

# America's Sickest Children

by Deborah Shelton Pinkney

Fifteen-year-old Delores, who had been in and out of the foster care system since she was six, didn't get an immunization or preventive screening in the nine years she depended on the state of West Virginia for health care. And when her eyeglasses were stolen from the group home where she lived, she didn't get another pair despite declining grades and her repeated pleas. Though she was eligible for free glasses under Medicaid, she still had none a year later, when a lawsuit was filed on behalf of the state's more than 2,300 foster children.

Gilbert, nine, is mentally retarded and autistic. Like Delores, he was eligible for services under a Medicaid preventive-care program, but his foster family was unaware of it. As a result, he went three years without preventive services and two years without a comprehensive physical exam.

Six-year-old Willie had dental problems so severe that some teeth were black while others had holes or were missing altogether. His caseworker knew but apparently did nothing, according to a class action lawsuit filed in April, 1992.

The nation had 442,000 foster children in 1991, more than twice as many as a decade earlier. Until now, their plight has been the domain of social welfare. But the failure of states to provide adequate health care to the Deloreses, Gilberts, and Willies in their custody has created a serious public health problem, say physicians and other child-health advocates.

Through research, litigation, and public education, they are bringing into focus the medical needs of these largely forgotten children. Said Mark Simms, M.D., associate professor of pediatrics at the University of Connecticut School of Medicine, "Health care issues belong in the center of what social-welfare agencies are doing, not on the periphery."

## Dismal Health Status

Children in foster care are far sicker than their peers in the general population, experts say. The high frequency of mental and physical health problems results from a combination of factors: poor health prior to placement, abuse and neglect, the effects of separation and frequent moves, and the lack of access to appropriate services. Health problems range from chronic physical conditions to developmental delays and emotional-behavioral disorders.

"This is the unhealthiest subset of American children that can be identified by any social parameter, said David Chadwick, M.D., director of the Center for Child Protection at Children's Hospital in San Diego. "They are sicker than poor children, homeless children,



and children living in the poorest sections of the inner-cities—unhealthier than any group you compare them to.”

Studies report that foster children have three to seven times the rate of chronic health problems as other Medicaid-eligible children. About a third have at least one chronic condition that affects their functioning, such as asthma, diabetes, or a seizure disorder, Dr. Simms said. They also have higher rates of vision, hearing, and dental problems. Some 15% of the children have birth defects, about three times the national average, according to Dr. Simms. About 15% to 20% are of short stature, compared with a national norm of about 5%. Physicians are unsure what causes short stature. It could reflect prenatal experiences, such as inadequate maternal nutrition or poor maternal health habits that interfered with the normal development of the fetus, or chronic undernourishment and neglect. Dr. Simms has reported that about 60% of preschool-age foster children are developmentally delayed in one or more areas of functioning. And more than half of school-age children perform below age level, with some as many as five grades behind, he said.

Studies also find that about half of foster children have moderate to severe emotional problems. Almost all experience some emo-

## Foster Children More Medically Complex

No national data exist on the health status of foster children. But smaller-scale studies sketch a troubling portrait:

- A 1993 San Diego study of 443 children found 33% had respiratory problems; 26%, hearing loss or otitis; 24%, psychological or developmental disorders; 22%, skin ailments, including bruises and burns; 14%, neurological problems; and 10%, eye conditions, including impaired vision.

- A 1982 study of 339 children in a Baltimore HMO identified 2.3 chronic health problems per child. Only 24% had no identifiable long-term problems. Types of disorders and prevalence: psychological and behavioral, 37%; eye, 35%; learning, 31%; skin, 22%; allergic, 17%; dental, 16%; otologic, 12%; physical growth and developmental, 12%; and musculoskeletal, 9%. Some 43% had been referred to psychiatrists.

- Of Medicaid-eligible children in California in 1988, the 50,000 in foster care were five times more likely to be hospitalized for mental illness. They were most likely, however, to be hospitalized for respiratory conditions, according to a study published in 1992.

- A 1992 Baltimore survey of 407 foster children living with relatives found that only 10% were free of medical problems. About half had one or two disorders, and 39% had between three and six. About 15% of the adolescents had elevated blood pressure. Asthma afflicted 26% of the youngest children and 8% of teenagers, compared with a national average of 5% for all juveniles. One in four foster children age four to five, and one in seven of those six and older, failed the vision test.

- A 1989 study of 113 Connecticut children age six and younger found that 40% had behavioral problems and 35% had at least one chronic medical problem. Of those with medical problems, 61% were delayed in one or more portions of the developmental assessment; 60% of the developmentally delayed were receiving no educational or therapeutic services. The prevalence of short stature was nearly three times higher than among preschoolers nationally.

tional stress from being placed in foster care, but as many as 90% of those who are disturbed have problems unrelated to the separation from their parents, said Edward Schor, M.D., associate professor of pediatrics at Tufts University School of Medicine. About two-thirds have difficulty forming attachments or have eating disturbances, anxiety, or depression.

In California—the state with the largest foster care population, 81,000—public wards represented about 4% of children eligible for Medi-Cal in 1988. But they made up 41% of all users of Medi-Cal mental health services, said Neal Halfon, M.D., M.P.H., associate professor of pediatrics and public health at the UCLA School of Public Health. Often those services were provided in response to a crisis that might have been averted by routine, preventive care.

The failure of state and county agencies to adequately provide and monitor health services comes at a time when children entering foster care are more likely to be physically, sexually, or emotionally abused or neglected than previous generations. A 1988 report by the American Academy of Pediatrics' Committee on Early Childhood, Adoption, and Dependent Care found that “more than 80% of the children in foster care have experienced physical or sexual abuse and/or neglect.”

“The kids who have been coming into the system over the last 10 years are very damaged children,” Dr. Simms said. “Foster care reflects society, and in the mid-1980s we saw an epidemic of homelessness, poverty, drug addiction, and HIV infection.” In addition, the threshold for removing children from abusive, neglectful homes may have risen, as overburdened agencies assume charge of only the most traumatized children—those most likely to have serious health problems, said Dr. Schor, who chairs the AAP's early childhood committee.

### Roots of Problem

Why aren't kids getting care? Authorities say one important reason is the lack of infrastructure to assess children's needs and ensure that quality care is provided. Services are fragmented and inefficient. For example, in San Francisco, with 3,500 foster children, no system ensures treatment of health problems detected during an initial screening, said Carole Shauffer, Executive Director of the Youth Law Center in San Francisco, which has gone to court on behalf of foster children.

“No one ever reviewed the files,” said Shauffer. “Foster parents didn't get the information they needed to make sure the children in their care got the treatment they needed.” The center threatened a suit against the city, but agreed not to sue while officials worked to implement a corrective action plan, she said. The problem is typical of what occurs in other states, Shauffer and other experts say.

“Too often the biological parent isn't a part of the process,” said Dr. Schor, “and you're dealing with a foster parent who may not know the child well and a social worker who is probably overworked and undertrained. Typically it's a child who needs a lot of referrals and you need to coordinate a lot of services.” Frequently there is also a woeful lack of medical information, he added. “Either there are no medical records or what exists is incomplete.”

Nationwide, the Children's Rights Project of the American Civil Liberties Union is involved in nine legal actions in eight states accusing government agencies of failing to provide services, including health care, to foster children. Those accused run the gamut from states and cities with large foster care populations, such as New York City, the District of Columbia, and Philadelphia, to smaller jurisdictions, such as Kansas City, Missouri, and the state of New Mexico.

There have been dozens of similar suits in recent years. One of those is the 1992 suit against West Virginia, filed by the National



Kathy Sloane

Health Law Program. Between May 1990 and June 1992, only 29% of West Virginia children in foster care received services under Medicaid's Early and Periodic Screening, Diagnosis and Treatment Services program, even though all were automatically eligible for such services, said Jane Perkins, a program staff attorney. Fewer than 2% received immunizations and only 11 children statewide received mandatory lead blood level tests. In August, the courts ordered the state's Dept. of Health and Human Resources to put together a remedial plan. "Social service departments certainly care about children's health," said Dr. Schor, "but it's not their top priority and they haven't worked very hard to find or develop health care systems for these kids."

At the provider level, poor reimbursement further hinders access to care. Fewer pediatricians are accepting Medicaid patients. The proportion declined from 85% in 1979 to 77% in 1989. And of those who participated in the program in 1979, 26% limited the number of Medicaid patients they saw, compared with 39% in 1989, according to Beth Yudkowsky, director of AAP's division of health policy research.

Experts agree that the foster care system was never designed to meet the long-term medical, emotional, and developmental needs of children, and is ill-equipped to deal with changing socioeconomic conditions such as the rise in poverty and drug addiction, especially among pregnant women. And, as financially strapped local governments scramble to make ends meet, the attention they pay the medical needs of foster children has declined, said Chris Dunn, former

## Passport to Better Care

Medical record-keeping for foster children is typically poor—hampered by frequent changes in social workers and foster parents, the absence of biological parents who can provide health histories, and the lack of coordination among multiple social services and health agencies. California's San Diego County overcame this problem in 1988 by establishing a computerized "medical-passport" system, which summarizes the health records of an estimated 6,300 children. This is how it works:

- When the Juvenile Court places a child in foster care, the name and identifying information are relayed by computer printout to four passport clerks.
- A clerk contacts the birth parents and uses a telephone interview form to obtain a health history. If birth parents can't be located, foster parents are interviewed.
- A computer-generated passport is mailed to foster parents and social workers. It includes the child's name, date of birth, sex, race, language, birth history, dental problems, height and weight, results of hearing and vision tests, previous health providers, information obtained from school records, and results of any health problem follow-ups.
- Foster parents are urged to bring the passport to all medical visits. Providers complete an encounter form after each visit and return it to the passport office, where it is reviewed by a nurse and entered into the data base.
- A new passport is automatically issued with each change in placement.

Not all passports are complete, however. And the process is not always smooth because it relies on the cooperation of all those involved. "It's an imperfect system, but it does a pretty good job of providing medical records," said David Chadwick, M.D., director of the Center for Child Protection at San Diego Children's Hospital. Dr. Chadwick had the idea for the program, which costs the county about \$240,000 per year, mainly for the salaries of four public health nurses, a social worker, and four clerks.

"This is a method by which we can improve the health of children in foster care," said Rick Clark, who oversees the program for the county. "If we can identify the medical needs and ongoing treatment requirements, we'll be able to do a better job." One drawback, Dr. Chadwick noted, is that the program can't track systemwide medical services utilization or health status. Dr. Chadwick said he plans to work to rectify that problem.

senior staff attorney for the ACLU's Children's Rights Project. "This is something we deal with in nearly every case. Medical needs and medical services are a big problem."

Meanwhile, the demand increases. From 1982 to 1990, the foster care population swelled from 202,000 to 406,000. Its 1992 total of 442,000 represents a 5% increase over the previous year, said Toshio Tataru, Ph.D., director of research for the American Public Welfare Association. And the total number of children served in 1992 was a far higher 659,000, with 238,000 entering care and 217,000 exiting it. By the year 2000, the foster care population is expected to reach 800,000 to 1 million.

### Taking Action

While public agencies grapple with the problem, physicians are moving to turn things around. The AAP is currently revising its Med-

icaid policy "to set parameters for increasing physician participation in the program," a spokesman said. In 1988, the pediatricians' group collaborated with the Child Welfare League of America to develop standards to improve medical services for foster children. These standards have been highly praised and circulated.

In communities, a handful of innovative programs are under way or in the planning stages. "We've made it a goal to make foster care a healing experience and want children to exit in better shape than when they came in," said Dr. Chadwick, who helped develop a computerized "medical passport" for foster children in San Diego County, Calif. Other efforts include specialized foster care clinics, resource centers, and assessment programs for special-needs children, such as those born drug-exposed or mentally or physically disabled.

Dr. Simms, on his own initiative, established a foster care clinic for children six and younger, which ensures a thorough evaluation within one month of placement and every six months while they are wards of the state. And Dr. Halfon is working with a county health task force to set up "a hub" of service providers in Los Angeles County who will ensure access to health care for the 60,000 foster children there. The plan calls for establishment of assessment and service centers at selected local hospitals, linked to a provider network of community-based health and social service professionals.

Child health advocates hope such efforts will pay off with increased support from government and other sources. With the fam-

ily stresses that fuel the need for foster care unlikely to abate, they say, the importance of improved services can only grow.

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## Foster Kids Draft Manifesto of Rights

*by Lisa Margonelli*

A former group home counselor remembers her job ruefully. The "home" wasn't much of a home, she says. The refrigerator was locked and counselors were only allowed to give kids "air hugs" since physical contact was taboo.

As the number of foster care kids in California has nearly tripled to 90,000 since 1984, the state has run out of one-family foster homes. Instead it is placing more and more foster kids with relatives or in group homes—facilities once used exclusively for delinquents.

Now a group of present and former foster youth, called California Youth Connections, has written a Foster Home Bill of Rights aimed at making foster care placements more homelike. Acknowledging that these young people are homeless through no fault of their own, the

