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Behavioral and Developmental Health Problems and Medicaid Costs for Youth Approaching Adulthood by Gender and Basis of Eligibility in Selected States: FY 2006

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# **Background**

In 2014, the Affordable Care Act will require all Americans, including young people aging out of the existing Medicaid program, to have health insurance (or pay a penalty). The physical, behavioral, and developmental health problems of the young people leaving Medicaid have rarely been studied. The purpose of this paper is to provide a snapshot of their health status and cost in selected states, focusing particularly on two high-cost groups that are automatically entitled to Medicaid—youth in foster care and youth receiving Supplemental Security Income (SSI). In addition, we focus on those with behavioral and developmental health problems, regardless of their basis of eligibility.

Over 15 percent of American youth have a diagnosable behavioral health problem, including mental health or substance abuse disorder problem, and a similar percentage have a developmental disorder (Boyle 2011), with substantial overlap in the groups. In addition, most life-long behavioral and developmental health problems are evident by adolescence (Institute of Medicine 2009).

There is a distinct gender difference in both the types of behavioral and developmental problems that boys and girls experience and whether those problems lead to service use (Zimmerman 2005). For example, girls are more likely to have depression or anxiety disorders, and boys are more likely to have ADHD or conduct disorders. Boys have a higher prevalence than girls of developmental disabilities. Furthermore, the prevalence of autism and related spectrum disorders is much higher among boys (Blumberg, Bramlett, Kogan, et al. 2013). In addition to these gender differences, use of behavioral health services increases with age, evidence that problems become more serious over time (Howell and Teich 2008; Ireys, Barrett, Buck, et al. 2010).

The cost of behavioral and developmental health services is high, particularly for adolescents. One study of mental health services in the late 1990s found that 60 percent of expenditures for all youth ages 0–18 are for adolescents, even though they represent only 35 percent of that age group (Ringel and Sturm 2001). American youth who are eligible for Medicaid or CHIP have a higher prevalence of behavioral or emotional problems, and are also more likely to receive treatment than other American youth (Howell, 2004; Kataoka, Zhang, and Wells 2002), and boys are more likely to use services for behavioral health problems (Garland, Hough, McCabe, et al. 2002). For such young people, Medicaid pays a large and growing proportion of the cost of their health services (Mark, Levit, Coffey, et al. 2007; Buck 2003). Medicaid also plays a substantial role in covering the cost of services for the most serious developmental problems, through both care in Institutions for the Mentally Retarded (ICF-MRs) and through Home and Community Based Service (HCBS) waivers for home-based care. While the total number of individuals receiving such services is small, their individual costs are extremely high to Medicaid, estimated to be an annual average of \$128,275 for ICF-MR residents, and \$61,770 for HCBS waiver recipients in the four states studied (Lakin and et al. 2008).

Two groups of Medicaid enrollees have a high prevalence of behavioral and developmental health problems and are particularly expensive. These are youth enrolled because they are disabled and receive Supplemental Security Income and those who are enrolled because they are in foster care. A study in four states found that SSI youth are from 2.9 to 9.4 times more expensive than non-SSI youth depending on the state (Kuhlthau, Perrin, Ettner, et al. 1998). Just over half of SSI adolescents have a mental disability, and almost two thirds are male (Rupp, Davies, Newcomb, et al. 2005–06).

Youth in foster care have been separated from their original families and thus are at particular risk of emotional and behavioral problems. Studies vary in methods, but all show a very high prevalence of such problems; the

behavioral health needs of young adults who are foster care alumni are equally high (Pecora, Jensen, Romanelli, et al. 2009). As with SSI youth, youth in foster care have high Medicaid expenses (Harman, Childs, and Kelleher 2000), and expenditures are highest for those with mental health conditions (Rosenbach 2001).

The transition to adulthood is difficult for any young person and is a time when continuity of mental and physical health services is at risk of disruption (American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians, Transitions Clinical Report Authoring Group 2011). This is particularly true for someone with behavioral health problems (Davis 2004). For youth enrolled in Medicaid approaching adulthood there is particular risk of a disruption in health services, since Medicaid entitlement through welfare (TANF) or the "poverty expansions" (i.e. youth who are entitled due to income and not welfare or SSI receipt) ends at age 19. Currently, almost half become uninsured at that time (Kaiser Family Foundation 2010). The Affordable Care Act will, in 2014, expand Medicaid to low-income uninsured adults if a state "takes up" the option to do so. Otherwise, a low-income young adult will be eligible for coverage in the health insurance exchange. In any case, a substantial disruption in coverage, services, and providers is possible as they age out of Medicaid.

SSI and foster care youth potentially have a more favorable situation than other Medicaid youth in terms of coverage continuity. If the adolescent's disability continues to be severe enough to entitle them to SSI, then Medicaid coverage will continue without interruption at age 19, although they may need to re-qualify. In the case of foster care, 30 states have taken the "Chafee option" to continue Medicaid coverage for foster youth up to age 21, and coverage up to age 26 will be mandatory for foster care alumni when the ACA is implemented in 2014 (Baumrucker, Fernandes-Alcantara, Stoltzfus, and Fernandez 2012). However a recent study showed that Medicaid coverage continuity in selected states taking the Chafee option varies considerably and is associated with Medicaid enrollment procedures and other state policies that do not always assure continuity of coverage (Pergamit, Chen, McDaniel, and Howell 2012).

The purpose of this paper is to describe the use and cost of Medicaid behavioral and developmental health services for youth approaching adulthood (at age 18), and to examine differences between groups in these measures. The paper focuses particularly on gender differences and differences between SSI youth, foster care youth, and other youth. This information is important in understanding the health needs of the young people who will be newly entitled to Medicaid under the Affordable Care Act.

#### Methods

This study includes information for all youth enrolled in Medicaid at age 18 in selected states. The analysis uses data compiled as part of a companion study investigating continuity of care and use of services for youth aging out of foster care in 10 states. The study states were chosen because all had adopted the "Chafee Option" to cover youth aging out of foster care under Medicaid until they turn 21. In addition, the states have adequate data for identifying foster care youth accurately in the Medicaid Statistical Information System (MSIS).<sup>1</sup>

The 10 study states are: Arizona, California, Florida, Indiana, Iowa, Kansas, Nevada, South Carolina, Texas, and Utah. These states are regionally representative of the South, Midwest, and West, but do not include any Northeast states. Although the states comprise over a third of all eighteen-year-olds in the nation, the population is heavily weighted towards a few large states—California (about half the youth in the study) and Florida and Texas (together comprising another third)—as well as few middle-size states (Arizona, Indiana, and South Carolina) that comprise most of the remainder. The smallest study states (Iowa, Kansas, Nevada, and Utah) together comprise only five percent of the study population. Therefore, the aggregate results presented in this paper are driven by results in the larger study states, especially California.

Data come from MSIS, which is a uniform data base that includes data on all Medicaid enrollees and their services in the United States. MSIS data are extracted from the eligibility and claims payment systems that each state uses to administer Medicaid, and the data are sent to the CMS regularly.<sup>2</sup> For this study we use the following MSIS variables:

- Basis of Eligibility. We use the following categories: SSI disabled youth; other foster care (excluding SSI disabled youth in foster care); and all other youth (generally these individuals are entitled either because their families receive Temporary Assistance to Needy Families or others with very low incomes).
- Age. The study group includes all Medicaid youth who reached their eighteenth birthday sometime during fiscal year 2006 (October 2005 – September 2006). Most females delivering a baby during the year are excluded from the study population.

- Gender.
- Presence of a behavioral or developmental health diagnosis (either mental health problem, substance abuse, or developmental delay) on a claim in FY 2006. The list of diagnoses, which includes all mental health and substance abuse problems coded in the Medicaid files, is shown in table 1.

### Table 1: Medicaid Youth Turning 18 in 2006 by State and Basis of Eligibility

Behavioral/Developmental Diagnosis	ICD Codes (3-digit)
Psychosis	290–299
Hyperkenetic Syndrome	314
Developmental Delay	315
Other Mental Disorders, such as Anxiety Disorders	300-302, 306-313, 316
Substance Abuse	303–305
Suicide or Self-inflicted Injury	E 950-959

Source: U.S. Department of Health and Human Services. 1991. *ICD-9-CM: International Classification of Diseases*, 14th edition, Washington, DC: U.S. Government Printing Office.

• Expenditures by type. The total expenditures for FY 2006 are analyzed by type of service, in the case of feefor-service spending; we also include managed care premium spending for youth in risk-based managed care programs. Expenditures are calculated by dividing the total annual expenditures for a particular group by the number of youth ever enrolled in Medicaid from that group in the fiscal year.

One limitation of the study is that youth enrolled in risk-based managed care covering behavioral or developmental services within a capitated premium likely will have fewer (or no) claims reflecting the diagnosis of their health service. In this situation they would not be flagged in the MSIS data as having such a diagnosis. This is especially important in the study states with a large number of youth in risk-based managed care in 2006 (Arizona, California, Florida, and Texas). This problem applies especially to youth who are not in SSI or foster care. However, Arizona, California, and Florida carve out<sup>3</sup> mental health services (although not substance abuse services), so enrollees with those services are likely to be flagged. In addition, almost all states with risk-based managed care have areas of the state where enrollment was voluntary in 2006 (Arizona is the exception), meaning that in those areas many youth are in fee-for-service programs.

The SSI and foster care groups have generally—even in the high-penetration managed care states—been excluded from mandatory Medicaid risk-based managed care, and have been enrolled on a voluntary basis. This is also true for youth in ICF-MR facilities or using HCBS waivers, so the most seriously developmentally disabled youth would be excluded from risk-based managed care. Still, regardless of the group analyzed, data on the proportion of youth with behavioral and developmental health problems will be underreported in the MSIS data to an unknown degree.

# **Findings**

Table 2 shows the study population by state, divided into three groups: SSI youth, foster care youth (non-SSI), and all other youth. The table shows total Medicaid enrollment for youth turning 18 during FY 2006, and the percent in each of the three study groups. Across all 10 study states, SSI youth are 5.7 percent of all Medicaid eighteen-year-olds, foster care youth (non-SSI) are 3.5 percent, and the remainder—the very large majority—are other youth (90.8 percent). These percentages vary from state to state. For example, SSI youth make up 11 percent of Florida Medicaid youth turning 18, but only 3.7 percent in California and Indiana. Similarly, the percentage of foster care youth varies from 1 percent (Arizona) to 15.4 percent (Kansas).

Part of the reason for such variation in the percentage distribution of Medicaid youth across the three study groups has to do with variation in how many youth are enrolled in Medicaid in each state. Table 3 shows that the percent of all youth enrolled in SSI ranges from 0.4 (Utah) to 2.8 percent (Florida); the percent in foster care ranges from 1.3 (Iowa) to 2.5 (Kansas); but the percent of all other youth turning 18 in 2006, and enrolled in Medicaid varies more widely, from 8.0 (Utah) to 36.3 (California). These other youth are likely to have more varying characteristics across states, particularly their family and other characteristics associated with income such as health status.

In addition to the variation in the proportion of youth in each study group, there is also substantial state variation in the percentage of youth who have a claim with a behavioral or developmental health diagnosis (table 4), as well as substantial variation across study groups. For example, across all 10 states, about one-third of SSI youth (34.4 percent) have a behavioral or developmental health diagnosis, while the percentage of foster youth is almost twice as high (62.4 percent). For all other youth, the percentage is much lower (9.5 percent), but still substantial.

Table 2: Medicaid Youth Turning 18 in 2006 by State and Basis of Eligibility

	SSI Yo	uth	Youth in Fos (Non-S		All Oth Medicaid `	-	Total Medicaid	Youth
State	N	%	N	%	N	%	N	%
Arizona	1,170	5.3	214	1.0	20,662	93.7	22,046	100.0
California	7,969	3.7	7,578	3.5	198,565	92.7	214,112	100.0
Florida	6,573	11.0	2,729	4.6	50,401	84.4	59,703	100.0
Indiana	755	3.7	425	2.1	19,229	94.2	20,409	100.0
Iowa	507	5.7	574	6.4	7,881	87.9	8,962	100.0
Kansas	447	6.8	1,015	15.4	5,113	77.8	6,575	100.0
Nevada	332	8.1	448	10.9	3,326	81.0	4,106	100.0
South Carolina	1,516	7.6	454	2.3	17,976	90.1	19,946	100.0
Texas	5,447	7.0	1,450	1.9	70,404	91.1	77,301	100.0
Utah	177	4.3	594	14.5	3,328	81.2	4,099	100.0
10 State Total	24,893	5.7	15,481	3.5	396,885	90.8	437,259	100.0

Note: Excluding pregnant females. SSI=Supplemental Security Income.

Source: Authors' analysis of the Medicaid Statistical Information System data files.

Table 3: Youth Turning 18 Enrolled in Medicaid by Basis of Eligibility and State, 2006

			Medicaid Youth			
State	Total Youth Turning 18 (N)	SSI Youth (%)	Youth in Foster Care (Non-SSI) (%)	All Other Medicaid Youth (%)	All Other Youth (Non-Medicaid) (%)	Total Youth Turning 18 In State (%)
Arizona	86,552	1.4	0.2	23.9	74.5	100.0
California	547,745	1.5	1.4	36.3	60.9	100.0
Florida	234,919	2.8	1.2	21.5	74.6	100.0
Indiana	92,059	8.0	0.5	20.9	77.8	100.0
lowa	44,734	1.1	1.3	17.6	80.0	100.0
Kansas	41,292	1.1	2.5	12.4	84.1	100.0
Nevada	32,663	1.0	1.4	10.2	87.4	100.0
South Carolina	64,840	2.3	0.7	27.7	69.2	100.0
Texas	354,027	1.5	0.4	19.9	78.2	100.0
Utah	41,423	0.4	1.4	8.0	90.1	100.0
10 State Total	1,540,255	1.6	1.0	25.8	71.6	100.0

Note: Medicaid youth exclude females delivering in year. Total youth is calculated from 2006 American Community Survey estimates for ages 15–19, and then divided by five.

Source: Authors' analysis of the Medicaid Statistical Information System data files and the 2006 American Community Survey.

Table 4: Percent of Medicaid Youth with a Behavioral or Developmental Diagnosis (DX) in Study States in 2006

	SSI Youth	Youth in Foster Care Non-SSI	All Other Medicaid Youth
State	(% with DX)	(% with DX)	(% with DX)
Arizona	34.2	65.9	16.1
California	37.3	55.1	6.7
Florida	27.0	60.8	8.7
Indiana	44.0	71.1	22.1
Iowa	49.1	62.7	19.9
Kansas	48.5	86.7	25.2
Nevada	43.7	51.1	12.9
South Carolina	41.8	75.8	17.2
Texas	31.9	76.4	8.1
Utah	52.0	75.9	15.3
10 State Total	34.4	62.4	9.5

Note: Excluding females delivering in year.

Source: Authors' analysis of the Medicaid Statistical Information System data files.

More noticeable is the large variation across states. For example, the percentage of SSI youth with behavioral or developmental health diagnoses varies from 27 percent (Florida) to 52 percent (Utah), for foster youth from 55.1 percent (California) to 86.7 percent (Kansas), and for other youth from 6.7 percent (California) to 25.2 percent (Kansas). The substantial variation in how behavioral and developmental health diagnoses are identified in the claims data explains some of the state variation. Other sources of variation are likely the availability of behavioral and developmental health services in the state, state policies on covering such services under Medicaid, and procedures for screening youth for problems and linking them to treatment. For example a report over a decade ago (Giliberti and Schulzinger 2000), showed that some states encouraged parents to relinquish custody of their children in order to obtain Medicaid coverage for severe mental health problems; there is likely continued variation at the state and local level in such policies.

Table 5 highlights gender differences in the presence of a behavioral or developmental health diagnosis. The table shows the percentage of all vouth (males versus females) that fall within certain categories. Eighteen-year-old males are much more likely to be enrolled in Medicaid through SSI provisions (8.5 percent of males versus 3.7 percent of females). The gender difference is not as pronounced for foster care, but within the foster care population, male youth are more likely to have a behavioral health diagnosis (as is true for other youth). Summing across all three populations, we find that 16.8 percent of male eighteen-vear-olds have a behavioral or developmental health diagnosis, compared to only 9.9 percent of female youth the same age.

Average annual Medicaid expenditures by basis of eligibility and state are shown in figure 1, illustrating the dramatic differences across states and bases of eligibility in Medicaid expenditures. A consistent pattern shows that SSI and foster care youth are much more expensive than other Medicaid youth. Average annual South Carolina expenditures for the latter (all other) youth ranges from \$1,340 in California, to \$3,312 in Kansas. Across all states, SSI and foster care youth consistently cost Medicaid at least 2-3 times as much per year than all other youth. While the average for SSI and foster

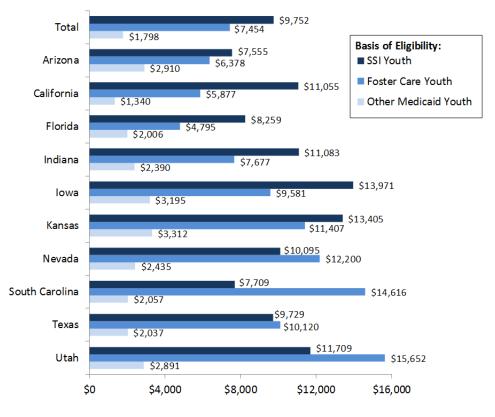
Table 5: Behavioral or Developmental Health Diagnosis (DX) by Basis of Eligibility and Gender for Medicaid Youth Turning 18 in Study States in 2006

	Percent of Medicaid Youth Turning 18		
Basis of Eligibility	Males	Females	
SSI Youth	8.5	3.7	
Behavioral/Developmental DX	3.0	1.2	
No Behavioral/Developmental DX	5.5	2.5	
Youth in Foster Care (non-SSI)	4.8	3.0	
Behavioral DX	3.0	1.6	
No Behavioral/Developmental DX	1.8	1.4	
Other	86.8	93.6	
Behavioral/Developmental DX	10.8	7.1	
No Behavioral/Developmental DX	76.0	86.5	
Total	100.0	100.0	
Total Medicaid Youth Turning 18	184,503	252,904	

Note: Excluding females delivering in year.

Source: Authors' analysis of the Medicaid Statistical Information System data files.

Figure 1: Average Annual Medicaid Expenditures by State and Basis of Eligiblity for Youth Turning 18, FY 2006



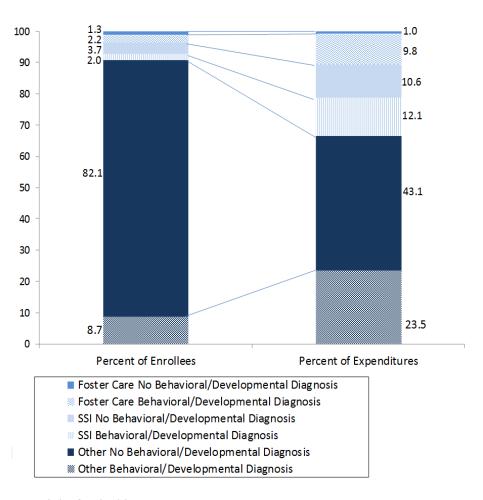
Note: Excluding females delivering in year.

Source: Authors' analysis of the Medicaid Statistical Information System data files.

care youth across the 10 states is similar (\$9,752 and \$7,454, respectively), there are wide differences in states in this pattern, with SSI youth substantially more expensive in some states (e.g., California and Iowa), and the opposite pattern in others (e.g., Nevada, South Carolina, Texas, and Utah). The MSIS files we analyzed do not contain data that explain these state differences.

Returning to the general pattern across all 10 states, figure 2 shows the differences in the proportion of enrollees and the proportion of expenditures in study states, according to study population and whether the individual has a behavioral or developmental health diagnosis. While 82.1 percent of Medicaid eighteen-yearolds are neither in SSI nor foster care, nor have a behavioral or developmental health diagnosis, only 43.1 percent of Medicaid expenditures are for such youth. In all cases—whether youth are in SSI, foster care, or the all other group— Medicaid youth turning 18 with behavioral or developmental health diagnoses have disproportionately higher Medicaid expenditures. The percentage of total expenditures for youth with behavioral or developmental health diagnosis is about five times as great as the percentage for those without such diagnoses, for SSI and foster care youth, and about three times as great for all other youth.

Figure 2: Percent of Enrollees and Expenditures by Basis of Eligibility and Presence of Behavioral or Developmental Diagnosis for Youth Turning 18 in 2006 in Study States



Note: Excluding females delivering in year.

Source: Authors' analysis of the Medicaid Statistical Information System data files.

The gender difference in prevalence of a behavioral or developmental health diagnoses shown previously in table 5 in turn leads to gender differences in average annual expenditures, with males being more expensive for Medicaid than females overall in this age group (figure 3).<sup>4</sup> On average, males turning 18 cost \$3,046 across the 10 study states in FY 2006, while females cost \$2,017. However, the gender difference is completely due to differences among the SSI and foster care youth, as there is little gender difference in average Medicaid expenditures for other youth. A major source of the overall gender difference comes from the higher percentage of males enrolled in SSI, and their higher average expenditures (in part due to the higher prevalence of behavioral or developmental health diagnoses for SSI males). In addition, the higher prevalence of behavioral or developmental health diagnoses among male foster youth contributes to the gender difference in average Medicaid expenditures overall.

Figure 4 shows expenditures by type of service for the three study groups. A large proportion of SSI youth expenditures falls within the ICF-MR/HCBS category. This category also includes some other Long Term Services and Support services such as therapies. Other expensive services for SSI youth are inpatient hospital services, outpatient services, and drugs. For foster youth, the most expensive services are outpatient services (which include clinics and physician services) and drugs. However there are three services categories related to

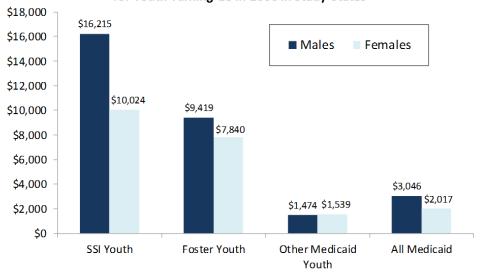
behavioral health care that are particularly expensive for this group: inpatient psychiatric hospitalization, targeted case management, and rehabilitation. The latter two are optional services that states can use to cover a range of "non-traditional" health services, such as day treatment, in-home services, or intermediate levels of inpatient services. For all other youth, it is difficult to discern their pattern of expenditures by type of service, because a substantial proportion of expenditures is for managed care premiums representing an undistinguishable bundle of services. It is evident that inpatient hospital, outpatient services, and drugs are the three most expensive service types for this group.

## **Conclusions**

The approach of adulthood is a critical period for assuring continuity of health services, especially for high-risk youth. This brief provides new data on this under-studied age group, at a time when health insurance options are changing under the Affordable Care Act. Several important conclusions emerge from this analysis of Medicaid data for youth turning 18 in the 10 states involved in this study.

States are very different in the proportion of Medicaid youth who are in foster care or in the SSI program at the time they transition to adulthood. This has large implications for state variations in the average cost of Medicaid for this age group. More research is needed on state variations in the process for enrolling teenagers into foster care and into the SSI program.

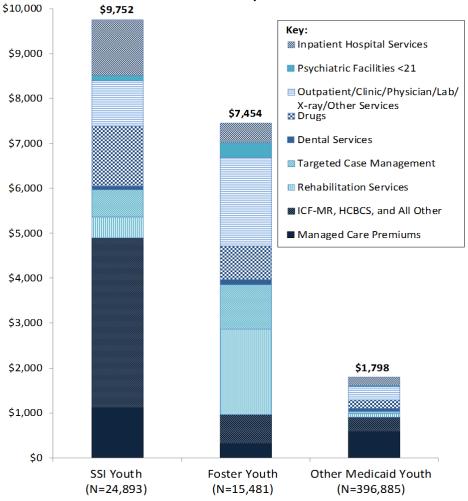
Figure 3: Average Medicaid Expenditures by Gender for Youth Turning 18 in 2006 in Study States



Note: Excluding females delivering in year.

Source: Authors' analysis of the Medicaid Statistical Information System data files.

Figure 4: Average Expenditures by Type of Service for Youth Turning 18 in 2006 in Study States



Source: Authors' analysis of the Medicaid Statistical Information System data files.

- The proportion of Medicaid youth approaching adulthood who have a reported behavioral or developmental disorder is high and there is substantial state variation. Some of the state differences are due to differences in how behavioral/developmental diagnoses are coded, and also in the degree of managed care penetration (which leads to under-identification of such conditions in the Medicaid data). However, other differences—such as access to behavioral/developmental health services—are also likely a critical factor in this variation. The source of these variations is another important topic for future research.
- A majority of Medicaid expenditures for this age group are for foster care youth, SSI youth, and those with behavioral/developmental diagnoses, although such youth comprise less than twenty percent of the Medicaid population in this age group.
- State variation in average expenditures is substantial for youth turning 18. Major sources of this variation derive from the state differences outlined above.
- There are substantial gender differences in average annual Medicaid expenditures. This is due to gender
  differences in disability status and prevalence of behavioral or developmental diagnoses. Among youth
  approaching adulthood, boys are more likely to be in foster care or SSI, and to have behavioral/
  developmental diagnoses, leading to higher average expenditures than girls.
- As youth age out of traditional Medicaid, continuity of enrollment in health insurance is critical, especially for high-risk youth (whether through Medicaid for the lowest income youth in states taking the Medicaid option under the ACA, or through other forms of health insurance through the health insurance exchanges).
- In addition to continuity of coverage, new attention should be given to continuity of the services received under Medicaid, as these youth approach adulthood. The gender differences shown here suggest that a particular challenge is to engage young men in continuing their care, and assuring that high quality services are available under Medicaid or other forms of health insurance.

## **Endnotes**

- 1. A data base maintained by the Centers for Medicare and Medicaid Services (CMS).
- 2. This project uses a special file of MSIS data that is prepared for the Urban Institute and some other users each year. See http://www.cms.gov/Research-Statistics-Data-and-Systems/Computer-Data-and-Systems/MedicaidDataSourcesGenInfo/MSIS-Mart-Home.htmlfor more information
- 3. "Carving out" services means that the main managed care plan does not cover the services.
- 4. Note that females who deliver a baby during the year are excluded from the study population, if the delivery is coded in the claims file.

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## **About the Authors and Acknowledgments**

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