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Toward providing equal access to health care for foster youth

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Abstract

This article examines the history of health care policy for older foster youth, and suggests new directions for continued progress. A review of previous research indicates that the high health needs of this group, coupled with their poor outcomes, are well established in the literature. Next, empirical evidence is presented, which demonstrates that over the past 10 years the proportion of older foster youth has increased steadily, even while the overall foster population has started to decline. These trends form an important impetus to developing programs and services that are tailored to older and aged out youth. More than two decades of federal legislation have brought some improvements, but fallen short of providing access to reliable health care. Today, most young adults continue leave the foster care system uncovered and at risk. However, foster youth are not the only group that has been historically denied health care coverage. In fact, new health care legislation addresses the issue of the uninsured, thereby providing a promising template for achieving equal access to health care for older foster youth. The paper concludes with broad policy and legal considerations aimed at developing foster youth health care parity in relation to the new standards contained within the recent health care reforms.

This article describes the unique health care needs of older and aged foster youth and documents the proportional increase of this group within the child welfare system over the last decade. In addition, a review of relevant legislative and data trends are

presented, citing Michigan as a case study and using data from the Midwest Evaluation of the Adult Functioning of Former Foster Youth. Finally, policy and legal approaches are considered in relation to health care reform.

Health Needs of Older Foster Youth

Large scale, generalizable studies regarding outcomes for older youth involved in the child welfare system are difficult to conduct due to the instability of this population and the lack of a comprehensive national approach to child welfare. However, many smaller studies have consistently found that foster children have serious health care needs. The high health needs of this group, coupled with their poor outcomes as adults, are well established in the literature and have been reported for decades.

There is significant evidence that, for most foster youth, the onset of both physical and mental health problems begin before they enter the child welfare system (Halfon, Berkowitz, & Klee, 1992; Leslie et al., 2000; Simms, Dubowitz, & Szilagyi, 2000). In fact, children with disabilities and high health needs are more likely to enter the child welfare system, and those with serious problems remain in care longer (Horwitz, Simms, & Farrington, 1994; Orme & Buehler, 2001).

Once in foster care, preexisting issues are often exacerbated, while new concerns arise. For many children, the foster care system itself becomes a source of abuse, neglect, and trauma (Fox & Berrick, 2007; Hochman, Hochman, & Miller, 2004; Pecora et al., 2005). One early study found that 47 percent of teens in foster care had a disability (Cook, 1990). In a California study, foster care youth constituted 41 percent of clients of mental health services, despite that fact that they make up only 4 percent of the eligible population (Halfon, Berkowitz, & Klee, 1992). Another California study found that 80 percent of children in their sample had one or more diagnosable mental disorder (Leslie et al, 2000). A study regarding psychiatric disorders among foster youth in Missouri found that youth were three times more likely to suffer from depression and two times more likely to suffer from PTSD than their peers (McMillen, et al., 2005). Psychotropic medication is a typical method of treatment for a wide range of such problems in foster care youth, although the validity of this approach is not well evidenced

(dosReis, Zito, Safer, & Soeken, 2001; Zima, Bussing, Crecelius, Kaufman, & Belin, 1999; Zito, et al., 2008).

According to a report by the American Public Human Services Association, “Unlike their younger counterparts, older foster care youth are more likely to stay in group home settings and have multiple foster care placements, and are less likely to be reunified with their biological families” (Patel & Roherty, 2007, p. 1; see also Chamberlain, 2002). Aging out and transitioning to adulthood is a particularly isolated, vulnerable time for older foster youth, and existing health problems typically become compounded by new stresses such as poverty, homelessness, low-employability, and low educational attainment (Barth, 1990; Child Welfare League of America, 2007; Courtney, Pilivan, Grogan-Kaylor, & Nesmith, 2001). After leaving the system, studies show that foster youth are more likely to experience multiple pregnancies and become young parents (Pecora, et al., 2003; Courtney, Dworsky, & Pollack, 2007). Aged out foster youth also experience chronic health conditions or disabilities at more than twice the rate of their peers (Courtney, Dworsky, Lee, & Raap, 2009). One longitudinal foster care alumni study found that rates of PTSD among former foster youth, at 25.5 percent, were twice that of Iraq War veterans, at 13 percent (Casey Family Programs, 2005).

As this health care profile demonstrates, there is an acute need for comprehensive health services among older and aged out foster youth. In addition to entering the child welfare system with serious health needs, many of these conditions worsen both in care and after aging out.

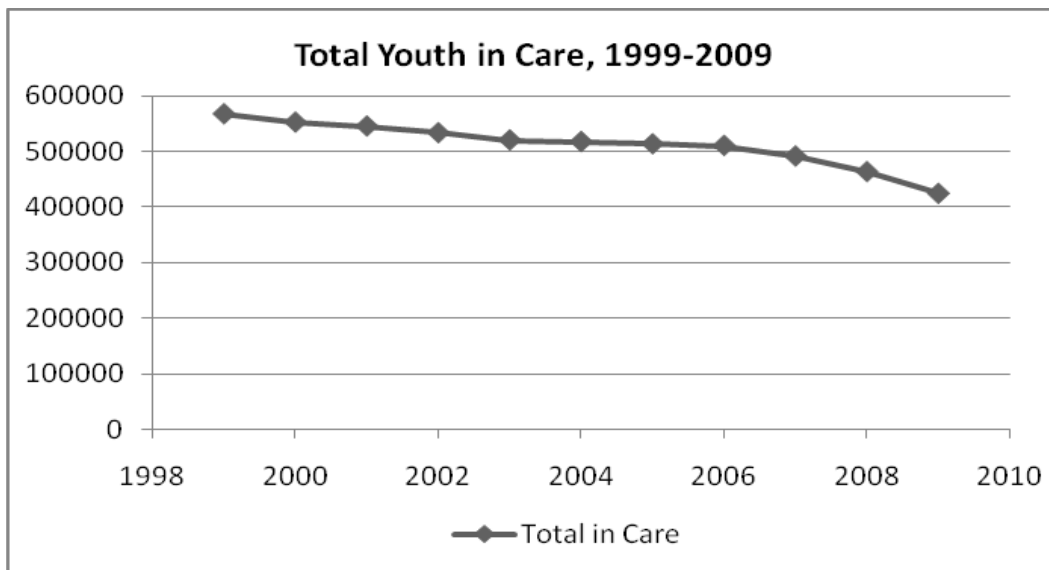
Older Foster Youth Are a Growing Population

Recent data regarding state and national child welfare trends indicate that older foster youth constitute a growing proportion of the overall foster care population. The Adoption and Foster Care Analysis and Reporting System (AFCARS) Report is an annual report from the Children’s Bureau, in the U.S. Department of Health and Human Services. This report constitutes a point-in-time count of all children in the foster care system on September 30th of each year. Data points include demographics, placement settings, case goals, case outcomes, length of stay, and others. In order to assess broad trends regarding older youth in the foster system, this study examined data from 1998 to 2009, the most recent years in which data has been made available. For the purposes of this assessment,

relationships among four variables were measured: the total number of youth in care (total), the total number of youth aged 16 or older in care (older), and the total number of youth aging out of care (aged), during each year (year).

Over the past ten years, the total foster care population has declined. AFCARS data reveal that in 1999, 567,000 children were in care. This pattern continues in subsequent years, and by 2007, this number had dropped to 491,000 children, below the symbolic one-half million mark for the first time since the 1980s. This pattern continues further after that, with the total falling to 423,773 in 2009. This downward trend is illustrated in Figure 1 below. Overall, the foster care population dropped by 25.3 percent between 1999 and 2009.

Figure 1: Total Number of Youth in Foster Care, 1999-2009.

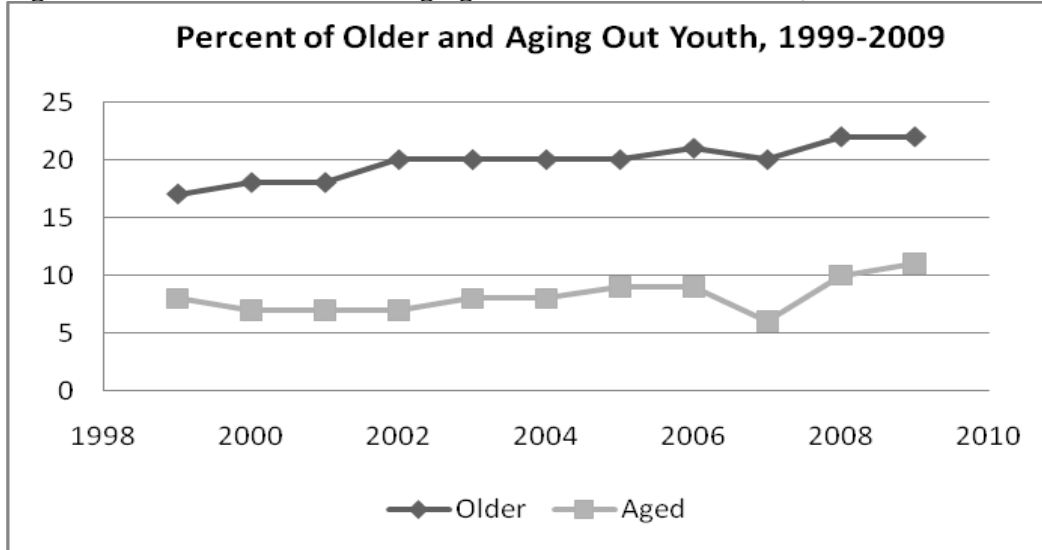


Source: Analysis of data from AFCARS Reports, 1998-2009.

During this same time period, the proportion of older foster youth in care and aging out of care increased. In 1999, older foster youth constituted 17 percent of the total youth in foster care. By 2009, this figure reached 22 percent. In 1999, only 8 percent of older youth were aging out of the system. By 2009, this number increased to 11 percent. The increase in older and aged out youth is illustrated in Figure 2 below. Overall, the percentage of older youth

in care increased by 29 percent from 1999 to 2009, while the percent of youth aging out increased by 38 percent.

Figure 2: Percent of Older and Aging out Youth in Foster Care, 1999-2009.



Source: Analysis of data from AFCARS Reports, 1998-2009.

To assess whether or not these trends are significant, I calculated the Pearson *r* statistics and *p*-values for each of the four variables, as illustrated in Table 1. I found three significant relationships among the variables. First, at the .001 level of significance, there is a statistically significant relationship between the total number of children in the foster care system and the year ($r=-.94$, $p<.001$). The relationship is robust and inverse, which indicates that as the year increases, the number of children in foster care decreases. Second, at the .001 level of significance, there is a statistically significant relationship between the total number of children aging out of the foster care system and the year ($r=.92$, $p<.001$). The relationship is robust and positive, which indicates that as the year increases, the number of children aging out increases. The final statistically significant relationship is between total number of children in the system and the total number of children aging out ($r=-.86$, $p<.01$). The relationship is also robust and negative, which indicates that as the total number of children decreases, the total number of children aging out increases.

Table 1: Pearson's *r* for all Variables

	Older	Year	Total	Aged
Older	1.0000			
Year	-0.3707 0.4207	1.0000		
Total	0.5242 -0.0979	-0.9447*	1.0000	
Aged	-0.2908 0.3856	0.9393*	-0.8557*	1.0000

Source: Analysis of data from AFCARS Reports, 1998-2009
* Statistically significant

The data demonstrates that significant changes have occurred within the foster care population over the last decade. In particular, the population is older and more likely to age out than in previous decades. While the total foster care population dropped by more than 25 percent, the older youth population increased by nearly 30 percent. These trends form an important impetus to developing programs and services that are tailored to older and aged out youth.

Legislation for Older Youth, 1986-2008

A review of nearly 25 years of federal legislation demonstrates that previous attempts to address the needs of aging out foster kids have brought important improvements and generally received wide-ranging support in both houses of Congress. However, these bills have fallen short of providing comprehensive, reliable health care. There are four relevant pieces of legislation that deal directly with services for older foster youth, which are outlined in Table 2 below.

The *Independent Living Program* of 1986 (P.L. 99-272) was enacted through the Consolidated Omnibus Budget Reconciliation Act, which amended Title IV-E of the Social Security Act. Due to the inclusion of the foster care provision within an omnibus bill, the voting record cannot be interpreted as either in support or opposition to the development of the Independent Living Program.

This initial federal approach to improving outcomes for foster youth was through the provision of in kind services, and this act created the first federally funded program to address the significant barriers faced by foster children transitioning into adulthood. It provided \$70 million in funding to be distributed to states and mandated programming to prepare foster children ages 16 to 18 to live independently in areas such as basic living skills, cleaning, cooking, and applying for jobs. The act did not specifically address health care needs.

The *Foster Care Independence Act* of 1999 (P.L. 106-169), or John Chafee Foster Care Independence Program, was passed with unanimous consent in the Senate and with minimal opposition in the House, which is a clear indication of broad political support. The Chafee Act doubled the previous funding for independent living programs to \$140 million annually. Further, eligibility was expanded to include children ages 14 to 21, and provide a wider array of services, such as educational vouchers and payments for room and board. Importantly, the Chafee Act provided states with the option and funding to extend Medicaid until the age of 21. By 2007, 17 states had enacted the Chafee option for extending Medicaid (APSHA. 2007).

Table 2: Legislative History: Foster Youth and Health Care

Year	Legislation	Health Care Provisions	Support
1986	Independent Living Program created through the Consolidated Omnibus Budget Reconciliation Act	None	Not Applicable
1999	Foster Care Independence Act (John Chafee Foster Care Independence Program)	States are given the option and funding to extend Medicaid to age 21.	<i>Senate:</i> Unanimous consent <i>House:</i> 380 to 6, with 48 present or not voting
2008	Foster Connections to Success and Increasing Adoptions Act	States retain the option and funding to extend Medicaid to age 21. States are given the option to extend foster care to age 21, with funding set to begin in FY 2011.	<i>Senate:</i> Unanimous consent <i>House:</i> Voice vote, indicative of high support

2010	Patient Protection and Affordable Care Act	Detailed health care plans must be a component of a youth’s transition plan beginning in 2010. States must extend Medicaid coverage to youth who were in care on their 18 th birthday to age 26 beginning in 2014.	<i>Senate:</i> 60 to 39, with 1 present or not voting <i>House:</i> 219 to 212
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Source: Analysis of data available on www.govtrack.us.

The *Fostering Connections to Success and Increasing Adoptions Act* of 2008 (P.L. 110-351) passed with unanimous consent in the Senate, and by voice vote in the House, which is a procedural tactic that demonstrated wide support. Fostering Connections provided states with the option of permitting foster children to remain in foster care until the age of 21, and Title IV-E reimbursement for the costs of this extension was made available at the start of fiscal year 2011. Eligibility for the foster care extension includes various levels of postsecondary school participation, employment, or a medical disability. Both the extension of foster care and Medicaid benefits through age 21 were again left to state discretion.

The *Patient Protection and Affordable Care Act* of 2010 (P. L. 111-192) passed with the minimum number of votes to avoid a filibuster in the Senate, and a thin margin in the House, which is indicative of considerable opposition. However, the components of the bill pertaining to foster youth were not a focus of the debates. The act mandated that, beginning in 2010, all states must include health care components into the transition plans for older youth. Significantly, beginning in 2014, states must extend Medicaid to the age of 26 for those youth who are in care at their 18th birthday. Although the extension of health care will be mandatory, states will continue to exercise discretion in implementation and service delivery.

Legislators and policy makers have not ignored the plight of older foster youth. To the contrary, targeted legislation has received wide-spread, bipartisan support throughout 25 years of changing political administrations. Even in the contentious atmosphere that accompanied the passing of the new health care legislation, provisions for foster youth were delayed, but left intact. The 2014 foster youth health care expansion plan represents the most comprehensive and profound legislation for this population in decades.

Despite the promise of this bill, significant challenges remain. Strong, organized opposition and fiscally strained states may mean some states will fail to implement the law in a way that best serves children. Currently, access to health care for older foster youth is contingent upon multiple factors, such as school and workforce participation, as well as complicated reenrollment processes. Given that existing systems will likely influence the development of future ones, the next section will examine recent trends in health care access among older foster youth.

Older Youth and Health Care

Health care access data are examined at two levels. First, a case study exploring how the Michigan Department of Human Services has implemented the Chaffee Act while under court receivership is presented. Second, longitudinal data regarding older foster youth in three Midwestern states is examined. Taken together, these data highlight the difficulties in designing the system that bridges the gap between legislative chambers and the doctor's office.

Michigan Case Study

The Chaffee Act and Fostering Connections provide guidelines and funding to individual states, which are then responsible for service delivery and implementation. As such, each state has its own distinctive child welfare system. This, along with the instability of older foster youth, can complicate measurement efforts. In Michigan, the Department of Human Services (DHS) is currently operating under a consent decree after settling a class-action lawsuit in 2008. As part of this agreement, comprehensive progress reports are issued by a third-party evaluator, Public Catalyst, approximately every six months. These circumstances provide both a unique window into the process of child welfare change, as well as a rich source of recent data.

Within the consent decree, DHS recommitted to providing the Chafee Medicaid extension through the age of 21 to all aging out foster children (Dwayne B. v. Granholm, 2008). According to baseline data established by Public Catalyst prior to consent decree implementation, in December of 2008 Michigan was providing

Medicaid to only 10 percent of foster youth exiting foster care (2009, p. 67). By the end of March 2009, this number declined to 4 percent (Ibid, p. 68). However, on September 30, 2009, this number increased dramatically to 34 percent (Public Catalyst, 2009, p. 118). Just six months later, DHS had enrolled 54 percent of youth in Medicaid, with another 25 percent of youth accessing Medicaid through a different program, for a total of 79 percent of older foster youth receiving Medicaid (Public Catalyst, 2010, p. 123). Overall, Michigan increased Medicaid enrollment for older foster youth by 90 percent within 16 months.

Notably, funding was not cited by DHS or the evaluation team as significant limitation to expanding Medicaid enrollment. In fact, according to the initial complaint, “In 2004, DHS turned down \$1.2 million in federal Chafee funds...because DHS’ dwindling workforce was insufficient to process or expend the funds as required by federal guidelines” (Dwayne B. v. Granholm, 2008, p. 52). Rather than financial limitations, both parties cite capacity and technical constraints. Not only did DHS lack the qualified work force, but foster youth and their workers were required to make burdensome individual requests for extended Medicaid coverage. The remedy to this was described in a 2010 report, in which “DHS reports that a significant part of this improvement results from an automated referral in its SWSS [data] system that is now triggered when most youth age out of care” (Public Catalyst, 2010, p. 123).

Clearly policy is a necessary, but not sufficient, part of providing health care to foster youth. Even if options and funds are made available federally, the system through which it is distributed must be practical for both youth and child welfare professionals.

The Midwest Study

The Midwest Evaluation of the Adult Functioning of Former Foster Youth (the Midwest Study) provides much needed outcome data that sheds light on how policies and programs are serving this vulnerable population. Collecting longitudinal survey data since 2002 from youth from the Illinois, Iowa, and Wisconsin foster care systems, the Midwest Study examines broad outcomes for foster youth. This data is then compared with a nationally representative sample of youth in the same age range. Data points are expansive, and include demographics, social supports, living arrangements,

public benefits usage, and a variety of health measures. For this assessment, rates of insurance usage are also examined. All of the data presented below are drawn from *Midwest Evaluation of the Adult Functioning of Former Foster Youth: Outcomes at Ages 23 and 24* (Courtney, Dworsky, Lee, & Raap, 2009).

Overall, former foster youth were 37 percent less likely to have health insurance than the general population, at 57 percent and 78 percent, respectively. The main source of health insurance for the foster youth were government health plans, such as Medicaid or State Children's Health Insurance Program at 67.6 percent, while the main source of health insurance for the general population was through their employer at 59.9 percent. Employer -based insurance was the second greatest source for foster youth at 21.6 percent, while the second greatest source for the general population was family, either parents or spouse, at 21 percent.

This research is important in a number of ways. First, the majority of foster youth had some form of health insurance. Unfortunately, 43 percent of youth were uncovered and at risk. Second, those foster youth who are covered remain heavily dependent upon government provided health care. Without these programs, a mere 32.4 percent of former foster youth would have health care coverage (see also Raghavan, et al., 2009). Third, stark inequalities exist in access to health care among foster youth and their peers. A full 80.9 percent of the general population gains access to health care through the traditional routes of family and work; only 26.8 percent of foster youth do so.

In the decade since the passage of the Chafee Act, limited access to health care continues to be the reality faced by older and aged out foster youth.

The Affordable Care Act

Notably, foster youth are not the only group that has been historically denied health care coverage. Eager to cut costs, over time insurance company practices created a complicated system of exclusion categories to push most young people from their parents' insurance near the age of 18. However, adulthood in America has undergone serious change over the last few decades. The early milestones of American adulthood – finishing education, financial independence from parents, and beginning a career – now begin

around age 25 (Arnett, 2000; Arnett 2004). During this transition period of emerging adulthood, and unlike the typical perceptions of wayward youth, most young people are involved in positive explorations and are hopeful about the future (Larson, 2000). As a recent study regarding cultural changes and public policy points out, “Significant mismatches exist between the emerging and varied pathways to adulthood that are now taken and the institutions and policies that affect young people” (Settersten, Furstenburg, & Rumbaut, 2004, p. 22). Simply put, the process of becoming an adult does not occur on an 18th or 21st birthday. Yet, many health care institutions have been guided by these arbitrary deadlines.

The Affordable Care Act passed in the face of serious opposition by utilizing a multidisciplinary approach: federal bureaucrats pointed to a public health crisis in which 30 percent of young adults are uninsured, one in six have a chronic illness, nearly half struggle to pay medical bills, and more people between the ages of 18 and 26 are uninsured than in any other age group (U.S. Department of Health and Human Services, 2010); economists demonstrated that net prevention costs are significantly lower than net emergency service costs (Wharam et al., 2007), as well as that expanded health care coverage will increase life expectancy, labor supply, and improve the overall functioning of the labor market (Council of Economic Advisers, 2009); and important constituencies from the health care field provided supportive and expert testimony (American Medical Association, 2010; American Nurses Association, 2009).

As a result of these efforts, the Affordable Care Act has set the new benchmark in health care policy for youth Americans: young adults today are eligible to remain on their parents’ health insurance until the age of 26 whether or not they are financially dependent upon them, living at home, employed, offered insurance through their employer, or attending college (Affordable Care Act, 2010, Sec. 2714). Further, it is the responsibility of the health insurance company to inform parents that their children remain eligible (Ibid, Sec. 2715). As this act makes clear, young people have a right to health care as they transition into adulthood, and they need help accessing it.

Creating Health Care Parity

The Affordable Care Act has provided a promising opportunity for closing the gap between young people and health institutions, in part by identifying and eliminating unfair practices. Below, broad recommendations for extending this change to foster youth, through both legislative and legal processes, are considered. Rather than a precise plan, the aim is to reorient efforts towards a system of equal access to health care. Foster youth deserve health care parity in relation to their peers and their health needs, not arbitrary federal guidelines.

Policy Recommendations

While the Affordable Care Act (2010) created a national framework for the reform and expansion of health care services, it is the states that are primarily responsible for design, implementation and administration. As the health care battle moves to the states, who has a seat at the table will matter a great deal. In addition to opposing forces and fiscal constraints, industry stakeholders, such as hospitals, physicians, and nursing homes, will have well-funded lobbyists pushing for their own self-interest. It is up to child welfare stakeholders to make sure the best interests of foster youth are represented during the critical years between now and 2014. Taking a cue from the broad movement needed to pass the bill at the federal level, policy makers, lawyers, judges, advocates, doctors, nurses, social workers, and practitioners from diverse fields must engage at the state level and ensure health care implementation serves the best interests of vulnerable foster youth. Below, two components which ought to be included in the 2014 Medicaid extension plan are discussed.

Automatic enrollment must be considered critical component of the 2014 plan. Individual requests for enrollment have proven burdensome for youth, parents, and child welfare workers. This is illustrated by the inclusion of automatic enrollment for youth remaining on their parent's insurance in 2010, as well as by the 90 percent increase in Medicaid enrollment in Michigan after the process became automated. Although the current system of state discretion does not preclude automatic enrollments, the lack of a requirement to do so has created serious inconsistencies and gaps

in coverage among states that opted to extend Medicaid through age 21. In Michigan, technical assistance and capacity, rather than funding, was key. In addition to state level advocacy, a federal mandate to automate health care enrollment for foster youth in 2014 may be a promising option for keeping more youth insured given the high-levels of bipartisan support for previous pieces of standalone legislation for foster youth.

A second critical component of the 2014 plan is access through entitlement, rather than eligibility. Eligibility requirements that are onerous for Americans broadly must be considered especially so for foster youth. Disruptions in employment and schooling are both normative during emerging adulthood and experienced at higher rates among former foster youth. Just as other Americans may remain on their parents' health insurance even if they are offered health care through their employer, are no longer in school, or experience a gap in workforce participation, so too should foster youth should remain eligible for Medicaid. Rather than removing and reinstating eligibility at the rapid pace of emerging adulthood, health care should become a source of steady support throughout a young person's transition.

Litigation Recommendations

As demonstrated by the Michigan case study presented above, litigation is a tool that can be used to affect change in the child welfare system. In fact, child welfare litigation resulted in the implementation of consent decrees in 30 states between 1995 and 2005 (Child Welfare League of America, 2005). This same process of reform through the court system might, as a last best option, be applied to health care. Previous legal scholarship has called for the extension of universal medical benefits through the age of 24 (Atkinson, 2008). However, this predates the recent extension. Given the two decades of litigation designed to improve the child welfare system, many prominent advocacy groups may already possess the organizational capacity to take up this proposed legal course.

Discussion

Foster youth deserve health care parity. Just like other young adults, foster youth are rarely able to purchase health care at the

ages of 18 or 21. However, unlike other young adults, aged out youth have less access to employer-based health care, lack biological parents through which benefits might be accessed, and rely heavily upon government health care plans that deny them coverage according to arbitrary deadlines and punish normative behavior. Also unlike other young adults, the transition as currently enforced by institutions is instantaneous, rather than gradual.

Foster children need an entitlement to automatic and comprehensive health care coverage to the age of 26 in order safely navigate the road from childhood and adulthood. Achieving this will require a broad-based advocacy approach similar to the health care reform movement. However, child welfare stakeholders can capitalize on the federal shift towards greater responsibility for older foster youth. Previous agency, legislative, and legal reforms have provided opportunity, but were often poorly delivered. Moreover, health care options for foster youth typically employ the very sort of exclusionary eligibility categories and burdensome reapplication processes that are now illegal practice for health insurance companies. As the population of older and aged out foster youth continues to increase, the problems that come from lack of health care will grow in magnitude, both for the individuals themselves and society as a whole. Providing foster youth with health care parity is a matter of public health, sound fiscal policy, child welfare, and social justice.

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