Health Care for Our Troubled Youth: Provision of Services in the Foster Care and Juvenile Justice Systems of California

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HEALTH CARE FOR OUR TROUBLED YOUTH: PROVISION OF SERVICES IN THE FOSTER CARE AND JUVENILE JUSTICE SYSTEMS OF CALIFORNIA

Executive Summary

Lack of access to high quality health care is a problem for most low-income people, but especially for young people in foster care and the juvenile justice system. Furthermore, adolescence is a particularly difficult developmental stage for youth, one requiring special emphasis on health care provision. The lack of adequate early intervention into the wide ranging health needs of many youths contributes to longer stays in foster care and deeper involvement in the juvenile justice system. The purpose of this report is to outline the health care needs and obstacles to health care access for foster care and juvenile justice youths, particularly adolescents, and to make recommendations for improvement.

Needs of Adolescent Youth in the Foster Care and Juvenile Justices Systems

The foster care and juvenile justice systems are populated by largely the same types of children; they are likely to come from low income families, likely to be minorities, and likely to already be suffering from inadequate health care (GAINS Center, 1999). The U.S. Surgeon General reports that low-income people of color have more illness and less access to adequate health care than the rest of the U.S. population (USDHHS, 2001). Minorities, especially African Americans, and low-income youth are represented in the foster care and juvenile justice systems disproportionately to the general population. Importantly, foster care and juvenile justice youth have significantly more medical and mental health problems even than demographically similar youth outside of the systems as well as equal or higher rates of mental illness than youths in the public mental health system (Goldstrom, et al., 2000).

Youth in these systems often have histories of inadequate health care, prenatal exposure to drugs or alcohol, parental substance abuse or mental health problems, abuse and neglect, and high prevalence of co-occurrence of two or more mental health problems, often including substance abuse. Not enough research has been done measuring specific rates of physical and mental illness in these systems. For the foster care population nationwide, estimates of the prevalence of medical conditions range from 30% to 80%, developmental problems from 20% to 61%, and emotional and behavioral problems from 35% to 85%. For juvenile justice youth, it is estimated that at least 10% have a serious medical problem and 75% have some mental, emotional, or behavioral health problem, with at least 20% of these being serious mental disorders.

Obstacles to Health Care Access

Entry into the foster care or juvenile justice system is an opportunity for intervention in the physical and mental health problems which so many of these youth have. It is also an opportunity to set into motion the treatment plans and related services—a continuum of care—that can, if properly executed, help create real improvement in the lives of these young people. The longer health issues go untreated, the more likely youths will return to one or both of these systems, with concomitant social and financial costs. There are many interrelated obstacles that

prevent youths in these systems from receiving the intervention and quality continuum of care that they require and deserve.

Access to health care for youth in and just exiting these systems is typically granted through federal entitlement programs, the costs and implementation of which are shared by the state and county. Youths in custody in the juvenile justice system, however, are not eligible for federal assistance. When federal programs do not contribute, there may be some state funding options, but most of the burden falls to the already cash-strapped counties.

Below market-level reimbursement rates to health care providers, largely determined by the federal Medicaid system, contribute to the lack of quality care and negatively affect the quantity, quality, and variety of services available. Federal programs also suffer from restrictive eligibility criteria and unstandardized, cumbersome application procedures. There can be gaps in coverage as a youth moves in and out of the system and between placements.

The shortcomings of federal and state assistance programs combined with the following make the process by which insurance eligibility is determined, needs are assessed, providers located, appointments scheduled and services provided slow, inefficient, and often unsuccessful.

- Wide variation in the regularity and thoroughness of assessments.
- Unstandardized health assessment tools and procedures.
- Repeated movements between placements.
- Lack of a single care coordinator.
- Low availability of providers and services.
- Inadequately maintained medical records.
- Overcrowding in juvenile halls.
- Lack of specialized training and interest on the part of staff and care providers.

Dental and vision care are very low priorities and usually only emergent cases are treated. It is particularly hard to locate dentists who accept the low rates of reimbursement and who are willing to treat youth with behavioral problems.

Lack of attention to cultural diversity and gender also hinder access. California's cultural diversity can create language barriers and cultural differences in perception and use of medical and mental health systems. Girls, who represent an increasing proportion of the youth in the juvenile justice system, have different medical and mental health needs than boys. In particular, the lack of specialized training for social workers in behavioral issues stemming from abuse disproportionately affects girls.

Recommendations

<u>Federal Programs and Health Insurance</u>. There are several important changes that must be made to entitlement programs to insure access.

• Reimbursements to providers must be supplemented.

- All youths involved in either system, including at first entry and upon exiting, should have "immediate and presumptive Medicaid eligibility" (Laurel, et al, 2001).
- Federal assistance eligibility rules need to be broadened and the process for applying for and maintaining coverage simplified.
- All stakeholders must be made aware of relevant rules and procedures.

<u>Continuity of Care.</u> Establishing and maintaining continuity of care is critical. It requires the smooth intertwining of several factors including insurance eligibility, medical records maintenance and sharing, case management, service provision, agency, provider and family collaboration, prevention and health education, resource management, and the influence of county, state, and federal policies and guidelines. Specific recommendations include:

- Establish a centralized medical information management system.
- Devote a single responsible specially trained care manager for each youth.
- Target health-related assistance and training for youth aging-out of the system.
- Develop culturally competent and gender-specific services and programs.
- Increase collaboration among all agencies and stakeholders.
- Create a centralized location for assessment and treatment.

Finally, a philosophical shift—supported by resources and training—must occur in juvenile justice practice. Instead of responding punitively to behavioral problems and "acting out," such behavior should be considered opportunities for needs identification and intervention.

<u>Research and Dissemination of Information.</u> Collaborative planning based on accurate data must be the cornerstone of the reform effort. Specific recommendations include:

- Conduct more research on the cultural, ethnic, gender, and socio-economic differences in access to health care.
- Collect accurate medical, mental health, and dental needs data.
- Evaluate the impact of model programs.
- Perform and regularly update an assessment of best practices in health care provision to assist all stakeholders—youths, parents, staff, providers, administrators, and lawmakers.

Using the data gathered, a comprehensive collaborative planning model should be implemented whereby key stakeholders in each local system develop a comprehensive county-level strategy and plan for providing a high-quality continuum of care that incorporates all available county, state, and federal programs.

Finally, to make systemic change, local, state, and federal policymakers and the public must be informed of the crisis in health care for our neediest young people. Education is vital to the proper policies and practices being put into place to break the cycle of out-of-home placements, school failure, and criminal behavior.

HEALTH CARE FOR OUR TROUBLED YOUTH:

PROVISION OF SERVICES IN THE FOSTER CARE AND JUVENILE JUSTICE SYSTEMS OF CALIFORNIA

"We are looking at a population who unfortunately seem to have a career pathway through the multiple public service systems, with the ultimate destination of the juvenile justice system. This career pathway begins with the identification of mental health needs by a child care teacher at age 5. It continues with a referral for special education at age 7, interaction with mental health and child welfare at age 9, a placement out-of-home at age 11, and inpatient psychiatric hospitalization at age 12. The career pathway concludes with involvement in the juvenile justice system at age 14. Not only does this alarming pathway point to the many failed opportunities for intervention...also shows that by the time a youth reaches Juvenile Probation, he/she is likely to have already experienced years of abuse, neglect, trauma, poverty, failed services, and institutional bias." (San Francisco Juvenile Probation, 2001)

INTRODUCTION

Children entering the foster care and juvenile justice systems often have a history of inadequate health care, prenatal exposure to drugs or alcohol, parental substance abuse or mental health problems, and abuse and neglect. It is also increasingly common that the physical or mental health conditions expressed by these youths are of such magnitude that they stretch their caregivers' ability to provide appropriate care. Our lack of adequate early intervention into the wide ranging health needs of many youths all too often leads them into deeper involvement in the juvenile justice system.

Lack of access to high quality health care intervention is a problem for all low-income people, but especially for young people in foster care and the juvenile justice system. Their needs are unique for four main reasons: 1) issues related to their usually abrupt entry into foster care or juvenile justice, 2) the high prevalence of a broad range of health conditions coupled with histories of inadequate care prior to entering the system, 3) the lack of a single party responsible for the coordination of each youth's treatment, and 4) the common occurrence of these youths moving between multiple placements within short time periods and with poor coordination (Laurel, et al., 2001).

These youths interact with a combination of several large and complicated systems: medical, mental health, social welfare, juvenile justice, education, and others. Understanding this complicated system is essential to understanding the problems of access to health care and to determining the steps necessary to begin solving these problems.

The intent of this report is to outline the health care issues for foster care and juvenile justice youths and make recommendations for improvement in the systems. The goals are to

briefly describe 1) the health care needs of youths, especially adolescents aged 12-17 years, in the California juvenile justice and foster care systems, 2) the processes by which these youth gain access to the medical, mental health, and dental services they need, 3) the steps of this process that are successful and the steps that require improvement, and 4) recommendations for making those improvements. In addition to reviewing the available literature and national, state, and county data, we interviewed representatives of the juvenile justice system, foster care system, and health care providers from five California counties (Orange, Sacramento, San Diego, San Francisco, Santa Cruz, and Sutter) as well as representatives of the state government in Sacramento.

Unique Needs of Adolescents in the Foster Care and Juvenile Justice Systems

Adolescence is a particularly difficult developmental stage in these systems for several reasons. First, the problems of adolescents are often neglected because child welfare systems often see older children as beyond hope or beyond their scope. One health care provider reported that, for both health assessment and treatment, the focus in the foster care system is on the younger child, especially those under 12, because "there is a presumption that the older children can more handle themselves." However, according to National Child Abuse and Neglect Data System (USDHHS, 2000), approximately one in four children for whom child protective services substantiated a report of abuse or neglect were between the ages of 12 and 17. This represents approximately 246,000 teenagers every year. While adolescents make up 25% of all substantiated maltreatment cases, about 40% of substantiated sexual abuse cases and 35% of physical abuse cases were for youths aged 12 and over. Also, it is likely that abuse and neglect of adolescents is underreported due to the age of the victims.

Second, juvenile justice and foster care youth of this age are on the cusp of adulthood and are aging-out of these systems. They require special preparation for attending to their own health care needs. Additionally, in terms of criminal behavior, older children who are accused of more serious crimes are treated as adults in many jurisdictions around the country. In most states, these youths "age-out" of the juvenile justice system at age 14 or 15.

Third, developmentally appropriate behaviors such as risk taking, struggles for independence, physical changes, and sexuality intersect with physical, mental, and emotional problems a youth might have. All this happens to adolescents at a crucial time when educational trajectories are paramount and the paths to adulthood are taking shape.

Fourth, the public is generally fearful of teenagers, and acting out behavior is not tolerated. Zero tolerance policies in schools don't allow for youthful indiscretions and push more youth into the juvenile justice system. Simultaneously, foundations of the juvenile court are being eroded as more and more youths are processed in the adult criminal justice system, where what commitment to rehabilitation exists in the juvenile system is nearly entirely replaced with punitive approaches.

Finally, adolescents are more likely to be victims of crime than any other age group. The number of youth who are the victims of crime is also influenced by socioeconomic factors in the communities where youth live prior to, during, and after juvenile justice or foster care placement. Rates of victimization can also illustrate the risks and stresses with which these youth are forced

to cope and for which health care providers need to be prepared to assess and treat. Overall rates of teenage victimization (including property crimes) vary little by race. However, the racial differences in the rate of violent victimization are considerable, according to the National Crime Victimization Survey (USDHHS, 2000). For example, in 1999, victimization rates involving rape, sexual assault, simple assault, and aggravated assault were 37% higher among African American youths 12-19 years of age than white youths of the same age. African American youths were almost twice as likely (92% higher rate) as white youths to be victims of aggravated assault.

Unfulfilled Standards of Care

The American Academy of Pediatrics and the Child Welfare League of America have each developed health care standards for youth entering foster care which include an immediate physical exam, a comprehensive multidisciplinary assessment within one month, and periodic reassessment. Federal entitlement programs have guidelines for the assessment and treatment of covered youth, but the specific procedures and services available are determined by each state. In theory, California abides by the federal guidelines of Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) and the American Academy of Pediatrics (AAP) for periodic assessment. California also extends coverage beyond Medicaid with Child Health and Disability Prevention (CHDP) and Healthy Families. However, as described below, access to services is often difficult, continuity is a large problem, and the quality of care suffers.

Having standards of care does not guarantee that those standards are upheld. This is particularly the case for the underserved and overlooked adolescent in the foster care and juvenile justice systems.

OVERVIEW OF THE FOSTER CARE AND JUVENILE JUSTICE SYSTEMS

In terms of the histories and needs of youths, the foster care system and juvenile justice systems in this country are populated by largely the same types of children: they are likely to come from low income families and communities, likely to be minorities, and likely to already be suffering from inadequate health care (GAINS Center, 1999). The U.S. Surgeon General reports that low-income people of color have more illness and less access to adequate health care than the rest of the U.S. population (USDHHS, 2001). African American, Latino, and low-income youths are each overrepresented in the foster care and juvenile justice systems throughout the country. Importantly, foster care and juvenile justice youth have significantly more medical and mental health problems even than demographically similar youth and have similar needs and rates of mental illness as youths in the public mental health system (Goldstrom, et al., 2000). Young people in these systems have enormous health care needs that are barely being addressed.

There are differences among the youths in these two systems. The majority of foster children are under 12 years of age, while the juvenile justice system is essentially entirely made up of youth over 12. Another difference is that juvenile justice youth are not eligible to receive the predominant source of health care coverage, Medicaid/Medi-Cal, while they are incarcerated.

These and other differences certainly lead to variation in access issues between these two systems; such differences are noted as applicable in the report. However, the two groups have more in common than they have differences. In fact, many cycle through both systems each year and are thus literally the same youth. The interconnection of the two systems is further illustrated by the fact that approximately 6% of children in foster care are supervised not by child welfare but by juvenile justice probation officers (CDSS, 2001).

California Foster Care

The foster care system in California is administered by county welfare departments and funded by federal, state, and county governments. Federal and state laws apply, but individual counties make decisions about the health and safety of children, including whether to remove children from their parents' custody. Counties are overseen by the state Child Welfare Services system (CWS; part of the Children and Family Services Division of the Department of Social Services).

Foster care is considered a temporary, not a long-term, solution for abused or neglected children. The foster care system is intended to provide a safe environment for the child while his or her parents attempt to resolve the issues that led to the child being removed from the home; the goal is a permanent reunification of the family or, only if that proves impossible, adoption. Approximately three-quarters of youth in foster care are eventually returned to their homes and parents. However, these young people often spend large portions of their young lives in foster care. The median length of stay for children who entered the system between 1998 and 2000 and have since left was 19 months; 75% left care within 37 months.

On July 1, 2001, there were a total of 96,444 children in the California foster care system between the ages of 0 and 18 years. This represents a 35% increase from the 71,291 children in foster care on the same date in 1991, although the number of foster children has been dropping since a high point in 1999. In terms of prevalence, the current rate per 1,000 children in the total state population is 9.3, while in 1991 it was 8.3. Of the total number in 2001, 43.7% (42,377) were between the ages of 11 and 18. Ethnicity and age proportions, including the disproportionate representation of African Americans, are in Table 1. African American adolescents are represented in foster care at even higher rates than young children. During 2001, 32,098 youths entered foster care for the first time, with 25% (8,147) of these between 11 and 17 years of age. Also, California has a higher than average proportion of youth in foster care compared to other states. (CDSS, 2001; Needell, et al., 2002.)

Table 1: California Foster Care System Caseload: One-day Snapshot, July 1, 2001

		Ages 0-1	8	Ages 11-18			
Ethnicity	N	%	Prevalence per 1,000 in State	N	%	Prevalence per 1,000 in State	
African American	33,221	34.2	44.7	15,897	37.5	51.9	
Caucasian	27,405	28.2	6.9	12,316	29.1	7.1	
Latino	32,719	33.7	7.4	12,723	30.0	8.5	
Asian	1,890	1.9	1.5	829	2.0	1.7	
Native American	1,234	1.3	23.0	510	1.2	21.6	
Total	97,024		9.3	42,377		10.5	

(Due to missing ethnicity data, columns will not sum to 100%.)

Source: University of California at Berkeley Child Welfare Research Center (Needell, et al., 2002)

Foster care out-of-home placements fall into two types, voluntary (where parents agree to give temporary custody of their child to the county) and petitioned (where a court orders that the child be removed from the parents). For either type, foster children may enter into a variety of placement settings, including a foster family related to the child (accounting for 38% of total California caseload in July, 2001), non-relative foster home (17%), foster family agency (20%), group home (8%), court-appointed guardian's home (7%), pre-adoptive placement (4%), other placement (5%), or classified as runaway (less than 1%). Group homes generally serve foster children with emotional or behavioral problems that require more intensive supervision and a more restricted setting; they vary in size from small, family-like settings to larger institutional facilities (LAO, 2001). Alternatives to group homes, foster family agencies (FFAs) are state-regulated, non-profit community agencies that recruit, train, and support foster parents who care for foster children that require more specialized care.

The California Legislative Analyst's Office (LAO, 2001) reports total expenditures for foster care in 2000-01 were over \$1.5 billion. Federal funding of foster care nationwide in 2001 was \$5.1 billion. State costs are shared by federal (50%), state (20%), and county (30%)

i "Group homes provide the most restrictive out-of-home placement option for children in foster care. They provide a placement option for children with significant emotional or behavioral problems who require more restrictive environments. The licensed group home is defined as a facility of any capacity which provides 24-hour non-medical care and supervision to children in a structured environment, with such services provided at least in part by staff employed by the licensee. Group homes run the gamut from large institutional type environments which provide an intense therapeutic setting, often called "residential treatment centers," to small home environments which incorporate a "house parent" model. As a result, group home placements provide various levels of structure, supervision and services. Group homes may offer specific services targeted to a specific population of children or a range of services depending on the design of their program. These services include substance abuse, minor-parent (mothers and babies), infant programs, mental health treatment, vocational training, mental health day treatment, sex offenders, wards only, emancipation and reunification." (CDSS, 2001)

governments.ⁱⁱ These figures do not include most health care costs, which are very difficult to estimate. Also, the LAO figures are understated because they are based on a caseload of 78,000, which does not include CalWorks funded foster care even though it is administered under the same system.

To reverse major increases in the number of youth in foster care and, in particular, the trend towards ever younger children staying in the system for increasingly longer periods, important legislation and various programmatic efforts have been implemented to increase adoptions and to assist parents and families at risk of losing custody of their children. Services provided include mental health, substance abuse, and parenting skills training. Foster care caseloads have been decreasing and although decreased caseloads allow caseworkers to place more emphasis on such things as health care provision, no evidence was found to show these efforts have affected health care access for foster care youth (AAP, 1994). However, the description of California's Child Welfare Demonstration Project illustrates both the renewed emphasis on providing the services necessary for long-term solutions to problems that lead to out-of-home placement for youth, and the interconnection of the foster care and juvenile justice systems: "This project was designed to promote permanence for children and families, divert some children from the overwhelmed and often overwhelming juvenile court systems and reduce the number of children in dependency status." (CDSS, 2001)

California Juvenile Justice

Juvenile justice is a county administered system, with the California Board of Corrections (BOC) as the state-level oversight agency. Youth incarcerated in the juvenile justice system at the County level are typically housed in one of three types of facilities: 1) juvenile halls which are designed to be temporary intake and processing facilities to house youth while they are going through the adjudication process and in some cases while they are serving court ordered detention, 2) camps or ranches which are facilities where youths serve their court ordered detention, and, 3) alternative detention which can include community residential facilities or home detention. Additionally, juvenile justice-involved youth may be placed in home supervision (with or without electronic monitoring). Fifty-three California counties operate juvenile facilities, including 51 juvenile halls, 6 special purpose halls, and 59 camps, ranches, and boot camps. Finally, children who have committed the most serious crimes or who have not been successfully placed at the county level usually become the wards of the California Youth Authority (CYA).

Juvenile detention (or juvenile hall) is a gateway into longer placements in the justice system and therefore is a critical point for assessment and intervention. The most recent year for which complete juvenile detention data is available for California is 2000. Based on the monthly average, 126,312 youths were booked into juvenile halls, typically the first point of entry into the

The rates per child paid to the caregiver by the state vary in each of these settings mainly according to the age of the child (the older the child, the higher the rate), but also according to the individual needs of the child, the cost of living in the area, and other factors. The monthly rate range reported on the LAO website is \$405 to \$569 for foster family homes, \$1,467 to \$1,730 for FFAs, and \$1,352 to \$5,732 for group homes. Foster family homes are also eligible for supplemental rates if their foster child has special needs.

system. Because the total number of bookings can include multiple bookings per individual, the most accurate illustration of the number of youth in the juvenile system is a one-day average (based on the average per day per month). In 2000, the daily average was 14,216 youth in some form of detention. Of these, 50% were in juvenile halls, 31% were in camps or ranches, and 19% were in alternative placements, including serving their detention at home under the regular supervision of a probation officer. These estimates of youth in detention do not include two important populations, youth detained by the CYA, and youth in the community on juvenile probation. Currently, there are approximately 7,000 young people housed in the 11 CYA facilities across the state. On an average day in 1993 (the most recent year of statewide data), there were approximately 53,000 youth on probation or parole (but not detained) in California. (BOC, 2000a.)

Although a decade ago girls represented a very small percentage of the total juvenile justice population, in 2000 they represented 16% of the juvenile hall population and 14% of detained youth overall (BOC, 2000b). As discussed below, the growing population of girls has particular medical and mental health needs to which the system has been slow to respond. Figures for the ethnic breakdown of detained youth vary by county.

Tables 2 and 3 describe the numbers and characteristics of youth in the juvenile justice system for the State of California and for the particular counties where interviews and information gathering was performed for this report.

Table 2: Age of Youth in County Juvenile Halls, Camps and Ranches* in California, 2000

Age	N	%
0-11	30	0.3
12-14	1,457	12.6
15-17	8,524	73.7
18+	1,548	13.4
Total	11,559	100.0

^{*}Based on Average Daily Population

Source: California Board of Corrections Juvenile Detention Profile Survey (2000)

Table 3: Characteristics of Counties Focused on in this Report (2000, except where noted)

	California	Orange	San Diego	Sacramento	San Francisco	Santa Cruz	Sutter
Setting	All	Mixed	Mixed	Mixed	Urban	Mixed	Rural
Total Population	33,871,648	2,846,289	2,813,833	1,223,49	776,733	255,602	78,930
Youth Pop. (0-18)	9,249,829	768,419	723,661	337,602	112,802	60,741	22,869
Foster Care*							
Total Caseload, July 1, 2001 (0-18)	96,444	4,206	6,994	5,651	2,330	314	252
Juvenile Justice**							
Detention Daily Average Pop.	14,216	892	933	683	190	56	na
Total Juvenile Arrests	243,090	15,528	20,171	8,084	3,069	2,034	502

Sources: *University of California at Berkeley Child Welfare Research Center (Needell, et al., 2002); **BOC, 2000a

PHYSICAL AND MENTAL HEALTH CARE NEEDS OF YOUTH

Estimates of the prevalence of medical conditions in the foster care population nationwide range from 30% to 80%. The most common problems include asthma, vision and hearing problems, malnutrition, skin abnormalities, dental problems, anemia, and failure to thrive. Estimates of the prevalence of developmental problems, such as language disorders, poor social-adaptive skills, learning disabilities, and cognitive impairment, range from 20% to 61% of foster care youth. Emotional and behavioral problems are also prevalent, with estimates ranging from 35% to 85%, although many psychologists and social workers believe nearly all foster care children are in need of some level of psychological response. If nothing else, some argue, the events immediately surrounding the children's placement in social services custody—e.g., the police raiding their house, the sight of their mother or father handcuffed and brought away, the trauma of separation from their home-life and community, even if abusive or neglectful—is a traumatic experience that needs an immediate response. (Laurel, et al., 2001)

There have been fewer generalizable studies of the rates of medical problems in the juvenile justice system, but data collection at the county and state level is improving, and estimates are emerging from reviews of studies of certain jurisdictions. A study of youth entering the juvenile justice system in a large city in the southeastern U.S. found that 10% of the youth had a serious medical problem (not including substance abuse or sexually-transmitted diseases) that required further treatment (Feinstein, 1998). Only one-third of the studied youth reported a regular source of medical care, and just one-fifth had a private physician.

Significantly, less than half of the families of the youths with serious medical problems were judged able and willing to take the steps to necessary get treatment for their child.

In studies of juvenile justice youth the most attention has been given, and necessarily so, to mental, emotional, and behavioral health problems. Generally speaking, the rates of mental health problems are alarmingly high. Many studies document rates not only greater than demographically similar youth in the general population, but rates often similar or greater than non-juvenile justice-involved youths being treated in the mental health system (Atkins, et al., In Press). The Center for Mental Health Services produced an excellent review of the literature regarding the health care needs of juvenile justice youth nationwide (Goldstrom, et al., 2000). They report that up to 75% of juvenile justice-involved youth have some mental, emotional, or behavioral health problem and that at least 20% of these are serious mental disorders. Some of their findings for juvenile justice youth include:

- a greater prevalence of mental disorders than in the general population and in community settings
- 50-90% have conduct disorder, the most common mental health problem
- up to 46% have attention deficit disorder
- 6-41% have anxiety disorders
- 32-78% have affective disorders
- 1-6% have psychotic disorders
- 25-50% have substance abuse disorders
- at least 50% have dual diagnoses, such as conduct disorder with ADHD, post-traumatic stress disorder (PTSD), or affective disorder
- 25-32% have been abused
- 6-28% have attempted suicide
- 12-26% have had psychiatric hospitalization
- 38-66% have had outpatient treatment for mental health problems

The co-occurrence of substance abuse disorders and other mental health problems is of particular concern. A study in Georgia found that up to 66% of incarcerated youth who have a substance abuse disorder also have at least one other mental disorder, and almost one-third have a mood or anxiety disorder. These rates of co-occurrence are often higher than among non-juvenile justice-involved youth and put the youth at greater risk for poor outcomes such as recidivism, out-of-home placement, and hospitalization (Marstellar, et al., 1997). Stress (such as being removed from home) and exposure to violence can also be factors that affect both the symptoms of mental health disorders and greater drug use. A 1998 study (Steiner, et al.) found that 49% of girls and 32% of boys incarcerated by the CYA met full diagnostic criteria for PTSD.

Other studies have shown that in over 80% of the cases of co-occurrence of substance abuse and mental disorders, the mental problem preceded the addictive behavior. This fact suggests that the drug use may at least start as a result of the mental illness before it becomes a

problem unto itself (USDHHS, 1999) and that timely and appropriate treatment, beginning with a comprehensive assessment upon entrance into the system, could forestall the addiction and its related poor outcomes. These relationships also have ramifications for treatment, case management, and aftercare of both the mental disorder and the substance abuse disorder.

The BOC (2000) reports the following daily averages in 2000: 1,097 youth detained in the County juvenile justice systems were taking psychotropic medication, and 1,753 were identified as requiring mental health services; these numbers represent 8% and 12% of the average daily population of detained youths. Also, there were a total of 878 attempted suicides by youth in custody in 2000.

As part of NCCD's Structured Decision Making assessments for the social welfare systems in two California counties (one large and one small county), case workers were asked to what extent the youth (age 0-18 years) for whom they were responsible had various needs. Twenty-five percent of foster care youth in the larger county and 42% of those in the smaller county were reported to have at least some emotional adjustment problems. Approximately 7.5% in both counties were reported to have at least somewhat impaired functioning due to medical or physical problems, and 8% in both counties were reported to have at least occasional delinquent behavior.

SYSTEM STRENGTHS AND DEFICIENCIES

Although specifics differ between the two systems, the juvenile justice and foster care systems share a set of interrelated obstacles to health care access for the youth they serve. These issues can be categorized into several subject areas, including insurance and entitlement programs, assessment, case management and responsibility, availability and coordination of services, medical records, health education and information dissemination, and staff training.

Entitlement Programs

Few youths in juvenile justice or foster care are covered by private insurance. Consequently, access to health care for youth in or just exiting these systems is typically granted through federal entitlement programs, the costs and administration of which are usually shared by the state and county. When these programs do not cover costs, there may be some state funding options, but most of the burden falls to the counties. The major programs of public funding for health care are briefly described below.

<u>Medi-Cal</u> (called Medicaid at the federal level) is implemented by states under federal guidelines. Medi-Cal provides comprehensive health insurance for low-income families in which the head of the family is either a single parent or unemployed. Federal law has certain minimum requirements, such as hospital care and certain physician services, while other services are left to the state to determine (Bazelon Center, 2001).

<u>Healthy Families</u> (called Children's Health Insurance Program [CHIP] at the federal level) began in 1998 and provides comprehensive health insurance for otherwise uninsured children of low-income families (those with an income of less than 250% of federal poverty level

or \$36,576 for a family of three). The program is growing but historically has had poor penetration into the population it is designed to serve, partly because the process of applying is confusing even to health care professionals, and reconfirmation of eligibility is required each year. Some streamlining has been done, but more is needed. The eligibility period was only recently extended to one year and needs to be extended further. Together, Medi-Cal and Health Families serve 3.6 million low-income families in California (Institute for Local Government, 2001).

Child Health and Disability Prevention (CHDP) is based on the federal Early and Periodic Screening, Diagnosis, and Treatment (EPSDT). CHDP was established in 1973 to provide preventative health screenings and immunizations to Medi-Cal recipients from birth to age 21 and Medi-Cal ineligible, low-income (less than 200% federal poverty level) children from birth to age 19. Upon entry into the foster care system, all children are eligible for an EPSDT screening and follow-up services. California requires that foster children receive re-screening every two years, though some counties require it every year. Local health departments usually have a nurse on staff who administers CHDP, including provider recruitment, assistance with medical appointments and transportation, filing of claim-reimbursement forms, outreach, and health education (LLWA, 2000). In recent years, Medi-Cal and the Healthy Families program have provided a broader range of these types of services, so CHDP has been moving toward being more of a "gateway" to assure access to assessment and health care through Medi-Cal and Healthy Families (LAO, 2001).

Other funding exists for services related to targeted needs, such as life-training programs for aging-out youth. The Independent Living program provides federal funding to states for education, employment and life-skills training, housing assistance, counseling, and access to healthcare for aging-out youth of 16 to 21 years of age.

Even when youth in these systems are covered by private insurance, health care services to meet their complex needs are not always sufficiently covered. For example, many insurance policies limit therapy sessions to 20 per year. Many professionals consider this number to be not nearly enough for a youth who has an ongoing mental health problem and to be especially inadequate for youth diagnosed with co-occurring disorders.

Determining Eligibility

Because the federal and state programs can pay for upwards of 70% of the costs of providing care to youth in the social welfare system, determining eligibility for state and federal funds is a high priority for counties when a youth is first removed from the home. Eligibility status determines not only who will pay but what services the youth will receive. For instance, a youth is more likely to receive a comprehensive assessment and subsequent treatments if the county can be reimbursed by the EPSDT/CHDP program for 70% of the costs rather than paying the entire bill from its general fund. Furthermore, counties using EPSDT/CHDP funds must follow the mandated assessment guidelines. Many counties, especially smaller ones, do not have similar requirements for services they pay for themselves.

In practice, counties perform a sort of step-down process by which they determine the highest level of eligibility. The basic steps include:

- Determine if the adult from whom the youth was taken (not necessarily the parent) was receiving federal assistance at the time of the removal. If so, the child is most likely eligible for the same coverage. For instance, if the adult was receiving Medi-Cal, coverage for the child can most likely continue under the same plan. If the adult was receiving federal assistance on behalf of the youth, such as SSI, then those payments can be collected into a trust fund in the youth's name and be used for such things as payment for services the youth receivesⁱⁱⁱ. (Maximum limits on the value of those trust funds were recently raised to approximately \$10,000.)
- If a youth is not eligible for a federal program, he or she may be eligible for a state program, such as State Therapeutic Option Program (STOP) coverage, which is a pool of funds designed to provide some services to youths not eligible under Medicaid. This program has limited resources, still requires substantial matching funds from the county, and not all counties are even aware of its existence (Interview).
- If no state programs can be accessed, health care coverage is funded through each county's general fund. Counties make attempts as often as possible to establish their own rate agreements with providers, and county budgets rarely allow for rates higher than Medi-Cal's. Some health care treatments, especially those related to developmental disorders, can be funded through other agencies such as the Department of Education, and some services can be accessed through targeted programs.

To pay for health care coverage, counties access state and federal funds through complicated systems and processes. Many California counties, especially smaller rural counties that may have as few as four full-time staff to administer their social welfare system, are forced to spend their limited resources in other ways. For these counties, it is literally cheaper to take the money from the county general fund than it is to pursue state and federal assistance.

Another technique used by large and small counties that want to make the most use of federal and state programs was referred to by one foster care system administrator as "creative financing." For instance, EPSDT/CHDP will generally pay for follow-up treatment for new illness revealed during an EPSDT assessment, but not for pre-existing illness. System administrators and providers have some discretion about what is considered a symptom of a pre-existing disorder and what is a new diagnosis. This discretion can create a dilemma. If an administrator accesses state and federal dollars to relieve the county general fund of a financial burden, the result could be a multiple diagnoses label in the youth's permanent record, which may adversely influence the youth's future treatment and placements.

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iii It should be noted that the loss of assistance to adult guardians can lead to hardships, such as less access to health care or homelessness, which further reduces the adult's ability to aid in providing care for the youth, including providing medical histories, providing consent for medications and medical procedures, or participating in family-based services.

Low Rates of Reimbursement

Medi-Cal's reimbursement rates are so low that it is difficult to locate providers who are willing to see patients without private insurance, especially in subspecialties in adolescent care. Those that will see youths on Medi-Cal often provide a lower quality of care and can refuse service to the more difficult youth (Interview). This problem is particularly severe for juvenile justice youth identified as having behavioral problems. One chief probation officer called the system "a provider's market" where youth who are perceived (rightfully or not) as problematic are refused service or are returned to juvenile hall from therapeutically oriented placements after relatively minor acting out.

In the last several years, Medicaid, to reduce costs, has changed from a predominantly fee-for-service system to one based on the managed care system. Prior to the Balanced Budget Act of 1997, fee-for-service was the norm and special waivers were required for states to enroll their beneficiaries in managed care plans. Although the implementation of managed care varies from state to state and, in fact, from county to county, by 1999 over 50% of all Medicaid users were in a managed care plan and the number continues to increase. Waivers are still required to include foster children in managed care programs; nevertheless, 60% of states, including California, have children in the social welfare system on managed care plans. Although reimbursement rates for providers under Medi-Cal managed care are more competitive than under the fee-for-service system, and although some improvements in the availability of services have been seen, providers and health services administrators agree that rates are still too low.

Everyone involved agree that the below market-level reimbursement significantly decreases the quality, the quantity, and the variety of programs necessary to serve the multifold needs of these adolescents. Directors of mental health and social service departments, representatives of state government, chief probation officers, frontline workers, and health care providers all agree that a primary goal of any reform should be to guarantee quality health care via comprehensive insurance for all youth regardless of the system they are in or the income level of their parents.

Laurel and her colleagues (2001) describe several access problems that specifically affect foster children on Medicaid, especially within the framework of managed care, including the following:

- Delays and breaks in the continuity of treatment while eligibility or alternative coverage is determined, including a lack of funding options for reimbursing providers who treat youth while coverage is still being determined.
- Cumbersome and unstandardized Medicaid applications and parent or guardian consent procedures.
- A lack of interagency cooperation among Medicaid, child welfare, and the providers, especially regarding health records and application procedures.
- Insufficient staff trained in the particular bureaucratic and health needs of foster care youth, and inadequate coordination of services for each youth.

Problems in Eligibility and Access to Coverage

Children detained or incarcerated in the juvenile justice system are not eligible for Medicaid, leaving their health care bill to the counties. Foster care children and youths on juvenile probation (but not detained), can usually be covered by one of the state or federal programs. Obstacles still remain to accessing these programs. For example, health care providers, social welfare and juvenile justice system staff, and, especially, parents and guardians often lack knowledge about existing programs and how to access them. The procedures to apply for and to maintain coverage are often confusing and cumbersome. Finally, eligibility restrictions preclude coverage for many in need.

Whether trained specialists are on staff or not, probation department staff, social workers, and health care providers often don't know what state and federal programs are available to assist them in providing health care for the youth in their charge. And when they do know where to look for help, the processes for accessing sources of state and federal aid are often perceived as too difficult or laborious to be worthwhile.

Some larger county systems have eligibility counselors whose job it is to know what assistance is available and how to access it, to train and assist other staff and providers, and to be aware of changes in eligibility criteria, coverage, and procedures. This is not just a matter of helping counties pay for services: we consistently heard in our interviews that individual youths are simply falling through the gaps left by inaccessible resources and that not just the quality but the quantity of services increase when agencies do a better job of accessing these funding programs.

Another consequence of the lack of expertise and resources to access available state and federal funding is the tremendous shortage of health care providers in juvenile justice facilities. Health care staffing shortages in the juvenile justice system is evident at CYA where there are constant vacancies for nurses, primary care physicians, and psychiatrists. Many of these positions could be at least partially paid for under federal programs such as EPSDT.

Collaboration Among Agencies

Health care access must be a coordinated effort between all participating agencies. In the last 10 years, medical, mental health, legal, law enforcement, educational and community entities that deal with youth have moved toward establishing such coordination. Federal, state, and local authorities have begun to recognize that coordination both improves the quality of care and increases efficiency and cost-savings.

The "career path" described in the quote at the beginning of this report is a troubling snapshot of the difficulty faced by all players in both of these systems. There are often failed opportunities for interventions, especially for youth with mental health problems. It also points out the need for collaboration among the many agencies that can influence these youths' lives. The quote concluded that "service delivery to this population has to be thoughtful, coordinated, strength-based, and tailored to the individual needs of each youth and his or her family." (SF Juvenile Probation, 2001) Other experts described the same circumstance in other ways:

Dealing with fragmented systems can enhance the problems faced by many young people with mental, emotional, or behavioral health problems who become involved in the juvenile justice system. Many may have lived in shelters because of abuse or neglect in the home or in therapeutic foster care (child welfare system). Concurrently, they may be in special education classes at school (educational system). Perhaps they have resided for a period in a residential treatment center or psychiatric hospital (mental health system). If they are arrested, even for something relatively minor such as trespassing, they come under the auspice of yet another agency and cast of characters, and their problems are likely to be exacerbated by the multiplicity of bureaucracies trying to help them.

It is also important to note that young people may enter the juvenile justice system without mental, emotional, or behavioral health problems; however, these problems may be triggered by a host of environmental stressors once they are there. (Goldstrom, et al., 2000)

When youth enter the systems, authorities have an opportunity to stop this cycle, to identify illness, begin appropriate treatments, and to inform the social workers, probation officers, case managers, providers, foster families, guardians, and, indeed, the child herself of a treatment plan for the illness. Too often authorities do not take this opportunity. Admirably, the California Department of Health and Human Services has instigated a program to train probation officers to recognize and respond to signs of child abuse and neglect.

Individual Education Plans (IEPs) are one way in which various systems and players must collaborate but where county resources are stretched and often unable to provide adequate services to the most needy youth. IEPs are plans developed by educators and the parents of mainly special education students to ensure that the child's needs are met, including education, treatment for mental, emotional, and behavioral disorders, and accommodation for physical problems. While IEPs are generally considered to be useful tools, they can become a hindrance for foster care and juvenile justice youth. First, IEPs can mandate a certain type of schooling that is simply not available if the youth's other needs are to be met. For example, for a youth to be placed in a residential facility, the facility must have an associated school where the youth can continue his or her education. These schools tend to provide only for very low performing students. An offender with a mental health or behavioral problem who is a high performing student cannot be placed there and may not receive needed mental health treatment. He or she may be forced to stay at juvenile hall for longer periods until a proper placement, sometimes out of the county or state, is found (with the county paying the ever increasing costs). Second, IEPs are not used to their full extent. For instance, IEPs can include plans to address problem behaviors and to recommend positive behavioral interventions (with the additional benefit that the problem behaviors recognized in the plan are not subject to standard disciplinary action, thus reducing juvenile justice involvement). However, according to mental health professionals in one large county, these behavior plans are not utilized in 80% of the cases where they could be beneficial.

Juvenile Justice Overcrowding

In 2000 the average daily population of California's juvenile halls (not including camps, ranches, or alternative incarceration) was 4% over the number of youth these halls were designed to house; on the days with the highest population, this number rose to 15% over the legal capacity. Twenty-two (17%) juvenile detention facilities reported being over their legal capacity for 15 or more days during at least month in 2000 (BOC). This overcrowding exacerbates health care problems in a variety of ways. Youths are at greater risk for violence or abuse by other youths and staff, staff supervision is reduced, already unmanageable caseloads of case workers and health care providers are increased, and available resources are further taxed. Juvenile halls or detention centers are intended as very brief holding facilities while vouth are assessed and adjudicated and until stable placements are found for them. However, juvenile halls are also used for other purposes, such as housing of youths ordered by the court to serve a sentence in detention or of youth being processed through the adult court system. These uses and the slow processing of cases lengthen the average stay at juvenile hall and thus exacerbate the overcrowding issue. The average length of stay in California juvenile halls was 27 days in 2000 and some hard-to-place youth stayed for up to a year. The average daily population of the camps and ranches, the other main forms of detention, was 11% under the maximum beds available; camps and ranches have more control over the numbers of youth they allow into their facilities at any given time, and the youth they refuse or delay receiving remain housed in already overcrowded juvenile halls.

Justice System Ethos

Does the mission of the juvenile justice system include ameliorative care? Courts can decree, as the U.S. Supreme Court has, that youth in state custody have a legal right to care, but the court cannot as easily affect the culture of the systems. Authorities are not always sure who is responsible for providing that care, or, even more undermining, how much care these children *deserve*.

Furthermore, detention is supposed to be short term, which contributes to the sense in the system that non-emergent and, especially, long-term health issues are not under their purview. But the fact is that the longer these health issues go untreated, the more likely these youth will return to the foster care or juvenile justice systems for longer and longer periods of time and the more the counties will pay when treatment is eventually provided. Also, without proper intervention, once youth turn 18 it is more likely they will end up in the adult correctional system or with other poor outcomes such as homelessness.

The punitive philosophy of the justice system, along with high caseloads and other factors, often leads to a reactionary, episode-based response to problem behavior. A youth acts out and that particular behavior is responded to, usually punitively, but deeper mental health issues may not be treated. One Chief Probation Officer illuminated this phenomenon by describing two types of children. The first is the basically "good kid" who is not prone to crime but has acute difficulty in social or pressure situations due to developmental or mental health problems. The second child is the one who, on the street, is a real danger to society but knows how to behave in custody and how to avoid further trouble. In the current system, it is too often the case that the first child falls into a cycle of acting out, punishment, and more acting out and

ends up being treated more and more like a criminal, while the other child slips through the system more or less unnoticed only to be released to potentially commit crimes in the community.

There is a practical illustration of these differences in philosophy. The director of a mental health agency of a medium-sized urban county described the increasing role of health care providers as "forensic evaluators" whereby physicians, psychologists, and social workers are asked to bridge the gap between their calling as providers of care and the decision-making role of the court system. The courts ask these professionals to make difficult decisions about youth's lives including possible removal from their parents' custody into foster care or out-of-home placements. The director described two issues that arise. First, courts don't realize that the sorts of assessments and reviews that they are asking health care workers to perform take large amounts of time and resources, and in most cases no special funding or resource allocations are made to account for that effort. Second, while health care workers understand and even advocate for the necessity of them playing a role in these decisions, it can leave them in positions of choosing courses of care based on information and factors that are in their minds too far removed from the basic tenets of health care provision.

Lack of High Quality Standardized Assessments

Youths enter the foster care and juvenile justice systems usually already underserved by the health care system, and sometimes that lack of care has led directly to their entering the system. For instance, the youth's offenses could be due to mental health disorders or substance abuse, or his or her home-life may have been disrupted by a mentally or physically ill family A youth's entry into either system is an opportunity for intervention. Initial assessments generally include a physical evaluation to identify any urgent needs and brief psychological/risk assessments for suicide or danger to the community or fellow detainees. Beyond this brief assessment, more in-depth physical and mental health evaluations are performed, generally at the discretion of the intake officer. Assessments paid for through Medi-Cal, EPSDT/CHDP, or Healthy Families have certain minimum requirements in terms of what is included and how often assessment must be performed. Regardless of who pays, particular tools and procedures for assessment vary between and even within counties. thoroughness and regularity with which assessments are performed on new and on-going wards varies widely according to the policies of county administrators, the setting in to which the child is placed, the health needs expressed at the time of assessment, and the various caseworkers, probation officers, and other staff who play a role in the child's supervision. The decision to perform or not to perform an in-depth assessment upon entry into the system and/or when needs are revealed as the youth steps through the system are perhaps the most crucial junctures in the process. Finally, the information gathered by staff during both brief and in-depth assessments goes largely unrecorded—only larger counties have adequate databasing systems in place. Even these, due to various reasons including confidentiality, hold little detailed data about physical and mental health issues.

Case Management and Training

Often, frontline workers and foster parents lack both basic understanding of the mental and physical health issues they most commonly face and training in recognizing the signs of

deeper disturbance. Probation workers and even social workers have little training in handling behavior problems in any way but punishment. But it is untenable to have trained psychologists handle every situation. An employee trained to recognize the symptoms and patterns of behavior of serious disorders, may be able to intervene before the cycles of institutionalization take hold and before too much damage is done. For instance, fighting may indicate to one employee a need for punishment while to another it may indicate a need for counseling. These contrasting views may point to a simple difference in opinions on rehabilitation and discipline. However, a properly trained employee should be able to see past opinions and recognize possible relationships between behavior, medical and mental health problems, and interventions. To one employee, head trauma may seem to be the result of fighting and need stitches, while to a welltrained and well-supported employee, it may indicate fighting and a need for stitches, but also the possibility of domestic violence (most domestic abuse involves injury above the neck), substance abuse (proneness to accidents), sexual abuse (self-mutilation), or even sleepdeprivation (possibly related to any number of larger problems). These deeper concerns may indicate a need for referral to counseling and possible alternative living arrangements and interventions. Many probation and social workers do not know where to turn when they need Training should be coupled with informational resources and expertise from assistance. participating professionals.

Not just frontline workers, but medical and mental health care providers, including medical social workers, nurses, physicians, psychologists and psychiatrists, must also have special training and interest in the multi-layered problems faced by foster care and juvenile justice youth. Health care professionals without such expertise may not be sensitive to the need for specialized and collaborative care. For example, treatment programs designed for substance abusers are typically not appropriate for youth with co-occurring mental health disorders. Such programs emphasize confrontation techniques and abstinence from all drugs including prescription medications (See USDHHS, 1999).

Improper assessment and unsuccessful treatment can result in a foster child being bounced from placement to residential treatment, family to family, and from the foster care system to the juvenile justice system, and a juvenile justice youth being bounced from detention to placement to detention, program to program, his record of bad behavior growing longer than his health treatment record.

Continuity of Care, Responsible Party, and Record-Keeping

In the foster care system, children removed from their homes are placed in one of three settings: a foster care family home, a foster family agency home, or a group home. Also, immediately after being removed from their homes, children may be housed temporarily in a shelter while their placement is arranged. The person responsible for the health care needs of the child in each of these settings is typically a different individual.

In the juvenile justice system, each youth is assigned a probation officer who is responsible for managing that youth's progress throughout the system. The probation officer supervises the youth to varying degrees according to the needs of the youth, the orders of the court, and the resources of the department, e.g., the probation officers' caseload. When a youth is placed in a facility, the direct supervision of the youth is handled by the facility staff, but the

probation officer is still responsible for tracking and oversight. The typical juvenile justice probation officer has too many cases and too little training to deal with health issues over and above the other needs of his or her job.

Juvenile justice or social services staff, biological parents or guardians, foster parents, primary care providers, specialists, school staff, residential home staff, and even the court may each have some level of responsibility for the typical foster care or juvenile justice youth. No single person is ultimately in charge of coordinating all the various services these youth require (Laurel, et al., 2001). To make matters worse, these various players may be separated by large geographical distances. For instance, a juvenile justice youth may be sent to a camp in another county, or a foster child with a specialized set of needs—probably coupled with numerous "failed placements"—may be sent to another county or even state. Youth in kinship care (in which relatives serve as foster parents), enjoy certain advantages such as more access to birth parents and a stronger sense of family. However, they often live in poverty with older relatives who do not understand or seek out the assistance available to them and who are not willing or able to ensure proper health care access (Ehrle, et al., 2001).

Youth in both of these systems are often moved back and forth between several placements as their needs are established and a stable, longer-term plan is formulated. This in addition to their original removal from their home and community when they were arrested or removed from their homes. The Institute for Research on Women and Families reported that over 25% of foster children are moved 3 or more times per year (IRWF, 1998). Each of these moves may bring with it a change in those responsible for the youth's health care, including different social work or probation staff, new care providers, and, in the case of foster children, new guardian or foster parents. This repeated movement makes the continuum of care, already a complex task, that much more difficult.

The coordinator of girls programs in San Francisco echoed the concerns of many interviewees—about girls *and* boys—when she stated that, while efforts are made to assess and begin treatment of girls while they are in juvenile hall, this relatively short period of proper care is the exception in the girls' lives. They come into the system having had little or no access to health care, especially mental health services, and they receive little follow-up care upon leaving juvenile hall, whether their next stop is an out-of-home placement or a return to their community.

This reality was illustrated by the juvenile justice staff at one urban detention center who described a child who was arrested and brought to their facility. While there, the child complained of not being able to see well in the classroom or when playing sports. He was seen by a visiting optometrist who gave him a prescription for eyeglasses. He was subsequently released from custody only to be arrested again a year later. During that year in the community, nobody had taken the steps necessary for him to actually get the glasses he needed; he came back to the detention facility with the same complaints still carrying the unfilled prescription.

The quality of the medical records is adversely affected by movements from placement to placement and the lack of a responsible party. Health care providers are often forced to spend their time and resources either repeating tests that they assume had been done but can find no record of, or tracking down the social worker, parent, or previous providers by telephone to determine what treatments and procedures have already been pursued. Furthermore, if the

problem is not currently presenting, the provider may not be aware of it at all, increasing the likelihood of treatment errors (e.g., unforeseen medication interactions) and chronic problems going untreated and growing worse. This can greatly increase costs and, more importantly, seriously compromise the health of the young person. The kink in the continuum of care can be as simple as missing the contact information for a child's biological parent so that consent can be given for the use of psychotropic medications or as serious as a missing list of medications to which a child may be allergic.

The Case Management System (CMS) Passport is a state-mandated process for assuring that the medical records of youth in both the juvenile justice and foster care systems are thoroughly maintained and stay with the children as they move through the systems. Probation officers, social workers, or guardians are responsible for carrying a hardcopy medical record—a blue folder—to each of the youth's medical, mental health, and dental appointments so that providers can review the notes of other providers and add their own. The Passport system began in 1989 with great promise, an excellent concept that has proved to be largely a failure in both design and utilization. Frontline workers say it is not real-time, its entry format is not standardized and not user friendly, and it is difficult to maintain by those responsible. Even in counties where the Passport is stressed:

- Social workers and probation officers have little time for its proper use.
- The importance of consistent and thorough documentation is not stressed to users.
- It too often lacks even the basic medical histories providers need to provide proper care.
- Even when used correctly, the format for information collection—based on chronological narrative—is counter-intuitive and inefficient.
- Each county determines both the format and content of the forms and the procedures used, so sharing records among counties is highly inefficient.

From the interviews we conducted in various counties, we found that the Passport system was not widely or successfully used, although its penetration is improving. Some smaller counties do successfully use their own system of collecting and sharing data. These successes are certainly aided by small juvenile justice populations but are also characterized by a strong commitment on the part of authorities to the coordinated sharing of data. Although case managers are overwhelmed with other duties, providers also complain that finding crucial information about a child's health history, information that should be easily accessible in their medical record, takes time and costs money that should be spent treating the child. In our interviews, it was also suggested that overworked staffers or the foster parents may at times be disinclined to properly maintain their ward's health record if it might expose a less than appropriate attention to health issues or even negligence on their part.

Dental and Vision

Bad teeth are prevalent for youths in both systems, but several factors leave dental and vision care as very low priorities and only emergent cases are usually treated. These factors include a low rate of reimbursement to dental care providers, an unwillingness on the part of some providers to treat youth with behavioral problems, the slow process by which eligibility is

determined, needs are assessed, and procedures are scheduled, and (perhaps by necessity) a focusing on other seemingly more important issues. Also, the prevalence of a fear of dentists among these troubled youth may make problem identification more difficult; sedation is required for even basic procedures for a large number of these youth.

Coverage for dental and vision care is usually included in federal programs, but finding providers who will work for the low reimbursement rates is even more difficult than with other medical services. Larger counties may have the facilities and staff to perform dental procedures on-site at juvenile halls, but most jurisdictions treat only emergent dental needs and do not perform regular dental check-ups or cleanings for juvenile justice youth. Dental care for foster care youth depends on the youth's setting, but a lack of single responsible party means that preventative procedures are often not pursued (Interview).

Unequal Access and Unequal Service Provision: Socioeconomics, Ethnicity, and Gender

Children of impoverished families have disproportionately high rates of mental, emotional, or behavioral health problems, are the least likely to have health insurance and access to adequate medical and mental health care, and are the most likely to fall through the gaps of public safety nets (Goldstrom, et al., 2000). Coping is made even more difficult by parents and family members who have their own mental and physical health problems. Also, the youth's mental, emotional, or behavioral health problems are often coupled with other problems such as learning disabilities. One study showed that when youth identified as having serious emotional problems drop out of school, 73% were arrested within five years (Garfinkle, 1997).

Low income and minority youth are overrepresented in both the foster care and juvenile justice systems. "There is considerable consensus that age, race, ethnicity, gender and socioeconomic status, more than diagnosis, determine whether a child or adolescent with mental, emotional, or behavioral health problems has contact with the juvenile justice system." (Goldstrom, et al., 2000). Whereas economically privileged white youths who have behavioral or mental health problems are more likely to receive private residential treatment, youths of color with similar problems are more likely to be entangled in the justice system.

Undocumented youth make up an increasing proportion of the juvenile justice population of certain counties. The BOC reports that undocumented youth represents just over 1% of the total juvenile justice population, but this figure may be understated and certainly southern and agricultural counties with higher numbers of undocumented workers have higher proportions of undocumented youth in their systems. For instance, San Diego County probation estimates over 8% of its juvenile probation youth who committed a felony were undocumented. Undocumented youth are rarely eligible for public medical assistance, with the exception of pregnant teenagers (Institute for Local Government, 2001). One chief probation officer said that with no Medi-Cal eligibility for this population, "the state is practically forcing counties to deport these kids back to their home countries." The costs of services offered to youth from undocumented families are paid for by already cash-strapped county social service and mental health agencies.

Language barriers, especially when parents are not fluent in English, create another formidable layer of difficulty across the spectrum of health care access issues described in this report. California is very diverse culturally and linguistically and there are many new immigrant

groups that have difficulty accessing services. For a medium-sized county in 1999, the breakdown was Black 51%, Hispanic 18%, Asian-Pacific Islander 17%, Caucasian 12%, Native American 1%, Other 1%. This problem can be lessened by hiring bilingual staff, but this is usually only a first step. Cultural differences in the perception of medical and mental health systems, public assistance, and justice and authority, create the need for culturally competent systems and services, tailored approaches to treatment, and extra efforts toward educating families about the purposes and requirements of each of these complicated systems.

Girls represent an increasing proportion of the youth in the juvenile justice system in California and the nation. Adolescent girls typically have different histories and risk factors preceding their involvement in the juvenile justice or foster care systems and have different medical and mental health needs than boys. They also require gender-specific treatments and services. Juvenile justice and foster care girls are more likely than boys to have suffered sexual abuse, to be victims of crimes, to have reproductive health issues, to suffer from depression, to attempt suicide, and to self-mutilate (Prescott, 1998; Edens & Otto, 1997). Girls are much more likely to run away from their placements. One mental health expert linked the high flight rates directly to prior abuse, describing a pattern where girls desire the esteem-building relationships their abusive household lacked, fail to find such support in the context of their placement, and run away to usually older boyfriends who are likely to lead the girl to pregnancy or criminal behavior. The lack of specialized training for social workers in behavioral issues that stem from abuse disproportionately affects girls. Even when abused children enter into mental health treatment, that abuse is often not specifically treated. Furthermore, in the reviewed counties, girls sometimes have long stays in detention because there are not enough gender-specific programs and gender-segregated living arrangements available. Some researchers argue that status offenses, which disproportionately involve girls, are being redefined as delinquent acts through a process called "bootstrapping" (Chesney-Lind, 1997). For example, a study of girls that were referred to Maryland's juvenile justice system for "assault" revealed that nearly all cases involved a family-centered argument (Mayer, 1994).

RECOMMENDATIONS FOR POLICY, PROGRAMS, AND RESEARCH

From the variety of problems and issues cited above, it is clear that there need to be changes in the manner in which health care is accessed and delivered to young people in the foster care and juvenile justice systems. Reform must happen within and among the various systems of the social safety net. Our recommendations are necessarily broad; and they cover policy issues, program development, and research and evaluation. The recommendations are organized into six categories: health coverage systems change, continuity of care and medical records, juvenile justice and foster care reform, parental and community involvement, research and evaluation, and technical assistance and dissemination of information.

I. Health Coverage Systems Change

Recommendation A: Institute continuous health coverage for every child regardless of the system they fall under. First, youths who are incarcerated or are in residential placement should be eligible for Medi-Cal. Gaps in coverage, such as for juvenile justice youth being

released to the community, need to be bridged. Medicaid eligibility for youth incarcerated in county juvenile justice systems would mean systemic change from the federal level down. Second, youths involved in child protective services and juvenile justice should have "immediate and presumptive Medicaid eligibility," so that care does not have to be delayed while eligibility or alternative coverage is determined (Laurel, et al., 2001). Third, we must ensure that youth exiting both the juvenile justice and foster care systems as young adults have a continuity of coverage and care. Gaps in crucial ongoing services such as medications for serious mental disorders often reduce to an impossibility a youth's chance for independence (Bazelon Center, 2001).

Recommendation B: Make it easier for families to meet the eligibility requirements of applying for and keeping Medi-Cal, CHDP, and Healthy Families. The California Office of Legislative Analyst recommends that 1) the various programs be integrated so that CHDP can serve as an effective route of access to Medi-Cal and Healthy Families, 2) providers play a larger role in encouraging patients to use the programs available, 3) eligibility criteria be broadened so that more low-income Californians can receive services, and 4) changes be made to the application process such as centralization, simplification, and assistance. These entitlement policies and procedures need to be simplified and streamlined to the extent possible.

Recommendation C: Educate every county, juvenile justice, foster care, and community health agency about eligibility criteria and application and renewal procedures for federal and state entitlement programs. This knowledge needs to be passed on to the families and youths involved in these systems. Responsibility for the necessary expertise and training could be given to one player in each system, such as eligibility counselors at juvenile hall or the main social services/foster care agency. This person would be given the necessary resources to fulfill his mission and be held accountable for his performance.

<u>Recommendation D:</u> Supplement Medicaid reimbursements to providers. High quality care is important to the well being of this traumatized and troubling population, and financial incentives are vital to receiving high quality care.

II. Continuity of Care and Medical Records

Continuity of care requires the smooth intertwining of several factors. These factors include insurance eligibility, medical records maintenance and sharing, case management, service provision, agency, provider, and family collaboration, health education and prevention, resource management, and county, state, and federal policies. The following are just a few specific recommendations that apply to the complicated issue of continuity of care.

<u>Recommendation E:</u> Create a centralized system for health care providers. Give providers easy access to medical records and improve continuity of care. Several groups of researchers and providers recommend a coordinated, standardized, centralized, and computerized Passport-type system that would maintain continuity of provider services and treatment plans.

However, some others we interviewed, especially director-level administrators, suggest that confidentiality concerns with an internet-based or extensive network may be too great to

overcome. Arriving at agreement about the design of the system would also be daunting. Still, health care providers suggest Passport should be accessible on-line to all who require its information, as necessary and within the bounds of confidentiality protections. This internet-based database should include a system for securing necessary consents, and should include insurance coverage and application facilitation. A possible model for an integrated medical records system is *All Kids Count*, a system being developed in a few parts of the country including Santa Clara county.

Recommendation F: Employ "health care managers" who should have a knowledge of the systems of social welfare and juvenile justice, as well as entitlement programs. These individuals would likely be registered nurses or medical social workers who would have specific training and expertise in the medical, developmental, and mental health issues common to foster care and juvenile justice youths. Their role would be to coordinate the health care of individuals. This responsible party would be able to negotiate the maze of systems and coverage issues.

Recommendation G: Assist youth leaving the system in securing the health insurance to which they are entitled. Efforts should be made prior to release to connect these youth with appropriate community services so that there is continuity of both coverage and care. Existing programs for aging-out youths should include emphasis on health care access, health education and prevention, and assistance with applications for public medical assistance. Springfield, Massachusetts has a model program for adult offenders. Agencies in the communities where the offenders will eventually be released provide health care services during incarceration to assure a more seamless transition after release. The same staff provide care to individuals both in and out of custody (Bazelon, 2001).

Recommendation H: Explore the possibility of creating a centralized location for assessment and treatment. In larger counties, satellite clinics would be set up to facilitate access. These clinics would allow for a centralization of the youth's records in one system, consistency in primary care providers, and staff knowledgeable of access to coverage.

III. Juvenile Justice and Foster Care Reform

Responding to most behavioral problems punitively and considering cases of "acting out" as episodic rather than as opportunities to identify needs and treat them means that more youth become more deeply involved with the juvenile justice system. This involvement lead to overcrowding, which leads to a lack of treatment. Lack of treatment leads to more acting out, and the cycle continues.

The core concerns of both the juvenile justice and foster care systems should be based on the treatment, rehabilitation, and health care needs of the youths these systems serve. Generally, the culture of the health care system is to care for the children, whereas the culture of the probation system focuses on protecting the community by punishing the kids. This inherent conflict directly affects the quantity and quality of health care delivery. Even when health care delivery programs are designed to work within the framework of the probation system, such as SF's Project Impact, a mental health program located in juvenile hall that performs in-depth

psychological and health screenings and facilitates treatment plans, the two cultures can clash. This conflict can lead to, at the least, difficulty getting such programs off the ground and, at worse, their failure. In some cases where the community, and even the probation department leadership, is supportive of attempts to change this culture, the attitudes of individual probation officers can perpetuate the problems. Directed training is required to affect change in attitudes throughout the system and the community.

Recommendation J: Funding to maintain and develop new diversion programs. The goal of diversion is to keep youth out of the juvenile justice system while providing services they would otherwise not be able to access. These programs, when possible, should be designed to treat not only diverted youth, but youth at risk for entering the juvenile justice system, foster care youth, and youth being released from these systems. One example of an attempt to divert youths to appropriate mental health treatment is the new Juvenile Mental Health Court in Los Angeles County.

Recommendation K: Reduce the movement of youths through various foster care and juvenile justice placements, with increased emphasis on appropriate permanent rather than short-term placement solutions. Moving a child or adolescent from placement to placement is very stressful to the individual and difficult for the system. Better continuity of health care could be accomplished if better services were provided to families caring for difficult to manage youths.

IV. Parental and Community Involvement

Recommendation L: Help parents become better health care advocates for their children. An example of this is a nationwide project called Project Keep. Its mission is to train parents in insurance and child health care issues and procedures. Another project called System of Care could become an important community and parental partnership for the benefit of children. System of Care is a state initiated approach to coordinated mental health care for California's impoverished youth, including foster care and juvenile justice-involved youth. First used in Ventura County in the late 1980s, it is characterized by the coordination of mental health care services through partnerships of all stakeholders, with extensive parent/guardian involvement. Parents, mental health professionals, representative from organization dedicated to medicine, education, child welfare, juvenile justice, vocational counseling, recreation, and substance abuse meet in committee to review and establish treatment plans tailored to each youth's physical, emotional, social, educational, and family needs. Individual System of Care projects still serve limited numbers of youth but have had some success in many California counties, large and small, including Santa Cruz and San Francisco, which has an award-winning program called Family Mosaic.

V. Research and Evaluation

<u>Recommendation M:</u> Study health care needs and access issues of youths across counties. Before determining long-term solutions, the medical, mental health and dental services adolescents require must first be determined. Special attention must be paid to ethnic, gender, socio-economic differences, and the specific health care needs of subpopulations of juveniles.

Recommendation N: Evaluate the impact of model programs attempting to increase access to appropriate and quality health care. There are several programs that attempt to bridge the gaps in service. These programs should be rigorously evaluated to determine whether they are able to accomplish their important goals and the associated costs.

Recommendation O: Create a report on best practices in health care provision for foster care and juvenile justice youths. The important decision-makers interviewed for this report clearly stated their need for readily available information on best practices. As the San Francisco Juvenile Probation (2001) report stated, "As the multiple public service systems move forward to solve the crisis of placements [and services] for youth involved in the juvenile justice system, it is extremely important that we continue to be kept updated on the latest evidenced-based best practices." Among other uses, a best practices report could argue for increased funding for programs of merit and decreased funding for those that have been shown unworthy.

<u>Recommendation P:</u> Conduct research to aid the development of internet-based access to health records. Technologically based solutions seem appropriate; however, there are serious concerns about confidentiality, a provider's ability to access the system, and the expense of such as system. These issues must be explored fully prior to implementing this potentially beneficial internet-based system.

VI. Technical Assistance and Dissemination of Information

Recommendation Q: Make collaborative planning based on accurate data the cornerstone of the reform effort. Use the Comprehensive Strategy to Address Serious and Violent Offending Youth as the model (Howell, 1995). This collaborative planning model should include the following four phases: mobilization, assessment, planning, and implementation. We assume that in completing this process communities will establish standards of care and practice including: 1) a comprehensive and standardized medical, mental health, substance abuse, and dental assessment, 2) early intervention into illnesses and health care issues, and 3) an education program to train frontline staff such as probation and social workers as well as the families or guardians of the youth in detecting the need for treatment and identifying appropriate intervention strategies. It is also recommended that this collaborative plan include the active participation of local and state medical, mental health, and dental associations.

Recommendation R: Prioritize dissemination of information on health care for youths in the foster care and juvenile justice systems. To make systemic change, local, state, and federal policymakers, and the public must be informed of the crisis in health care for our neediest young people. The social and financial costs of providing adequate health care to adolescents to break

the cycle of out of home placements, school failure, and criminal behavior must be presented in a clear and concise manner.

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