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Health Care at the Crossroads: Health Experiences and Perceived Health Access Among
Emancipated Foster Youth in Alameda County, California

by

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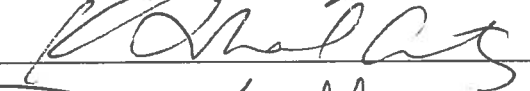University of California, Berkeley

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Spring 2007

Dedication

This thesis work is dedicated to the participants in this project and to all children and youth in the foster care system, and to the health and social services providers who serve them.

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Chapter 1. Literature Review

I. INTRODUCTION:

Each year, an estimated 20,000 youth emancipate from the child welfare system in the United States, and a growing body of research on outcomes for these youth suggests that many of them face significant challenges as they make the transition to adulthood (GAO 1999; Courtney, McMurtry et al. 2004; Courtney and Dworsky 2006).

A particularly troubling finding from the literature on the transition experiences of foster youth is that in addition to coping with the stresses of adolescence, the complex and cumulative effects of childhood traumas and upheaval, and the numerous challenges associated with the transition to independent living, many of these youth are faced with unique health issues and obstacles to medical care (Barth 1990; English and Grasso 2000; English, Morreale et al. 2003; Courtney and Dworsky 2005; English, Stinnett et al. 2006).

Youth who "emancipate" or age out of the child welfare system frequently experience debilitating physical and mental health problems, and also experience substance abuse issues at greater rates than their counterparts in the general population (English and Grasso 2000; Massinga and Pecora 2004). They have also been found to face significant barriers to needed medical and dental care that persist even years after they have left the child welfare system (Cook 1994; Courtney, Piliavin et al. 2001; Courtney and Dworsky 2005).

The unique health issues of emancipating or transition-aged foster youth often begin long before they enter the child welfare system. It has been well established that children and adolescents who enter the child welfare system frequently have or are at risk of having significant acute, chronic, or disabling health conditions, often as a result of the

abuse and neglect that they experienced prior to entering the system (American Academy of Pediatrics: Committee on Early Childhood 2000; English and Grasso 2000; Simms, Dubowitz et al. 2000). Furthermore, many children and youth enter foster care with sparse or incomplete records of their birth, developmental and health histories, which poses additional challenges to their acquisition of prompt and appropriate medical care (McCarthy and Woolverton 2005). While in the foster care system, many children and youth are subjected to numerous changes in housing placements, guardianship and case management which impact the availability and continuity of health care, particularly for youth with chronic conditions and disabilities (DiGiuseppe and Christakis 2003; Kools and Kennedy 2003). The health status of children entering care, the health care experiences of foster children and youth while in care, and the preparation for independent health care management that older youth receive prior to leaving foster care system may have important implications for their later health and well-being as they enter adulthood.

Yet while it is clear that emancipated foster youth often suffer from poor health outcomes and encounter difficulties in accessing healthcare after emancipation, much remains to be understood of the specific barriers to healthcare that foster youth face as they transition out the child welfare system. In addition, important questions remain about the effectiveness of recent legislation expanding benefits to transitioning youth, and the ways that state and regional variations in healthcare entitlements come to bear on their healthcare access (English and Grasso 2000; English, Morreale et al. 2003; English, Stinnett et al. 2006).

For example, as of October 2006, only 11 US states had implemented the Medicaid Expansion Option of the Foster Care Independence Act of 1999 (FCIA), which extends health benefits and entitlements for foster youth who were in care on their 18th birthday through age 21 (English, Morreale et al. 2003; English 2006; English, Stinnett et al. 2006). While this crucially important expanded coverage has the potential to improve access to care among transition-aged foster youth who are under 21, little is known about the degree to which this coverage is reaching its intended target population. Even less is known about the health access and health experiences of foster youth who emancipate *before* the age of 18 (and in so doing, may opt out of extended coverage), or the experiences of former foster youth after their extended coverage has ended at age 21.

Furthermore, when it comes to the scholarly literature and discourse on the health needs of transition-aged youth and their post-emancipation health-related experiences and outcomes, youths' own voices are conspicuously absent. A small number of studies have solicited emancipated youth's appraisals of their preparation for independent living in general and their experiences in foster care (Barth 1990; McMillen, Rideout et al. 1997; Georgiades 2005). However, few, if any studies have specifically sought youths' appraisals of the pre-emancipation preparation and information they received with regard to health issues or health care; and few if any studies have solicited their recommendations for how to improve the preparation of other transition-aged youth and reduce barriers to health care access. Additional research is needed to understand how former foster youth feel about their preparation for navigating the adult health care system, the barriers and challenges to health care access faced after emancipation, and

youths' suggestions for improving both pre-emancipation health education and programming and post-emancipation health care access.

Furthermore, given the local and regional differences in the quality and quantity of social supports and health services available to transitioning foster youth, additional local studies are needed to identify the degree to which local policies and programs and services affect access to care for this population.

This literature review seeks to examine what is known of the factors, policies and processes that influence the health status and health access of youth emancipating from out-of-home care. It is intended to provide the policy and literature context for a locally conducted, exploratory qualitative study of the health experiences and perceived health access of young people who emancipated from foster care in Alameda County, California.

The review is organized into four thematic sections. The first section will provide an introduction to child welfare system terminology, an overview of the process by which children and youth enter and exit the system, and a brief history of recent child welfare policy pertaining to children and youth in out of home care, with a focus on the role of federal, state, and local child welfare agencies in ensuring the health and well-being for youth who have been placed in foster care. There will also be a discussion of recent state and local policies concerning preparation and support for older youth exiting the foster care system to enter adulthood, with a focus on benefits and entitlements related to physical and mental health care.

The second section will review the literature on the health status of children and youth in foster care in the US. It will then turn to a discussion of the health and

developmental sequelae of childhood maltreatment. Finally, it will provide a discussion of the conceptual frameworks used within child welfare research and practice to understand and address the vulnerabilities conferred by experiences of maltreatment, and to enhance positive adaptation of children and youth.

The third section will hone in on the specific developmental stages of adolescence and emerging adulthood, and will explore the intersections between health and development during these life stages, as they relate to health status and outcomes in adulthood.

The fourth and final section will review what is known of the outcomes for young people who have left foster care by emancipating or aging out of care, including a discussion of what is known of their health status and access to health and mental health care. In addition, there will be an examination of the literature on youths' own perspectives about their foster care and independent living experiences, and their recommendations for improving service provision to other out-of-home youth.

SECTION 1: DEFINING TERMS/POLICY CONTEXT

Child Welfare and Foster Care Defined:

As described by Mallon and McCartt-Hess (2005), "all children and youth need a stable, nurturing, and enduring relationship with at least one adult who assures that their physical, emotional, educational, and social needs are met and who protects them from harm." They assert that the primary role of the child welfare system in the 21st century is to intervene when families are perceived to be unable to meet these basic needs, and to

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act "*in loco parentis*" (in place of the parent) to ensure the safety, permanency and well-being of children and youth (Mallon and McCartt-Hess 2005).

The child welfare system at large is defined as "a group of services designed to promote the well-being of children by ensuring safety, achieving permanency, and strengthening families to successfully care for their children"(Children's Bureau 2006a). The system includes a vast array of services for children and their families that support the prevention of abuse and neglect, as well as intervention services, and for children who are unable to remain within the custody of their parents, 24-hour substitute care placements, or "out-of-home care."

Out-of-home care refers to a diverse array of placements and services provided to children and their families that are provided by state and local child welfare agencies and other community organizations when a child must be removed from their home due to concerns about child safety, or in the presence of serious behavioral or physical health conditions that cannot be adequately managed by the family (Children's Bureau 2006b). Out-of-home placements for children include foster family homes, group homes, treatment foster homes, residential or group homes, and kinship or relative's homes. The term "foster care" is often used interchangeably with out-of-home care, although some use it to refer only to foster family homes (Children's Bureau 2006b). For the purposes of this review, the two terms will be used interchangeably.

Defining Abuse and Neglect

According to the Child Abuse Prevention and Treatment Act of 1974 (CAPTA) which was reauthorized in 1996, child abuse and neglect may be defined, at a minimum,

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as "any recent act or failure to act on the part of a parent or caretaker which results in the death, serious, physical or emotional harm, sexual abuse or exploitation; or an act or failure to act which presents an imminent risk of serious harm"(Child Welfare Information Gateway 2005). In addition, individual states have their own definitions of abuse and neglect. In combination, the abuse and neglect definitions as described in CAPTA and those of individual states form the basis upon which states may intervene on behalf of a child or youth who is determined to be at risk (Child Welfare Information Gateway 2005).

The Process of Placement in Child Welfare and Foster Care

The circumstances that bring children and youth into contact with the child welfare system and foster care are numerous, and are frequently quite complex. Most often, children and youth initially come to the attention of the child welfare system due to reports or findings of abuse or neglect (Shirk and Stangler 2004). If allegations of abuse or neglect are substantiated by a child welfare system investigation, juvenile and family courts subsequently determine whether the children should be removed from the home of their family or other caregivers (Ellis, Dulmus et al. 2003).

Under more recent regulations (described further below) child welfare agencies must make "reasonable efforts" to maintain children in their homes and prevent the placement of children and youth in foster care through the provision of supportive services, including family preservation services, counseling, and substance use treatment for adult caregivers. However, when these supportive services are determined to have been unsuccessful, the court may place children in an out-of-home care setting and must

authorize a "permanency plan" (a plan for the eventual placement of the child in a permanent living situation, e.g. a relative or non-relative foster family home, adoptive home, or other setting)(Courtney and Hughes-Heuring 2005).

The Pathways of Exit from Foster Care

Children typically exit the foster care system by being placed in a "permanent" living situation; this may include being reunited with their families, residing with a relative, being adopted, or entering into a formal guardianship arrangement. Some children exit foster care by being transferred into the jurisdiction of another agency or institution (e.g. the juvenile justice system or the mental healthcare system). Others exit the system by running away; youth who make such "unplanned" exits from the system may be referred to as "absent without leave" or AWOL.

Finally, a number of older youth exit foster care by "aging out" or "emancipating" from the system either when they reach the age of majority (usually 18); some youth are allowed to stay for a short period beyond the age of 18 in order to complete high school (Courtney and Hughes-Heuring 2005). In 2004, 23,121 young people in foster care exited the system in the US through emancipation (Children's Bureau 2006).

For the purposes of this review, the term "transition-aged youth" will be used to describe older youth in foster care who will are likely to be discharged from foster care through emancipation or "aging out." Emancipated youth will refer to youth who have been legally discharged from the system. As a point of additional clarification, it should be noted that while emancipated youth are no longer within the legal custody of the child

welfare system, some of these youth may still receive supportive services through the system in the form of "aftercare" programming.

Reasons for Placement in Foster Care

Most children enter foster care as a result of parental neglect or abuse that is situated within a larger context of extreme poverty, family and/or community violence, parental substance abuse, parental mental illness, HIV, incarceration and/or homelessness (American Academy of Pediatrics 2002; Downs, Moore et al. 2004; American Academy of Pediatrics 2005). As many scholars have been careful to point out, it is often the case that the personal and environmental pressures and problems faced by parents are further compounded by erosions in the social safety net (including the elimination of funding for family preservation and drug treatment programs) (Downs, Moore et al. 2004; Segal 2007).

Finally, a small but significant proportion of foster children and youth are placed in foster care because their individual health or mental health needs exceed their families capacity to care for them at home (Simms and Halfon 1994; GAO 2003).

Roles and Responsibilities Within the Foster Care System

While within the foster care system, children are under the legal custody of the state. Title IV-E of the Social Security Act (42 U.S.C. 670) constitutes the legal framework by which states administer foster care programs (Downs, Moore et al. 2004; Courtney and Hughes-Heuring 2005; Courtney and Heuring 2006; Children's Bureau 2006b). At the local level, juvenile and family courts oversee the care of foster care

wards by state and local public child welfare agencies, and ensure that the state fulfills its

obligations to foster care children under the doctrines of *parens patriae* (VanBergeijk and

McGowan 2001; Courtney and Hughes-Heuring 2005; Courtney and Heuring 2006). A

number of public and private agencies and individuals may also provide various

supportive services to children and youth in foster care, as well as their families.

However ultimately the responsibility for providing appropriate care to meet children's

needs falls with the state. When child welfare agencies remove a child from their home,

it is implied that the state is capable of providing better care for that child, than its parents

could (Chernoff, Combs-Orme et al. 1994).

An important part of the state's responsibilities to foster care children and youth is

ensuring that they have adequate health and mental health care. Almost all children in

foster care are eligible for health and mental health care insurance coverage through

states' Medicaid programs, however their eligibility may arise through different

mechanisms (Redmond 2003; McCarthy and Woolverton 2005). In general, children and

youth in foster care are made eligible for Medicaid through one of 2 mechanisms: 1)

eligibility to receive federal foster care payments under Title IV-E of the Social Security

Act, or 2) eligibility through other means (e.g. poverty, disability, or other factors)

(Redmond 2003).

Beyond the Medicaid coverage provided by the state, children's day-to-day

access to health and mental health care may require the efforts of a number of different

service providers. Depending on an individual child's living arrangements and

involvement with social services, the process of ensuring both routine health and mental

health care access, as well as treatment for injuries and illnesses may involve the efforts

of a complex team of individuals including social workers, case managers, guardians and foster parents, and the staff of residential/group homes. As will be addressed further below, there are a number of factors that conspire to create barriers to adequate health and mental health care for foster children and youth.

Foster Care Demographics

According to the most recent estimates from the Federal Adoption and Foster Care Analysis and Reporting System (AFCARS) from September 30, 2004, there were 517,000 children and youth residing in foster care in the United States (Children's Bureau 2006). These youth were living in a variety of settings: 46% were residing in non-relative foster family homes, 24% were living with a with a relative ("kinship care"), 19% were living in group homes or other institutions, and 1% were residing in a supervised independent living program. The average age of children in foster care in 2004 was 10.1 years. Thirty-five percent of the young people in foster care were 14 years old or older.

Children of color are disproportionately represented in the child welfare system. As reported by the Child Welfare League of America, in 2003, children of color (including African American/Black, Latino/Hispanic, American Indian/Alaskan Native, Asian, Hawaiian/Other Pacific Islander, and biracial or multiracial children) constituted 42 percent of the US population of children under 18. However, these same groups of children together accounted for 58 percent of the children in the foster care system (CWLA 2005).

While a thorough treatment of this issue is beyond the scope of this literature review, it is crucial to note that the available research consistently suggests that children of color are at no greater risk for abuse and neglect than white children (Derezotes, Testa et al. 2005; McRoy 2005). However, there do appear to be correlations between the risk for maltreatment and poverty (McRoy 2005). Ultimately, the over-representation of children of color is likely to be the result of a combination of factors including the disproportionate likelihood of poverty among certain racial and ethnic groups, the lack of sufficient social safety nets for low-income families, the lack of available rehabilitative and family preservation resources, the disproportionately high rates of maltreatment investigation and substantiation in communities of color, and the greater likelihood of removal of children of color from parental custody. In addition, once they have been placed in foster care, children of color tend to remain there for longer periods of time, and are less likely to be reunited with their birth families, and less likely to be adopted than white children (McRoy 2005).

Recent Trends in Child Welfare Policy: Promoting Permanency, Increasing Accountability

While in decades past, child welfare system placement was viewed as an end-point or permanent solution to the predicament of children whose birth families were deemed unable to ensure appropriate care, the last twenty to thirty years have heralded a shift in child welfare's views and objectives with regard to removal of children and their placement in out-of-home care (McDonald, Allen et al. 1996). In particular, surges in out-of-home placements during the 1960s and 1970s, led to the emergence of research

identifying the problem of "foster care drift" (the retention of children and youth in the system for long periods of time, transferring from placement to placement with little concrete direction). Researchers during this period also drew attention to the child welfare system's lack of effort to support healthy connections (or even reunification) between children with their biological families, and the lack of support for permanent placements for children in homes with adoptive families or guardians (Simms 1991a; McDonald, Allen et al. 1996; VanBergeijk and McGowan 2001; McGowan 2005).

These critiques led to a problematization of previously held views of long-term foster care as a end-point or solution, and resulted in the eventual passage of the Adoption Assistance and Child Welfare Act (AACWA) of 1980 (P.L. 96-272). The AACWA sought to ensure that children would be placed in foster care only when necessary, and defined a clear set of objectives or planned trajectories for out-of-home placement (McDonald, Allen et al. 1996; McGowan 2005). These objectives were, in order of preference: 1) reunification with families; 2) adoption; 3) guardianship; and 4) long-term out-of-home care. The AACWA also identified permanent placement or "permanency" as the goal of out-of-home placement; it emphasized that measures should be taken to hasten the process of identifying permanent placements (e.g. via dispositional hearings and periodic case reviews), and that long-term foster care should be seen as a solution of last resort (McDonald, Allen et al. 1996; Allen and Bissell 2004). Thus, the AACWA represented an important paradigm shift from foster care placement as an end-point to foster care as a temporary intervention, and also contributed to the growing attention to *outputs* (exit destinations) from the foster care system and *outcomes* or long-term effects of foster care placement (McDonald, Allen et al. 1996).

While the passage of the AACWA was followed by a brief period of decline in the numbers of children in foster care, both reports of abuse and neglect and the numbers of children in foster care began to increase during the late 1980s and through the 1990s due to the combined effects of insufficient funding for preventive services, increases in drug abuse, economic hardship and the disintegration of social safety nets for families (e.g. through welfare reform legislation), surges in HIV infection rates, and increases in homelessness. (Simms 1991a; McDonald, Allen et al. 1996; Allen and Bissell 2004; Pasztor, Hollinger et al. 2006). The increased numbers of children and youth in foster care during this period prompted several new legislative changes aimed at enhancing family preservation efforts to prevent removal of children from parental custody, and increasing opportunities for permanent placement as a means of helping children exit the foster care system more rapidly (VanBergeijk and McGowan 2001; McGowan 2005).

The Adoption and Safe Families Act (ASFA) of 1997 was one of the first pieces of national legislation to explicitly describe the responsibility of state and local child welfare agencies for ensuring that the physical and mental health needs of children and youth in foster care are being met (McCarthy and Woolverton 2005). In particular, the ASFA contained specific provisions addressing the need for states to develop standards for ensuring the health and safety of children and youth in foster care (Allen and Bissell 2004).

Shortly thereafter, the Child Welfare Final Rule, published by the US DHHS in 2000, put into effect a process of Federal Child and Family Services State Reviews (CFSRs). These reviews are intended to increase the accountability of states for providing adequate services to ensure the best possible outcomes for children in out-of-home care

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(Courtney, Needell et al. 2003; Allen and Bissell 2004). The CFSRs assess 3 major outcomes concerning the status of children in foster care. These outcomes are as follows: 1) child safety, including protection of children from abuse and neglect, and the assurance that children are safely maintained within their homes when possible; 2) permanency, ensuring that children have permanency and stability in their living situations, and that family connections are maintained; and 3) family and child wellbeing, including the support of families' capacity to provide for their children's needs, provision of appropriate services to meet children's educational needs, and provision of services to meet children's physical and mental health needs (Committee on Ways and Means 2004). With regard to this third area, the CFSRs ultimately represent another codification of the government's responsibility for meeting the mental and physical health needs of children and adolescents in the child welfare system. However thus far, despite this added legislative impetus for states to improve outcomes for children in state-supervised foster care, many states, including California, have continued to struggle or fall short of meeting federal standards for child safety, health and well-being (Children's Bureau 2003).

Federal Policies and Services for Older Youth in Foster Care

While policy changes over the last several decades reflect growing efforts to shorten the length of time children and youth spend in foster care, and to connect them with permanent living situations, there is a significant number of youth for whom permanency is not ultimately achieved during their time in the foster care system. These youth, along with youth who enter foster care during their late adolescence, may remain

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in foster care until they emancipate from the system. As previously described, emancipation can occur when young people reach the age of majority (18 in most states) or graduate from high school (Courtney and Hughes-Heuring 2005).

For many of these youth, exiting the foster care system also involves the termination of state and federally-mandated benefits and entitlements, including financial benefits for housing and education, job training, counseling, and health and mental health care and insurance coverage (Foster and Gifford 2005; Osgood, Foster et al. 2005). In addition, for some youth, the process of being discharged from foster care can mean the end of certain forms of social contact and supportive networks, including visits with social workers and other social service agency staff, foster parents and guardians, and peers in foster care (Collins 2004). The transition to adulthood is fraught with rapid and profound changes for many youth, but for foster youth, this particular set of changes and upheavals with its broad implications for social, emotional, environmental, and financial supports, can be especially overwhelming.

Decades of research on the later life circumstances of former foster youth has consistently documented both short-term difficulties and negative long-term outcomes for this population. These difficulties and negative outcomes will be examined in greater detail in section 4 of this review, but to address them briefly here, prior research has identified that former foster youth frequently experience considerable housing instability and homelessness, low educational attainment and income instability, and high rates of enrollment in public assistance programs, criminal justice system involvement, incarceration and exposure to violence in the forms of both physical and sexual victimization (Festinger 1983; Barth 1990; Cook 1994; McDonald, Allen et al. 1996;

Courtney, Piliavin et al. 2001; Reilly 2003; Courtney and Dworsky 2005). These troubling findings have in turn prompted several important pieces of legislation which provide funding and support for the establishment of programs to assist youth with the transition to adulthood (Collins 2004). This legislation includes the Independent Living Initiative of 1985 (P.L. 99-272) and most recently the Foster Care Independence Act of 1999 (P.L. 106-169) (Collins 2001; Collins 2004).

The Independent Living Initiative of 1985 (ILI) amended Title IV-E of the Social Security Act to allocate federal funds toward the establishment and implementation of Independent Living Programs (ILP), a set of services designed to help foster youth, ages 16 and over, develop independent living skills (Scannapieco, Schagrin et al. 1995; GAO 1999). The ILI established the first federal program dedicated specifically to the support and funding of services for transition aged foster youth (Nixon 2005). As originally outlined, the federal funds authorized by the ILI could be used toward a basic set of programs and services including training in daily living skills, tutoring and educational support, employment assistance, individual and group counseling, outreach programs for eligible youth in foster care, and the creation of an individualized, written transitional independent living plan (Scannapieco, Schagrin et al. 1995; Collins 2001).

Despite the importance of the ILI as an initial step toward acknowledging the unique needs of older youth in foster care and allocating resources to support them, research on the post-emancipation circumstances of former foster youth following the implementation of the ILI continued to demonstrate poor outcomes (Barth 1990; Nixon 2005) . A 1999 study of Independent Living Programs by the US General Accounting Office found that although state ILPs were providing an array of services to support

youth in the transition to independence, there were also many areas of unmet service need, and few formal mechanisms for assessing the effectiveness of ILP programs in serving their target population (GAO 1999).

A more recent development in the growing effort to expand independent living services for older youth in foster care has been the passage of the Foster Care Independence Act (FCIA) of 1999 (Public Law 106-169). The FCIA amends Title IV-E of the Social Security Act to authorize increases in federal appropriations to states to fund independent living services for transition aged foster youth, and allows states greater flexibility in the administration of ILP programming (Collins 2001). With regard to the health and well-being of older youth in foster care, a specific provision of the FCIA, called the "Medicaid Expansion Option" provides states with the option of extending Medicaid coverage to all youth who were in foster care on their 18th birthday, through age 21. As of this October 2006, California is one of only 11 states to implement the expanded Medicaid Option of the FCIA (English 2006; English, Stinnett et al. 2006).

The trend in federal policies concerning transition-aged youth in foster care appears to be moving toward a broader, more standardized and more accountable approach to service provision. In particular, the FCIA represents a particularly important stride in enhancing the supportive services available to young people exiting foster care. However, despite these important strides, there continue to be marked variations between states and local child welfare jurisdictions in terms of the quality and quantity of independent living supports offered to transition-aged and emancipated youth, and few formal mechanisms for assessing the efficacy of programs in reaching and serving their target populations.

State Policies Affecting Older Youth in Foster Care: California

In addition to its implementation of important federal legislation such as the FCIA

Medicaid Expansion, California has also taken other measures at the statewide level to

improve the quality and scope of independent living and transitional services to

transition-aged youth. Most recently, the Mental Health Services Act or Proposition 63,

passed in 2004 introduced a 1% income tax increase for taxpayers with income in excess

of $1 million dollars to generate funds for expanded mental health and human service

programs and resources for a broad group of beneficiaries, including transition aged

foster youth (California Department of Mental Health Services 2004; California

Department of Health and Human Services 2006). While the design of programs and

allocation of funding is still a work in progress, the MHSA represents a key step toward

improving the ability of California counties to meet the needs of youth people, both in

and out of the foster care system, who are making the transition to adulthood.

SECTION 2: HEALTH AND DEVELOPMENTAL CONTEXT

While the previous section examined the historical and political forces that impact

the health status and health access of foster youth in their transition to adulthood, this

section seeks to undertake a closer examination of the developmental, social, and

environmental processes and events that inform the health status of foster youth and their

access to health care. This section will begin with a review of the literature addressing

the health and social experiences of children and youth in foster care. It will then turn to

an examination of the health and developmental sequelae of childhood maltreatment. Finally, there will be a discussion of the conceptual frameworks used within child welfare research and practice to understand and address the vulnerabilities conferred by experiences of maltreatment, and to enhance positive adaptation of children and youth.

Health Status and Developmental Issues of Children and Youth in Foster Care

The Health Status of Children and Youth Entering Foster Care

The health problems of children and youth in foster care often begin long before they enter the child welfare system. It has been well documented that both children and adolescents entering child welfare frequently have or are at risk of having significant acute, chronic, and/or disabling health conditions, often as a result of the abuse and neglect that they experienced *prior* to entering the system (American Academy of Pediatrics: Committee on Early Childhood 2000; English and Grasso 2000; Simms, Dubowitz et al. 2000). Previous studies of the health status of children entering foster care have found that between 87% and 95% of children have at least one medical problem, and 50 to 60% have *multiple* physical health conditions (Chernoff, Combs-Orme et al. 1994; Risley-Curtiss and Kronenfeld 2001).

What factors account for the intensity and complexity of health care needs for children and youth entering foster care? To begin, as previously described, it is important to note that most children are placed in foster care due to abuse or neglect that has occurred in a milieu of extreme poverty, homelessness, parental mental illness or disability, domestic or community violence, HIV infection, or substance abuse (Simms

and Halfon 1994; Hansen, Mawjee et al. 2004; McCarthy and Woolverton 2005; Jee and Simms 2006b). Children in foster care are more likely than their non-child welfare system involved peers to have had a parent with mental illness or alcohol/drug dependency, and to have experienced prenatal exposures to infections or illicit drugs (Leslie, Gordon et al. 2005a). Each of these factors, alone or in combination, is known to be associated with a greater risk of poor health among children, and contribute to the greater baseline health need of many children and youth entering foster care (Takayama, Wolfe et al. 1998; Simms, Dubowitz et al. 2000; Rosenberg and Robinson 2004; Rounds and Ormsby 2006).

Furthermore, as a group, children and youth entering foster care are more likely to have received suboptimal or inadequate routine preventive health care prior to entering state custody; this may be attributable to medical neglect or to structural factors such as lack of access to affordable or geographically accessible health care. Whatever the contributing cause(s) may be, upon entry, children and youth often have significant unmet health care needs (Simms and Halfon 1994; Halfon, Mendonca et al. 1995; Simms, Dubowitz et al. 2000).

Depending upon the immediate circumstances surrounding their removal from the home, children and youth may also enter care with acute or emergent health and mental health problems that result from the abuse and neglect they have experienced. These health problems may include injuries, infections, gynecologic and sexual health concerns, suicidal ideation, post-traumatic stress disorder and/or other forms of emotional distress (Chernoff, Combs-Orme et al. 1994; Takayama, Wolfe et al. 1998; Simms, Dubowitz et al. 2000).

Finally, a subset of children and youth are placed in foster care, not necessarily because of abuse or neglect, but rather because they have intense health or mental health needs that exceed their birth family's capacity to provide for them within the home (Simms and Halfon 1994; GAO 2003). For these children, child welfare (or juvenile justice system) placement may be sought as a means of ensuring access to needed medical or mental health care, and other supportive services that would not otherwise be available. Currently there are no formal federal or state mechanisms for tracking the numbers of children and youth placed in care to receive health and mental health services. However, a 2003 GAO survey of state child welfare offices in 19 states and county juvenile justice officials from 30 counties estimated that in the fiscal year 2001, over 12,700 children were placed into either the child welfare or juvenile justice systems solely to receive mental health services (GAO 2003). Underlying causes and constraints that prompted child welfare or juvenile justice system placement included child medical/mental health need that exceeded the family's resources, lack of sufficient insurance coverage or restrictions on the scope of services provided, and geographic constraints (including lack of appropriate local services). Ultimately these children and youth with their intense health care need also contribute to the larger picture of health care need and utilization by the foster care population (GAO 2003).

The Health Status of Children and Youth within the Foster Care System

Given the health status of children and youth entering foster care, it is hardly surprising that children and youth within the foster care system have disproportionately high rates of health, mental health and developmental problems. Common physical

problems include dermatologic problems, neurologic problems, malnutrition, dental caries, elevated blood lead levels, anemia, infectious diseases, asthma and abnormalities in growth, hearing and vision (Swire and Kavaler 1977; Leslie, Hurlburt et al. 2003; American Academy of Pediatrics 2005). However, the most prevalent health problems in the foster care population are psychological and behavioral problems (Schor 1982; Risley-Curtiss and Kronenfeld 2001; American Academy of Pediatrics 2005). Among the most common mental health problems are externalizing behaviors, such as attentional disorders, conduct disorders, and aggression. High rates of comorbidity with both externalizing disorders and internalizing disorders, such as depression and anxiety, have also been documented (Kools and Kennedy 2003; Leslie, Hurlburt et al. 2003; Leslie, Gordon et al. 2005a). Furthermore, as previously noted, children and youth in foster care frequently have a complex mixture of multiple physical and mental health problems that affect several aspects of their functioning (Simms and Halfon 1994).

Even when compared with other children from the same socioeconomic background, foster children have been found to have markedly higher rates of serious emotional and behavioral problems, birth defects, dental problems, asthma, and developmental delays (American Academy of Pediatrics 2002; Halfon, Inkelas et al. 2002; English, Morreale et al. 2003; Hansen, Mawjee et al. 2004).

Structural Factors that Influence the Health Status of Foster Children and Youth

Child health experts agree that all young children require routine, comprehensive medical examinations (including developmental assessments, preventive care, dental care, and immunizations) as well as treatment for minor illnesses and injuries, in order to

grow up healthy (GAO 1995). As described above, the basic health needs of foster children are frequently greater than those of other children, due to their need for specialized care and treatment for prenatal substance exposures, growth and developmental delays, chronic infections, emotional trauma, and disabilities (American Academy of Pediatrics 2005). Yet there is considerable evidence to suggest many children and youth do not receive the full scope of care they need while within the foster care system, particularly with regard to dental care, mental health services, substance abuse treatment, and adolescent health services, including reproductive health care (GAO 1995; American Academy of Pediatrics 2002; English, Morreale et al. 2003; McCarthy and Woolverton 2005; Jee, Barth et al. 2006a).

As many child welfare researchers have pointed out, in addition to the disproportionate health care needs of foster children and youth, structural and systemic factors associated with the child welfare system itself contribute in important ways to their poor health.

To begin, many children and youth enter foster care with sparse or incomplete records of their birth, developmental, family, and health histories. This lack of essential historical information often poses significant barriers to their acquisition of prompt and appropriate health care once they enter state custody (Simms and Halfon 1994; McCarthy and Woolverton 2005).

While within the foster care system, children and youth are frequently subjected to numerous changes in housing placements, guardianship and case management which impact the availability, quality, and continuity of health care (DiGiuseppe and Christakis 2003; Kools and Kennedy 2003). Children and youth are often placed under the care

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and supervision of case workers, guardians, and foster parents who may be equipped with very little information about the child's health, developmental, and abuse histories, and may be afforded few supports for identifying and receiving assistance with health, developmental and behavioral problems (American Academy of Pediatrics: Committee on Early Childhood 1987; Davies 2004).

In addition, many researchers have drawn attention to the lack of uniform policies, procedures, and monitoring systems for ensuring health care access for foster care children. While professional and advocacy agencies, such as the American Academy of Pediatrics, and the Child Welfare League of America have developed numerous standards and guidelines to ensure comprehensive care for children and youth in foster care, few states have implemented these standards, and there remain few mechanisms for formally tracking the health status of children and youth in foster care(American Academy of Pediatrics 2005; McCarthy and Woolverton 2005).

Research has also drawn attention to the fragmentation between health and social services, which can contribute to inefficient communication between health and social service providers and delays in service provision. Also mentioned are the shortages in medical, dental and mental health providers who accept public insurance coverage such as Medicaid, and the prolonged wait times for community-based medical and mental health care. In addition, some have drawn attention to the barriers posed by children's immigration status and limitations in the scope of Medicaid coverage (Simms, Dubowitz et al. 2000; Risley-Curtiss and Kronenfeld 2001; American Academy of Pediatrics 2002; Kools and Kennedy 2003). Thus, despite their often intensive health and mental health need, the health and mental health care experiences of many children and youth in foster

care are frequently inadequate, crisis-oriented, sporadic, and fragmented (Kools and Kennedy 2003; American Academy of Pediatrics 2005).

Health and Development Issues for Foster Youth: The Sequelae of Abuse in Childhood and Adolescence

Both maltreatment and foster care have been identified as experiences associated with significant risks for poor developmental outcomes, and important implications for children and youth's long-term health and well-being (Davies 2004; Alexander and Schrauben 2006; Lawrence, Carlson et al. 2006; Rounds and Ormsby 2006).

The experience of parental or familial maltreatment has numerous, complex, and often long-lasting effects on children's health and development (Davies 2004). Child development researchers have long noted that infants and young children whose early emotional and physical needs have been met tend to form strong, healthy attachments to childhood caregivers and later, to peers and other adults; whereas infants who experience emotional neglect or deprivation during early childhood may later demonstrate difficulty with social relationships and self-image (Ainsworth and Bowlby 1991; Bowlby 2003). With regard to child welfare system-involved children in particular, researchers have noted that infants and young children who have had experiences of emotional or physical neglect or prolonged physical abuse frequently demonstrate difficulty forming secure attachments with adult caretakers (Simms, Dubowitz et al. 2000; Davies 2004) In addition, children who have experienced physical and sexual abuse may experience difficulty with forming secure attachments due in part to the trauma of betrayal and

experiences of physical violation that can affect their ability to trust and accurately interpret the intentions of others (Davies 2004).

Children who have experienced physical or sexual abuse may also demonstrate symptoms and behaviors associated with post-traumatic stress disorder. Investigations of the developmental impacts on chronic abuse have shown that children who have survived chronic abuse may even show signs of physiologic responses to their experiences of trauma and abuse, such as alterations in the hypothalamic-pituitary-adrenal (HPA) axis, and elevations in levels of endogenous opioids; such physiologic responses have been associated with states of persistent hyper-arousal and/or dissociation (Davies 2004).

The impacts and responses to maltreatment vary widely by life stage. As described by Davies (2004) effects of maltreatment during infancy can include depression, poor regulation of affect, persistent arousal, and anger. Toddlers may demonstrate heightened levels of aggression, anger and inappropriate hostility. Preschoolers may show poor social skills, and may be aggressive or disruptive. School-aged children may demonstrate developmental delays, poor academic performance, cognitive disorganization, and maladaptive coping and problem-solving strategies. Children who have experienced neglect may demonstrate a diminished sense of self-worth, and decreased self-efficacy.

In addition, foster care placement itself, like childhood maltreatment, lies outside of the realm of typical childhood experience, and is associated with vulnerabilities to adverse developmental outcomes (Lawrence, Carlson et al. 2006). Even when children and youth have experienced significant maltreatment, dysfunction, and/or disordered attachment to a biological parent, the process of removal from the parental home and

placement in a new, unfamiliar environment may still represent a disruption to the attachment process and bring about profound feelings of loss or a sense of rejection (Davies 2004; Lawrence, Carlson et al. 2006).

The physical process of removal from the home may be particularly traumatic. Children and youth may be injured, hungry, tired, disheveled, and/or confused, and may suffer extreme distress, or even feelings of guilt associated with being separated from their families (Simms, Dubowitz et al. 2000). Furthermore, many researchers have identified the importance of sibling networks of support and interdependence among abused and neglected children. Children and youth who are separated from their siblings upon removal from the home, may experience additional loss as these support networks are disrupted (Davies 2004). In addition, the high mobility of foster children and youth within the system may further challenge their ability to develop and maintain secure and healthy attachments to caregivers, family members, peers, and community members (Taussig 2002).

Ultimately, childhood maltreatment and foster care involvement both represent experiences of adversity that constitute important sources of risk and vulnerability to the health and well-being of children and youth.

Conceptual Frameworks for Understanding Children and Youth's Responses to Adversity

While childhood maltreatment and foster care placement constitute experiences of extreme adversity that have been associated with vulnerability to poor outcomes in later life, it is crucial to note that many young people demonstrate considerable perseverance

and positive adaptation despite these experiences. The factors and processes that underlie the positive adaptation to adversity has been a growing source of interest for scholars in the field of child welfare.

A number of theoretical frameworks have been used in an attempt to understand the mechanisms and pathways by which life circumstances, experiences, and events influence children's development and health to yield outcomes. However, of the numerous frameworks that have been invoked, the risk and protective factors framework has emerged as a particularly relevant model for the study of the complex interplay of factors that impact the health and developmental status of and outcomes for foster children and youth, and other youth who have experienced extreme forms of adversity (Masten, Best et al. 1990; Taussig 2002; Fraser and Terzian 2005; Lawrence, Carlson et al. 2006; Pecora 2006).

Within the risk and protective factors framework, "risk factors" are defined as elements that increase the likelihood of a problem or negative outcome. These elements include family poverty, parental substance abuse or mental illness, and community violence, as well as stressful or traumatic life events such as the death of a parent, experience of a serious illness or disability, and experiences of rape, abuse or neglect (Sandler 2001; Fraser and Terzian 2005; Pecora 2006). Blum et al. (2002) have recently pointed out that the term "risk" can be problematic in that it has been used in a number of contexts; for example it has been used to describe both external social factors, such as poverty and single-parent families, and *risk-taking behaviors* (such as smoking, driving under the influence, and unprotected sexual intercourse) with which individuals may predispose themselves to an outcome. They have therefore advocated for a conceptual

clarification between risk behavior, and 'vulnerability', defined as "an interactive process between *social contexts in which a person lives* [e.g. abusive/violent environments] and a set of underlying factors that when present, place the young person 'at risk' for negative outcomes" (Blum, McNeely et al. 2002).

Protective factors function in the presence of risk to protect individuals from the effects of risk factors, and to produce successful adaptation (Carbonell, Reinherz et al. 1998; Smokowski, Mann et al. 2003; Masten, Burt et al. 2004a; Fraser and Terzian 2005). Fergus and Zimmerman (2005) propose that protective factors may be categorized as either "assets" or "resources." Assets, they suggest, are *intrinsic* factors that support positive adaptation and functioning, such as coping skills, self-efficacy, and competence. Resources, by contrast, are *extrinsic* social or environmental factors that help mitigate risk, such as parental support, mentoring, and community organizations that promote and develop children and youth's assets (Fergus and Zimmerman 2005).

Observations of the successful adaptation of children who have experienced significant vulnerability or adversity have led to the elaboration of a theory of *resilience*. Resilience has been defined as "a dynamic process encompassing positive adaptation within the context of significant adversity" (Luthar, Cicchetti et al. 2000b). Others have expounded on this definition to suggest that resilience can also include successful avoidance of the negative effects of risks, sustaining competence and positive functioning in times of stress, and recovering well from traumatic events (Fergus and Zimmerman 2005; Fraser and Terzian 2005). Resilience as a construct initially emerged from studies of the patterns of functioning among patients with schizophrenia, and later, the children of schizophrenic mothers (Garmezy 1974; Masten, Best et al. 1990; Luthar, Cicchetti et

al. 2000b). Since these early studies, the concept of resilience has garnered great interest in the fields of child and adolescent health and development, as a means of understanding the factors and processes that support positive health and developmental outcomes despite experiences of adversity and hardship (Luthar, Cicchetti et al. 2000b; Masten, Burt et al. 2004a).

In particular, with regard to adolescent development, resilience theory has formed the foundation of the framework of *positive youth development* which seeks to place emphasis on adolescents' assets and strengths, rather than focusing solely on their problems and deficits; and to identify key protective factors that can be used in interventions and programs to promote resilience and positive outcomes (Nixon 1997; Kegler, Oman et al. 2005). As described by Nixon (1997) "a positive youth development approach places value on young people regardless of their situations and emphasizes their strengths and potential...it does not deny the existence of serious problems or the need for specialized services to confront these problems. It does, however, promote a shift in emphasis from the need to diagnose and treat the problem, or convict and control the offender, to the need to develop an nurture the person" (Nixon 1997).

Resilience and positive youth development also have a special relevance in child welfare policy and practice. Increasingly, an understanding of the factors that support resilience has been sought by child welfare scholars as a means of informing policy and practice that enhances recovery from victimization and maltreatment and promotes positive adaptation among children and youth in foster care (Henry 1999; Fraser and Terzian 2005; Pecora 2006). Similarly, a philosophy of supportive positive youth development has increasing emerged in the discourse on child welfare policy and

practice, particularly with regard to older and transition-aged foster youth. For example, as described in Nixon (2005), a positive youth development approach, including the enhancement of foster youths' assets (including individual strengths and competencies) and their resources (including connections to family, community and peers), and ample opportunity for youth input and participation, forms the basis of the Child Welfare League of America's standards for Transition and Independent Living and Self-Sufficiency Services (TILSS) (Nixon 2005).

Many scholars of resilience theory have also noted that there can be important limitations to individual resilience and positive adaptation to adversity. Resilience appears to be content and context specific; that is, youth may be resilient to some types of risks and not others (Masten, Burt et al. 2004a; Fergus and Zimmerman 2005; Fraser and Terzian 2005). In addition, individual assets such as coping skills have been noted to depend on a number of factors including age, developmental stage, cognitive and emotional maturity, other personal attributes, and the presence and availability of external resources (Carbonell, Reinherz et al. 2005). Ultimately, resilience and positive adaptation appear to necessitate the existence of an adequate match between life circumstances and individual psychosocial assets (Carbonell, Reinherz et al. 2005).

Still others have pointed out that social and structural forces, such as discrimination based on race, sexual orientation or disability/ability, can have important implications for the accessibility of support and opportunity structures. Investigators from the field of adolescent health have also pointed out that young people with physical or socially constructed "differences," and youth who have had experiences of extreme hardship or adversity, including foster youth, may face forms of social marginalization

that impede their access to certain forms of care and support (Alexander and Schrauben 2006).

From the field of sociology, the work of Stanton-Salazar (2001) has also made important contributions to the understanding of the structural forces, such as institutionalized racism, language barriers, and class inequality, which can preclude the ability to form potentially helpful social networks. In his studies of the school and kinship networks of youth of Mexican origin in U.S. high schools, Stanton-Salazar highlights the ways that hierarchies of race, class, gender and language can impact the availability of support and opportunity structures for youth, and strongly influence youth's responses to and willingness to engage with these structures (Stanton-Salazar 2001; Stanton-Salazar, Chavez et al. 2001).

Thus, while it is of crucial importance to determine the factors that support positive adaptation to adversity, it is also important to acknowledge the ways in which social and structural forces may impact young people's access to the assets and resources that enable adaptation to adversity. This may be particularly true for foster children and youth, whose experiences of psychosocial and physical upheaval, in the form of frequent changes in placement and supervision, may pose significant challenges to their access to consistent and stable support systems.

Ultimately, a commitment to developing youths' assets and protective factors, promoting resiliency, and incorporating positive youth development approach in the provision of services to foster youth, demands continued effort to ensure that systems of support and social connection are both accessible and inclusive.

SECTION 3: ADOLESCENT DEVELOPMENT AND THE TRANSITION TO ADULTHOOD

In a life course perspective, the health, developmental and social experiences accrued by young people during their childhoods have important implications for their later health status. However, it is increasingly recognized that childhood experiences are not the sole determinant of adult outcomes; rather, they constitute a significant part of a much larger picture. Indeed the subsequent life stages of adolescence and young adulthood also bring a host of developmental, social and environmental changes that can have profound and lasting impacts on health. This portion of the review will examine the developmental tasks and processes of adolescence and emerging adulthood, and their relevance for health and well-being during the transition to adulthood and in later life.

Normative Adolescent Development and "Emerging Adulthood"

Defined by most scholars as the period between the ages of 10 and 18 or 24, adolescence is typically a time of myriad and important transitions and transformations. During adolescence, young people experience a series of profound physical changes in body shape and size, as well as important emotional and cognitive changes (Erikson 1968; Elliot and Feldman 1990; Lerner and Galambos 1998; McManus 2002; Brindis, Morreale et al. 2003; Lemon, Hines et al. 2005; McCarthy and Woolverton 2005; Steinberg 2005).

Major normative developmental tasks of adolescence can be summarized into 4 groups: 1) the development of identity (including the acquisition and incorporation of morals and values, and the construction and remodeling of the self); 2) the development

of social competence (including negotiating social relationships with the same and opposite sexes); 3) separation and individuation from family; and 4) preparation for adult roles and responsibilities (Elliot and Feldman 1990; Carbonell, Reinherz et al. 2005; Alexander and Schrauben 2006). As young people execute these tasks, they are confronted with the challenges of learning to navigate and modulate their environments; honing complex reasoning, decision making, judgment and problem-solving skills; deepening their understanding of the world and their place in it; and learning to negotiate social relationships with others (Elliot and Feldman 1990; Harter 1990; Byrnes 2002; Masten, Burt et al. 2004a; Steinberg 2005).

Recently, scholars in the field of development have described an additional distinct developmental phase among young people in industrialized societies. Termed "emerging adulthood", this phase roughly spans the period of between the ages 18-25. It is primarily concerned with the further development and exploration of identity, particularly in the areas of love, work, and worldviews, and the transition to adult roles and responsibilities (Arnett 2000; Roisman, Masten et al. 2004; Masten, Burt et al. 2004a). In many societies, the period of emerging adulthood also coincides with attainment of the legal age(s) associated with certain privileges (e.g. voting or purchasing alcoholic beverages) or social constructed obligations (paying adult ticket fares or registering for military service); accordingly it is a time during which young people may be afforded new opportunities, responsibilities, and risks (Masten, Burt et al. 2004a; Foster and Gifford 2005).

There is even evidence from the field of neurobiology that the period of emerging adulthood entails considerable neurologic change including synaptic pruning of the

prefrontal cortex, alterations in the cortex and limbic regions of the brain, and continued myelination of intracortical and mesolimbic dopamine systems (Schulenberg, Sameroff et al. 2004).

Tasks of the Transition to Adulthood

While there is considerable variation in what may be deemed "normative" in terms of the tasks associated with the transition from adolescence to adulthood, in a general sense, these tasks have been suggested to include departure from the family home, entry in the worlds of the workforce or higher education, the establishment of marital relationships or cohabitation with romantic partners, and parenthood (Collins 2001; Osgood, Foster et al. 2005). In short, the transition to adulthood is a period marked by tremendous contextual and social role changes, opportunities, responsibilities and risks, and continued individual neurodevelopmental growth. It is also a time during which an individual's decisions, assets and resources have a particular bearing on their responses to stress, adverse life events, and risky situations.

The factors, policies, and processes that enhance resiliency and positive adaptation during the transition to adulthood have been a source of growing interest to scholars and policy makers alike (Masten, Burt et al. 2004a; Osgood, Foster et al. 2005; Settersten 2005). In particular, recently scholars from the field of mental health have pointed out that while early childhood experiences have an important bearing on outcomes in later life, the experiences of adolescence and young adulthood may be crucial mediators of adult psychopathology and mental health, and may even reverse the effects of early experiences (Schulenberg, Sameroff et al. 2004).

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Health and Developmental Issues in Adolescence and the Transition to Adulthood

The developmental tasks of both adolescents and 'emerging adults' intersect with their health needs and health status in a number of ways. First and foremost, both adolescence and emerging adulthood have been identified as periods of heightened experimentation and risk taking behavior (Turner, Irwin et al. 1993; Kools and Kennedy 2003). Experimentation and risk-taking can be a normal and important part of life skills development and the exploration of identity, but they may also have profound implications for present and future health and well-being. As many have pointed out, the major causes of morbidity and mortality during adolescence are associated with risk-taking behaviors (Millstein and Litt 1990; Turner, Irwin et al. 1993; Brindis, Morreale et al. 2003). For the past 20 years, the top 3 causes of death among adolescents have remained accidents, homicides, and suicides (McManus 2002). As described by Brindis et al. (2003), 7 major categories of risk-taking behavior account for 70% of adolescent morbidity and mortality, these are: drug and alcohol abuse, unsafe sexual activity, violence, injury-related behavior, tobacco use, inadequate physical activity, and poor dietary habits. In addition, as proposed by Lerner and Galambos (1998), poor decision-making during adolescence (e.g. involving sexual activity, criminal activity, substance use, and school performance) may also entail greater and more negative consequences for youth than the consequences of poor decision making in childhood.

Unfortunately, the risk behaviors often seen in adolescence do not necessarily wane as youth leave their teenage years behind. Rather, as suggested by Arnett (2000), the prevalence of many types of risk behavior, including unprotected sex, most types of

substance abuse, and reckless driving, actually peaks during the period of emerging adulthood. This is due in part to the process of identity exploration, but may also be attributable to the greater social freedom of older adolescents, who are less likely than younger teens to be monitored by adults or constrained by other roles and responsibilities (Arnett 2000). In this regard, the developmental processes that are a normative part of adolescent and emerging adult development may have profound impacts on health status.

A further intersection between developmental tasks and health status is that developmental processes and stages strongly inform young people's attitudes and beliefs about health, their awareness and interpretation of their own health status, their understanding of health information, their capacity to manage health and mental health-related issues, their health-care seeking behaviors and their perceived health access (Millstein and Litt 1990; Freed, Ellen et al. 1998; Ryan, SG et al. 1998; Carlisle, D Shickle et al. 2006). For example, numerous studies of adolescent's health seeking behaviors have described the adolescent's attitudes and beliefs about confidentiality and its importance as a major determinant of adolescents' utilization of health care services, particularly those services related to sexual health and substance use issues (Ford, Millstein et al. 1997; Brindis, Morreale et al. 2003; Society for Adolescent Medicine 2004; Carlisle, D Shickle et al. 2006).

An additional link between development and health status/access is that during adolescence, age (i.e. minor status), and socially-constructed notions of youth's maturity and autonomy are strongly linked to access to health care. For example, parent or guardian consent is a pre-requisite for the receipt of most general medical services for youth under the age of 18; however, in some US states, certain "sensitive services,"

including those pertaining to pregnancy, family planning, and treatment for sexually transmitted diseases, substance abuse, and certain mental health conditions, may be obtained by minors themselves, without parent or guardian consent (Jones, Purcell et al. 2005).

Older adolescents and young adults are also more likely than any other age group to be uninsured or under-insured, which can serve as a significant barrier to their health care access and can impact their ability to receive timely and adequate preventive care and treatment (Oberg, Hogan et al. 2002; Brindis, Morreale et al. 2003). Such observations are worrisome considering that access to care has been identified as a "protective factor" that reduces the likelihood of poor health outcomes by providing early interventions to prevent future health conditions, and buffering the effects of current health conditions (Fraser and Terzian 2005; Rounds and Ormsby 2006).

In summary, adolescence and emerging adulthood are periods of rapid physical, emotional, and cognitive change, during which young people have a unique set of health risks and vulnerabilities that stem from the interplay of risky behaviors, developmental processes, and policies (informed by social and cultural norms) that impact their health status and access to care.

The Transition to Adulthood for Foster Youth

As described in section one, the transition to adulthood for youth in foster care and other government institutions (e.g. juvenile justice) is unique from that of other youth who have not experienced such systems. Youth who have resided in public care have often experienced years of pervasive involvement of various social service systems and

providers in virtually all aspects of their lives. However, upon reaching the age of majority, this involvement ends, and youth are often confronted with the abrupt termination of both supportive services and state and federally-mandated benefits and entitlements (Foster and Gifford 2005; Osgood, Foster et al. 2005). In addition, for some youth, the process of being discharged from foster care can mean the end of certain forms of social contact and supportive social networks, including visits with social workers and other social service agency staff, foster parents and guardians, and peers in foster care (Collins 2004). Recognition of this unique set of changes and challenges has prompted some researchers to count foster youth among a larger population of young people who face certain vulnerabilities during the transition to adulthood (Osgood, Foster et al. 2005).

In particular, research on the foster youths' transitions to adulthood has honed in on the ways that the developmental tasks of adolescence and emerging adulthood can occur in radically different settings and ways than for other youth not involved with the child welfare system (Collins 2001; Kools and Kennedy 2003; Alexander and Schrauben 2006).

To begin, the process of "separation from family" for youth residing in foster care is quite different from that of other youth. As many child welfare scholars have pointed out, most young people in contemporary American society are able to draw upon the support and resources of family members well beyond the age of 18 to mediate the social and financial difficulties associated with leaving home (Collins 2001; Lemon, Hines et al. 2005). Many American youth depend heavily on the financial and emotional support of parents as they transition into adulthood, and as many as half of young people return to

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live in their parental home for at least a brief time after initially "leaving the nest" (Collins 2001).

However, for youth residing in most foster care placements, the gradual path by which most youth in the general population leave their homes is not an option. As previously described, young people residing in foster care have typically undergone an experience of early, prescribed, traumatic separation from their families, often in the context of dysfunction, abuse or neglect (Collins 2001; Alexander and Schrauben 2006). The experience of shifting between multiple temporary foster families and guardians, may further alter their notions of home as a stable and reliable environment. And with regard to the transition to adulthood, the emotional and financial support of parents and family members are often unavailable to foster youth during their adolescence and the transition to adulthood (Collins 2001; Lemon, Hines et al. 2005).

Foster youth also face formidable challenges to the development of social competence and the ability to form healthy social relationships. As mentioned above, foster care children and youth often experience multiple placement transitions that disrupt their ability to achieve success in school and maintain relationships with friends, family members, foster parents, teachers, health and social service providers, and community members. The consequences of such upheaval can include difficulty forming healthy attachments, social isolation, poor academic performance, and behavioral problems (Browne 2002; Kools and Kennedy 2003; Alexander and Schrauben 2006).

A small body of research has attended to the negative impacts of maltreatment and foster care involvement on self-esteem and identity development among older foster youth. These impacts include a sense of alienation, marginalization, diminished self-

worth, and stigmatization among adolescents in foster care (Simms 1991b; Kools and Kennedy 2003). A qualitative study by Kools (1999) examining the impacts of long-term foster care experiences on adolescent development found that the experiences of uncertainty as a result of repeated placement changes, along with perceived stigmatization associated with foster youth status, led to 'self-devaluation' and processes of 'self-protection.' Kools proposed that foster youths' strategies for self-protection may include concealing foster youth status and keeping relationships superficial to avoid pain or disappointment. Kools further suggested that the consequences of such self-protection include the projection of a thin veneer of self-reliance or 'pseudoindependence' which may mask an inability to express concrete long-term goals; and a lack of future orientation. This lack of future orientation may ultimately preclude the development of concrete strategies for goal attainment.

The findings of social detachment and marginalization, pseudoindependence and a lack of future orientation among foster youth are particularly concerning considering the proposed roles of meaningful healthy connections with supportive adults; the ability to "envision the future;" and goal-orientedness in the development of resilience of youth who have overcome adversity (Kools 1999; Collins 2001; Aronowitz 2005; Hines, Merdinger et al. 2005).

Finally, with regard to the preparation for adult roles and responsibilities, there are a number of ways in which the circumstances and experiences of foster youth differ from those of other youth. As mentioned above, foster youth are confronted earlier on than other youth with the expectation that they must prepare to be self-sufficient by the time they reach the age of majority or emancipate. In addition, as Simms (1991) has

pointed out, many of the major decisions that must be made on behalf of foster youth while they are in care must be filtered through a complex network of authority figures including foster parents, guardians, social workers, and other adults. Often such decisions are made with only minimal input from the youth themselves. Such situations may lead foster youth to perceive a "diffusion of authority" among adults, and a sense of personal disenfranchisement (Simms 1991b).

Ultimately, in many ways, foster youth have a unique and more complicated set of stresses than other youth, including the experience of "non-normative stresses" such as neglect, maltreatment, and/or abuse; the experience of removal from their birth home and placement in foster care, with its associated implications for identity development and sense of place within social and familial networks; the experience of frequent school disruptions and changes in housing placements; and the need to prepare for independence at an earlier age than most youth who reside with their families. Furthermore, as some have pointed out, the expectations of "self-sufficiency" and "independence" for youth exiting foster care are not only unrealistic, but perhaps also inappropriate and contrary to the goal of helping young people to be socially connected and civically engaged (Collins 2001; Propp, Ortega et al. 2003).

Health and Developmental Needs of Older Youth in Foster Care: A Review of the Literature

Massinga and Pecora (2004) have suggested that necessary supports to ensure the well-being of older youth in foster care include stable living environments, healthy friendships with same-aged peers, stable connections to school, educational supports

(including appropriate remediation), comprehensive medical and mental health services, caring adults, networks of social support, and comprehensive life skills preparation. Yet they suggest that much remains to be done to broaden the focus of supportive and youth development services for foster youth beyond the current emphasis on clinical and rehabilitative programming to include more holistic programming in social development, academics, job preparation and experience, and recreation.

With regard to the specific health and mental health needs of older foster youth, English et al (2003) suggest that these include "comprehensive health assessments, and general dental examinations, preventive services (e.g. nutrition and exercise counseling; anticipatory guidance), teen pregnancy prevention and family planning services, services to prevent or treat HIV or AIDS and other sexually transmitted diseases, other reproductive health care, mental health and substance abuse services, treatment for acute and chronic health problems, and case management." They further suggest that while these needs are quite similar to those of other adolescents, the intensity and urgency of these needs may be greater for foster youth (English, Morreale et al. 2003).

Several studies have emphasized the need for additional prevention education and support to reduce health risk behaviors among foster youth. It has been suggested that foster youth may be more likely than other youth to engage in health risk behaviors, such as risky sexual behavior and substance use; and may engage in these behaviors at an earlier age and with a greater intensity (Becker and Barth 2000; Carpenter, Clyman et al. 2001; Elze, Auslander et al. 2001; Edmond, Auslander et al. 2002; Taussig 2002). Foster care involvement has also been associated with an increased risk of early and/or unintended pregnancy; young women in foster care have been found to be 2.5 times more

likely than those not in foster care to have been pregnant by the age of 19 (Carpenter, Clyman et al. 2001; McGuinness, Mason et al. 2002; Bilaver and Courtney 2006).

Increased engagement with health risk behaviors and risk of early pregnancy may be related in part to the sequelae of childhood trauma, abuse or exploitation; inadequate and fragmented education about health and healthcare, family planning and sexually transmitted diseases; and/or economic and subsistence pressures, e.g. survival sex (Becker and Barth 2000; Carpenter, Clyman et al. 2001; Taussig 2002). The literature suggests a need for socially relevant and developmentally appropriate health and sexuality education for youth in out-of-home care (Becker and Barth 2000; McGuinness, Mason et al. 2002).

An additional health and mental healthcare need for older foster youth is access to sufficient, timely and appropriate insurance coverage for health and mental health services, and the ability to retain these services during the tumultuous period of the transition to independence (English, Morreale et al. 2003; Allen and Bissell 2004). As described in section one of this paper, only a handful of states have elected to implement the expanded Medicaid Option of the FCIA, meaning that in most states youth lose their Medicaid coverage when they turn 18 or emancipate from care (English, Stinnett et al. 2006). The loss of coverage that occurs when youth exit from the system can have important bearings on the course of their treatment for various medical and mental health concerns, and their access to future care should new health and mental health issues arise.

In summary, older adolescents in foster care have a unique set of health needs which necessitate access to affordable, comprehensive, continuous and accessible care.

Few, if any studies have described the adequacy and appropriateness of pre-emancipation health-related programming and there exist few standardized mechanisms for ensuring that transition-aged youth leave care prepared to navigate the adult health care system.

Although much remains to be understood of the best practices for ensuring smooth transitions from pediatric to adult health care systems for foster youth, there is a vast literature on "health care transitions" (or HCTs) for other populations of young people including youth with special health care needs and youth with severe mental illness (Callahan, Winitzer et al. 2001; Reiss 2002; Rosen, Blum et al. 2003; Vostanis 2005; Heflinger and Hoffman 2006). While the particularities of the foster care system and the unique health and developmental needs of foster youth must be acknowledged, there may be some important and applicable lessons from the existing literature on HCTs that may be drawn upon to smooth health-related transitions for youth aging out of foster care.

For example, the existing literature on health care transitions strongly advocates for the development of coordinated, "health care transition plans," the design of which begins years in advance of necessary health care transitions (e.g. from pediatric to adult-oriented providers). Key components of HCT plans include the establishment of a "medical home" that serves as a site for comprehensive care and coordination of services; the designation of key care providers who can serve as facilitators for the transition process; the early engagement of providers in the adult health care sector; and the creation of ample opportunities for the youth's own input and leadership during both transition plan development and execution (Callahan, Winitzer et al. 2001; Reiss 2002; Rosen, Blum et al. 2003). In addition, access to affordable, comprehensive, and

continuous health insurance has been identified as a critical component of successful transitions to the adult health care system (Rosen, Blum et al. 2003). It is possible that a more concerted effort to develop planned health care transitions for foster youth; improve communication between service providers while also cultivating young people's sense of self-efficacy with managing health-related issues; and ensuring continuous health care coverage may prove to be important strategies for improving access to care during the transition to adulthood.

SECTION 4: POST-EMANCIPATION OUTCOMES: A REVIEW OF THE LITERATURE

Despite nearly a century of awareness and concern over the adult outcomes for young people who have experienced foster care, and a more recent resurgence in legislative, scholarly, media, and public interest in improving child welfare outcomes, there remain only a small relatively number of formal research studies that have examined the adult outcomes of youth and adults who have experienced foster care (McDonald, Allen et al. 1996; Kerman, Barth et al. 2004; Courtney and Hughes-Heuring 2005; Newsom 2006; Siegel 2006; Eckholm 2007; Knight 2007).

Further complicating an understanding of child welfare outcomes is the fact that existing research on adult functioning of former foster youth often has significant limitations (McDonald, Allen et al. 1996; Courtney, Piliavin et al. 2001; Kerman, Barth et al. 2004; Massinga and Pecora 2004; Pecora 2006). These limitations include methodological variations in study design and rigor, small sample size, lack of standardization, and lack of comparison groups. These studies are also complicated by

external variables such as the individual characteristics of children and their birth families, differences in social and environmental factors affecting the child, the nature of the abuse history and the reasons for placement, service characteristics, length of time in care, and type of placement (McDonald, Allen et al. 1996; Collins 2004; Kerman, Barth et al. 2004; Massinga and Pecora 2004). In addition, the study of child welfare outcomes is hampered by the lack of standardization of policies and programs among state and local child welfare agencies, and the regional variations in access to resources and programs (e.g. educational support, social and health services, community organizations). Such limitations make it difficult to draw reliable and/or broadly generalizable conclusions about the foster care experience and its long-term effects on children and youth.

Nonetheless, the existing small scale, regional studies and the handful of large scale studies provide an important foundation for our understanding of the challenges youth face as the transition out of foster care and into adulthood, and highlight potential areas for improvement in the provision of services to children and youth during and after their time in state care. Taken together these studies suggest that there is much to be done to improve outcomes for youth leaving foster care, for consistently, child welfare researchers have reported that foster youth often encounter formidable challenges across multiple life domains both during their transition out of the foster care system and in later adult life (McDonald, Allen et al. 1996; Collins 2001). The following sections summarize the major findings from the existing literature on youth who have emancipated from the foster care system in the US.

Housing Instability and Homelessness

Studies of young people who have emancipated from foster care have demonstrated that these youth experience alarmingly high rates of housing instability and homelessness. Housing instability is often a predicament faced by youth at the time of their emancipation from foster care. A 2003 study of 100 recently emancipated foster youth in Nevada found that nearly 1/3 did not have a secure place to live at the time of emancipation (Reilly 2003). Echoing these troubling findings, a recent study of the intersections between housing, employment and homelessness and a history of foster care by Lenz-Rashid (2006) reported that of the 4355 youth that emancipated from foster care in California during the fiscal year 2000-2001, an alarming 65 percent were homeless at the time of their emancipation (Lenz-Rashid 2006).

Studies of young people who have recently left the foster care system suggest that these youth continue to face significant housing instability in the years following their discharge from the system. Between 12 and 36 percent of youth in several studies had experienced at least one night of homelessness, and 35 percent of youth in one study reported moving 5 or more times since leaving care (Cook 1994; Courtney, Piliavin et al. 2001; Reilly 2003).

Additional insights into outcomes for former foster youth have come from the literature on homelessness. Several studies have documented the high prevalence of foster care experiences among homeless youth and young adults (Piliavin, Sosin et al. 1993; Roman and Wolfe 1997; Zlotnick, Robertson et al. 1999; Lenz-Rashid 2006). Zlotnick et al (1999) reported that between 10.2 percent and 38.6 percent of homeless adults in several regionally specific studies reported a history of childhood out-of-home

placements. Among a sample of 252 homeless young adults accessing homeless support services in San Francisco, 43 percent reported having a history of foster care placement (Lenz-Rashid 2006).

Some have speculated that the tremendous upheaval and frequent placement changes experienced by children and youth in foster care, and the disruptions to attachment and support systems, in conjunction with experiences of maltreatment, pose significant challenges to young peoples' ability to develop the skills necessary to maintaining stability in housing situations (Zlotnick, Robertson et al. 1999). Some have even specifically proposed that the experiences of "drifting" between placements and caregivers in foster care creates a disaffiliation from the institutions of family, and may ultimately result in an identification with the lifestyle of "drifting" in adulthood (Penzerro 2003).

Educational Attainment

The educational attainment of young people who have left the foster care system has emerged as another area of concern. Young people who have left foster care are less likely than their peers in the general population to earn a high school diploma or GED, and have lower rates of college attendance (Courtney and Hughes-Heuring 2005).

An early study landmark study by Festinger (1983) examined the circumstances of young adults who had recently exited foster care in New York and found that over 1/3 (34.6%) of the 277 respondents had not completed high school by the time of their discharge from foster care (Festinger 1983). In his 1990 study of 55 youth who had

exited from out-of-home care in the San Francisco Bay area, Barth (1990) found that more that half (55%) of youth left foster care without a high school degree (Barth 1990).

While much has changed in the years since these studies were conducted with regard to foster care policy and material supports available to emancipating foster youth, more recent studies continue to give a troubling picture of the educational attainment of young people who emancipate from foster care. In their cross-sectional study of 84 youth leaving care in Missouri, McMillen and Tucker (1999) reported that 61 percent of these youth had received not received a high school diploma by the time of their exit from out-of-home care (McMillen and Tucker 1999).

In a more recent and currently ongoing longitudinal study of the adult outcomes of former foster youth in the Midwest states of Illinois, Iowa and Wisconsin, Courtney and Dworsky (2005) reported that by age 19, many transitioning foster youth had experienced significant life challenges and poor outcomes compared to their same aged peers in the general population. Approximately one third of the transitioning foster youth in their 'Midwest' sample had received neither a high school diploma nor a GED, compared to fewer than 10 percent of 19-year olds from a nationally representative sample of youth. In addition, only 18 percent of the Midwest foster youth sample were enrolled in a four-year college, compared with 62 percent in the national sample (Courtney and Dworsky 2005).

The low educational attainment of young people leaving foster care has been attributed in part to high rates of special education involvement, as well as to the school disruption many young people experience as a result of multiple placement changes during their time in foster care (D'Andrade 2005; Pecora, Williams et al. 2006). Because

educational attainment is known to be linked to employment opportunities, the low educational attainment of young people discharged from foster care is all the more concerning (Courtney and Hughes-Heuring 2005).

Income Instability and Lack of Economic Self-Sufficiency

Yet another area of concern that has been repeatedly identified across several studies of young people who have left care is the high rate of income instability and a lack of economic self-sufficiency. In Barth's 1990 study of youth leaving care in San Francisco, 53 percent of respondents indicated that they had experienced "serious money troubles" such as not being able to purchase food or pay bills since leaving foster care (Barth 1990). In another study, 41 percent of respondents reported not having enough money to cover their basic living expenses (Reilly 2003).

Young adults who have transitioned from foster care have also been found to have higher rates of dependence on public assistance than the general population (Courtney and Hughes-Heuring 2005). A study of youth exiting care in Wisconsin found that nearly one-third (32%) had received public assistance since their discharge from care (Courtney, Piliavin et al. 2001).

The financial instability of young people leaving care is thought to be connected to the low educational attainment and minimal work experience possessed by many young people exiting from care. In Barth's 1990 study, one third of youth respondents reported that a lack of education and skills constituted the greatest barriers to obtaining the kind of work they wanted.

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Court System-Involvement and Incarceration

Young people who have left foster care have also been found to have higher rates of court system involvement than the general population (Courtney and Hughes-Heuring 2005). Courtney et al (2001) found that 18 percent of recently-emancipated youth had been arrested at least once in the twelve to eighteen months since their exit from care.

It may well be that youth's struggles to make ends meet may contribute in no small part to their involvement with criminal activity. In Barth's study 33 percent of emancipated youth respondents reported that they had done something illegal in order to get money; examples of such activities included stealing to get food, prostitution and drug dealing (Barth 1990).

In another study, emancipated youth again described significant challenges with making ends meet and turning to illegal activities for money: twenty-four percent of respondents reported selling drugs at least once, and 11 percent reported trading sex for money since leaving care (Reilly 2003).

Early Pregnancy and Parenting

Several studies of youth in foster care and youth who recently emancipated have found high rates of early pregnancy and parenting among this population. A study conducted by the Chapin Hall Center for Children between 2002 and 2004, found that by the age of 19, almost half of young women in foster care have been pregnant, compared to 1/5 of their peers who were not in foster care (Bilaver and Courtney 2006).

Exposure to Violence/Victimization

High rates of exposure to violence and physical and sexual victimization have also been identified among young people leaving foster care. In a 2001 study of young people leaving care in Wisconsin, 25 percent of young men and 15 percent of reported experiences of violent victimization following their discharge from care. Again, it is likely that such victimization may be linked to the circumstances young people may find themselves in as a result of factors such as income and housing instability.

Health and Mental health Issues and Outcomes for Youth who have left care

A number of studies have indicated that many young people discharged from foster care experience serious or disabling health issues in the years following emancipation, and allow face considerable barriers to accessing health care.

Barth (1990) found that 44 percent of the respondents in his sample of Bay Area emancipated youth had experiences of a serious illness or accident since leaving foster care. Twenty-four percent of the young people in this sample reported requiring hospitalization. Nearly 40 percent of the youth respondents lacked health insurance. Forty percent of respondents described having problems or worries about medical bills either "sometimes" or "often." While approximately half of the sample rated their health to be good or excellent, 38 percent indicated that they had a current untreated health problem. When surveyed about the most common health problems they faced since emancipating from care, the most cited responses included family problems, dental issues, depression, headaches, sleep problems and weight problems (Barth 1990).

In her summary of findings from the National Evaluation of Title IV-E Independent Living Programs for Youth in Foster Care (to date the only national study of outcomes for emancipated foster youth), Cook (1994) found that 30 percent of respondents reported difficulty accessing needed health care, with lack of insurance cited as the primary barrier. The findings of the Wisconsin-based Foster Youth Transitions to Adulthood Study (Courtney, Piliavin et al. 2001) reported similar findings with 44 percent of respondents indicating problems securing affordable health care, and lack of insurance posing a major barrier to care.

Most recently, reports from the Midwest Evaluation of the Adult Functioning of Former Foster Youth found that while 87 percent of young adults in the study sample described their health as good to excellent, 24.3 percent reported that health conditions limited their ability to engage in vigorous activity, and nearly 10 percent indicated that health conditions limited their ability to engage in moderate activity. The respondents in this study also tended to describe their health less favorably than their same-aged peers from a national sample of youth who had not experienced foster care. The foster youth in the Midwest sample reported more emergency room visits and more hospitalizations during the past five years than their peers (Courtney and Dworsky 2006).

The prevalence of mental health issues has also been repeatedly identified in studies of outcomes for young people who have left foster care. In his 1990 study of youth who had left care in the San Francisco Bay Area, Barth used The Center for Epidemiologic Studies Depression Scale (CES-D) and found high rates of depression among study participants. Courtney and Dworky (2006) reported that among the young people in their Midwest Evaluation sample, one third were found to suffer from

depression, dysthymia, post-traumatic stress disorder (PTSD), social phobia, alcohol abuse, alcohol dependence, substance abuse, or substance dependence (Courtney and Dworsky 2006).

Another large scale study of adults who experienced foster care in Oregon and Washington found that within the past year, over half of the study respondents had clinical levels of at least one mental health problem, such as depression, PTSD, social phobia, panic syndrome, or substance dependence; and nearly 20 percent had three or more mental health problems. Most strikingly, the authors found that rates of PTSD among this group of foster care alumni were up to two times as high as for U.S war veterans, with one in four alumni having experienced PTSD within the past 12 months (Pecora, Kessler et al. 2005).

Finally, a qualitative study of the correlations between individual resilience, successful transition to adulthood and education achievement among a group of fourteen former foster youth attending a four-year university found that despite remarkable academic success, all of the respondents described varying degrees of current difficulty with aspects of psychological function and emotional health (Hines, Merdinger et al. 2005). Several respondents described feelings of depression, sadness, or anxiety related to past experiences of abuse and family dysfunction, and complex and unresolved emotions with regard to biological family members. Respondents also described current pressures associated with balancing education, careers, family, housing and "an overarching fear of failure." These results provide important insights into the pervasive nature of young peoples' experiences of trauma and the ways that such experiences are

often carried into adulthood and may evolve as young people enter into new social roles and contexts.

Recent Policy Changes and Access to Care for Emancipated Foster Youth

As described in section one, the passage of the Foster Care Independence Act (FCIA) of 1999 brought with it the potential for significant change in the ability of states to offer expanded health care access to emancipated youth up to age 21. However, as mentioned previously, only a handful of states have actually implemented the Medicaid Expansion option, and as of this writing, there are no published studies which offer specific insights into the effects of this expanded access.

Nonetheless, one recent study, the previously described Midwest Evaluation, has examined the effects of a certain state-specific policy changes on access to care for emancipated foster youth. Specifically, the authors have examined the outcomes associated with a unique program in Illinois which allows youth to voluntarily remain in foster care, under the supervision of the Illinois courts until the age of 21. The investigators compared the differences in health insurance status and health care utilization between foster youth who remained in care after age 18 and those who had left care.

With respect to health insurance status, they found that 71.3 percent of all study participants reported having health insurance. However, a closer look at the differences between youth who had remained in care after age 18 versus those who had left care, revealed that 98.2 percent of those still in care reported having health insurance, compared with only 47.1 percent who had left care. Regarding health care utilization

and access to care, the investigators found that 21.4 percent of youth who had left care reported not receiving medical care that they needed within the past year, compared with only 4.6 percent of those still in care. Echoing the findings of previous studies, youth in the Midwest study again cited uninsurance and the perceived cost of care as the major barriers to their health care access. Finally, with regard to mental health care access, over one fifth of respondents reported receiving psychological or emotional counseling. Those still in care were twice as likely (28.5%) to have received counseling than those who were no longer in care (13.7%) (Courtney and Dworsky 2006). These results strongly suggest that allowing young people to voluntarily remain in care beyond the age of 18 may significantly improve their access to health and mental health services.

What Would Have Helped: Youths' Appraisals of Programming and Services Received in Foster Care

While the outcomes described above paint a relatively grim picture of how young people fare after exiting the foster care system, it is important to note that not all foster youth experience such challenges, and that many former foster youth demonstrate remarkable resilience in their transitions to adulthood.

It is also worth noting that many of the challenges experienced by young people after emancipation have important connections to experiences of upheaval and disrupted attachment that are often a direct result of young people's involvement with the child welfare system. A growing body of literature on best practices in child welfare policy has sought to address issues such as educational disruption and placement instability with the goal of reducing system-associated risks for foster children and youth (D'Andrade

2005). However, the existing evidence suggests that there is ample room for improvement.

Former foster youth's own critiques and appraisals of their experiences in care can offer key insights into the successes and shortcomings of foster care policy and practice. However, to date only a handful of published research studies have solicited young people's perspectives about their time in foster care, their experiences with independent living programs (ILPs) and their suggestions for improvements that could be made to better support current and future foster youth (Barth 1990; McMillen, Rideout et al. 1997; Georgiades 2005).

In these existing studies, emancipated youth have tended to speak frankly about the pain associated with having been removed from their homes and placed in foster care (Georgiades 2005); the stigma and social isolation associated with being raised in foster care (McMillen, Rideout et al. 1997; Georgiades 2005); and the tremendous financial, social, and emotional challenges faced following their discharge from the system (Barth 1990; McMillen, Rideout et al. 1997; Georgiades 2005). In general, independent living skills classes were seen as helpful; and instruction in financial management was particularly appreciated (McMillen, Rideout et al. 1997; Georgiades 2005). However, respondents in some studies noted gaps in the curricula. The respondents in the study by Barth (1990) recommended greater attention to life skills education in general, as well as housing preparation. A later study by Geogiades (2005), carried out after the passage of the policies such as the FCIA (which specifically sought to improve ILP services), identified gaps in the areas of parenting skills and housing preparation.

One study also examined the views of former foster youth who did not participate in independent living programs and found that many attributed their non-participation to being unaware that they were eligible to enroll in the ILPs (Georgiades 2005). This finding is important as it raises questions about the uniformity and equality of access to basic entitlements, information, and support for older youth in the foster care system.

Finally, across all three studies, respondents mentioned the benefits of having social contact and opportunities to engage in social activities with other youth in foster care, including youth who had already left care (Barth 1990; McMillen, Rideout et al. 1997; Georgiades 2005). These findings suggest the benefits of facilitating social connectedness as a part of the preparation for emancipation, and the particular importance of enhancing opportunities for interaction and dialogue between foster youth.

While these studies add a crucial perspective to existing literature on post-emancipation outcomes and youths' appraisals of their experiences in care, more information is needed about other areas in which young people have been shown to experience difficulty. In particular, while the available data suggest that youth experience health and mental health problems, no formal studies have addressed youths' perspectives about the information and preparation they received regarding health benefits and entitlements through the foster care system, and no studies have solicited youths' suggestions to improve the health care access of young people who have exited care.

II. CONCLUSION:

The available literature suggests that while important strides have been made toward improving the support and preparation of young people transitioning out of the foster care system into adulthood, much remains to be done to ensure that these young people have the skills, resources, and support they need, particularly with regard to access to health and mental health care. Foster youth often have a unique set of experiences and circumstances that conspire to create formidable challenges to their health and well-being during the transition to adulthood. They have experiences of various forms of maltreatment, as well as traumatic loss, upheaval and displacement within the foster care system. In addition they are confronted with the dramatic changes in social roles and expectations, the opportunities, responsibilities and risks specific to the period late adolescence/emerging adulthood, and the abrupt loss of supportive services as they exit public care.

Research on outcomes suggests that many young people experience significant difficulties in multiple domains of functioning after exiting from foster care, including housing instability and homelessness, low educational attainment, income instability, early pregnancy and parenting, exposure to violence, high rates of court-system involvement and incarceration, as well as debilitating health and mental health problems and difficulties accessing health care. However important questions remain about how best to improve the education and preparation youth receive in advance of emancipation, particularly with regard to health and mental health care, and what strategies might enhance access to care after emancipation. Foster youths' own perspectives represent a

necessary contribution to any such discourse on the services, programming, and policy

for young people in transition out of the child welfare system to adulthood.

Chapter 2- Research Findings

I. BACKGROUND:

As discussed in the preceding literature review, studies of outcomes for young people who have emancipated from the foster care system suggest that they may face unique health issues and obstacles to medical care during their transition to adulthood. Existing research has documented that emancipated foster youth often experience debilitating physical and mental health problems, and encounter significant difficulty securing health insurance and accessing health care after being discharged from the child welfare system (English and Grasso 2000; Courtney, Piliavin et al. 2001; Massinga and Pecora 2004).

Yet when it comes to the scholarly literature and discourse on the health needs of transition-aged youth and their post-emancipation health-related experiences and outcomes, youths' own voices are conspicuously absent. While a handful of studies have explored the views of former foster youth with regard to their foster care experiences in general, and their perspectives about independent living skills programming, no studies have focused specifically on emancipated foster youths' views regarding health-related education and preparation received while within the foster care system (McMillen, Rideout et al. 1997; Georgiades 2005). In addition, much remains to be understood of foster youths' own perceptions of the barriers to care faced during the transition from the child welfare system.

An improved understanding of youth's perceptions of their preparation for navigating the adult healthcare system, and the factors that help or hinder access to healthcare after emancipation has tremendous potential benefits. Such information is of

extreme relevance to health and social service providers, and agencies, who serve foster youth, as it may lead to more informed program development and service provision. In addition, given the growing media and legislative attention to the negative outcomes for young people leaving public care, and new state and federal measures to improve child welfare system outcomes and accountability, an understanding of youth-perceived factors that help or hinder access to care is also of relevance to the work of policy-makers and local and state administrators.

The goals of this study were to solicit and describe the health care experiences and perceived health access of emancipated foster youth in the years following their exit from the foster care system in Alameda County, California, with the objective of answering four major research questions or domains of inquiry. These domains of inquiry were as follows:

1. What do former foster youth identify to be the **major health and healthcare access issues** they face in their post-emancipation years?

2. What are the **factors, policies, and processes that help or hinder** post-emancipation access to care?

3. How do former foster youth feel about the **adequacy and appropriateness** of their pre-emancipation preparation for navigating the adult healthcare system? And,

4. What are former foster youth's **recommendations for improving the pre-emancipation preparation** of transition-aged foster youth, and **facilitating access to care** for emancipated foster youth?

II. METHODS

Study Design

A qualitative approach was used to carry out this exploratory study of the health experiences and perceived health access of emancipated foster youth. The study was conducted over the course of a year and a half, and consisted of 2 phases of data collection. The first phase of data collection consisted of field observation and site visits for the purposes of understanding the landscape and infrastructure of health and social services for children, youth and young adults, particularly those involved with the child welfare system. The second phase of data collection consisted of focus groups and individual in-depth interviews with emancipated foster youth and individual in-depth interviews with key informant health and social services providers who serve emancipated foster youth in their patient or client population.

Approaches to Data Collection

Multiple qualitative data collection methods, including focus groups and individual interviews, and multiple interview sources (including both emancipated youth and health and social services providers) were used in this study for the purposes of "triangulation." Triangulation refers to the use of either multiple data collection methods

and/or different sources of data, with the intent of enhancing the reliability and validity of the interpretations of qualitative research findings (Willms, Johnson et al. 1992; Green and Thorogood 2004). By applying a triangulation approach, one method of data collection may be used to test the validity of findings from another method of data collection, or to reduce the biases inherent in having only a single perspective on a given issue. It is thought that where the data from different sources converge, there is likely to be greater reliability. By contrast, divergent data can lead to a deeper understanding of the complexity of a given issue or concept, and can prompt the development of new hypotheses or areas of inquiry (Willms, Johnson et al. 1992). The comparison and contrast of response data from focus groups and individual interviews from multiple interview sources was used in this study in an attempt to achieve a deeper understanding of the emergent themes.

As described by Madriz (2003), focus groups are "a collectivistic rather than an individualistic research method that focuses on the multivocality of participant's attitudes, experiences and beliefs." Focus groups are advantageous in qualitative inquiry in that they have the potential to create spaces in which collective group testimonies may be heard, while allowing the investigator to bear witness to social interactions between participants. In addition, focus groups can be useful in the examination of sensitive topics, such as dissatisfaction with systems or services (Green and Thorogood 2004). Furthermore, as some have noted, the process of sharing common experiences may engender self-validation and affirmation, which may contribute to a greater sense of personal empowerment (Madriz 2003).

With regard to the health services research, focus groups are a well-established strategy for exploring the views of consumers of health services or participants in a health-related program (Green and Thorogood 2004). And notably, focus groups have been used in prior research with emancipated foster youth as a means of examining their perspectives about their experiences in independent living skills programs (McMillen, Rideout et al. 1997). Focus group were used in this study in order to examine emancipated foster youth's collective experiences and perspectives with regard to the four domains of inquiry: 1) health issues faced by emancipated youth, 2) factors, policies and processes that help or hinder access to care, 3) the adequacy and appropriateness of pre-emancipation preparation for health care management, and 4) suggestions for improvement.

In contrast to focus groups which revolve largely around group dynamics and collective experiences, individual in-depth interviews are "a specific kind of interaction in which the researcher and interviewee produce language data about beliefs, behavior, ways of classifying the world, or about how knowledge is categorized" (Green and Thorogood 2004). Compared with focus groups, individual interviews may also offer the opportunity for participants to speak more openly about personal experiences or controversial views than they might in a group setting. Individual interviews were conducted with foster youth for the purpose of generating more personal, individualized narrative accounts of youth's perspectives and experiences with regard to the four domains of inquiry.

In addition to focus groups and individual interviews with youth, individual interviews were also conducted with health and social service providers who serve youth

in their patient and client populations. As professionals who interact with both with individual youth, as well as the health care and social service systems system at large, providers may have unique insights into both youth's individual experiences with health care as well as the broader structural and political factors that influence access to care. The purpose of these interviews was to elicit provider's perspectives about the major health issues faced among transition-aged foster youth and the factors that help or hinder their healthcare access. Thus these interviews constituted an additional data source and vantage point from which to examine health issues and barriers to care faced by transition-aged youth.

All interviews and focus groups were conducted by the lead investigator, an African American woman in her late twenties, who identified herself as a medical and graduate student.

Recruitment and Sampling

The participants in this study were young people between the ages of 18 and 24 who had legally emancipated from the foster care system in Alameda County, and were currently residing or receiving services in Alameda County. As this was an exploratory study, no attempt was made to achieve a representative sample of the total population of emancipated foster youth currently residing or receiving services in Alameda County.

However, efforts were made to obtain some diversity among the youth participants, hence the sampling approach for this study employed a combination of convenience sampling and purposive sampling methods. Convenience sampling is a 'catch as catch can' approach to sampling in which the investigator draws from a sample that is locally

available and willing to participate in the research. Convenience sampling can be an appropriate approach for exploratory studies in which relatively little is known about what issues will emerge as relevant (Green and Thorogood 2004). Emancipated youth were recruited via flyers and word of mouth outreach at youth/young adult serving agencies and organizations throughout Alameda County, and subsequently volunteered to participate in the study, yielding a *convenience* sample.

Purposive sampling permits the researcher to select cases that illustrated a feature or process of interest (Silverman 2001). In this study, purposive sampling methods were employed in an effort to achieve heterogeneity among participants in 2 domains: 1) *involvement in work, school or other pursuits*; in order to explore health access among youth in college and workforce settings, as well as youth who were unemployed; and 2) *sampling of youth in both Northern and Southern regions of Alameda County*; in order to explore geographic and transportation-related factors that might mediate access to and availability of healthcare among this population. The purposive component of the sampling strategy involved strategic selection of sites for outreach and the posting of flyers.

In addition, at the study's outset, the inclusion criteria for study eligibility stipulated that youth participants needed to have emancipated from foster care in Alameda County, however later, two exceptions to these criteria were made in order to achieve additional diversity among the sample. These exceptions were made for a pair of youth who emancipated from care in other California counties, but who were currently residing in and receiving services in Alameda County. These youth were included in the study because their health care responses provided important insights into the challenges and

barriers to health care associated with high mobility and frequent inter-county transfers common among this population.

Provider participants were recruited via their association with youth serving agencies and/or through professional contacts. Attempts were made to recruit providers from variety of disciplines including health, mental health, and social services.

Data Collection:

Focus groups with youth:

A total of three 60-minute focus groups were held with a total of 11 emancipated foster youth at three different youth/young adult-serving agencies. The focus groups were scheduled in advance with the permission of the host agency, and were advertised in the week prior to the date of the focus group to inform prospective participants about the study and the focus groups. The focus groups were facilitated using a semi-structured interview guide (see Appendix A), and were digitally recorded.

Individual interviews with youth:

A total of ten individual in-depth interviews were conducted with emancipated foster youth, each lasting between 30 and 45 minutes. One interview was conducted as a paired interview with two emancipated youth, to accommodate their interest in being interviewed together. Youth participants were interviewed either on-site at an agency or off-site in a café depending on their preference. The interviews were conducted using a semi-structured individual interview guide (see Appendix B), and were digitally recorded.

Key informant interviews with health and social service providers:

A total of four 45-minute interviews were conducted with key informant providers working in youth/young adult serving agencies with a reputation for serving transition-aged foster youth among their patient population. These interviews were conducted at the providers' offices. The interviews were conducted using a semi-structured interview guide (see Appendix C) tailored to solicit provider's perspectives about the health issues faced by transition-aged and emancipated foster youth, and were digitally recorded.

Procedure for Focus Groups and Individual Interviews with Youth:

Focus groups and individual interviews with youth were preceded by a brief meeting between the lead investigator and prospective research participants to assess interest in participation and ensure eligibility for the study. Youth participants were then provided with an overview of the project, its objectives, and an explanation of the informed consent process. Youth were informed that their participation was voluntary and confidential, and would not affect the care or services received through agencies with which they might be involved. All youth and providers signed an informed consent form to participate in the study.

Prior to starting focus groups, light snacks or pizza were served by the lead investigator, and there was a brief period for introductions and socializing. This was followed by a review of the confidentiality procedures and a discussion of ground rules

for group discussion. Individual interviews were also initiated with a brief period for introductions, and a review of confidentiality procedures.

Both focus groups and individual interviews were conducted with a semi-structured interview guide with questions intended to elicit responses that corresponded to the four domains of inquiry. The first set of questions explored respondents perspectives about the major health issues faced by emancipated foster youth. The second set of questions examined the factors that help or hinder access to care, and the perceived ease or difficulty around accessing health care. The third set of questions solicited youths' perspectives about the adequacy and appropriateness of their preparation for managing their healthcare after emancipation. The fourth set of questions solicited youths' suggestions for improvements in the pre-emancipation preparation of transition-aged youth, and improvements to enhance health access for emancipated foster youth.

Upon completion of the focus groups and individual interview discussions, youth participants were asked to complete a brief, anonymous socio-demographic survey that requested self-report information about gender, race/ethnicity, length of time since emancipation from foster care, current living arrangement, educational attainment, and current health insurance status (see Appendix D).

Following completion of the demographic survey, a short debriefing session was held to clarify any unresolved questions that arose during the discussion, and to provide individual youth with information and referrals. Youth participants were offered a list of free or low-cost health clinics, including youth clinics and clinics that accept Medi-Cal, as well as mental health service providers, crisis and counseling hotlines, and shelter/emergency housing services. Youth who described an unmet health or mental

health need, or who expressed an interest in receiving assistance with a health insurance problem were offered a referral to a youth/young adult friendly agency, or other appropriate service provider. Finally, all youth participants were compensated with a $20 gift card in exchange for their participation.

Data collection procedure: Provider study component:

Provider interviews were preceded by a review of the study objectives and confidentiality procedures. The interviews were conducted using a semi-structured interview guide which explored the following issues:

1. providers' experiences regarding the health-related needs of transition-aged and emancipated foster youth

2. providers' perceptions of the factors that help or hinder health care access among transition-aged and emancipated foster youth

3. providers' perceptions of sources of health-related information for foster care patients and clients, and the adequacy and appropriateness of this information, and

4. providers' suggestions for changes in policy and practice that would improve health access and health outcomes for transition-aged and emancipated foster youth.

Following each interview, provider respondents were offered a $6 coffee card in appreciation of their participation.

Institutional Review Board Approval

The protocol for this research was approved by the University of California at Berkeley's Institutional Review Board (The Committee for the Protection of Human Subjects).

Analysis:

All recordings of interviews and focus groups were transcribed. The transcripts were then coded by the lead investigator using a framework analysis approach. As described in (Green and Thorogood 2004), framework analysis is " a content analysis method which involves summarizing and classifying data within a thematic framework"; in this case, the thematic framework consisted of the four major domains of inquiry ("health issues"; "factors policies and processes that help/hinder access"; the adequacy and appropriateness of pre-emancipation preparation"; and "suggestions for change"). A framework analysis approach is particularly helpful for generating policy or practice-oriented research findings and was therefore a useful approach in an applied research study such as this.

As outlined by Green and Thorogood (2004), framework analysis consists of four steps. The first step is *familiarization*, in which the investigator reviews the raw data (focus group and interview recordings, field notes, and transcripts) until she is familiar with them in their entirety. The second step consists of a *thematic analysis*, from which the coding scheme is generated; the 'themes' within the framework become the basis for the development of codes. In the third step, referred to as *indexing*, the codes in the data set are systematically indexed by topic. In the fourth step, referred to as *charting*, the data are re-arranged into charts according to their thematic content.

In accordance with a framework analysis approach, the interview and focus group transcripts were reviewed several times for familiarization. During the thematic analysis phase, the data were coded using N-Vivo 2.0, a qualitative data analysis program. The codes were then indexed and organized into charts according to theme.

The investigative framework, as well as samples of focus group and interview transcripts, and the coding scheme were reviewed on an ongoing basis with the lead investigator's advisor.

III. FINDINGS:

Participant Demographics

The demographics and characteristics of the 22 emancipated youth participants are presented in Table 1 below. The majority of study participants were young women. The age range of participants was 18-23 years old, with an average age of 20. With regard to racial ethnic background, the majority (77 %) of the study participants self-identified as African American.

The participants were residing in a variety of housing situations including transitional housing apartments, college dorms, and relatives' homes. Forty-one percent stated that they were currently residing in their own apartments.

A majority of participants (73 %) indicated that they were currently enrolled in some form of school, including general equivalency diploma (GED) programs or two or four-year colleges. Six participants (27 %) indicated that they were not currently in school, but reported that they were either working or seeking employment.

Finally, with regard to health insurance status, sixteen of the twenty-two youth participants stated that they currently had health insurance, five reported that they were uninsured, and one participant was unsure of their insurance status. Notably, of the five youth who self-identified as being uninsured, all were over 21 years old and described having lost their Medi-Cal coverage upon reaching their 21st birthday.

Table 1 Demographics of Emancipated Youth Participants

	Youth Participants	
Number of focus groups	3 (Total of 11 youth participants)	
Average N/group	4 (3.6)	
Range	3-5	
Number of individual interviews	9	
Number of paired interviews	1	
Total number of participants	22	
Young Women	18	
Young Men	4	
Age Range	18-23	
Average Age	20	
Average years since Emancipation	2	
Race/Ethnicity	N	%
African American	17	77 %
Latino/a	2	9 %
White	2	9 %
Biracial/Multiracial	1	5 %
Living Arrangement	N	%
Own Apartment	9	41 % *
Transitional Housing	5	22 %
Relative's home	4	18 %
Foster family home	1	5 %
School dorm	1	5 %
Friend's house	1	5 %
Don't have a place to stay	1	5 %
School/Employment Activities	N	%
Currently in school of any kind (2 or 4 year college or GED program)	16	73 %
In college (2 or 4 year programs)	11	
In a GED program	3	
Type of school not indicated	2	
Currently working or seeking employment	6	27 %
Health Insurance Status		
Currently have health insurance	16	
Do not have insurance	5	
Unsure of insurance status	1	
Age range of uninsured youth	21-23	
* The numbers in this column do not add up to 100% due to error introduced by rounding.		

Findings:

The findings from the individual interviews and focus groups are summarized below, and are organized according to the four key areas of inquiry outlined previously. The names of participants have been withheld to protect their confidentiality, and certain identifying information has been omitted or changed to ensure greater anonymity.

INQUIRY 1: HEALTH ISSUES FOR EMANCIPATED YOUTH

When asked to identify the major health issues faced by youth recently emancipated from foster care, the participants identified a variety of health issues and concerns, with mental health and dental/orthodontic needs ranking among the most recurrent themes. Additional health issues included injuries and accidents, reproductive and sexual health, and nutrition. Finally, housing instability and homelessness also emerged as issues with significant bearing on young people's health.

A. Mental Health

Mental health issues were consistently identified by youth participants as ranking among the most pressing health problems faced by former foster youth during the post-emancipation years. Respondents' descriptions of the mental health issues faced by emancipated youth ranged from general or non-specific issues such as 'mental issues', needing 'therapy', or 'having a disorder' to more specific issues such as 'feeling depressed', 'being stressed' and having 'trust issues.'

Youth identified two major factors that contributed to mental health issues among transition-aged foster youth; the experiences of trauma that *preceded or precipitated* youths' placement into foster care, and the experiences associated with *involvement* with the foster care system itself.

With regard to the trauma experiences that preceded placement, some respondents explained that the mental heath issues experienced by former foster youth could stem from the abuse, neglect or family dysfunction that precipitated their placement into the foster care system. One young woman suggested that mental health issues for former foster youth can stem from a variety of traumatic childhood experiences, from parental substance use to physical or verbal abuse. As she put it;

> I think mental health is a big [issue] that can get overlooked. [L]ike y' know, someone grew up in a home and they were around alcoholics... That's a *mental* thing... Because they may have this addiction that's not necessarily outwardly seen so much... Again, to me, it all goes back to mental health. Like those things can traumatize you!...A number [of youth] have been in abusive homes or situations where they may not even notice it but they're going back to those type of abusive relationships, whether it be a boyfriend; a girlfriend; friends who verbally abuse; things like that.... I just think mental health is generally a big thing.

Another young woman alluded to the phenomenon of voluntary placement of children into the foster care system by their parents, due to inability to provide care for the child's intensive health or mental health needs. She was also careful to acknowledge that while mental health concerns are common, they are not universal. In her words,

> [E]verybody who's in the system has had something happen to them that caused them to be in the system. And that causes trauma. And that trauma can lead to a mental illness, but not everybody ends up with a

> mental illness. So, I think *mental illnesses* are a big thing in the system...
> [O]r, well, people with disorders can end up in the system, maybe because
> their parents don't know "oh, well my child has this disorder." And
> instead of helping them deal with that disorder, they're like "Oh, my god, I
> can't take care of 'em no more." And throw them in the system. And
> they're not thinking whether or not they [the kids] are just acting out and
> being bad, or whether they might have a disorder.

In addition to the experiences of abuse, neglect or the intensive health needs that *precipitate* placement in the foster care system, youth also suggested that the experience of *being in* foster care itself also has the potential to cause emotional trauma. The traumatic experiences that youth incurred while within foster care—from numerous placement changes to difficult relationships with foster parents--were identified as sources of ongoing psychosocial distress for youth during the transition to adulthood. As one young woman stated:

> I think that people have a lot of issues. Like, I guess they have problems
> getting over what they've been through *with* the foster care system. A lot
> of kids I know have been abandoned, or when they were in foster care
> their foster parents had 'em on military kind of stuff.

Youth described that experiences of childhood trauma (whether they occurred prior to or during child welfare system placement) can have significant impacts on young people during the transition to adulthood. Among the major sequelae of trauma described by respondents were "trust issues", depression and diminished self-esteem.

Several youth participants evoked the term "trust issues" as in describing the effects of repeated experiences of trauma and abandonment associated with being in foster care. As one young woman commented:

> A lot of people still have mental issues from being in foster care, and a lot of people still have that mentality…trust issues. Stuff like that…And when they get into the world, it's like everybody's after them, and everyone's against them.

Youth suggested that the consequences of such trust issues, during the transition to adulthood, could be quite significant. Trust issues were cited as a source of difficulty in some young people's relationships with peers and partners, and a barrier to their willingness to seek assistance for problems. As one young woman, aged 22, explained, 'trust issues' resulting from repeated experiences of abandonment by caseworkers within the system may preclude emancipated youth from asking for help when they need it.

> …You have trust issues. You really don't trust anybody, cuz you think "oh, if this doesn't go right, they'll just send a new social worker." So, you just have an issue of trust… [when you're in the system] you become dependent on these people doing things for you, but when you get out, you don't have people helping you really. [T]here are things you don't know how to do, but you don't *trust* people enough to ask them how to do it.

In addition to trust issues, youth also described the sequelae of trauma in terms of its effects on self-esteem and interpersonal relationships during the transition to adulthood. Some youth described feeling depressed or overwhelmed by new roles and expectations in adulthood that they felt unprepared for. Others described the impacts of their experiences of trauma on their self-esteem as they made the transition from adolescence to adulthood.

For example, one young woman explained that her methods for coping with emotional trauma became centered on excelling in school and being in relationships. As she stated:

I'm still struggling to get past it, just trying to cope, and do all the things that I do. And I think I've changed, because I've changed on the outside but really in my heart it's very, very painful...I think for me-- I kinda went into achieving....I would pick up these habits as far as the way I thought about myself – [like] "Okay if I don't feel good enough what can make me good enough? Oh school. If I excel in school and if I do all these things I'll be more accepted by people....I'll feel better about myself." Or "If I have a boyfriend I'll feel better about myself. That means I'm somebody."
...I just want to be able to express myself and be free and be me; who I *really* am instead of putting up this performance, and putting up this bar. "I'm so and so. I have it all together. I go to school. I got all these scholarships..." But really I'm traumatized. I feel like a victim. I don't have very good, very high self-esteem.

A number of youth respondents stated that in the years since their emancipation, they had found themselves confronted in new ways with the impacts of their past experiences of trauma and foster care. For some respondents, the transition into new social roles such as parenthood, or the entry into new relationships had prompted them to re-examine difficult experiences or problematic family dynamics. Some youth described attempting to understand or recover missing elements of their personal histories; for example, one young woman commented:

...It does... It hits me all the time. Issues that I was dealing with back then come back now, cuz like, I really don't know about my past. I have to... just things about... figuring out about my past, like "If this is a certain way, then that's why"...

Some youth even expressed that in the post-emancipation period they had developed a renewed interest in receiving counseling or other forms of emotional support to help them come to terms with difficult experiences from their childhoods. One young

man described coming to the realization of how much he'd been affected by his

experiences in foster care only after he was living on his own. He conveyed that with his

newfound sense of perspective about himself and his past experiences, he had also

developed an understanding of his potential need for counseling. In his words;

> I could just say that… you know, mental state--like, I know that everybody got they problems. Well I got my *own* problems… I still think I need counseling. Like really. I used to have people tell me that all the time, and now I take it. Like when I was I was in the group homes, like I had a lot of stuff happen to me… like a *lot* of stuff, and I'm saying like, it was out of this world, you know what I'm saying? There are people who've been in worse situations, but I've been through some *stuff*. And it messes with my head, it do. At first it didn't, but after a while… ….And it's like, I didn't really start trippin' about how much it did to me until I was on my own. 'Cuz like, when you're in the system, man, you're really being pampered--- I'm gon' be real wit you. And when you come out, you just really see….

Another respondent expressed a similar interest in counseling that had arisen since her

emancipation. She described;

> As far as counseling and stuff like that goes, in the foster care system I *did* have counseling, however, I stopped going due to my own will. But it did catch up to me, because, now that I sit down, I'm like, I *need* counseling, I need somebody to talk to, you know? And, I mean-- I don't know…[there were] a lot of things that happened to me within the system, that kinda caught up to me…
>
> ….I thought I was over everything….I thought, "I got all my problems out and it's okay now", but that's not what happened. And now I'm 20 years old and I'm like, dang…I need somebody to talk to! Just somebody to talk to… because with foster care youth, trust issues are *major*. Whether you're in or you're emancipated out the system, it's with you for the rest of your life. Period!

Another young woman who is currently receiving counseling services, explained that she had experienced a change of heart about speaking with a counselor. Despite having had negative experiences of therapy during her time the system, she described that she had since undergone changes in her life circumstances that had brought about a renewed interest in understanding and coming to terms with past trauma and strained family relationships.

> Both me and my friends, we all *had* to do therapy when we were in care. It was forced, so we pretty much had to; and we were like, "We'd rather go do something else." We couldn't take it seriously. It was forced! If we'd *wanted* to, it would've been a different story...
>
> But *after* care, as a matter of fact in the last year or so, we've all been trying to figure out what's going on with our lives, why we have resentment towards certain people, and for some of us, why we have anger problems. We're just trying to figure out *why*... so we've been going to therapy. But we really wish we had used it when we had it [in the system]. But it was kind of hard; maybe there was a lot going on, or maybe we were acting out, or maybe we just didn't want to go.
>
> ....I think it's that I'm older, I have my own child to worry about, and there's all this stuff going on, and I'm having a hard time dealing with it. Plus, there are things from the past that I'm having a hard time dealing with. I'm trying to figure out ways to reconnect, but also distance myself from [people in my family], and I'm like, 'I can't do this alone.' I *know* I can't. So I need someone who might be able to see it from the outside in.

When asked if she felt that it was important for youth to have access to counseling in the post-emancipation period, she remarked:

> I think it's more important to have *afterwards*, than when we're *in* care; because when we're in care, the majority of people I know, even people I'm not in contact with, we went to therapy and it was like, a joke. It was something we *had* to do. We couldn't take it seriously; there was so much going on. And we probably had attitudes towards the therapists... and it's not *their* fault, but they, at the time, didn't know that. So, I guess, things

like that, you have to be *willing* to do, and it can't be forced. So if you want to go to therapy, you should go on your own.

This young woman's comments suggest that factors such as age, developmental stage, autonomy and personal choice may shape youths' receptiveness to counseling and therapy. She further suggests that youth in foster care may benefit more from the therapeutic process when they themselves are able to initiate it or have some decision-making power over whether or not to participate.

B. Dental and Orthodontic Issues

A number of youth respondents stated that they had current, unmet dental health needs. Reasons given for the particular difficulty of securing dental care included disruptions in Medi-Cal coverage and waiting periods, inability to pay for services and/or lacking dental insurance, not remembering to go regularly and not having a regular dental care provider. As one young woman stated;

> I think that going to the dentist is really hard for [youth coming out of the system] to keep on top of... going to the dentist twice a year. And as a result, people tend to forget. And then, in a *lot* of situations, like me, I don't *have* a specific dentist, so I just call around and see who accepts my Medi-Cal.

Youth also recounted personal experiences of unmet orthodontic needs. In many cases, youth expressed that it was known that they would need braces even while they were within the system, but because the high cost of orthodontic care and their status as the non-biological children of their caregivers, their need for braces was never attended to during the time that the youth were in care. Several youth very poignantly described that

the disinterest among their caregivers in getting them braces was a painful reminder of

their status as non-biological children. As one young woman recalled:

> Yeah. Like for me, I'm trying to get braces. I need braces and I can't
> afford them....It's been a problem. It's like I said, things that you would
> *think* you could get help with, like my teeth...I'm trying to get braces but I
> can't because they're saying it's outside of my insurance or I can't afford
> it. So that's hard for me...
> ...People knew [I needed braces even as a minor]. But with me being in
> the system, they knew that I needed braces, and what not, but I'm not their
> child, so it's not their concern to do that for me. And so basically, what
> they did is just left it to where now, it's *my* concern. And *I* have to get it
> done now. And it's something that makes me feel incomplete, 'til I get
> my braces.

Several respondents explained that because they were in school or had only

recently entered the workforce, they had little to no income or savings with which to pay

for braces. They were therefore forced to either go without braces or pay by credit card,

incurring significant debt. As one young woman described:

> Actually, I went and I had to pay out my pocket. [to get braces]. [The
> insurance] wouldn't cover it. So now, since *they* wouldn't pay for it, *I* had
> to pay for it, and now I'm in debt for now what-- $3000? $4000? For
> braces! So, that's how either way you get screwed over; because they
> don't want to *help* you pay for it, and *they* don't want to pay for it, so *you*
> have pay for it... and if you can't pay for it--because of certain situations,
> or whatever-- then it goes on your credit and you're screwed for even
> longer...when you *want* services!

C. Other youth-identified health issues:

Other health issues that emerged among the youth respondents included nutrition

and dietary issues, reproductive and sexual health issues, injuries and asthma.

Youth raised concerns about poor nutrition, insufficient knowledge about healthy eating, and lack of access to affordable, healthy food as problems among recently emancipated youth. As one youth described:

> Maybe people have health problems, cuz they're not eating right. I know someone who always used to get sick, cuz they're not eating right, and can't afford the food they need to get. I guess after a while it catches up.

With regard to reproductive and sexual health, youth respondents expressed concern that their peers were at risk for early pregnancy, and sexually transmitted diseases (STDs), including HIV. One young woman offered that the risk of STDs might be a problem for recently emancipated young people because of their newfound independence from the system. She explained, "I would say that because a lot of us are like, just young, and just got out the system, and just trying to be on our own... I would say STDs is a big medical issue."

A number of youth alluded to "injuries" as a health problem among emancipated foster youth. Some mentioned personal experiences of serious injuries such as "I was hit by a car", and others described their experiences of less emergent injuries and chronic musculoskeletal problems. In addition, several youth participants described having asthma.

D. Housing instability and insurance status as health issues

In addition to the aforementioned health issues, housing instability and homelessness also emerged as life circumstances common among emancipated foster youth that were associated with an increased vulnerability to a variety of physical and

mental health problems. Youth explained that many recently emancipated youth are at risk for homelessness because they lack stable living arrangements at the time of emancipation from care, and are often unable to return home to their families. In one of the focus groups, an 18 year old young woman respondent explained, "I know a lot of people, when they emancipated, they're homeless. And people who don't have family to go to, people who can't go back to their family when they emancipate end up homeless."

A male respondent in the same focus group concurred about the difficulties that can confront emancipated youth when they try to return home to their biological families. Recalling his own experiences of a strained reunion with his family after emancipation, he commented:

> That's real. That's what happens. Even though I've changed, they're like, "Nope!" And it's hard to readjust, you can't get back them years. So that's why a *lot* of people go homeless, cuz they can't go back. Like with me... people just remember me as bad.

Although youths' current or previous experiences of homelessness were not specifically solicited in the demographic survey, a number of respondents recounted personal experiences of housing instability since their emancipation. A total of 5 youth (23% of the total) mentioned being homeless or staying in a shelter for a period of time following their emancipation from foster care.

One young man, aged 20, described his difficult transition from a life hustling on the streets to his present situation working full-time and residing in transitional housing.

> Oh, I work [*now*]. [When I was on the streets] I tried to start over, but they [the system] didn't help me. I didn't get *no* help from them. No

> resources. And I was homeless. And then I stayed in a shelter. I *made* myself go to a shelter, but I [had already] spent two months in the street …I just wanted to start over. And I got *no* help. So I don't need them. I don't get anything from them. When I call them, I don't get no return calls.

A 20-year old young woman recounted her tumultuous post-emancipation path as follows:

> Since 18, I've been on a rollercoaster. Like when I first turned 18, I came to this agency, and then I was staying with my mom, and then I had my own place. Then I was homeless for about 2 years. Now I'm working, going to school, and have my own place.

Some youth drew connections between experiences of homelessness/housing instability, and various health issues and a lack of access to healthcare. When asked about a period when he was unable to go to the doctor when he needed to, one 21-year old young man recalled that during the period when he was homeless, he often found himself in situations in which he felt exposed to other sick individuals. As he put it:

> Well, basically, the times when I was homeless [I couldn't go to the doctor]. I was actually in a spot where I was homeless and I was staying in the kind of area where I could get sick. I was exposed to a lot of people with colds. And riding the BART train from place to place, I was around a lot of people who had the cold virus.

Another respondent described the ways that housing instability can be a significant source of emotional stress, and can *become* a health or mental health issue when the need to secure a safe place to stay takes precedence over other aspects of self-care. As she explained:

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For one, if people had stable housing they would be able to keep their *mind* together. Because it's hard to get housing and stuff, and focus on what you need to do for *yourself*, when you're sleeping on the BART every night, or riding back and forth on the bus.

In another interview, a second respondent made a similar connection between homelessness and both mental and physical health, stating:

I believe there's a model for total health. I mean, if you have a place to live, to me, you're going to be more healthier, like mentally, if you don't have to worry about stuff like not having somewhere to live, or actually staying on the street where you're more prone to homelessness, or when the winter time comes and you're sick more, or stuff like that.

Another respondent made an association between post-emancipation housing instability issues and the personal safety and well-being of emancipated youth. She explained that housing instability during the transition period places some young people at increased risk for both homelessness and domestic violence. In her words:

For me, talking to a lot of people who are getting ready to emancipate out of the system, I will ask them, like, "Where are you going after you get out the system?" And I would say like 45 percent are going back to their family, 45 percent didn't know where they were going, and 10 percent are getting ready to have transitional housing or are getting their own spot. But it's like, I would say that, either they're going back to their family, or they don't *know* where they're going; and that means a lot of 'em are going to end up homeless. People are also staying with their boyfriends or girlfriends-- which in my opinion is *not* cool, because if it don't work out, and you get into an argument, then you ain't got a place to stay. Or, you end up having domestic violence and shit, cuz you don't have *no choice* but to live with each other, because you can't *afford* nowhere else.

Themes related to the second major area of inquiry, specifically, the factors, policies and processes that help or hinder access to health-related information and health care, are presented below. Factors that *facilitate* access to care will be presented first, followed by factors that serve as *barriers* to care.

I. Factors, Policies, and Processes that facilitate access to health-related information and health care

Two major themes emerged as facilitators of access to health-related information and health care; connections to agencies, and pregnancy or parenting.

A. Connections with agencies:

A number of people indicated that their connections to various youth or young adult serving agencies were an important way for them to get health-related information and assistance that they might not otherwise be able to access. One young woman explained that connections with youth/young adult-serving agency were important because of the relative lack of services for emancipated youth and the unwillingness of most agencies to serve young people with limited financial means. As she put it:

> Wow. If I wasn't in contact with places like this, I'd be kinda stuck.... cuz there's not really anything else out there to help you if you've been in the system, other than county places, or non-profits. Cuz other places, if you don't have the money, they don't have time for you.

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Another youth respondent explained that being connected to agencies facilitates access because some services can only be accessed with a referral from another provider, and other services are difficult to find without assistance. She commented:

> If you haven't heard about agencies such as this one, and others, then you won't know where to go. Because at certain places you need a referral to get into them, or if you need a therapist, you might not know about to go about getting one, or you may not know if you have Medi-Cal… cuz you have to pay for that stuff. And if you don't have none of that stuff, it's basically like, "Oh, well."

Connections to agencies were also identified as important sources of psychosocial, emotional, and material support during the stressful period of transition out of foster care. One respondent described her connection to one particular agency as a crucial source of support and assistance during her difficult transition. She commented:

> This is the only place I really deal with…. because they give you so much, and work with you in so many different ways, and on so many different levels. For the past 3 years I've been here, and they've seen a tremendous change in me…from going from 'rock bottom' to "okay, you're on your way to something great in life."

In addition, a number of youth expressed that their participation in life skills programs, such as the county-operated Independent Living Skills Program (ILSP), gave them much-needed preparation for navigating the healthcare system as young adults. One young woman cited her involvement with ILSP as a crucial source of stability and encouragement during a time in her life when she was at risk for dropping out of school. She recalled:

I've always been raised to know that I'm going to college. It's been instilled in me since I was like, one or two years old. But when I went to high school, that's when I really started to question myself. And I'd gone through a period where I just said, "I don't care anymore." But, I mean, I think that a lot of people are better than the situation they're in now, and they deserve better, and they might just not have the resources or the confidence they need to push through whatever obstacles they're going through right now. And that's why I thank [social services] every single day; because going to those classes kept me off the streets, kept me on the right track, and also helped me pay for college.

B. Parenting and access to health care and health-related information:

A few young women stated that much of their understanding of the health care system and self-care came through their experiences of becoming a parent. One young woman described finding out about health care benefits through a case manager to whom she was assigned as a young mother. She recalled:

I found out [about health benefits] through when I was in high school, because I had my son when I was still in high school. I had a case worker, referred for my son. And that was through [a clinic in this county] and she's the one who gave me all that information, whatever I needed, I could just ask her. Although there's not very many, there's a few workers that will do that. Most of 'em'll be like "oh, I don't know that, I don't know that information" or whatever, and you find out on your own. So I found out through her.

II. Factors, Policies, and Processes that hinder access to health-related information and health care

A number of factors, policies and process were identified by respondents as barriers to health care access; these included the lack of information about when or where

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to go for care, problems with insurance, being undocumented, or having embarrassment or confidentiality concerns. Lacking sufficient access to one's health records also emerged as a significant issue among this group of respondents. The following section will provide a brief summary of youth's responses concerning each of these barriers.

A. Lack of Information

One of the dominant themes that emerged in discussions of barriers to health care access for emancipated foster youth was a lack of sufficient information. Many of the youth respondents indicated that emancipated youth may face barriers to health care access because they may lack sufficient information about self-care, when or where to go to receive health care, and how their health care benefits work.

One respondent ranked lack of education about health and self-care as the most significant health issue for emancipated foster youth, and reasoned that it may lead to delayed care seeking. In her words:

> Probably the biggest health issue is not being educated about health. I know a couple people who go a long time with being sick and don't get no help because they weren't being taught that.

Another respondent concurred, suggesting that many emancipated youth may not be familiar with the process of health care-seeking. As she stated, "Well, most people don't even have health care afterward, don't know how to get it, don't know where to start, and don't know how to get a primary doctor, and any of that..."

One young person suggested that youth may not have received sufficient information about *when* to go to the doctor while within the system because their health

care encounters are often arranged and managed by caregivers or guardians. As she noted:

> [W]hen you're in the system, mostly, like, *they* are your guardians, the staff there. So *they* make sure you got a doctor, and that you got a doctor's appointment. But when you're on your own, it's harder, because you're by yourself and you're trying to make it on your own, and you might not know *when* to go.

Notably, in their descriptions of the problem of lack of access to health related information, some respondents raised the concern that certain groups of youth may be at particularly great risk for missing out on informational resources and support due to being disconnected from independent living skills programs during their time in the system. One young woman suggested that access to health-related information may vary among the foster care placements. In particular, she noted that youth in group home and foster home settings and youth who do not participate in independent living skills programs may not receive certain health-related information, stating:

> I don't think a lot of them get the information. Like, I was at one group home where, they were considered a mental health group home, and you didn't have to have a mental problem to go there. But since they had a mental health component, they got more funding, so they were able to bring more guest speakers in, and stuff. So they had a course on sex-ed, and they had a course on anger management, but that was about it. But as of overall health, if you don't go to ILSP, I think it's hard to get a hold of information, because, you know, some group homes--a lot of group homes--don't teach you that. And unless you have a dedicated foster parent, which is really hard to find, you won't get it from a foster parent either.

In addition, some respondents worried that so-called 'difficult-to-reach' youth (i.e. youth with truancy problems who skip life skills classes) may not have received the same amount of information and support as youth who were more attendees of life skills courses. As one young person explained:

> When you're in the system, they give you programs to go to, but if you are a minor, like *I was*, and you wanted to do whatever you wanted to do, and said "forget everybody else," then you're not going to get the resources that you need. You're not going to learn how to take care of yourself. The people who stay in these programs and are actually successful in graduating, they may have a better chance of knowing more, versus someone like me.

Others observed disparities in treatment and equity of access to services and information among their peers in foster care. One young woman commented on what she observed to be differential treatment of foster youth in the system and suggested that sometimes providers' personal morals and values might preclude their willingness to assist a young person in need. As she explained:

> I think there needs to be more of a fairness between, you know, whether you share resource with one kid or share resource with another kid. Because I can go in and say, "Whoa, you guys, I have this problem," And I'll get a response. Then [someone else] can go in and say, "I have this problem," and get a *different* response. And then my friend can go in and try for this and get a totally *different* one. I mean, I think it's just people in general have their "favorites" or have …morals in the way. There are *always* morals in the way… [people will be like] "Well I don't think that's a good idea. Why are you doing that?"
> [But] I think we need the support. *We* don't have parents that are like, "I love you regardless of the fact that you're going to have an abortion." Or "I love you regardless of this being your 4th kid and you're 18…I love you regardless." I'm not saying these people need to *love* them, I'm saying that we need the services; we need what they are going to offer and ….so I think it should be more of just the same for everyone.

B. Problems with insurance coverage

A second major theme that emerged as a barrier to health care access was problems associated with insurance coverage. A number of respondents described having problems with their Medi-Cal insurance that led to them either being denied care or billed for services. In several cases, the problems appeared to be attributable to Medi-Cal forms that had been filled out incorrectly or sent to an obsolete or incorrect address. One young woman recounted an incident in which she was denied care because she lacked her Medi-Cal Card which had been lost in the mail. She recalled:

> Right after I got emancipated, I lost my health insurance card, and it took them about three months to get it to me. Normally it takes about two weeks. And it was actually at [another location], and nobody had told me. And I thought I had health insurance, but nobody was accepting me.

Having Medi-Cal coverage from another county also emerged as a barrier to health care access. Two youth respondents in the sample emancipated in California counties other than Alameda County, and one of these youth described having problems accessing care due to having Medi-Cal coverage from his county of origin. As he put it:

> They say that …I have to have [my coverage] switched over to *Alameda* County. Right now, they say that my coverage don't show up [in the computer system]. And I don't know *what's* going on.

Another cause of disrupted benefits among the study participants was being absent with out leave (AWOL) from a placement at the time of emancipation. Under the Medicaid Expansion Option of the Foster Care Independence Act (FCIA) of 1999,

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current California policy mandates that youth in foster care on their 18th birthday are eligible to receive Medi-Cal services until the age of 21 (California Department of Social Services 2000). A caveat of this policy is that youth who run away from placement or make other such "unplanned" exits prior to their 18th birthday may lose eligibility for extended health care coverage. One respondent, who was AWOL from a foster care placement at the time of her emancipation, lost her health care coverage in this manner. She explained:

> My coverage was terminated because, as of my emancipation hearing, I was considered AWOL, even though my social worker knew where I was, cuz I was not in my designated placement, so I was technically considered AWOL. I also kinda slipped through the cracks, because if you're on AWOL when you emancipate, they won't give you Medi-Cal coverage. If I'd known that was the case, I would've just went to the foster home and been like "Hey."

As a result of this disruption in coverage, she described, "I wasn't able to get my prescriptions; I wasn't able to get *anything*. I was going around with no health coverage *at all*."

The loss of insurance benefits upon turning 21 also emerged as a major barrier to health care access. It is notable that of the youth participants who self-identified as being uninsured, *all* were aged 21 or older. Several respondents who were age 21 or older specifically described losing their coverage through the system on or around their 21st birthdays, and reported that they'd not been able to secure insurance through other means (e.g. through a job, school or a family member).

Youth argued that the process of losing one's health insurance through the system can lead to uncertainty about one's ability to access health care. One respondent

explained that such uncertainty, coupled with concerns about having to pay for services, may prevent them from seeking care. In her words:

> Some people, who just turned 21, they want to go [get medical care], but they're not quite sure if their Medi-Cal's still on. So they don't want to risk paying… Usually they just let the sickness wear off.

For some youth, lack of insurance posed significant negative consequences, including the generation of medical bills that could not be paid. As 21-year old respondent commented:

> It's like, "How am I gonna pay for it?" Especially when you go to the ER-- they're gonna charge you an-arm-and-a-leg even to *sit* on one of their *chairs*-- So it's like, I have past-dated bills that I cannot pay…

Another respondent, also 21-years old, indicated that she was unable to get an essential medication because of her uninsurance. She stated, "I have asthma. I can't get a refill on my inhaler because I don't have my Medi-Cal."

Without Medi-Cal, some respondents were forced to seek financial assistance with paying for healthcare by enrolling in the county's medically indigent services program (CMSP), which uses money from state and county general funds to provide payment assistance for low-income, uninsured adults residing in Alameda County (County of Alameda Health Care Services Agency No date). However, CMSP coverage is only accepted at designated clinics and county hospitals, limiting the number of places patients can go for care. Furthermore, patients may be faced with long wait times, even

for relatively simple services such as prescription refills. A 23-year old respondent described her own experience with using the CMSP coverage as follows:

> The way they're doing things now is, you have to go to Highland and sit there for six hours, and they're gonna put you on the county [insurance] for five days if you need to go get an asthma inhaler, or whatever it is that you need.

C. Being undocumented:

Being undocumented also emerged as a barrier to healthcare access. One respondent stated, "I think it's hard when they don't have papers; like when they're illegal...it's really hard for them to get healthcare." When asked if the system offers assistance to foster youth who are undocumented, she explained that while people may receive some services and be eligible for short-term coverage, they may not have access to the full range of services available to youth who have legal US residency. As she put it:

> Yeah. I think they do [get some services], because I have a friend [in the system] and she don't have papers, but they helped her with--well, they can help her, but it's not the *same*. It's hard. It always is hard for them to get something from a hospital...Like, well, [my friend] she was pregnant, and she needed to go to a hospital and take care of her son, when she was pregnant. So she went, but then they said she needed Medi-Cal, but she [didn't] have papers. So she went to the Medi-Cal office, and they said she had to wait. And she could get one kind of Medi-Cal, but it would just be for nine months, and after that they couldn't help her. So she was getting help, but after that she didn't have Medi-Cal anymore.

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D. Embarrassment and confidentiality concerns as barriers to care:

In addition to factors such as lack of information and structural and policy-related barriers to care, some youth expressed that embarrassment, fear, and concerns about confidentiality and privacy might also serve as barriers, by precluding some emancipated youth from seeking health care, even when it might be relatively accessible. In one respondent's words "I think [accessing health care] is easy, it's just that some people may be embarrassed."

Another respondent agreed that care was accessible, but suggested that certain health concerns, such as sexually-transmitted diseases and pregnancy, might provoke anxiety around seeking care. She stated, "I think in general a lot of people are scared to go to the doctor, if they think they might be pregnant, or have an STD. But I think it's definitely accessible."

E. Difficulties accessing health records

Finally, in addition to the aforementioned factors that preclude health care access, a number of youth described significant difficulty with obtaining their medical records. While inability to access one's health records do not necessarily create an obstacle to health care access, they can disrupt the continuity of health care and can also create challenges for youth in other life domains (for example, some academic institutions and employers require documentation of the necessary immunizations for their students or employees).

One young woman recalled having significant difficulties accessing her health records, and stated that because she was unable to locate them, she had to have her immunizations repeated. As she explained:

> *I* used to have to get my [medical] records for school, cuz I pretty much took care of myself, even when I was in the foster care system. They could never give me my records. Like, to this *day* I can't get my immunizations. I don't even know where my immunizations are-- I just started getting them over, because I don't know where they are and nobody else knows where any of my stuff is!

Another young person described having to go all the way back to another county where she'd spent some of her time in care, in order to obtain part of her medical records. She recalled:

> I needed to get [part of my medical record] and I had to go back to the county where it was done, and it was just another process...And it's just a whole bunch of trouble, when I feel like the social worker who you were dealing with or the probation officer, *they* should have a packet that says, you know, this is all your information for when you get out there. Cuz you really need it!

Having to *pay* for copies of one's medical records also emerged as a problem for emancipated youth. One young woman described her troubles accessing her health records, commenting, "That has actually been kind of difficult, because my health provider charges me almost $40 for all my records. And I'm living on a budget, so I can't really afford that."

The third area of inquiry sought to solicit youths' appraisals of the adequacy and appropriateness of the 'health-related information' youth received prior to emancipation, including information about their health benefits and entitlements through the foster care system, how to access the health care system (e.g. how and when to schedule healthcare appointments, when to go to the emergency room), principles of self-care, wellness and illness prevention, and what to do in the event of a problem with one's healthcare coverage. Among this group of youth respondents, there were a variety of perspectives about the adequacy and appropriateness of their pre-emancipation preparation for managing health-related issues after emancipation.

Some youth expressed satisfaction with the information they'd received about addressing their health care needs and accessing the adult health care system after emancipation. One young woman stated:

> I think I'm pretty satisfied myself. I don't think it's so much about *knowing* the information, as *putting that information into play.* Because when you're in foster care, you're told the information, you *have to* go for a check-up. But now that I'm out in the real world, it slips my mind sometimes.

Another young woman praised the information she'd received through her life skills classes with the social services agency, stating:

> I will say that ILSP does a great job in teaching you, like "You have Medi-Cal till you're 21. These are the papers you need to do. This is this; this is that. This is how you do the college forms. These are the steps. Today we'll work on this. This is how you eat and how you set the table, when you're going to eat." I mean they did a *lot*. Independent Living Skills Program is an awesome program. And they do have an area where they do teach you about your healthcare and how it works and stuff like that.

By contrast, other youth acknowledged that they'd received *some* health education through various agencies they were involved with through the system, but now perceived certain gaps or short-comings in their pre-emancipation preparation for health care management. Many respondents expressed that while they received basic information about their entitlement to healthcare benefits until age 21, they felt that they did not necessarily receive sufficient information about the specific medications and services covered by their Medi-Cal. In one young person's words:

> [In the system] they usually just tell us that we have healthcare until we're 21, but they don't tell us specifically *what the benefits are...* what you can get while you're health care is still going on. They tell us we should talk to a Medi-Cal worker about getting things transferred until we're 21, and then, that's basically it. They don't tell us what you can get. Like half the time, I don't know, if you wanted to go get birth control pills, you probably wouldn't know you'd have to get a *certain kind*. They don't tell you stuff like *that*. Just the basics.

Another young woman also expressed that the information she'd received wasn't very detailed, stating,

> Well, I really didn't receive a lot of health information, except basically, when I was in [life skills class], it was kind of brief, they said basically there was something about a reactivation insurance, something like that, and like when you turn 18, its gonna cut off, so take advantage of it while you can. Get your checkups and everything, go get your physical, and

stuff like that, but they never really went into great detail, like about what's the steps.

Still other youth respondents expressed the sentiment that they'd receive little to no preparation for managing their healthcare prior to emancipation. For example, some of the responses to interview and focus group questions about whether youth had received information about the health benefits and where to go for care while in the system included:

- "Not really, I had to look everything up myself";

- "I don't think I got any...I ain't heard about [anything]."

- "No... it's more, like, up to you to research that"; and,

- "Is that a trick question?"

Key gaps in preparation and health issues for emancipated youth

As described in the findings for inquiry 1, both sexual/reproductive health and diet and nutrition were identified by respondents to be significant health issues faced by emancipated youth. These issues also emerged as areas in which respondents expressed that their peers had received variable or insufficient amounts of information while within the system.

Several respondents expressed concern about unplanned or early pregnancy and STDs as health issues faced by their peers. One respondent suggested that STDs might be a problem because many young people might not be using sufficient protective methods or thinking about the need to protect themselves. In her words, "Some people I

know catch STDs. Because they're not using what they're supposed to be using, and not thinking what they're supposed to be thinking."

When asked if youth in foster care receive information about reproductive health and STD prevention, one young woman suggested that the some youth were learning about family planning and reproductive health issues too late. Specifically, she remarked that they learn "when it *happens* to them." When subsequently asked if she felt that sufficient sexual health and family planning information was distributed to youth in care, she explained that some information was available from certain agencies, but in general, it was insufficient. She recalled: [At one agency] "I saw one article on HIV and that was it. Just one. And I saw countless handouts on financial stuff, and everything else." Explaining the consequences of not receiving sufficient information about STD prevention and reproductive health, she commented: "[P]eople aren't learning, so they're having unprotected sex."

As with reproductive and sexual health issues, dietary and nutrition issues surfaced as an issue around which youth might be receiving insufficient education and training while in care. One respondent expressed that she did not feel as though she'd received sufficient information about healthy eating while in the system, and commented:

> I think that maybe, some of the foster parents could've trained us better on that. Because when I was in a foster home, they just told us what to do and just did everything for us... buy the food, but didn't let us pick out anything. I think it could've been taught in the foster home.

Another young woman, recalled her experiences with group home placements, and concurred about not having received sufficiently detailed information about the importance of maintaining a balanced diet, while in the system. She recalled:

> Group homes, they'll fix dinner for you, but they won't tell you why they fix what they fix, you know? They might put in a lot of vegetables, but they don't *tell you* 'oh, we're putting in a lot of vegetables because you need these certain vitamins.'

INQUIRY 4: SUGGESTIONS FOR IMPROVEMENT TO PRACTICE AND POLICY

The purpose of the fourth domain of inquiry was to solicit youth's suggestions for improvements that could be made in direct service provision and health and social welfare policy concerning the health of transition-aged and emancipated foster youth. This section will begin with an overview of youth's suggestions that relate to *direct service provision* by individuals and youth-serving agencies, and will then turn to youth's suggestions for changes in local and state governmental policy regarding the health and social welfare of youth exiting foster care.

I. Youths' suggestions for improvement in direct-service provision by individuals and agencies

Youth respondents offered a number of suggestions for improvements in the provision of health-related information to current and emancipated foster youth. Youth were asked a series of questions intended to elicit their suggestions for the types of health-related information youth should receive prior to emancipation. They were also

asked when such information should be provided, who should be involved with its provision, and in what formats such information could be shared with transition-aged foster youth. The following is a summary of their responses.

A. Types of health-related information youth should receive

Youth respondents expressed that transition-aged foster youth should receive more information about the practical aspects of care seeking (e.g. where to go for care and how to make an appointment), the services covered by their Medi-Cal benefits and how to address problems with coverage, strategies for self-care, including nutrition and stress management, and information about a variety of medical and mental health issues.

B. When information should be distributed

With regard to *when* youth in care should begin to receive information about managing their health care after emancipation, respondents expressed that this should begin *well in advance* of emancipation. While it was not a universal experience, some respondents seemed to suggest that they'd received very little information and preparation in advance of emancipation with regard to taking care of their own health needs. As one young woman explained:

> They should be educating people *way* before they exit. Not when you turn 18. Cuz I remember I came and it was like, I signed a paper and it was like, "Well, you know about this and you know about that." I signed the paper, and they made a copy and gave it back to me, and I'm like, "Okay, so what do I do now?"
> And they're like, "Oh, you're out the system."
> "Okay, so well... what do I do *now*?" Nobody told me... and I found everything out by myself.

C. Who should be involved with providing youth with health-related information

When asked *who* they felt could or should be involved with educating transition-aged foster youth about their health care benefits and how to navigate the adult health care system after emancipation, the youth respondents identified a number of different parties whom they felt out to be involved.

Several youth respondents suggested that individuals associated with foster youth's placements (including foster parents, relative caregivers [kinship caregivers] and group home managers and staff) should be better trained to provide this information to the youth residing in their care.

Other youth identified social services agencies and social workers as key providers of health-related information to transition-aged youth. One young woman reasoned that social services agencies, foster youth serving agencies, and placement agencies were best positioned to provide this information because foster youth are more likely to be familiar with them. As she explained:

> I think definitely social services [should be involved].... And I think it would be more accessible if it's from social services or an agency we're familiar, rather than just somebody random coming up and telling us.

In addition to guardians, caregivers, and social services staff, youth also identified other entities with whom transition-aged foster youth are likely to be involved, who might potentially play a role in improving youth's understanding of their health benefits, and providing them with psychosocial support during the transition to adulthood. One young woman suggested that high schools could also play a role in providing

psychosocial support to foster youth and providing them with information about their health benefits. When asked who could or should be involved with helping youth understand health-related information, she stated:

> I mean obviously the schools; and to elaborate on that; the schools don't really *care* about the foster kids. They just kind of-- especially up here, there are *big* high schools. They have a hard enough time dealing with the rest of the kids, so it's like, a lot of foster kids to me feel very alone and very segregated. They're not with their families. They're at school, they might not have like the best looking stuff. So I think that if they created a program where foster kids could go in anonymously, because the foster kids could come in and they can just get all the information they need.

This young woman suggests that older foster youth may face particular isolation or marginalization in high schools, and that these schools could perhaps do more to provide psychosocial and practical support and information to foster youth.

D. Strategies for distributing health-related information

Youth respondents identified a number of potential methods for distributing health-related information to youth; including education of caregivers and guardians, meetings between youth and social service providers, classes, packets and handouts, posters, advertisements, and peer-based outreach. These findings are discussed briefly below.

1. Education of caregivers and guardians

As mentioned in the previous section, youth expressed that caregivers are strategically positioned to be key purveyors of health-related information to foster youth.

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However, several youth suggested that caregivers in particular could benefit from more information and clarification about the health care entitlements of foster youth, so that they could be better poised to educate and advocate for the youth in their care. One young woman had the idea of holding a convention for foster parents and foster youth, to facilitate the sharing of information about foster youth's benefits and entitlements. In her words:

> I think they could do, like, a convention, to where foster parents could bring foster children, like, to inspire them, so they could get all this information. That way if they're not in ILSP, or they aren't in touch with their social worker, they can get this information.

2. *Direct service providers, social workers, and probation officers*

A number of youth felt that health-related information should be shared during meetings between social workers or probation officers and older youth in foster care. One respondent commented that the information about health care providers and health benefits should be shared verbally, with documentation of important contact numbers for further assistance; she stated:

> My personal opinion is that they need to be able to sit down and *discuss* it. I mean, this person is close to being an adult; they should be able to sit down and have an adult conversation about these services. They should be told "okay, these are the services you have," and it should be put down in writing, that contact information, if something goes wrong. Or put in writing what services they have, that way they [youth] can always look back and say "Hey, okay, this is what services I have. This is where I need help in, so they can help me with that here."

However, a few respondents cautioned that meetings between foster youth and social workers might not occur with enough frequency to ensure that the youth would receive sufficient information about their healthcare. As one young woman noted:

> I only saw a social worker maybe once a year, twice a year. And I don't really think that's enough time for them to explain [health benefits information] to us. It has to be a progressing process. So, I wouldn't recommend that.

3. Classes

A number of youth supported the idea of classes as a means of distributing health-related information. Several youth described having received information about their health care benefits in a classroom setting, and finding this to be helpful.

However, other respondents raised some important critiques of classroom-based approaches to distributing health information, arguing that they might not afford youth sufficient opportunities to receive individualized attention or ask personal questions. For example, as one young woman explained:

> ...[T]he system is tricky because you're in there by yourself, but then at the same time, you always have to do things with a group. It's like you're not by yourself, *everything* is group oriented. Like, if I want to ask a question, it's for the whole group, nothing is for myself. And that holds people back from actually asking the questions that they really want to ask, or if they really need help. [N]othing was ever... really personal.

Ultimately, while classroom-based education may be an efficient means for distributing certain health information to foster youth, it may not be the ideal strategy to

reach all youth, and some youth may still benefit from more individualized opportunities to discuss health-related issues and ask questions.

4. *Written information and Advertisements*

A number of respondents suggested that a handout or informational packet might be a useful way of sharing health-related information with transition-aged foster youth. One young woman suggested the need for a brief handout on health benefits and services, stating:

> Well, me personally, I think they should write a little 2 page front and back little thing, just about healthcare. I think each category that a kid is gonna go through, they need to have it on paper. Like stating your Medi-Cal benefits after you're 21, what you should do. Have a list of things that they should do...and how to go about it.

Another respondent suggested that a packet might be useful. In her words:

> I think that the kind of information they should get is, again, like a packet, with like, the clinics that are in your neighborhood. Where you should go. Where social services, social security are. How to keep your insurance going. How old you have to be.. like when you turn 19, it's going to cut off, and you have to re-do the form again. Just something to tell you the basics of what you have to do in order to keep your health, and things up.

Several respondents suggested that advertisement and media-based outreach, including tv and radio commercials, could be a potential strategy for providing foster youth with information about their health benefits. As one young man suggested:

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They should flash those, you know, cheap $20 commercials about healthcare on TV-- It should be like, "are you a foster care kid or former foster youth between the ages of ....? Then you're automatically approved for such and such!"

In addition to media advertisements, one respondent suggested that information about foster youth's health benefits and entitlements should be posted in youth-serving agencies and foster care placements, to make the information constantly accessible. In her words:

You know how they have like, when you come into a group home, like, a bill of rights? Like 'Rights and responsibilities' that's s'posed to be posted up on the wall, like we in praise of it, or whatever....So they should do the same thing [with health-related information]. Make that law that you gotta have something posted like for every county, so that people know where to get that information from.

A fellow focus group participant agreed that posting health benefits and entitlements information would make it easier for foster youth to know their health care rights, if they did not receive this information elsewhere (e.g. through a packet or class); and might also facilitate youths' ability to take action in the event that their needs were not being met. As she commented:

If [the youth] ain't been given that information, they can read that [poster] and know [the people in charge are] messin' up and say "well, I need this and this and that and y'all ain't providing it for me."

It is noteworthy that individual respondents favored different strategies for disseminating health-related information, suggesting that what works for reaching some youth may not be effective for reaching all youth. One respondent described the

importance of having health-related information in writing so that youth can refer to it later, stating:

> They need to have [the health information] in writing, so a lot of kids can understand it. Cuz when you talk to us, sometimes we don't understand it. They're like, "Okay, this is what's going to happen…" But half of the time, you know, if I've got a lot of stuff on my mind, I'm not gonna remember it. You know? So they need to have it in writing. On paper.

However, another respondent explained that a packet of written information might go unused if it was perceived as being too lengthy or complex, stating:

> But if they give out a packet and its like a thousand pages, you don't know what you're reading…. Cuz, I've gotten paper work and been like "okay, what am I reading? What does this mean? I don't understand this." So you put it to the side…

Another respondent agreed about the potential limitations of written information, and the benefits of verbal explanation, stating:

> I don't think the packet really works. I think it's good that it's there, maybe for a reference, but if you never use it, you don't reap the benefits of the book. So I think it's better if somebody sits down with you before you emancipate, maybe even your social worker, and you guys decide, "well, I need this kind of doctor." And you set them up before they leave.

Ultimately it may be the case that multiple modalities of information distribution including person-to-person discussion, written information and media advertisement, may be needed to maximize the number of youth receiving health-related information.

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5. Peers as Mentors and Outreach Workers

A number of youth respondents suggested that there could be greater involvement of emancipated youth as peer mentors or outreach workers to provide information and assistance to transition-aged youth still in care.

One young person suggested that outreach and advertisement about foster youth's health entitlements should involve or feature "kids that come from the system, cuz peers are gonna to listen to peers." Other respondents spoke to the sense of isolation young people can feel after exiting the system, and described the potential value of incorporating greater involvement of former foster youth as peer mentors for transition-aged youth as a means of both sharing information and creating social connection. As one young woman put it:

> You know, I think they need more like, mentor-type things, where people coming out of the system can be with people who are emancipated, who know the things that you're going to have to go through. So like, if I just got out of the system, let's say, I'm 16 years old, and you're 25. [I can say] "Can you help? Do you know anything that can help me, like financially? Give me some advice on how *you* handled it"… cuz when you feel like you're alone, that's the *worst* feeling possible. When you feel like no one else is going through it, everyone's doing fine but you. It's just really scary.

Another young woman described the possible benefits of mentorship to older emancipated youth, stating; "I think that would help the person who's mentoring to still push themselves to continue to beat the odds of being a former foster kid."

II. Changes to policy to improve pre-emancipation preparation of transition-aged

youth and improve health access for emancipated youth

During focus groups and individual interviews, youth were asked a number of questions designed to elicit their suggestions for improving health and social welfare *policy* concerning the health and well-being of transition-aged foster youth. Youth identified a number of policy-level changes that they felt might help to improve the health access of transition-aged and emancipated foster youth. Among the most recurrent suggestions for change were increasing services and support programs for youth in transition and extending health care benefits past the age of 21.

Several youth felt strongly that there ought to be more programs for young people aging out of foster care. When asked what she would tell a state policy maker, such as the governor, about what types of support and services foster youth need to ensure their access to health care and support their well-being, one young woman responded:

> I think I would tell the governor that we need more programs for when we're getting ready to transition into adulthood. Because to me, it's not okay to just throw a young adult out into the world of wolves, and expect them to know what to do with themselves. I mean, from the time you're born til you're 18, you're considered a minor. When you're 18, you have a legal authority to do as you feel. But things are not okay, because you don't know which way to go. You know? If you had a surrogate parent, they were taking care of you, if you had your mother and father, they were taking care of you. If you didn't have no one but the system, then they were taking care of you. And it's not right. We need more support systems.

With regard to the need for extension of health care benefits past 21, many youth also emphasized that young adults are unlikely to have access to insurance through other means after leaving the system. They explained that many recently emancipated youth

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may still be completing high school or college when they turn 21, or may have

insufficient work experience to have secured a job with healthcare benefits. As one young

woman responded:

> [A]s far as Medi-Cal and things like that, I feel that they should make it
> longer, instead of just like, when you're 21. Because when you're 21,
> you're still just getting out there and just testing the waters, and it's really
> hard for you just to get insurance or insurance benefits on a job. Or some
> people don't have the experience, because some people lack opportunities-
> -like a high school diploma or a GED. Because 21 you're barely--I mean
> 18, is bad enough-- they just kick you right out the system! But then 21,
> you're just really becoming official!

Another young woman agreed, commenting:

> Now, I'm not saying "Baby us forever", or "Give us free Medi-Cal for
> ever"…I'm not saying that. By 24, you should have a good enough job,
> or go to school, and have insurance. But 21 is still kind of early. You're
> only 2 or so years into junior college, you're still young, you haven't
> really reached the age where you can…I mean, it's hard with my jobs
> now!

Youth also reasoned that not having insurance after age 21 may place people at

risk for poor health outcomes. In particular, one respondent explained that young adults

need Medi-Cal because they are unlikely to go to the doctor in general, and even less

likely to go if they are uninsured. In her words:

> And I think that Medi-Cal, especially for foster youth, should go until
> they're 24 or 25. Because right now, it's our main time where we're not
> thinking about diseases out there. People who don't have medical
> [insurance] don't get check-ups….They're [the system's] not looking at
> none of that. They're like, "Past 21, they can do it on their own." It's not
> necessarily true.

The following is a summary of the findings from the key informant interviews with health and social service providers. In the interest of protecting the confidentiality of this relatively small number of provider respondents, their professional descriptors and gender have been withheld.

I. Health issues for transition-aged foster youth

The health issues identified by providers to be among the most significant issues for transition-aged and emancipated foster youth were comparable to the issues identified by youth respondents. These issues included mental health needs, reproductive and sexual health concerns, injuries and musculoskeletal complaints, and nutrition and dietary concerns.

As with the youth interviews and focus groups, mental health issues and their lasting impacts during the transition to adulthood were a primary focus of discussion among the providers. As one provider noted:

> [Among the issues seen in my clinical practice] Mental health is a big one too. And a lot of that comes from social issues as far as housing [and] schooling....and trauma. Emotional trauma...that's big time.

Another provider commented that while in care, youth may receive mental health services from an overburdened mental health system that does not adequately address their needs, and then after emancipation, youth may lose access to stabilizing medications

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and treatments, placing them at risk for psychiatric decompensation and homelessness. The provider observed:

> ...These kids are leaving the system depressed. And the mental health system is another problem in itself, even if kids *have* insurance, it can be bad. A lot of time when folks are in the system, they have access to mental health services, but the services are stretched because [the service providing agencies] are taking care of a whole lot of people, and I'm not sure they're getting the care that they totally need. Then they've left the system, have no insurance and are on psychiatric medication. How are they going to continue the medication? Well, they're not. And lo and behold, some of them become homeless. Many end up on the streets because they have no medication that they keep them stable and on the right track.

II. Factors, policies and processes that help or hinder youths' access to care

Providers were also asked questions intended to solicit their perspectives about the factors, policies, and processes that help or hinder young people's access to care. Factors that facilitate access to care will be addressed first, followed by barriers to health care access.

A. Facilitators of access to care

With regard to factors, policies and processes that facilitate access to care, several providers described their own efforts to ensure continuity of care and coverage for their transition-aged clients. Providers described their efforts to enroll patients in specialized forms of low-cost coverage, such as Family PACT (a state-wide reproductive health program that provides low-to no cost coverage for income-eligible individuals of reproductive age), as a means of circumventing some young adults' ineligibility for Medi-Cal, and ensuring access to at least some form of health care. One provider

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commented on the strategic use of Family PACT encounters by adolescent health providers as a springboard to connect young patients with other types of more general medical care. In the provider's words:

> I think that talking with other providers, we've gotten around some of those things with a program called Family PACT. Because Family PACT is for reproductive health, and pretty much anybody can get it, if they don't make a whole lot of money... So, what I've done, and what a lot of [other] providers do is sign these young people up for Family PACT. Then you make it a Family PACT-focused visit, but also, "Oh, you have asthma— here's a [medication] sample." Or "Oh, you have pneumonia, I have some samples of azithromycin." So I think that through vehicles like that some providers have gotten around some of that stuff.

B. Barriers to Care

Provider respondents identified a number of potential barriers to health care access faced by their clients and patients transitioning out of the foster care system. These barriers included distrust and public system fatigue among youth, as well as structural factors such as lack of accessible and appropriate health services in the community.

To begin, several providers spoke to the ways that repeated experiences of upheaval and broken trust, sometimes within clinical or therapeutic settings, can profoundly affect young people's interest in and willingness to seek health care, and their faith in the ability of healthcare providers to meet their needs. One provider observed a sense of "fatigue" with social services and other public systems among older youth in foster care, which the provider attributed in part to repeated experiences of broken trust. The provider further suggested that clinicians may not always be adept at working with young people to overcome these trust issues. In the provider's words:

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...[T]here's a certain amount of care, adult, and public system fatigue among the 18+ kids... So, I think it takes a certain cultural charisma with the provider, and you need to have a certain level of restraint and skill in trust-building. So I think that one of the key challenges is the challenge of alliance building....Kids are smart. Many of them recognize that their trust was harmed simply from their placement in the foster care system to begin with. Often it's the result of a mandatory report, or sometimes even delivered in a therapeutic setting, where the kid understood it as a confidential setting and it ultimately was not, or maybe it was but, for understandable reasons that trust had to be transgressed. And that doesn't mean that the therapeutic bond is broken, because it actually can be quite rich therapeutically, but unfortunately, the skill of clinicians varies, and sometimes it is quite damaging.

In addition to public system fatigue and mistrust, providers also identified a number of logistical and structural barriers to care. One provider described the lack of services for young adults in general as a barrier to health care access among emancipated foster youth. In the provider's words:

The barriers are quite simple. That there's really no place to go... We've figured out that the way you serve *kids* is that you go find them where they're at; they're in school. Or if you look at what's happening in *adult* medicine, access is often a function of geography and patterns of behavior; that's why we're building clinics in strip malls, because people go to shops, so why not build a clinic where they go? We don't really understand the patterns of behavior among *young adults* in this society. We don't honor them. We don't investigate them, and so I can't really even answer that question. If you're going to ask "where do 18 to 24 year olds go?"

This same provider pointed out that mental health services for young adults in Alameda County are not only lacking in availability, but also somewhat imbalanced; with the majority of resources devoted to services for severely and persistently mentally ill individuals, and very few resources for other types of care.

In this county, there are resources for children on Medi-Cal, and relatively robust ones. But once you become an adult, we have a bifurcated system in Alameda County. If you're severely and persistently mentally ill, the county has resources that are extraordinary. But our behavioral health care system with regard to adults has signed a pact with the devil, we've said, "we're going to do this to contain costs and achieve a standard of care: we're going to focus on the severely and persistently mentally ill." And if you look at our county's investments in behavioral health, you'll see a huge investment on that end. While in primary care settings, there's very little mental health. So, it's a challenge. Just to find it. Just to find behavioral health supports is difficult in the adult system.

Providers also described the ways that structural factors, such as Medi-Cal eligibility criteria and authorization policies could serve as barriers to health insurance and health care for emancipated foster youth. As one provider noted:

I mean, the uninsurance issue gets exacerbated among 18 to 24 year olds....in terms of structural issues such as public benefit, and reauthorizing your Medi-Cal on an annual basis, or simply being dropped if you're not a part of the system when you're 18. So I think that there are some policy things that could be done. Extending benefits to 24, making it easier. But, the public system rations care through barriers to access.

Providers further suggested that structural barriers to insurance access can place youth at risk for poor health outcomes. Echoing some of the youth respondents' sentiments about uninsurance as a barrier to health-care seeking, one provider stated:

What happens to young folks is that they think "I have no insurance, I can't get help" or they go to the emergency room...or they get a bill, but they can't pay it.... And a lot of preventive issues that could've been taken care of sooner, can go by the wayside, and by the time they see someone, it's too late, or it's progressed. So, it really affects negatively on the young person's health when they don't have the financial resources to pay for healthcare.

III. Adequacy and appropriateness: Gaps in pre-emancipation preparation

Providers identified a number of gaps in the pre-emancipation health-related preparation of the transition-aged youth in their care. Among the most frequently mentioned gaps were the lack of sufficient information about self-care, illness prevention and health benefits.

In addition, paralleling youths' expressed frustrations about the difficulties in obtaining their medical records, provider respondents also raised the issue that some transition-aged foster youth may not have received sufficient information about their health status and health history during their time in the system. One provider described that the lack of sufficient health history can pose significant challenges for subsequent providers in their efforts to treat the youth. In particular, the provider described encountering large numbers of transition-aged foster youth receiving supplemental security income (SSI) as a result of having been diagnosed with a disability; however, the provider noted that many of these youth had little understanding of their medical or mental health diagnoses. In the provider's words:

> I find that it seems that a lot of kids are on SSI for various issues, but aren't seeing a doctor, aren't seeing a therapist, and don't even know what their diagnosis is. And it just comes out that "Oh, I get SSI." And I have to try and figure out what for... I feel like probably someone tried to set them up with some sort of financial assistance and got the ball rolling and then the medical piece of it dropped away, and they're just continuing on with their social security part, getting their income... I try [to get the information], but sometimes they don't even know the name of the doctor, they'll be like "I think it was at such-and-such clinic" but they don't remember exactly who it was that helped them to get this.

IV. Suggestions for Change:

Providers generated a number of suggestions to improve the provision of health-related information and services to transition-aged youth. Two of the more recurrent suggestions are the need for more holistic and interdisciplinary approaches to care provision and strategic collaborations to improve access to certain types of care, and the need to extend access to care beyond age 21.

A. The need for more holistic and interdisciplinary approaches to care provision and strategic collaborations to improve access to care

Several providers spoke to the need for more multi-disciplinary and holistic approaches to health policy and health service provision for transition-aged youth and emancipated young adults. Providers also spoke of the need for more collaboration between different health professionals from different disciplines to improve access to certain types of care. In particular, one provider addressed the difficulty young adults may have in accessing mental health care both as a result of the lack of available services in the community, and in some cases, as a result of youths' own reluctance to seek mental health care due to previous negative experiences or the social stigma surrounding mental illness. This provider suggested integrating behavioral and mental health care with other forms of medical care that young people may be more likely to use and trust, may be a potential strategy for restoring young people's trust in health care providers, and enhancing their access to care. In the provider's words:

I think that one of the reasons it's so crucial to integrate primary care and behavioral care is that it's still a protective experience in the medical world. The more that behavioral health can glob onto that [primary care] machine and connect to that, and be legitimated by it, that's helpful. A lot of young adults have had the experience of getting confidential, often reproductive health care, and in that moment, trust is won and earned and sustained...often over time.

...So I think that would be a strategy -- to be sure that you develop some sort of sense of an *integrated medical home* that includes behavioral health care, primary care, and social services. But that is not clearly aligned with anything other than the client or patient. Something that offers a choice, and a selection of the provider and there's clear understanding of the containment of confidentiality and trust.

The same provider emphasized the connections between health and housing and employment stability, and highlighted the importance of integrating social services, and housing and employment support into health services provision, stating:

...[S]ocial services would be a critical component of an integrative medical home. Because these kids have nowhere to go. Housing, that's just an issue to which they return over and over again. Housing and employment. So, and the options are limited...hopefully, we're getting past the point where we see health as the absence of disease. Health is a dynamic exchange between decision making and luck, and available resources. And it's an ideal. It's an action. Health is. So, they're inexorably intertwined health, housing and employment.

B. The need to extend health care coverage past age 21.

Several providers expressed the need to extend coverage past 21 for emancipated foster youth. As one provider suggested:

Everyone who comes out of foster care should automatically have Medi-Cal to age 24. Without any reauthorization, just give them their Medi-Cal number and never look at it again, and [ensure that it] can't be dropped. Once we've taken you from your home, you get free medical care through age 24.

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However, another provider was skeptical about the political support for extending care past 21 for all emancipated youth. Instead, this provider favored an approach in which certain youth who were frequent users of the health care system could be tracked for follow-up and provided with extended coverage. In their words:

> I think [the policy approach] should not be to *guarantee* that they have health insurance, but it should be a case by case basis, where they look at the need of that child, and whether there are yearly physical exams, and just to do some preventive health. That would be enough to make sure that people stay healthy. I also think that they should pay for, through the foster care system, people who track these young people, and if they find that they're having issues. Then there should be funds set aside for access to get the care that they need.

Finally, all of the providers made strong arguments for the transition to adulthood as a critical period for health interventions and the provision of preventive care. They spoke of promoting access to care during the transitional years as an important strategy for ensuring better outcomes in later life, by providing earlier interventions around health risk behaviors and health problems that could later become chronic health issues. As one provider observed:

> To make a general statement, yeah, [young adults] are a healthy population, but a lot of bad habits, vices, cancers, can start in this age range, and won't be picked up until later. But why not pick it up sooner? So, in general, they are a healthy population, but still there are a lot of prevent[able] things that when they get older, go into a whole different realm.

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IV. DISCUSSION

This exploratory study solicited the perspectives of a sample of emancipated foster youth in Alameda County with regard to the major health issues faced after emancipation from foster care; the factors, policies, and processes which help or hinder access to health care; youths' appraisals of the adequacy and appropriateness of their pre-emancipation health-related preparation; and their suggestions for changes to health-related policy and service provision for transition-aged and emancipated foster youth. Additional interviews with health and social services providers explored their perspectives on the health issues and barriers to care faced by transition-aged and emancipated youth, and provide an additional means of triangulation around the key areas of inquiry.

The findings of this study are in agreement with existing research on the transition to adulthood for former foster youth in that youth participants in this study described encountering significant challenges in accessing health care after emancipation from foster care (Barth 1990; Courtney, Piliavin et al. 2001; Courtney and Dworsky 2006).

With regard to the major health issues faced by young people during the post-emancipation period, these findings are also in accordance with existing research highlighting the significance of young people's struggles with mental health issues following their exit from foster care (Barth 1990; Hines, Merdinger et al. 2005; Pecora, Kessler et al. 2005). The respondents in this study poignantly described the ways that their experiences of trauma and abuse continued to have a significant impact on their well-being, self-esteem and relationships with others during the transition to adulthood.

Study findings are also in agreement with existing research describing the benefits of foster youth's connections to supportive adults, agencies, and other institutions during transition to adulthood (Cook 1994; McMillen, Rideout et al. 1997; Mallon 1998; Propp, Ortega et al. 2003). Youth in this study described that their connections to adults and agencies were key sources of logistical and emotional support after emancipation. In addition, the responses from study participants affirm previous findings regarding the value of peer interactions between foster youth as a source of social support and guidance (McMillen, Rideout et al. 1997; Georgiades 2005).

While traditionally efforts to prepare older foster youth for adulthood focused on developing the skills necessary to achieve "independence" and self-sufficiency, a growing body of research has demonstrated the benefits of cultivating supportive, caring relationships, social connectedness and "interdependence" as promising practices for improving functional outcomes and psychosocial well-being in adulthood (Propp, Ortega et al. 2003; Osterling and Hines 2006). The findings from this study lend additional support for the benefits of ensuring that transition-aged youth have a network of social support as they make their way to adulthood.

The findings from this study also offer additional depth to the current understanding of the health-related experiences of foster youth in transition to adulthood, particularly with regards to their health needs and barriers faced in accessing health care.

For example, building on prior research findings concerning the significance of mental health issues during the transition to adulthood, the findings from this study suggest that for some foster youth, the transition into new life roles and responsibilities may spark a renewed interest in therapy or other forms of emotional support after they

have left care. However, it is noteworthy that this time period is typically one of *decreased* access to social and emotional support, as benefits through the foster care system come to an end. Ultimately, these findings suggest the need for increased efforts to ensure access to mental health care and support after emancipation.

Lack of access to dental and orthodontic care also emerged as particularly troublesome health issues among the youth respondents. These types of care may be especially difficult for young people to secure access to and to pay for, given their limited or even non-existent insurance coverage, and modest financial means during the years following emancipation. Findings from this study suggest that transition-aged foster youth may benefit from additional support and advocacy in identifying dental care providers in the community who will accept their coverage or who offer sliding scale services. Regarding orthodontic needs, transition-aged youth may benefit from greater advocacy on behalf of their providers and caregivers for accessing these services *before* they emancipate.

Youth and providers alike made important connections between housing instability/homelessness and health. These findings suggest continued efforts to improve the availability of safe and affordable housing options for emancipated foster youth may also have implications for their health and wellbeing. Similarly, efforts to ensure access to appropriate health and mental health support for emancipated youth may enhance their ability to retain stable housing and employment and to remain in school.

In addition to providing new insights into the health issues faced by young people exiting the foster care system, this study also offers a deeper understanding of the specific barriers to care faced by foster youth in the transition to adulthood. Prior research has

identified insurance problems and the cost of health care as barriers to health care access for emancipated youth (Barth 1990; Courtney, Piliavin et al. 2001; Courtney and Dworsky 2006). The findings from this study suggest that even when emancipated youth are eligible for insurance coverage through the system (e.g. Medi-Cal) they may still face considerable impediments to health care access. Some of these impediments are logistical or structural in nature, for example having one's card sent to the wrong address or having out-of-county Medi-Cal. Thus there may be a need for changes to the system of Medi-Cal administration for foster youth, to further facilitate their access to benefits, and reduce disruptions in coverage. Such changes might include online Medi-Cal renewal to eliminate the loss of documents associated with address changes, and statewide Medi-cal eligibility codes for foster youth that are transferable to any county.

Study findings also suggest that youth over 21, whose coverage through the system has ended, may face formidable barriers to care. This can place them at risk for poor health outcomes, as both youth and providers alike mentioned that young people without insurance may delay care-seeking due to concerns about having to pay for treatment. Thus, while the expanded access to care afforded by the FCIA of 1999 constitutes an important first step in improving the health access of emancipated youth, the end of services at age 21 may still leave young people stranded and without sufficient resources to obtain much needed healthcare. Many youth and providers suggested a need for extending access to Medi-Cal insurance through the system beyond age 21.

This study also contributes to an understanding of the gaps in the pre-emancipation health-related information given to young people in foster care. Youth and providers alike suggested the need for more standardized, and accessible information

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about self-care and illness prevention; more detailed information about the scope and coverage of services available through Medi-Cal; and how, when, and where to access the adult health care system.

Youth had diverse opinions about how best to distribute health-related information to youth still in the system. Ultimately, ensuring that health-related information is provided via a number of different pathways and modalities, including education within placements, individualized benefits counseling, classes and written information, may increase the likelihood that youth receive and retain the information that they need. Youth participants in this study also expressed the need for additional opportunities to receive one-on-one education and counseling that would enable them to obtain more individualized information or ask personal questions. In addition, youth and providers alike saw the need for improved education of caregivers and guardians about foster youths' healthcare benefits and entitlements so that they might be better advocates for the youth in their care.

Furthermore, based on the youth participants' comments, there appears to be a need to address disparities in access to information that may exist within the system; with certain groups of youth, including 'difficult to reach' young people, and youth who do not participate in ILSP, being at an increased risk for missing out on information pertaining to health care and health benefits. Prior research has pointed out that 'difficult to reach' youth are often under-prepared for independent living and under-supported during their transitions to adulthood (Georgiades 2005). As Georgiades (2005) has pointed out, many so-called 'difficult to reach' youth may have very legitimate reasons to harbor anger toward the foster care system, or may have distanced themselves from the

system at a time when they were not in the position to determine what was in their own best interest. Such youth may be at risk for missing out on essential information and services because they are deemed too challenging to work with. However, these same youth may be in the greatest need of additional support and engagement. Additional measures should be taken to ensure that all youth, including 'difficult to reach' youth receive sufficient information about self-care, health care benefits, and how to navigate the adult health care system.

Based on the comments of the provider respondents, transition-aged youth also may benefit from support for identifying additional types of health insurance coverage for which they may be eligible (e.g. Family PACT). Such programs may serve as a crucial means of access to health care for emancipated youth, particularly when they are no longer eligible for Medi-Cal through the system. Both youth and providers also suggested the need for young people to have assistance with locating and accessing their medical records in advance of emancipation.

Finally, this study builds upon prior work highlighting the importance of social interactions *between* foster youth as a crucial source of support during the transition to adulthood, and suggests the need for more formal opportunities for peer-based education and mentorship for transition-aged foster youth. A growing body of literature demonstrates the benefits of mentorship programming for outcomes for adolescents in foster care. However, the majority of this research has focused on mentorship arrangements that pair foster youth with adult mentors (Massinga and Pecora 2004; Osterling and Hines 2006). Few, if any, studies have specifically examined the benefits of peer-based mentorship for transition-aged foster youth, although some have suggested

the need for more youth mentors to serve as role models during the transition from foster care (Barth 1990; McMillen, Rideout et al. 1997; Georgiades 2005). There is also evidence documenting the benefits of the informal and organic networks of emotional and logistical support and guidance that are often formed between young people who have exited care (Mallon 1998). In addition, within the policy arena, advocacy organizations comprised of current and former foster youth have played a crucial role in the development and evaluation of programs and legislation concerning foster youth (California Youth Connection 2000; Nixon 2005; Rodriguez 2005; California Youth Connection 2006).

Given the growing interest in applying a positive youth development approach to service provision in child welfare and foster care, the increased inclusion of foster care alumni can be seen as an essential part of a operationalizing such an approach, and improving the accountability of the foster care system to the youth it serves (Nixon 2005).

V. LIMITATIONS

There are several important limitations to this research. To begin, qualitative studies are fundamentally limited in terms of their generalizability. This small sample size of this study limits the generalizability of the study findings even further.

Secondly, with regard to recruitment and sampling, it is important to note that youth were convenience sampled through their association with or participation in agencies and organizations. Although purposive sampling strategies were employed in

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an effort to recruit youth experiencing a variety of life circumstances, from enrollment in college or employment, to unemployment and homelessness, the association of all youth participants with agencies or organizations may not reflect the health care experiences and perceived health access of the general population of emancipated youth in Alameda County, and particularly youth who are disconnected from agencies or support persons. There is every reason to suspect, based on the literature on homeless youth and young adults that youth who are disconnected from agencies and support people may be at an even greater risk for poor health status and unmet health need.

Young men were under-represented in this sample, and therefore their health-related perspectives and experiences were not well-represented in this study. The sample also does not include any 'early emancipators' (youth who emancipated before age 18); therefore important questions remain about health-related experiences and perceived access to care for this group.

In addition to the under-representation of young men and early emancipators, there are also certain groups of emancipated youth who were not successfully recruited for participation in the study, including young people who identified as being undocumented immigrants. Based upon the commentary of one youth participant, there is reason to believe that undocumented youth who have aged out of foster care may face a unique set of barriers to health care acquisition during the transition to adulthood, including an inability to receive full-scope Medi-Cal due to their non-resident status. In addition, important questions also remain about the health-related experiences of youth who may face marginalization within the system or barriers to care due to their cultural or linguistic backgrounds, and youth with special health care needs and disabilities. The

experiences of youth and young adults who are incarcerated or residing in in-patient treatment facilities were also not examined here.

In addition, it is worth noting that several youth who participated in individual interviews were interviewed at agencies by their choice, or for the sake of convenience, but this may have affected their ability to speak freely. Furthermore, the researcher was unknown to the youth/young adult participants, which may have impacted the content of interviews.

Because this was an exploratory study focusing primarily on foster youth's subjective experiences, primarily during the post-emancipation years, only limited data were gathered about young people's pre-emancipation circumstances. No attempt was made to obtain access to case files, medical records or health insurance information. Nor was any attempt made to routinely collect self-report data on young people's length of stay in foster care, reasons for placement, or the type(s) of placements experienced (e.g. foster family homes vs. kinship care), although many youth described these elements in their responses. The lack of standardized pre-emancipation data makes it difficult to make observations or inferences about the quality and quantity of pre-emancipation health education and health care access. In addition, as the focus groups and individual interviews called for the recollection of past events, there is the potential that recall bias may have affected the validity of the findings.

Finally, due to the sensitive and personal nature of some of the interview and focus group content, the interview transcripts were not shared for an independent review. Samples of the coding scheme and anonymized quotations were shared with the lead investigator's advisor for the purposes of achieving some inter-rater agreement, but the

entire coding scheme was not reviewed by a second reviewer, which may limit the validity of the findings.

VI. CONCLUSION:

The findings from this study suggest that there is considerable room for improvement in the provision of health-related information, support, and services to foster youth in transition to adulthood. A summary of recommendations based on the study findings is presented in Table 2 below.

To begin, youth who are still in care may benefit from a more concerted and consistent effort to provide them with comprehensive information and education about self care, insurance benefits and entitlements, and the navigation of the adult health care system. This information and education must be offered well in advance of emancipation and should be distributed via multiple modalities. In addition, measures should be taken to ensure that such information is accessible to all youth in care regardless of placement types or participation in life skills programming.

Caregivers, guardians, and caseworkers are strategically poised to be key providers of health-related information and advocacy to foster youth in advance of their emancipation. Pediatric and adult health care providers are also poised to offer crucial advocacy in the formation of health care transition plans, the enrollment of youth in health coverage programs such as family PACT to ensure access to coverage for certain services even after Medi-Cal ends, and the brokerage of health care referrals to ensure more comprehensive care.

These findings also underscore the need for broader county, state, and even federal policy changes to improve the healthcare safety net for foster youth in transition to adulthood. At the local or county level, these policy changes should include a more concerted effort to enhance access to comprehensive health and mental health care for young adults. As suggested by the respondents in this study, additional transitional services such as housing are also crucial to ensuring the well-being of young people leaving care. In addition, the best practices for developing peer-based educational programming for transition-aged foster youth represents an area of much-needed future research.

Policy changes at the state level should include a state-wide expansion of access to healthcare entitlements through the foster care system beyond age 21 (and probably through age 24). It is noteworthy that certain individual California counties have already taken steps to locally expand access to care for emancipated foster youth. For example, in 2004, San Francisco County moved to expand Medi-Cal coverage to age 24 for emancipated foster youth within the county (Adolescent Health Working Group 2004). However, changes within individual counties are insufficient to address the needs of the much larger population of emancipated foster youth in the state. Furthermore, as evidenced by the findings of this study, incompatible Medi-Cal policies between counties can pose barriers to healthcare access for foster youth who relocate to other counties. To ensure healthcare access for all transition-aged youth in need of care in California, and minimize the barriers posed by individual county Medi-Cal bureaucracies, the ideal solution would be a state-wide extension of Medi-Cal beyond age 21. Additional research is needed to determine the economic and logistic feasibility of such an

undertaking, however it is likely that enhancing access to preventive care for emancipated young adults might ultimately reduce current expenditures of public dollars on emergency care for young adults who are uninsured.

Finally, future studies of outcomes for former foster youth must continue to engage youth's own input and perspectives about their experiences within the foster care system and their suggestions for improvements to service provision.

Table 2 Recommendations for Practice and Policy

Recommendations for Youth Serving Agencies, Social Workers and Probation Officers

• Provide youth with comprehensive information and education about self care, health benefits, and the process of navigating the adult health care system.
 	
   o Health-related Information should be offered well in advance of emancipation.
 	
   o Information should be distributed via multiple modalities (e.g. one-on-one counseling, pamphlets, classes, and media advertisements)
 	
• Expand opportunities for peer-based education and outreach
 	
• Agencies or service providers that work with caregivers and guardians should ensure that they receive sufficient information about youths' health benefits and entitlements
 	
   o Strategies for outreach to caregivers and guardians include conventions and social gatherings
 	
• Assist youth with locating their medical records in advance of emancipation
 	
• Assist youth with locating health care providers within the adult health care system
 	
• Enhance opportunities for youth input and participation in program design and evaluation

Recommendations for Health Care Providers
For foster youth still in care • Assist foster youth and their guardians with developing health care transition plans in advance of emancipation • Assist youth with obtaining medically necessary treatments and procedures (e.g. dental/orthodontic care) while they are still in the foster care system • Assist youth with locating and obtaining medical records *For emancipated youth* • Assist youth with identifying and enrolling in health care plans such as Family PACT • Assist youth with identifying appropriate health, mental health and dental care providers in the community

Recommendations for Local and State California Policy Makers
• Enhance the availability of comprehensive medical and mental health services for transition-aged youth and young adults • Reduce logistical barriers to the continuity of insurance coverage for foster youth • Expand access to transitional housing and other supportive programming for emancipated foster youth • Implement a statewide expansion of health care coverage for emancipated foster youth beyond age 21 • Incorporate mechanisms for soliciting foster youth's feedback and participation in program design and evaluation

REFERENCES:

Adolescent Health Working Group. (2004). "Issue Brief: Ensuring Access to Healthy Young Adults Program for Transitioning Foster Youth." Retrieved October 2, 2006, from http://www.ahwg.net/projects/Foster%20Youth%20Brief(larger%20font).pdf.

Ainsworth, M. S. and J. Bowlby (1991). "An ethological approach to personality development." American Psychologist **46**(4): 333-341.

Alexander, B. and S. Schrauben (2006). "Outside the margins: youth who are different and their special health care needs." Prim Care **33**(2): 285-303.

Allen, M. and M. Bissell (2004). "Safety and stability for foster children: the policy context." Future Child **14**(1): 48-73.

American Academy of Pediatrics (2002). "Health of Young Children in Foster Care." Pediatrics **109**(3): 536-541.

American Academy of Pediatrics (2005). Fostering Health: Health Care for Children and Adolescents in Foster Care, 2nd Edition. District 11, New York State, American Academy of Pediatrics.

American Academy of Pediatrics: Committee on Early Childhood, A. a. D. C. (1987). "Health of Foster Children." Pediatrics **79**(4): 644-646.

American Academy of Pediatrics: Committee on Early Childhood, A. a. D. C. (2000). "Developmental Issues for Young Children in Foster Care." Pediatrics **106**(5): 1145-1150.

Arnett, J. J. (2000). "Emerging adulthood: A theory of development from the late teens through the twenties." The American Psychologist **55**(5): 469.

Aronowitz, T. (2005). "The role of "envisioning the future" in the development of resilience among at-risk youth." Public Health Nurs **22**(3): 200-8.

Barth, R. P. (1990). "On Their Own: The Experiences of Youth after Foster Care." SO: Source Child & Adolescent Social Work Journal, 1990, 7, 5, Oct, 419-440 **7**(5): 419-440.

Becker, M. and R. Barth (2000). "Power Through Choices: The Development of a Sexuality Education Curriculum for Youths in Out-of-Home Care." Child Welfare **79**(3): 269-282.

Bilaver, L. and M. Courtney. (2006). "Foster Care Youth." Science Says Retrieved January 12, 2007, from http://www.teenpregnancy.org/works/pdf/ScienceSays27_FosterCare.pdf.

Blum, R., C. McNeely, et al. (2002). "Vulnerability, Risk and Protection." Journal of Adolescent Health 31S: 28-39.

Bowlby, J. (2003). The Making and Breaking of Affectional Bonds. New York, NY, Routledge.

Brindis, C. D., M. C. Morreale, et al. (2003). "The unique health care needs of adolescents." Future Child 13(1): 117-35.

Browne, D. (2002). "Coping Alone: Examining the Prospects of Adolescent Victims of Child Abuse Placed in Foster Care." Journal of Youth and Adolescence 31(1): 57-66.

Byrnes, J. P. (2002). "The development of decision-making." Journal of Adolescent Health 31(Suppl6): 208-215.

California Department of Health and Human Services. (2006). "Mental Health Services Act Home Page." Retrieved April 26, 2006, from http://www.dmh.cahwnet.gov/MHSA/default.asp.

California Department of Mental Health Services. (2004). "Mental Health Services Act." Retrieved February 1, 2007, from http://www.dmh.ca.gov/mhsa/docs/Mental_Health_Services_Act_Full_Text.pdf.

California Department of Social Services (2000). All County Information Notice No. I-117-00. California Department of Social Services, State of California Health and Human Services Agency.

California Youth Connection (2000). Foster Youth Proposals to Improve Mental Health Services: The Consumer's Perspective. San Francisco, California Youth Connection: 1-16.

California Youth Connection (2006). Final Report: Are Group Homes Picture Perfect? Findings and Recommendations from the Youth Led Evaluation Project. Y. L. E. Project. San Francisco, California Youth Connection: 1-55.

Callahan, S., R. Winitzer, et al. (2001). "Transition from Pediatric to Adult-Oriented Health Care: A Challenge for Patients with Chronic Disease." Current Opinion in Pediatrics 13: 310-316.

Carbonell, D., H. Reinherz, et al. (2005). "Adaptation and Coping in Childhood and Adolescence for Those at Risk for Depression in Emerging Adulthood." Child & Adolescent Social Work Journal 22(5-6): 395-416.

Carbonell, D., H. Reinherz, et al. (1998). "Risk and Resilience in Late Adolescence." Child & Adolescent Social Work Journal 15(4): 251-272.

Carlisle, J., D Shickle, et al. (2006). "Concerns Over Confidentiality May Deter Adolescents From Consulting their Doctors: A Qualitative Exploration." Journal of Medical Ethics 32: 133-137.

Carpenter, S., R. Clyman, et al. (2001). "The Association of Foster Care or Kinship Care With Adolescent Sexual Behavior and First Pregnancy." Pediatrics 108(3): 46-52.

Chernoff, R., T. Combs-Orme, et al. (1994). "Assessing the Health Status of Children Entering Foster Care." Pediatrics 93(4): 594-601.

Child Welfare Information Gateway (2005). Definitions of Child Abuse and Neglect: State Statutes Series. Child Welfare Information Gateway.

Children's Bureau. (2003). "Child and Family Services Review, CFSR: California 2003." Retrieved April 28, 2006, from http://www.dss.cahwnet.gov/cfsr/res/pdf/011303/CFSRfinalreport.pdf.

Children's Bureau (2006). The AFCARS Report: Preliminary FY 2004 Estimates as of June 2006 (11). Administration on Children Youth and Families, US Department of Health and Human Services. 11.

Children's Bureau (2006a). How Does the Child Welfare System Work? US Department of Health and Human Services and Adminstration on Children Youth and Families, Childrens' Bureau.

Children's Bureau (2006b). Out-of-Home Care: Overview. US Department of Health and Human Services and Adminstration on Children Youth and Families.

Collins, M. (2001). "Transition to Adulthood for Vulnerable Youths: A Review of Research and Implications for Policy." Social Service Review(June): 271-291.

Collins, M. (2004). "Enhancing Services to Youths Leaving Foster Care: Analysis of Recent Legislation and its Potential Impact." Children and Youth Services Review 26: 1051-1065.

Committee on Ways and Means (2004). The 2004 Green Book: Section 11- Child Protection, Foster Care and Adoption Assistance. US House of Representatives, Government Printing Offices, Washington DC: 1-140.

Cook, R. (1994). "Are We Helping Foster Care Youth Prepare for Their Future?" Children and Youth Services Review 16(3/4): 213-229.

County of Alameda Health Care Services Agency (No date). County Medically Indigent Services Program (CMSP) Brochure. C. o. A. H. C. S. Agency.

Courtney, M. and A. Dworsky (2005). Midwest Evaluation of the Adult Functioning of Former Foster Youth: Outcomes at Age 19. Chicago Illinois, Chapin Hall Center for Children at the University of Chicago.

Courtney, M. and A. Dworsky (2006). "Early Outcomes for Young Adults Transitioning from Out-of-Home Care in the USA." Child and Family Social Work 11: 209-219.

Courtney, M. and D. H. Heuring (2006). The Transition to Adulthood for Youth "Aging Out" of the Foster Care System. On Your Own Without a Net: The Transition to Adulthood for Vulnerable Populations. D. Osgood, E. Foster, C. Flanagan and G. Ruth. Chicago, IL, The University of Chicago Press: 27-67.

Courtney, M. and D. Hughes-Heuring (2005). The Transition to Adulthood for Youth "Aging Out" of the Foster Care System. On Your Own Without a Net: The Transition to Adulthood for Vulnerable Populations. D. Osgood, E. Foster, C. Flanagan and G. Ruth. Chicago, IL, The University of Chicago Press: 27-67.

Courtney, M., B. Needell, et al. (2003). "National Standards in the Child and Family Services Reviews: Time to Improve on a Good Idea." Working Paper 341 Retrieved April 27, 2006, from http://www.jcpr.org/wp/WPprofile.cfm?ID=401.

Courtney, M. E., S. L. McMurtry, et al. (2004). "Housing problems experienced by recipients of child welfare services." Child Welfare 83(5): 393-422.

Courtney, M. E., I. Piliavin, et al. (2001). "Foster youth transitions to adulthood: a longitudinal view of youth leaving care." Child Welfare 80(6): 685-717.

CWLA. (2005). "Children of Color in the Child Welfare System." Child Welfare League of America/National Data Analysis System, Retrieved March 14, 2007, from http://ndas.cwla.org/Include/text/Children%20of%20Color05.pdf.

D'Andrade, A. (2005). Placement Stability in Foster Care. Child Welfare for the 21st Century: A Handbook of Practices, Policies and Programs. G. Mallon and P. M. Hess. New York, NY, Columbia University Press: 608-622.

Davies, D. (2004). Child Development: A Practitioner's Guide. New York, NY, The Guilford Press.

Derezotes, D., M. Testa, et al. (2005). Race Matters in Child Welfare: The Overrepresentation of African American Children in the System. Washington, DC, Child Welfare League of America.

DiGiuseppe, D. L. and D. A. Christakis (2003). "Continuity of care for children in foster care." Pediatrics 111(3): e208-13.

Downs, S., E. Moore, et al. (2004). Child Welfare and Family Services: Policies and Practice. Boston, Massachussetts, Pearson Education.

Eckholm, E. (2007). Offering Help for Former Foster Care Youths. New York Times. New York, NY: 1.

Edmond, T., W. Auslander, et al. (2002). "Differences between sexually abused and non-sexually abused adolescent girls in foster care." J Child Sex Abus 11(4): 73-99.

Elliot, G. and S. Feldman (1990). Capturing the Adolescent Experience. At the Threshold: The Developing Adolescent. S. Feldman and G. Elliot. Cambridge Massachussetts, Harvard University Press: 1-13.

Ellis, R., C. Dulmus, et al. (2003). Essentials of Child Welfare. Hoboken, NJ, Wiley and Sons, Inc.

Elze, D., W. Auslander, et al. (2001). "Untangling the Impact of Sexual Abuse on HIV RIsk Behaviors Among Youths in Foster Care." AIDS Education and Prevention 13(4): 377-389.

English, A. (2006). Health Care for Vulnerable Young Adults. Adolescence and the Transition to Adulthood, Chicago, IL, Chapin Hall Center for Children.

English, A. and K. Grasso (2000). "The Foster Care Independence Act of 1999: Enhancing Youth Access to Health Care." Journal of Poverty Law and Policy: 217-232.

English, A., M. C. Morreale, et al. (2003). "Access to health care for youth leaving foster care: Medicaid and SCHIP." J Adolesc Health 32(6 Suppl): 53-69.

English, A., A. Stinnett, et al. (2006). Health Care for Adolescents and Young Adults Leaving Foster care: Policy Options for Improving Access. Center for Adolescent Health and the Law and The Public Policy Analysis and Education Center for Middle Childhood Adolescent and Young Adult Health. Chapel Hill, NC and San Francisco, CA.

Erikson, E. (1968). Identity, Youth and Crisis. New York, NY, Routledge.

Fergus, S. and M. A. Zimmerman (2005). "Adolescent resilience: a framework for understanding healthy development in the face of risk." Annu Rev Public Health 26: 399-419.

Festinger, T. (1983). No One Ever Asked Us: A Postscript to Foster Care. New York, NY, Columbia University Press.

Ford, C., S. Millstein, et al. (1997). "Influence of physician confidentiality assurances on adolescents' willingness to disclose information and seek future health care. A

randomized controlled trial." Journal of the American Medical Association **278**(12): 1029-34.

Foster, E. and E. Gifford (2005). The Transition to Adulthood for Youth Leaving Public Systems. On the Frontier of Adulthood: Theory, Research and Public Policy. R. Settersten, F. Furstenberg and R. Rumbaut. Chicago, IL, University of Chicago Press: 501-533.

Fraser, M. and M. Terzian (2005). Risk and Resilience in Child Development. Child Welfare for the 21st Century: A Handbook of Practices, Policies, and Programs. New York, New York, Columbia University Press: 55-71.

Freed, L., J. Ellen, et al. (1998). "Determinants of Adolescents' Satisfaction With Health Care Providers and Intentions to Keep Follow-Up Appointments." Journal of Adolescent Health **22**: 475-479.

GAO (1995). Foster Care: Health Needs of Many Young Children are Unknown and Unmet: Report to the Ranking Minority Member Subcommittee on Human Resources. US General Accounting Office. Committee on Ways and Means House of Representatives. **GAO/HEHS-95-114**.

GAO (1999). Foster Care: Effectiveness of Independent Living Services Unknown. United States General Accounting Office, United States General Accounting Office: 1-32.

GAO (2003). Child Welfare and Juvenile Justice: Federal Agencies Could Play a Stronger Role in Helping States Reduce the Number of Children Placed Solely to Obtain Mental Health Services. United States General Accounting Office. **GAO-03-397, April 21, 2003**.

Garmezy, N. (1974). "Children at Risk: The Search for the Antecedents of Schizophrenia. Part II: Ongoing Research Programs, Issues, and Intervention." Schizophrenia Bulletin(9).

Georgiades, S. (2005). "Emancipated Young Adults' Perspectives on Independent Living Programs." Families in Society **86**(4): 503.

Green, J. and N. Thorogood (2004). Qualitative Methods for Health Research. Thousand Oaks, CA, Sage Publications.

Halfon, N., M. Inkelas, et al. (2002). Child Welfare Agency Use of Standards for Health Care to Children in Foster Care. Policy Brief. UCLA Center for Healthier Children Families and Communities.

Halfon, N., A. Mendonca, et al. (1995). "Health Status of Children in Foster Care: The Experience of the Center for the Vulnerable Child." Archives of Pediatrics & Adolescent Medicine 149: 386-392.

Hansen, R. L., F. L. Mawjee, et al. (2004). "Comparing the health status of low-income children in and out of foster care." Child Welfare 83(4): 367-80.

Harter, S. (1990). Self and Identity Development. At the Threshold: The Developing Adolescent. S. Feldman and G. Elliott. Cambridge, Massachussetts, Harvard University Press: 352-387.

Heflinger, C. and C. Hoffman (2006). "Transition Age Youth in Publicly Funded Systems: Identifying High-Risk Youth for Policy Planning and Improved Service Delivery." Journal of Behavioral Health Services and Research.

Henry, D. (1999). "Resilience in Maltreated Children: Implications for Special Needs Adoption." Child Welfare 78(5): 519-540.

Hines, A. M., J. Merdinger, et al. (2005). "Former foster youth attending college: resilience and the transition to young adulthood." Am J Orthopsychiatry 75(3): 381-94.

Jee, S. H., R. P. Barth, et al. (2006a). "Factors Associated with Chronic Conditions Among Children in Foster Care." Journal of Health Care for the Poor and Underserved 17(2): 328.

Jee, S. H. and M. D. Simms (2006b). "Health and well-being of children in foster care placement." Pediatr Rev 27(1): 34-6.

Jones, R., A. Purcell, et al. (2005). "Adolescents' Report of Parental Knowledge of Adolescents' Use of Sexual Health Services and their Reactions to Mandated Parental Notification for Prescription Contraception." JAMA 293(3): 340-348.

Kegler, M. C., R. F. Oman, et al. (2005). "Relationships Among Youth Assets and Neighborhood and Community Resources." Health Education and Behavior 32(3): 380-397.

Kerman, B., R. Barth, et al. (2004). "Extending transitional services to former foster children." Child Welfare 83(3): 239-62.

Knight, H. (2007). Aid Urged for Older Foster Kids. San Francisco Chronicle. San Francisco: B-1.

Kools, S. (1999). "Self-protection in adolescents in foster care." Journal of Child and Adolescent Psychiatric Nursing 12(4): 139.

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Kools, S. and C. Kennedy (2003). "Foster child health and development: implications for primary care." Pediatr Nurs **29**(1): 39-41, 44-6.

Lawrence, C., E. Carlson, et al. (2006). "The impact of foster care on development." Development and Psychopathology **18**(1): 57-76.

Lemon, K., A. Hines, et al. (2005). "From Foster Care to Young Adulthood: The Role of Independent Living Programs in Supporting Successful Transitions." Children and Youth Services Review **27**: 251-270.

Lenz-Rashid, S. (2006). "Employment experiences of homeless young adults: Are they different for youth with a history of foster care?" Children and Youth Services Review **28**(3): 235-259.

Lerner, R. and N. Galambos (1998). "Adolescent Development: Challenges and Opportunities for Research, Programs, and Policies." Annu Rev Psychol **49**: 413-446.

Leslie, L., M. Hurlburt, et al. (2003). "Comprehensive assessments for children entering foster care: a national perspective." Pediatrics **112**(1 Part 1): 134-142.

Leslie, L. K., J. N. Gordon, et al. (2005a). "Addressing the developmental and mental health needs of young children in foster care." J Dev Behav Pediatr **26**(2): 140-51.

Luthar, S., D. Cicchetti, et al. (2000b). "The Construct of Resilience: A Critical Evaluation and Guidelines for Future Work." Child Development **71**(3): 543-562.

Madriz, E. (2003). Focus Groups in Feminist Research. Collecting and Interpreting Qualitative Materials. N. Denzin and Y. Lincoln. Thousand Oaks, CA, Sage Publications.

Mallon, G. (1998). "After Care, Then Where? Outcomes of an Independent Living Program." Child Welfare **77**(1): 61-78.

Mallon, G. and P. McCartt-Hess (2005). Introduction. Child Welfare for the 21st Century: A Handbook of Practices, Policies and Programs. G. Mallon and P McCartt Hess. New York, NY, Columbia University Press.

Massinga, R. and P. Pecora (2004). "Providing better opportunities for older children in the child welfare system." Future Child **14**(1): 150-173.

Massinga, R. and P. J. Pecora (2004). "Providing better opportunities for older children in the child welfare system." Future Child **14**(1): 150-73.

Masten, A., K. Burt, et al. (2004a). "Resources and Resilience in the Transition to Adulthood: Continuity and Change." Development and Psychopathology **16**(2004): 1071-1094.

Masten, A. S., K. Best, et al. (1990). "Resilience and Development: Contributions from the Study of Children Who Overcome Adversity." Development and Psychology 2: 425-444.

McCarthy, J. and M. Woolverton (2005). Healthcare Needs of Children and Youth in Foster Care. Child Welfare for the 21st Century: A Handbook of Practices, Policies and Programs. G. Mallon and P. McCartt Hess. New York, NY, Columbia University Press.

McDonald, T., R. Allen, et al. (1996). Assessing the Long-Term Effects of Foster Care: A Research Synthesis. Washington, DC, Child Welfare League of America Press.

McGowan, B. (2005). Historical Evolution of Child Welfare Services. Child Welfare for the 21st Century: A Handbook of Practices, Policies, and Programs. G. Mallon and P. M. Hess. New York, NY, Columbia University Press: 10-46.

McGuinness, T., M. Mason, et al. (2002). "Becoming Responsible Teens: Promoting the Health of Adolescents in Foster Care." Journal of the American Psychiatric Nurses Association 8(3): 92-98.

McManus, R. P. (2002). "Adolescent Care: Reducing Risk and Promoting Resilience." Prim Care Clin Office Pract 29: 557-569.

McMillen, J., G. Rideout, et al. (1997). "Independent-Living Services: The Views of Former Foster Youth." Families in Society 78(5): 471-479.

McMillen, J. C. and J. Tucker (1999). "The status of older adolescents at exit from out-of-home care." Child Welfare 78(3): 339.

McRoy, R. (2005). Overrepresentation of Children and Youth of Color in Foster Care. Child Welfare for the 21st Century: A Handbook of Practices, Policies and Programs. G. Mallon and P. McCartt-Hess. New York, NY, Columbia University Press: 623-634.

Millstein, S. and I. F. Litt (1990). Adolescent Health. At the Threshold: The Developing Adolescent. S. Feldman and G. Elliott. Cambridge Massachussetts, Harvard University Press: 431-456.

Newsom, G. (2006). Helping Foster Youth Make the Transition to Adulthood. San Francisco Chronicle. San Francisco: B13.

Nixon, R. (1997). "What is Positive Youth Development?" Child Welfare 76(5): 571.

Nixon, R. (2005). Promoting Youth Development and Independent Living Services. Child Welfare for the 21st Century: A Handbook of Practices, Policies, and Programs. G. Mallon and P. McCartt-Hess. New York, NY, Columbia University Press: 573-582.

Oberg, C., M. Hogan, et al. (2002). "Health Care Access, Sexually Transmitted Diseases and Adolescents: Identifying Barriers and Creating Solutions." Current Problems in Pediatric and Adolescent Health Care 32: 315-339.

Osgood, D., E. Foster, et al. (2005). Introduction: Why Focus on the Transition to Adulthood for Vulnerable Populations? On Your Own Without A Net: The Transition to Adulthood for Vulnerable Populations. D. Osgood, E. Foster, C. Flanagan and G. Ruth. Chicago, Illinois, The University of Chicago Press: 1-26.

Osterling, K. and A. Hines (2006). "Mentoring Adolescent Foster Youth: Promoting Resilience During Developmental Transition." Child and Family Social Work 11: 242-253.

Pasztor, E. M., D. S. Hollinger, et al. (2006). "Health and mental health services for children in foster care: the central role of foster parents." Child Welfare 85(1): 33-57.

Pecora, P., R. Kessler, et al. (2005). Improving Family Foster Care: Findings From the Northwest Foster Care Alumni Study. C. F. Programs.

Pecora, P., J. Williams, et al. (2006). "Assessing the Educational Achievements of Adults who were Formerly Placed in Family Foster Care." Child and Family Social Work 11: 220-231.

Pecora, P. J. (2006). Child Welfare Policies and Programs. Social Policy for Children and Families: A Risk and Resilience Perspective. J. Jensen and M. Fraser. Thousand Oaks, CA, Sage Publications: 19-66.

Penzerro, R. M. (2003). "Drift as Adaptation: Foster Care and Homeless Careers." Child & Youth Care Forum. Special Issue: Children and Homelessness 32(4): 229-244.

Piliavin, I., M. Sosin, et al. (1993). "The Duration of Homeless Careers: An Exploratory Study." Social Service Review 67(4): 576-598.

Propp, J., D. M. Ortega, et al. (2003). "Independence or Interdependence: Rethinking the Transition From "Ward of the Court" to Adulthood." Families in Society 84(2): 259-266.

Redmond, P. (2003). Children Discharged from Foster Care: Strategies to Prevent the Loss of Health Coverage at a Critical Transition. Kaiser Commission on Medicaid and the Uninsured, Henry J. Kaiser Family Foundation.

Reilly, T. (2003). "Transition from care: status and outcomes of youth who age out of foster care." Child Welfare 82(6): 727-46.

Reiss, J. (2002). "Health Care Transition: Destinations Unknown." Pediatrics 110(6): 1307-1314.

Risley-Curtiss, C. and J. J. Kronenfeld (2001). "Health care policies for children in out-of-home care." Child Welfare 80(3): 325.

Rodriguez, J. (2005). "California Youth Connection: Organizing Foster Youth for Change." Journal of Law and Poverty(July-August): 170.

Roisman, G., A. Masten, et al. (2004). "Salient and Emerging Developmental Tasks in the Transition to Adulthood." Child Development 75: 123.

Roman, N. and P. Wolfe (1997). "The Relationship Between Foster Care and Homelessness." Public Welfare: 4-9.

Rosen, D., R. Blum, et al. (2003). "Transitions to Adult Health Care for Adolescents and Young Adults with Chronic Conditions: Position Paper of the Society for Adolescent Medicine." Journal of Adolescent Health 33(4): 309-311.

Rosenberg, S. and C. Robinson (2004). "Out-of-Home Placement for Young Children with Developmental and Medical Conditions." Child & Youth Services Review 26: 711-723.

Rounds, K. and T. Ormsby (2006). Health Policy for Children and Youth. Social Policy for Children and Families: A Risk and Resilience Perspective. J. Jenson and M. Fraser. Thousand Oaks, CA, Sage Publications: 131-166.

Ryan, S., M. SG, et al. (1998). "Adolescents' Knowlege of Their Health Insurance Coverage." Journal of Adolescent Health 22: 293-299.

Sandler, I. (2001). "Quality and Ecology of Adversity as Common Mechanisms of Risk and Resilience." American Journal of Community Pyschology 29(1): 19-33.

Scannapieco, M., J. Schagrin, et al. (1995). "Independent Living Programs: Do they make a difference?" Child & Adolescent Social Work Journal 12(5): 381.

Schor, E. (1982). "The Foster Care System and the Health Status of Foster Children." Pediatrics 69(5): 51-528.

Schulenberg, J., A. Sameroff, et al. (2004). "The Transition to Adulthood as a Critical Juncture in the Course of Psychopathology and Mental Health." Development and Psychopathology 16: 799-806.

Segal, E. (2007). Social Welfare Policy and Social Programs. Belmont, CA, Thomson Education.

Settersten, R. (2005). Social Policy and the Transition to Adulthood: Towards Stronger Institutions and Individual Capacities. On the Frontier of Adulthood: Theory, Research

and Public Policy. R. Settersten, F. Furstenberg and R. Rumbaut. Chicago, IL, University of Chicago Press.

Shirk, M. and G. Stangler (2004). On Their Own: What Happens to Kids When the Age Out of the Foster Care System? Boulder, CO, Westview Press.

Siegel, R. (2006). Life After Foster Care: A Tale of Two Boys. USA, National Public Radio: 22:50.

Silverman, D. (2001). Interpreting Qualitative Data. Thousand Oaks, CA, Sage Publications.

Simms, M. D. (1991a). "Foster children and the foster care system, Part I: History and legal structure." Curr Probl Pediatr 21(7): 297-321.

Simms, M. D. (1991b). "Foster children and the foster care system, Part II: Impact on the child." Curr Probl Pediatr 21(8): 345-69; discussion 370.

Simms, M. D., H. Dubowitz, et al. (2000). "Health care needs of children in the foster care system." Pediatrics 106(4 Suppl): 909-18.

Simms, M. D. and N. Halfon (1994). "The health care needs of children in foster care: a research agenda." Child Welfare 73(5): 505-24.

Smokowski, P., E. Mann, et al. (2003). "Childhood Risk and Protective Factors and Late Adolescent Adjustment in Inner City Minority Youth." Children and Youth Services Review 26(2004): 63-91.

Society for Adolescent Medicine (2004). "Confidential Health Care for Adolescents: Position Paper for the Society of Adolescent Medicine." Journal of Adolescent Health 35: 160-167.

Stanton-Salazar, R. D. (2001). "Manufacturing Hope and Despair: The School and Kin Support Networks of U.S.-Mexican Youth. Sociology of Education Series." Isbn.

Stanton-Salazar, R. D., L. F. Chavez, et al. (2001). "The Help-Seeking Orientations of Latino and non-Latino Urban High School Students: A Critical-Sociological Investigation." Social Psychology of Education 5(1): 49-82.

Steinberg, L. (2005). "Cognitive and affective development in adolescence." Trends in Cognitive Sciences 9(2): 69-74.

Swire, M. and F. Kavaler (1977). "The Health Status of Foster Children." Child Welfare 56(10): 635-653.

Takayama, J., E. Wolfe, et al. (1998). "Relationship Between Reason for Placement and Medical Findings Among Children in Foster Care." Pediatrics 101(2): 201-207.

Taussig, H. N. (2002). "Risk behaviors in maltreated youth placed in foster care: A longitudinal study of protective and vulnerability factors." Child Abuse & Neglect 26(11): 1179.

Turner, R., C. Irwin, et al. (1993). "Autonomy, Relatedness, and the Initiation of Health Risk Behaviors in Early Adolescence." Health Psychology 12(3): 200-208.

VanBergeijk, E. and B. McGowan (2001). Children in Foster Care. Handbook of Social Work Practice With Vulnerable and Resilient Populations. G. A. New York, NY, Columbia University Press: 399-434.

Vostanis, P. (2005). "Patients as Parents and Young People Approaching Adulthood: How Should We Manage the Interface Between Mental Health Services for Young People and Adults?" Current Opinion in Psychiatry 18: 449-454.

Willms, D., N. Johnson, et al. (1992). A Qualitative Study of Family Practice Physician Health Promotion Activities. Doing Qualitative Research. B. Crabtree and W. Miller. Thousand Oaks, CA, Sage Publications. 3.

Zlotnick, C., M. Robertson, et al. (1999). "The Impact of Childhood Foster Care and Other Out-of-Home Placement on Homeless Women and their Children." Child Abuse & Neglect 23(11): 1057-1068.

Appendix A
Focus Group Interview Guide

General Questions
1. Tell me about your living situation since you emancipated:
   - Prompts: staying in own apartment/home, staying with family, staying with a friend, staying in a shelter, living on streets, no place to stay

2. Are you currently working, in school, other?
   a. currently participating in aftercare?
   b. currently taking care of anybody or financially supporting anyone other than yourself?

I. Health issues for Youth: What are they?

1. What do you think are some of the major health issues that emancipated foster youth are dealing with? What kinds of health services are important for emancipated youth?
   - *Possible probes:* What about....
     a. asthma, diabetes
     b. STDs, pregnancy
     c. Mental health: stress, depression, anxiety, sleep problems
     d. Substance Use: drugs, alcohol, tobacco
     e. Relationship abuse
     f. Body image, weight issues, nutrition, physical activity
     g. Other stuff: vision, dental problems

II. Getting Health Care: is it easy or difficult? Is it sufficient? What are the barriers?
1. How easy or difficult is it for emancipated youth to go the doctor after they emancipate?
   c. Can folks go when they need to?
   d. Where can they go?
   e. How are they treated by the doctors, nurses and staff?

2. Since you emancipated, have any of you ever needed to see a doctor, dentist, or counselor and not been able to go?
   f. What kinds of things do you guys think make it difficult for former foster youth to get the services they need?

3. What would you tell another teen in foster care who was about to age-out about where they could get health care? If they were really sick, where would you tell them to go? Who else can folks turn to when they need help with a health problem?

4. Were there any big changes in your health or health insurance when you emancipated?
   g. Have you ever had problems with your health insurance or with paying for your medical care since you've been emancipated? If so, what was that like?

5. How easy or difficult is it for folks to access to their health records or shot records after they emancipate?

III. Preparation for Independent Living and Health care:
1. What kinds of information about taking care of their health do foster youth get before they emancipate?
   - Prompts: getting shots and check-ups? Going to the dentist? Family Planning and safe sex? Support for Depression and other mental health issues?
   a. Where do foster youth get their health information from?

2. Before youth emancipated do they usually get information about Medi-Cal? From who?
   h. Did anyone give you information about who to call if you had a medical problem?

3. Are foster youth given enough preparation to take charge of their own health issues after emancipation?

IV. Suggestions for Change:

1. Who do you think should be involved with making sure emancipated youth are able to get healthcare when they need it?

2. What kinds of information should foster youth get about taking care of their health once they emancipate?

3. What would be the best way to share health information and resources with foster youth who will be emancipating soon?

4. If you had 5 minutes to talk with a local politician (e.g the Mayor or the Governor) or someone who makes decisions about policy, what would you guys tell them needs to be changed about the system to help emancipated foster youth get what they need to stay healthy?

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Appendix B
Individual Interview Guide

General Questions
1. Tell me a bit about your living situation since you emancipated:
   - Probes: staying in own apartment/home, staying with family, staying with a friend, staying in a shelter, living on streets, no place to stay

2. Are you currently working, in school, other?
   - i. currently participating in aftercare?
   - j. currently taking care of or financially supporting anybody other than yourself?

I. Health issues for Youth: What are they?

1. What do you think are some of the major health issues that emancipated foster youth are dealing with?
   - *Possible probes:* What about....
     - a. asthma, diabetes
     - b. STDs, pregnancy
     - c. Mental health: stress, depression, anxiety, sleep problems
     - d. Substance Use: drugs, alcohol, tobacco
     - e. Relationship abuse
     - f. Body image, weight issues, nutrition, physical activity
     - g. Other stuff: vision, dental problems

II. Getting Health Care: is it easy or difficult? Is it sufficient? What are the barriers?

1. Have you been to the doctor since you emancipated? What was it like?
   - a. How did you know where to go?
   - b. How did you get there?
   - c. Did anyone help you (i.e. telling where to go/transportation)?
   - d. In general, can you go to the doctor when you need to?

2. Since you emancipated, have you ever been really sick or needed to see a doctor, dentist, or counselor and *not* been able to go?
   - a. What kinds of things made it difficult for you to get the services you needed?

3. What would you tell another teen in foster care who was about to age-out about where they could get health care? Where would you tell them to go? Who else could give them assistance?

4. Were there any big changes in your health or health insurance when you emancipated?

b. Have you ever had problems with your health insurance or with paying for your medical care since you've been emancipated? If so, what was that like?

5. Have you needed to or wanted to access to your health records or shot records since you emancipated (e.g. for a job or school or transferring to a new doctor)? What happened? How easy or difficult was it to get the health records you needed?

III. Preparation for Independent Living and Health care:

1. What kinds of information about taking care of your health did you get before you emancipated?
    - Prompts: getting shots and check-ups? Going to the dentist? Support for Depression and other mental health issues? Family Planning and safer sex? Nutrition (including grocery shopping for yourself) and exercise?

2. Before you emancipated did anyone ever talk to you about Medi-Cal or health insurance?
    a. If so, who?
    b. Did anyone give you information about who to call or where to go if you had a medical problem?

3. In your opinion, are foster youth given enough preparation to take charge of their own health issues after emancipation? Was there anything you wish you'd learned sooner about how to take care of your health?

IV. Suggestions for Change:

1. Who do you think should be responsible for/involved with making sure emancipated youth are able to get healthcare when they need it?

2. In your opinion, what kinds of information should foster youth get about taking care of their health once they emancipate?

    c. What do you think would be the best ways to share this information with foster youth?
        - Prompts: a health-related class? Peer educators? A brochure or booklet?

3. If you had 5 minutes to talk with a local politician (e.g. the Mayor or the Governor) or someone who makes decisions about policy, what would you tell them needs to be changed about the system to help *emancipated* foster youth get what they need to stay healthy?

Appendix C
Interview Guide: Key Informant Interviews with Providers

Inquiry 1: Health issues for youth
1. For what kinds of visits do you most often see the foster youth in your patient population?
    ❖ Prompts: ER visits, reproductive health, preventive care, IZ, mental health, sports physicals, specialty care, other)

    ❖ How are your patients who have been in foster care referred to you (how do they enter into your care)?

2. What has been your experience regarding the medical needs of transition aged foster youth compared to non-foster youth?
    ❖ In your opinion, what are some of the major health and developmental needs of transition-aged foster youth? What factors in their lives influence their health (e.g. living situations, access to food, schools, relationships with family, friends and caregivers).

    ❖ In your county, what would you say are the main health issues for foster youth once they've emancipated or left care? How would you describe their health care access after they've emancipated?

Inquiry 2: Providers Perceptions about Foster Youth Health Care Coverage and Access:
1. In your experience, do transition-aged foster youth get the health services and coverage they need, when they need them? What about after they emancipate?

2. What are the factors, policies and processes that make it easy or difficult for youth to get care when they need it?

Inquiry 3: Sufficiency and Appropriateness

1. Where do the youth in your practice get information about health? Where else do the youth in your practice receive health services?

2. Do you feel that your patients/clients in the foster care system receive enough information about where to get health care and how to take care of themselves?

Inquiry 4: Suggestions for Change

1. Have you eve experienced difficulty with successfully helping a foster youth or linking them to a service you felt they needed? What was the outcome?

    ❖ Was there anything that could have changed or helped the situation?

2. Who could/should be involved with ensuring that foster youth receive the health information and health care that they need?

3. Are there any ways in which foster youth access to care could/should be improved? [If you had 90 minutes to speak with the Mayor or the Governor, what, if anything, would you tell them needs to be changed about the health care system for foster youth?]

Appendix D
Youth Participant Demographic questionnaire

1. How old are you?_____

2. What is your gender? (circle one)

   Male   Female   TG   Intersex   Other_____

3. How would you describe your race/ethnicity?
   a. African American or black
   b. Asian American, Asian or pacific islander
   c. Latino/a
   d. Native American
   e. White or Caucasian
   f. Biracial or multiracial
   g. Other:_____
   h. I choose not to answer this

4. How many years ago did you emancipate?_____

5. What kind of place are you living in right now? (Choose one)
   a. Your own apartment or house
   b. A friend's house
   c. A relative's house
   d. In a motel
   e. In a school residence hall or dorm
   f. Don't have a place to stay
   g. Other _____

6. Are you in school? YES   NO   (Circle one)

7. How much school have you completed? (Circle one)
   a. Still working on a high school diploma or GED
   b. I got High school diploma or GED
   c. Currently in college (community college or 4-year college)
   d. I graduated from college
   e. I completed an Associate's degree.

8. Do you have health insurance (like Medi-Cal) right now? (circle one)

   YES / NO / I DON'T KNOW