- and family-serving systems
- The proper collection, retrieval, and use of relevant data
- Continuous quality assurance processes that periodically evaluate health outcomes
- Education and training for children, families, and professionals on health care issues
- The effective use of resources

## Scope of the Standards

The *CWLA Standards of Excellence for Health Care Services for Children in Out-of-Home Care* describe best practices for the planning, provision, and evaluation of health care services for children in out-of-home care. They address the needs of children for physical, dental, and mental health services as well as developmental

services and describe how out-of-home care providers and child welfare workers, working in collaboration with health care providers, can meet those needs.

These standards describe:

- the principles that provide the framework for the provision of health care services for children in out-of-home care
- the process for assessing the health care needs of children
- the range of health care services that children in out-of-home care may require
- the programmatic components needed for the effective organization and administration of health care services for children in out-of-home care
- the role of community support in ensuring that the health care needs of children and families are met

Chapter 1 defines “health care” and describes the principles underlying and the goals to be achieved in providing health care services to children in out-of-home care. Chapter 2 describes the health care assessment process, providing guidance on initial health assessments, comprehensive health assessments, periodic assessments, and the child’s health care plan. These assessments include physical health, mental health, developmental status, and oral health. Chapter 3 describes the range of health care services that children in out-of-home care need and provides guidance on the provision of these services. Chapter 4 describes the organization and administration of health care services for children in out-of-home care. Chapter 5 describes the important role of the community in supporting the provision of health care services to children and families.

The standards are intended for a broad audience, including public and private child welfare agencies, physical and mental health professionals, administrators, courts, juvenile justice staff, legislators, educators, community members, consumers, family members, and others concerned with building and maintaining healthy children, families, and communities. The standards are complemented by a number of CWLA “best practice” products, intended to build on the standards framework and provide detailed guidance in particular areas of practice. These resources

are listed in the reference section to this volume as well as online at [www.cwla.org](http://www.cwla.org).

In this text, the term *child welfare agency* refers to all child welfare agencies responsible for the care of children in out of home. Depending on the jurisdiction, *child welfare agency* may refer to the public child welfare agency that holds legal responsibility for children or private child welfare agencies that have responsibility for the placement and care of children under contracts with the public child welfare agency.

The AAP periodicity guidelines are referenced in the standards. The guidelines are available online at <http://www.aap.org/policy/periodicity.pdf>.

Other standards are cross-referenced in this text. References to “HC” indicate that other health care standards are cross-referenced in this volume. References to other volumes of standards are also used with the following codes:

- A = *CWLA Standards of Excellence for Adoption Services*
- AN = *CWLA Standards of Excellence for Services for Abused or Neglected Children and Their Families*
- AP = *CWLA Standards of Excellence for Services for Adolescent Pregnancy Prevention, Pregnant Adolescents, and Young Parents*
- FC = *CWLA Standards of Excellence for Family Foster Care*
- FP = *CWLA Standards of Excellence for Services to Strengthen and Preserve Families with Children*
- TIL = *CWLA Standards of Excellence for Transition, Independent Living, and Self-Sufficiency*
- RC = *CWLA Standards of Excellence for Residential Services*

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