



CHILDREN'S AID  
AND FAMILY SERVICES

# *Children's Medical Services & Advocacy Center*



**ACHIEVING THE GOLD STANDARD OF MEDICAL CARE**

**For severely traumatized and medically needy infants,  
children and teenagers in foster care**

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## CHILDREN IN FOSTER CARE DESERVE QUALITY HEALTHCARE

**In 2011, Children’s Aid and Family Services expanded its medical services by launching a Medical Services and Advocacy Center. This has greatly increased the agency’s ability to meet the increasingly complex medical needs of the special needs infants, children and teenagers in its foster care programs.**

The Center’s medical team provides direct medical care, including physical examinations, triage and acute care and treatment. They also perform medical screenings, prevention education, care coordination and advocacy for care and treatment, working as needed with each child’s primary care provider. The Center’s medical team also provides training and support to staff working in the agency’s group homes and to foster and adoptive families caring for children. Staff at the Center also provide vital advocacy for care and treatment on behalf of a large number of children who have been repeatedly deprived access to the type of consistent, high-quality medical care they need.

**The Medical Services & Advocacy Center is located at the agency’s 200 Robin Road building, in Paramus, N.J. Headed by Medical Director, Dr. Anne Armstrong-Coben, it is staffed by a team of three nurses who work in close concert with the agency’s psychiatric, clinical, and child care teams. The Center uses a proactive team approach to working with all involved in the coordination of chronic condition care, coordination of complex services in conjunction with appropriate community-based providers, referrals to specialists, and assistance with transitions – especially to adult services.**

### *Our Commitment to Hope and Healing*

**A sometimes invisible population of children—those in foster care who have special needs—is struggling to receive the medical care they need to heal from their traumatic pasts and live healthy and productive lives.** A confluence of factors, including a lack of Medicaid providers, lost and disjointed health histories, and poor coordination of care among the many systems delivering services to these children, has resulted in a paradigm of medical care in which doctors are often forced to treat children under less than ideal circumstances; without complete records of their immunizations, chronic care histories, or other specialty services, doctors and other health care professionals are left guessing as to why a child may be taking a particular medication or what the best treatment choices may be for that child. Due to the high prevalence of multiple foster care placements, these children are often treated by a seemingly endless stream of medical providers, who never have the opportunity to get to know them and their unique histories (which often include abuse and neglect). In addition, these medical professionals often lack the necessary training or experience in working with children in foster care and understanding their intense needs, making proper diagnoses and treatment even more challenging.

The end result is an entire population of children—unquestionably the state’s most vulnerable children—who are not receiving the consistent, high-quality medical care they need and deserve. Their medical care is fragmented and often crisis-oriented. These children typically come to us with health conditions which are chronic, under-identified, and under-treated, and that will have profound effects on the rest of their lives. Left untreated, many of these health problems (such as chronic asthma) will result in long-term damage. **These traumatized children are the ones most at risk in our society for violence, school failure, teen pregnancy, severe emotional problems and homelessness. The odds are stacked against them, and it is imperative that we be proactive about their futures.**

Committed to providing quality health care to our children, we challenged ourselves to look across our program competencies and emerging research regarding children in foster care with special health care needs to identify a patient-centered model of care that would effectively address their immediate and medically complex needs. We engaged the collective expertise of a volunteer advisory committee, comprised of some of the area’s leading pediatricians and hospital administrators, and it is thanks to their valuable

insight and our dedicated and committed staff that we were able to identify the Medical Services and Advocacy Center (based on the medical home model of care) as the model of choice for ensuring access to consistent, high-quality medical care for the vulnerable children we serve.

**The Medical Services and Advocacy Center, which opened in February 2011, provides these children with the “gold standard” of optimal health care to ensure the *level and intensity* of medical services they need to grow and thrive. In 2012, the Center was selected as just one of eight programs nationwide to receive a federal grant of \$43,745 a year for five years by the Department of Health & Human Services’ Health Resources & Services Administration under the Healthy Tomorrows Partnership for Children program. Aside from this grant, this vital initiative is supported entirely through philanthropy. Since the opening of the Center, we have been fortunate to receive strong support from individuals, foundations and corporations passionate about sustaining our medical program and ensuring that our children receive the medical care and supports they need to recover from their difficult beginnings and lead healthy and productive lives.**

### *Agency Overview*

Children’s Aid and Family Services is one of northern New Jersey’s oldest and largest regional nonprofit providers of human services and child welfare programs. Our mission is to preserve, protect and, when needed, provide families. **In its 113-year history, the agency has placed more than 11,000 children with loving, nurturing adoptive families and assisted thousands of other children with foster care.** Each year, the agency serves approximately 300 children in our eight group and professional parent foster homes, therapeutic family foster homes, foster homes for medically fragile infants and toddlers, and children who reside in other foster homes who are in need of adoption services. Because virtually all of the children coming into the agency’s care have been so terribly wounded, with the majority of them also neurologically impaired, they enter our care with physical, psychological, and developmental disabilities that further disadvantage them. Many of the children have serious behavioral and mental health issues as well as social and learning challenges. Many of them also have chronic medical conditions (often as a result of their histories of trauma, abuse and neglect) and are greatly in need of specialized medical services to provide them with the level, intensity and consistency of medical care needed to help them to heal from their difficult pasts. These children range in age from infants to teenagers, and while their stories are different, they all long for the same thing – unconditional love and a stable “forever” family.

In addition to our services for traumatized children, each year more than 14,000 individuals and families are supported by other community programs supporting at-risk and low-income families. **Children's Aid and Family Services is extremely proud to be among the nation’s elite organizations accredited by the Council on Accreditation for Children and Family Services.** The agency is licensed as an outpatient facility by the New Jersey Division of Mental Health & Hospitals, and all children’s services are licensed by the New Jersey Department of Children & Families. The agency’s 280-member staff, assisted by more than 500 dedicated volunteers, is committed to providing services in a culturally competent and sensitive manner, respectful of the diverse backgrounds of our clients.

### *Statement of Need*

**The extent of the physical and mental health problems facing formerly abused and neglected children in foster care is truly alarming. Research has shown that, nationally, nearly 90 percent of children entering the child welfare system have physical health problems, and more than 55 percent have two or more chronic conditions.**<sup>1</sup> Another assessment of children entering foster care found that an

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<sup>1</sup> L. K. Leslie, J. N. Gordon, L. Meneken, K. Premji, K. L. Michelmore, and W. Ganger. “The Physical, Developmental, and Mental Health Needs of Young Children in Child Welfare by Initial Placement Type.” *Journal of Developmental & Behavioral Pediatrics*, June 2005, v26 i3 p177(9).

estimated 25 percent have three or more chronic conditions.<sup>2</sup> The rates of psychotropic medication use for these youth are significantly higher (ranging from 13-52 percent) than for the general youth population (four percent). **In fact, a Government Accounting Office study recently found that, as a group, children in foster care are sicker than homeless children and children living in the poorest sections of the inner city.**

**Sadly, although they are a uniquely disadvantaged group, access to medical care for infants, children and teenagers in foster care is fragmented, highly inconsistent and difficult to manage.** While some significant strides have been made in recent years in New Jersey to improve the state child welfare system's approach to care, current models of health care delivery fail to properly address the needs of this highly transient and medically complex population. As children move from place to place, often after a period of receiving little or no medical care, they are referred to a mix of providers or clinics that frequently have no knowledge of, or access to, the child's medical history. There is no systematic approach or cohesive system of health care available, nor is there a mechanism in place to identify, recruit and educate the broader medical community on the intricacies of caring for children in foster care. Further, children in foster care usually lack consistent adult support and, consequently, they have no one able to advocate for their medical care. Because they rarely see the same pediatrician or nurse more than once, they never have the opportunity to develop a trusting relationship with a medical provider. Distrust of adults is a significant issue for these children given their histories of abuse and their experience of constant upheaval and uncertainty. Developing a trusting relationship in which there is open dialog about symptoms and feelings is a critical component in achieving appropriate and effective medical care.

**With children in foster care using both inpatient and outpatient mental health services at a rate 15 to 20 times higher than the general pediatric population, the need to implement best practices to promote optimal health for these children has become a critical goal of the child welfare system.**

### *Changing Lives - One Child at a Time*

**The Medical Services and Advocacy Center supports approximately 150-200 infant, children and teenage foster care clients each year. The vast majority of the children and adolescents we serve have both physical and mental health problems, which are inextricably linked and require treatment in a holistic environment, taking into consideration each child's medical, psychiatric and trauma histories. Achieving positive outcomes for our children, given their complex needs, is highly dependent on the effective integration of these services across primary pediatric care, psychiatric services and all other social and health care systems.**

Recognizing that current models of health care for children in foster care fail to provide a cohesive, comprehensive model of care, the staff at the Medical Services and Advocacy Center works in close concert with our on-staff psychiatrists, psychiatric nurse, other clinical staff, community pediatricians and medical specialists to ensure a more comprehensive and integrated approach to caring for our children. The result is consistent, prompt, first-rate care to address their severe medical and mental health challenges.

**Individual child advocacy has led to improved care for our children in a great many cases. In many instances, the lives of the children in our care have been completely transformed thanks to the tenacious investigation, follow-up and interventions of the Center's staff.** Below are just a few examples of the many ways our Center's dedicated and talented staff is helping our children to recover from their difficult pasts and live healthier and more productive lives. These children are representative of the many children in the agency's care with special health care needs.

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<sup>2</sup> L. K. Leslie, M. S. Hurlburt, J. Landsverk, K. Kelleher et al. "Comprehensive Assessments for Children Entering Foster Care: A National Perspective." *Pediatrics*, July 2003.

- **Lamar\***<sup>3</sup>, a young adolescent boy, came to the agency **with a diagnosis of Fetal Alcohol Syndrome**. It was clear that Lamar’s diagnosis, coupled with his difficult behaviors, foretold a bleak future for him, severely narrowing his chances for adoption as long-term developmental and behavioral issues are expected with this type of disorder. **It would be extremely difficult to find a family willing to open their hearts and home to a child with such a dire diagnosis**. Recognizing the need for a thorough and comprehensive investigation of Lamar’s case, the agency’s Medical Services and Advocacy Center staff worked closely with psychiatric staff to track down previous medical records, which they knew would be key to differentiating other abnormal behaviors that might be attributed to Fetal Alcohol Syndrome. Fortunately, the efforts of the agency’s dedicated and talented medical and psychiatric staff paid off, as specialists concluded that **Lamar did not, in fact, suffer from Fetal Alcohol Syndrome**. The diagnosis was eliminated from Lamar’s medical history, and the agency’s staff developed and implemented a more appropriate plan of care to address Lamar’s physical and behavioral challenges. **With this new plan, Lamar’s behaviors and school performance improved significantly and, recently, Lamar found a home with a loving and caring “forever family.”**
- **Kayla\***, a teenage girl living in one of our group homes, came to the agency with multiple ailments, including severe abdominal distress. **She was taking six different medications** prescribed by medical specialists, who were not able to follow-up on her care due to frequent changes in her foster care placement as a result of her behavioral issues. The Center’s staff tracked-down lab work and test results from various locations and analyzed the data. As the picture became clear that previous testing had ruled out the most serious of diagnoses (ulcer, cancer, infectious disease), the Center’s staff consulted with the psychiatric team to refocus efforts on trauma-based behavioral therapy within the residential milieu. Karla’s behaviors improved, her abdominal symptoms subsided, and the need for the prescribed medication was reevaluated by the same specialists (eliminating the need for repetitive testing). Karla is **now stable and taking over-the-counter digestive enzymes, as needed**, and a daily multivitamin. She is progressing well in her work at the group home and in school, and reunification with her family is the ultimate goal.
- **Eddie\*** came into the agency’s care with a **preliminary diagnosis of neurofibromatosis (a genetic disease with significant medical implications)** and possible seizure disorder. After gathering and reviewing all available medical records and liaising with the agency’s psychiatric staff to discuss Eddie’s mental health status and the use of antiepileptic drugs to control both behavior and alleged seizures, it was agreed to have Eddie reevaluated by a pediatric neurologist. Based on the comprehensive health summary compiled by the Center’s staff and a full neurological exam, the neurologist was able to determine that **Eddie was not at risk for either diagnosis and that no further test or work-up would be necessary**.

**As you can see, a key challenge for the agency is that many of the children in our care face severe psychiatric, behavioral, and emotional issues that can exacerbate (and sometimes mimic) existing, often chronic, medical problems. The special challenges of helping these vulnerable children, whose earliest experiences, environments and relationships are not loving and nurturing, but rather what scientists have termed tragically “toxic,” requires the care and expertise of specially trained medical professionals, knowledgeable about the impact of abuse, neglect, and other forms of trauma, and the availability of intensive supports. The Medical Services and Advocacy Center is uniquely designed to provide that expert level of care.**

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<sup>3</sup> \* indicates name changes to protect client confidentiality

## *A Place of Hope and Healing* *The Medical Services & Advocacy Center*

The Medical Services and Advocacy Center builds on the agency's existing medical, psychiatric and behavioral health expertise to ensure access to the full continuum of medical care necessary to help these children on the path to healing. **Just as important, the Center's on-site medical staff, each with a background in working with traumatized children, has become familiar to our children and developed supportive and trusting relationships with them.** The Center is located at 200 Robin Road in Paramus, New Jersey, in a dedicated portion of the agency's administrative offices. The Center occupies a refurbished classroom, subdivided to include consultation and training rooms, an examination area, and a handicap accessible restroom. Operating hours are flexible to accommodate visits after school and in the early evening, and staff is available for home visits as well as emergency on-call telephone support 24/7, as needed.

**The Center is staffed, on site, by a licensed pediatric Advanced Practice Nurse (APN), who works under the supervision of Dr. Anne Armstrong-Coben, a pediatrician and Assistant Clinical Professor of Pediatrics at Columbia University Medical Center. Dr. Armstrong-Coben (affectionately known as "Dr. Annie" to our children) serves as the Center's Medical Director and supervising physician pursuant to a Medical Services Agreement with Columbia University Medical Center.** Her efforts were instrumental in spearheading the new Center and her notable successes in medical advocacy for vulnerable youth have earned her the reputation as one of the area's leading advocates promoting the welfare of vulnerable youth. Dr. Armstrong-Coben formerly served as medical director at Covenant House in Newark, New Jersey, where she helped develop a new medical facility providing quality health care for homeless and at-risk youth. She also served as a medical consultant to New Jersey's Office of the Child Advocate. Dr. Armstrong-Coben received her Bachelor of Arts in 1985 from Amherst College and her M.D. in 1989 from Columbia University, College of Physicians and Surgeons. The other members of the agency's medical team are a part-time Advance Practice Nurse, who works with the medically needy infant and toddler foster care program, and a full-time Registered Nurse, who works with the agency's therapeutic group foster homes. Dr. Armstrong-Coben and the nurses work in close concert with the agency's psychiatric, clinical, and child care staff.

The Center was specifically designed to implement a model of health care commonly referred to as a "medical home." A medical home is not a house, office, hospital or other medical facility, but rather an approach to providing primary care that is accessible, continuous, comprehensive, coordinated, compassionate and culturally effective care. (*American Academy of Pediatrics*) This model of care is endorsed by the American Academy of Pediatrics and the Child Welfare League of America as the "gold standard" of medical care for children in foster care.

**Since opening in February 2011, the Medical Services and Advocacy Center has dramatically increased the agency's ability ensure access to high-quality, consistent medical care to meet the increasingly complex medical needs of the infants, children and teenagers in our foster care programs.** Coordination of health care has been a key focus of the Center's staff, in addition to building an extensive network of relationships with primary care providers, medical specialists and staff at the state's Division of Child Protection and Permanency. The Center's staff oversees the coordination of every aspect of the children's medical care, including helping to ensure that the children are quickly and properly evaluated for placement in our foster homes, that they receive annual medical exams, blood work and other medical tests as needed, and that appropriate specialist treatment is secured and effectively coordinated. The Center's staff coordinates the children's care with community-based primary care providers, advocates on the children's behalf, including case management and placement work with state child welfare providers, and works with insurance carriers and medical providers to change coverage and link children to new providers, as needed. The Center's staff also provides some direct medical care and performs outreach work in the field at the agency's eight group foster homes and in the homes of individual foster families throughout northern New Jersey. As health education is essential to providing effective health care to this uniquely disadvantaged

population of children in foster care, a key function of our Center's staff is also to educate agency employees and the children living in our care about health issues pertinent to the care of infants, children and teenagers in foster care.

**The Center currently provides the following services:**

- Preventive pediatric care through education and anticipatory guidance;
- Hearing and vision screening;
- Immunization screening;
- Direct Medical Care (as more particularly described below);
- A network of referrals to and telephone consults with medical providers;
- Medical advocacy for the children;
- Support for and coordination of care with the existing nursing team and psychiatric team, including comprehensive healthcare case management;
- Support for foster, biological, and adoptive parents as well as agency staff and community providers;
- Collation of information for a health "passport" for each child, to include past medical history as well as ongoing medical diagnoses and treatment.

In March 2012, the agency was granted state approval to provide direct medical care for the children on site at the Center and in our group and individual foster homes. This has greatly enhanced the services we are able to provide to our children. Under this enhanced model of care, the Center's staff is able to provide a comprehensive physical exam and evaluation of each child as he or she enters the agency's care as well as follow-up exams, on a regular basis, depending on need (generally every one to three months initially, and thereafter every six months).

The Center's staff also sees the children for acute care visits (e.g., to evaluate and possibly treat a rash, when a primary care provider is unavailable and an ER visit is not warranted) and writes prescriptions in consultation with the child's primary care provider. The staff's ability to provide direct medical care will not only reduce the number of unnecessary doctor and emergency room visits, but it will serve to strengthen effective partnerships with community primary care providers. Perhaps most importantly, it will serve to foster the establishment of trusting relationships between the children and the Center's staff as well as provide increased opportunities for individualized health education for the children. Direct care services are provided on site at the Center's 200 Robin Road facility and in each of the agency's foster homes, as needed.

***Please Help Us Help More Children Receive the Gold Standard of Care***

*Caring for such deeply wounded children and helping them to heal from their tragic pasts is a formidable challenge. Children's Aid and Family Services is at the forefront of this work and has a well-established reputation for developing innovative and effective solutions to some of the most pressing challenges faced by child welfare professionals. While a major portion of the agency's operating budget comes from a partnership with state agencies, these sources are insufficient to provide the quality and intensity of services necessary to achieve successful outcomes. Our core commitment to assisting foster children traumatized by abuse and neglect and providing them with the integrated supports and critical medical care necessary to ensure their healthy development requires philanthropic support. The annual operating budget for the Medical Services & Advocacy Center is around \$240,000, and with the exception of \$43,745 of revenue from a federal grant, all costs are entirely underwritten by philanthropy.*

***The Medical Services and Advocacy Center promises to transform the way medical care is delivered to our children, allowing us to offer the "gold standard" of optimal care to the severely traumatized infants, children and teenagers we serve. The Center offers an innovative and effective solution to a genuine, long-standing, and systemic problem. An investment in the Medical Services and Advocacy Center helps to ensure that our children receive the high-quality, nurturing pediatric medical care they so greatly need and deserve. Truly, there is no investment with a healthier return.***