Medicaid Waivers and Public Sector Mental Health Service Penetration Rates for Youth

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ABSTRACT

**Background:** To assist families of youth with serious emotional disturbance in financing youth’s comprehensive care, some states have sought and received Medicaid waivers. Medicaid waivers, waive or relax the Medicaid means test for eligibility to provide insurance coverage to non-poor families for expensive, otherwise out-of-reach treatment for youth with Serious Emotional Disturbance (SED).

**Aims of the Study:** Waivers promote treatment access for the most troubled youth, and the present study investigated whether any of several Medicaid waiver options—and those that completely omit the means test in particular—are associated with higher state-wide public sector treatment penetration rates.

**Methods:** The investigators obtained data from the U.S. Census, SAMHSA’s Uniform Reporting System, and the Centers for Medicare and Medicaid Services. Analysis employed random intercept and random slope linear regression models, controlling for a variety of state demographic and fiscal variables, to determine if a relationship between Medicaid waiver policies and state-level public sector penetration rates could be observed.

**Results:** Findings indicate that, whether relaxing or completely waiving Medicaid’s qualifying income limits, waivers increase public sector penetration rates, particularly for youth under age 17. However, completely waiving Medicaid income limits did not uniquely contribute to penetration rate increases.

**Conclusions and Implications:** States offering Medicaid waivers that either relax or completely waive Medicaid’s means test to qualify for health coverage present higher public sector treat-
ment rates for youth with behavioral healthcare needs. There is no evidence that restricting the program to waiving the means test for accessing Medicaid would increase treatment access.
PUBLIC RELEVANCE STATEMENT

States rely heavily on Medicaid to fund intensive home- and community-based services for youth with serious emotional disturbance, limiting access to vital mental health care for the many of such youth who are privately insured or uninsured. This study found that Medicaid waivers, which promote treatment access by waiving or expanding the means-test limit to Medicaid for the most troubled youth, increase public sector penetration rates for youth under age 17.
INTRODUCTION

Representing approximately 8 to 12% of all youth in the United States (Costello, Egger, & Angold, 2005; Costello, He, Sampson, Kessler, & Merikangas, 2014; Kessler et al., 2005), youth with Serious Emotional Disturbance (SED) have both a “DSM-based mental disorder” and symptoms severely impairing their functioning in school, home, or the community (Behavioral Health Statistics and Quality, 2016, p. 2). They are more likely to drop out of school (Strompolis et al., 2012), may have difficulty achieving stability in secondary education and vocational settings (Zigmond, 2006), and adolescent youth have increased risk of substance use (Wu et al., 2008) and criminal justice involvement (Mordre, Groholt, Kjelsberg, Sandstad, & Myhre, 2011). Their potential to harm themselves or others places them at risk for chronic or long-term placement in a residential placement in either psychiatric, correctional or foster settings (Fields & Ogles, 2002; Peiper et al., 2015). Parents and caregivers of youth with SED are also impacted, reporting greater strain, especially in the form of grief, depression, and anxiety (Corliss, Lawrence, & Nelson, 2008; Heffinger & Taylor-Richardson, 2004; Richardson, Cobham, McDermott, & Murray, 2013).

Only about 25% of youth with SED receive any mental health treatment (Costello et al., 2005, 2014). A significant portion of parents of a youth with SED report barriers to accessing care, and particular difficulty in obtaining needed specialty services for their child (Owens et al., 2002). Despite parity laws, private insurance continues to provide minimal coverage for mental health services, usually only covering basic outpatient services (Bailey & Davis, 2012; Barry & Busch, 2008; Ireys, Pires, & Lee, 2006). Because states are required to provide specialty services through Medicaid’s Early Periodical Screening, Diagnosis, and Treatment (EPSDT) mandate, many state systems have come to rely heavily on Medicaid to fund Home and Community
Based Services (HCBS) (Howell, 2004). Further, as more state dollars are invested in the state Medicaid match, funding for mental health safety net programs is shrinking (Frank, Goldman, & Hogan, 2003; Howell, 2004).

Given these factors, it is not surprising that individuals with public insurance are more likely to access mental health care than those with private insurance (Burns et al., 1997; Walker, Cummings, Hockenberry, & Druss, 2015). Only 10% of uninsured or privately insured youth obtain mental health care, compared to 44% of youth with Medicaid (Baily & Davis, 2012; Howell, 2004). However, 30 to 40% of youth with SED are privately insured or non-Medicaid eligible and uninsured (Mark & Buck, 2006), suggesting that many youth with SED are not receiving any mental health care due to cost barriers (Rowan, McAlpine, & Blewett, 2013). After exhausting their private insurance plans and discovering that they do not qualify for public insurance or safety net programs, some of these families may turn to the child welfare or juvenile justice system to obtain affordable services for their youth, sometimes relinquishing custody in this process (Friesen, Giliberti, Katz-Leavy, 2003; U.S. General Accounting Office, 2003; Osher, & Pullmann, 2003; Hill, 2017).

To avoid such tragedies, many states have improved treatment financing and access by seeking “Medicaid waivers.” These policies waive selected Medicaid rules to promote the use of specialty community-based programming for youth with SED. Such waivers eliminate or relax Medicaid’s means test limits for parents’ income and certify eligibility by assessing the clinical need of the child instead. For waivers that omit the parental means test, if the youth meets clinical eligibility by demonstrating risk for residential placement, the youth is considered as a “family of one” and the means test is applied to the child alone. Unless the child has significant in-
come of his or her own, this mechanism allows families of middle and high income levels to access the intensive home- and community-based services paid for exclusively by Medicaid.

Medicaid waivers can be used to finance provision of intensive community-based services to youth and adults with complex medical and/or mental health needs (e.g. autism, developmental delays, traumatic brain injuries, as well as severe mental health disorders) that might otherwise need residential or long-term care. Waiver options vary in requirements and objectives but all promote access to comprehensive community-based care to target populations (Friedman & Rizzolo, 2016; Ng, Stone, & Harrington, 2015).

Several waiver programs are currently in use for youth with SED. Twenty states employ the Tax Equity and Fiscal Responsibility Act (TEFRA) Medicaid Eligibility Option, also known as “The Katie Beckett Option” (Semansky & Koyanagi, 2004). This waiver provides middle-income disabled youth with the same coverage as other Medicaid-eligible youth by omitting the parental means test, and basing eligibility on the clinical need of the child and their personal income level and assets. Ten of these twenty states extend TEFRA to youth disabled by SED. Covered services include comprehensive community-based care such as case management and in-home and community support services.

A second waiver option promotes innovative programming for youth with SED. Medicaid home- and community-based Services waivers fund community-based alternatives to hospital-based and residential care authorized under section 1915(c) of the federal Social Security Act (“HCBS waivers” or “1915(c) waivers”). Nine states currently offer an HCBS waiver specifically designed to target youth with SED requiring inpatient or residential care (HCBS SED waiver), providing them with specialty at-home and community care at a cost equal to or less than hospital-level care (Ireys, Pires, & Lee, 2006). From 2007 to 2012, eight additional states and one
HCBS SED waiver state also participated in a federal demonstration to offer Medicaid HCBS Waivers targeting youth with SED ordinarily served in Psychiatric Residential Treatment Facilities (PRTFs), or youth transitioning out of such facilities, to serve them more effectively and at a lower cost through community-based services (“HCBS PRTF Waiver”) (Urdapilleta, et al., 2013). Specialized services provided under these waivers often include respite care, peer support for families and youth, or wraparound service planning. Each type of Medicaid waiver is further described in Table 1.

[Insert Table1]

Research about TEFRA waiver programs is almost non-existent, but one study concluded that TEFRA was instrumental in reducing cost barriers to needed healthcare services (Chan, Jahnke, Thorson, & Vanderburg, 1998). Because 1915 (c) Medicaid waivers are used extensively by states to increase access to HCBS for many target populations, the knowledge base about these waivers is more developed. Several descriptive studies document large variation across state HCBS waiver programs in spending, types, and intensity of services provided to particular target populations, and the numbers served through them (Friedman, Lulinski, & Rizzolo, 2015; Friedman & Rizzolo, 2016; Harrington et al., 2001; Kitchener, Ng, Miller, & Harrington, 2005; Ng et al., 2015; Rizzolo et al., 2013). Such discrepancies result in HCBS access disparities across states (Harrington, LeBlanc, Wood, Satten, & Tonner, 2002), and make evaluation and comparison of state programs challenging. In spite of these complexities, 1915 (c) waivers serving a variety of target populations have been studied vigorously for the past two decades. A 2006 review of such studies concludes that, though most studies were based in research designs with unresolved potential confounders, such programs were generally associated with increased public costs, but greater client and care provider welfare (Grabowski, 2006).
SED-focused Medicaid waivers are intended to broaden access to community-based programming for youth with SED by directly extending coverage to families otherwise not qualifying for Medicaid and creating new community-based treatment options. Limited evaluation exists, however, regarding Medicaid waivers specifically for this population. Findings in a handful of preliminary studies of such HCBS 1915(c) waivers suggest that state adoption expands the array of community-based services available to these youth and their families, allows more families to access intensive mental health care in the community, and has helped keep more youth in their homes (Friesen et al., 2003; Ireys, Pires & Lee, 2006; Solhkhah, Passman, Lavezzi, Zoffness, & Silva, 2007).

Youth covered under a Medicaid waiver obtain access to the public treatment system and its wide array of specialized services, developed with Medicaid financing, for treating and rehabilitating youth with SED. Their entry should register state-wide by increasing public sector penetration rates. Further, by reducing the financial burden of care to the greatest extent, it would be expected that states with waivers that omit the parental means test (“Full Waivers”) would have higher public sector penetration rates than states with waivers that only expand the Medicaid means test limits (“Partial Waivers”).

Medicaid waivers’ relation to state-wide measures of public service access, as would be expected if enough eligible youth with SED were reached with full or partial Medicaid waivers, has not yet been investigated. Accordingly, this study examines the relationship between the presence of Medicaid waivers and state public-sector mental health services penetration rates. It asks whether a state’s use of any type of Medicaid waiver is associated with higher statewide mental health public sector penetration rates. It also evaluates whether the current waiver options, when granted to youth with SED by relaxing means test eligibility limits or eliminating
them altogether, promotes greater treatment access. The study is a preliminary step toward unraveling the role of Medicaid waiver enactment in facilitating access to public sector care for youth with SED nationwide.

**METHODS**

The study used a cross-sectional, longitudinal research design, observing fifty states over six years, employing random effects linear regression models with random slopes and intercepts. The principal independent variable was the presence or absence of state Medicaid waivers targeting youth with SED, whether relaxing or eliminating the customary Medicaid means test limit for parents. A second independent variable assessed whether eliminating the means test was incrementally more effective.

The dependent variable was states’ child mental health service system public sector penetration rates. Control variables included state characteristics (population size and density, median income), percentage of the state youth population who have SED, the number of public sector mental health providers serving youth in the state, and treatment system financial characteristics (total mental health expenditures, ambulatory care revenues). A time trend variable was also created and added to the model to control for normative expansion of mental health systems over time.

**Data Sources**

Values for principal independent variables were collected from a variety of sources. The presence of an HCBS SED waiver in the state was collected from the CMS webpage listing Medicaid waivers and demonstrations. The presence of HCBS PRTF waivers was gathered from the National Evaluation of the Medicaid Demonstration Waiver Home- and Community-Based Al-
ternatives to Psychiatric Residential Treatment Facilities report delivered to congress in May of 2012 (Urdapilleta, et al., 2013).

TEFRA waiver status was gathered from two sources and cross-referenced to ensure the states were using TEFRA during the years 2007 to 2012: a study of states’ use of TEFRA waivers in 2001 (Semansky & Koyanagi, 2004), and a report by Boston University’s Catalyst Center, found at their website and retrieved on July 24, 2015. The Catalyst Center’s report is drawn from their 2010 Medicaid Survey, and is cross-referenced with a 2011 article (Musumeci, 2011).

Data for the response and some control variables were gathered from SAMHSA’s Center for Mental Health Services (CMHS) Uniform Reporting System (URS). Penetration rates and fiscal data were collected from URS reports for each state, from 2007 to 2012. Data for additional control variables (state population, population density, income per-capita, and percent of youth who have SED) were collected from the U.S. Census Bureau data website in October and November of 2015, and from the 2015 Mental Health America Report. Estimates of provider density in each state were drawn from the Substance Abuse and Mental Health Data Archive’s (SAMHDA) National Mental Health Services Survey (N-MHSS) conducted in 2010.

Principal Independent Variables

A variable was created reflecting a state’s use of any type of Medicaid waiver. “Any Waiver” is a binary variable: “0” for a given year if a state had no effective waivers, and “1” if it had an effective waiver. Additionally, states were coded with an additional variable, “Full Waiver.” States whose waivers, granted under any authority, completely eliminated the minimum income requirement for parents were coded as “1.” States that did not offer waivers and states with “partial waivers” (waivers that relax income limits rather than omitting them altogether) were coded as “0”. Aggregating non-waiver states and partial waiver states in this variable permits the
model to test the waiver’s impact against all states not offering any waiver, as well as full waivers against partial waivers. Data were collected as follows and was retrieved in July of 2015.

Researchers observed the listing of waivers in each state on the CMS website, and noted the presence of an HCBS SED waiver in the state, as well as what year the waiver was made effective. To be classified as having an HCBS SED waiver, the data collection team read the waiver description listed on the website; the description needed to state clearly that the target population was youth (under age 21 years) with SED. State applications were examined to determine if the 1915 (c) waiver omitted the means test, or simply expanded it. 1915 (c) states that waived the means test were coded as “1” for the “Any Waiver” and 1 for “Full Waiver” variables.

States that were listed as participants in the PRTF demonstration project were coded with as “1” for the “Any Waiver” variable for 2007 through 2012, because the demonstration project spanned from late 2007 to late 2012. A report to Congress on the demonstration (National Evaluation of Medicaid Demonstration: Home- and Community-Based Alternatives to Psychiatric Residential Treatment Facilities, Year 2 - Implementation Status Report, 2010) was examined to discern financial eligibility criteria for the HCBS PRTF waiver in each state. Kansas, South Carolina, and Alaska waived the parental means test, delivering services to youth based on the risk of PRTF admission or upon PRTF discharge. These states were coded with a “1” for the “Any Waiver” and “1” for “Full Waiver” variables for the years of the demonstration, 2007 to 2012. Virginia switched from expanding the means test to omitting it altogether in June of 2010. This state was coded with a “0” for 2007-2009, and “1” for 2010 to 2012 for “Full Waiver”, and coded with “1” for 2007 to 2012 for “Any Waiver”. Remaining PRTF states were coded with a “1” for “Any Waiver” and “0” for “Full Waiver.”
For TEFRA (TEFRA), if a state was 1) included on the Semansky & Koyanagi (2004) list from 2001, and the Catalyst Center’s list compiled from 2010 data, and 2) if the state was identified as extending definitions of “disability” to include mental health disabilities in Semansky & Koyanagi’s 2004 study, it was assumed that the state offered the TEFRA option extending to mental health-related disabilities during the study years, 2007 to 2012. Because this type of waiver always eliminates the parental means test, it was then coded with a “1” for all six years for the “Any Waiver” and “1” for “Full Waiver” variables. States that have TEFRA options, but do not extend them to include mental health disabilities, were coded as “0” for both variables. A full listing of what type of waiver is offered by each state is displayed in Table 2.

Control Variables

Public expenditures and ambulatory revenues. Because more spending on service delivery might yield higher public sector penetration rates, and because relatively generous financing encourages provision of care, this study controlled for state investment in services by including total expenditures for public mental health services (provided or funded by the state mental health agency). To control for the level of investment in home- and community-based services each state demonstrates, models also included revenues from ambulatory mental health services. This fiscal variable was retrieved from SAMHSA’s URS expenditure and revenue data.

Population size, density, income level. The state population size was also collected for each year, for each state, as a means of controlling for key background state characteristics. To control for variance in regional mental health need, the population density variable was collected from 2010 census data and applied to each state for each year, from 2007 through 2012, making it invariant over the time of the study. In rural areas, mental health need has been demonstrated to be greater, and providers shown to be fewer in number (Howell & McFeeters, 2008; Holt &
Adams, 2013). The median income was collected for each year, for each state, as a proxy to control for the level of insurance coverage within each state as well as the level of economic need in each state, both of which have also been shown to be related to mental health need and access (Kataoka, Zhang, & Wells, 2002; Zimmerman, 2005).

**Percent youth with SED.** To control for the level of the state population’s need for services, a variable representing the percentage of the state youth population estimated to have SED was included in the models. As this data was not available from the years of the study, and research has demonstrated estimated level of SED to be fairly constant (Costello et al., 2005, 2014; Kessler et al., 2005), this variable was drawn from the 2015 Mental Health America Report, Parity or Disparity: The State of Mental Health in America.

**Public sector providers serving youth.** The number of providers in each state may relate to penetration rates, as families are more likely to access treatment if it is nearby and immediately available—both of which are more likely if there are more providers available in an area (Bishop, Seirup, Pincus, & Ross, 2016; Cook, Doksum, Chen, Carle, & Alegría, 2013). Estimates of provider supply in each state were drawn from the Substance Abuse and Mental Health Data Archive’s (SAMHDA) National Mental Health Services Survey (N-MHSS) conducted in 2010. The following types of mental health treatment facilities were included in the 2010 N-MHSS: Psychiatric hospitals, non-federal general hospitals with a separate psychiatric unit, VA medical centers, outpatient or day treatment or partial hospitalization mental health facilities, residential treatment centers (RTCs) for children and adults, and multi-service, non-hospital mental health facilities. The survey excluded military treatment facilities, Indian Health Service or tribally operated facilities, any private practitioners, or small group practices not licensed as a mental health clinics or centers, and jails or prisons.
The N-MHSS relied on facilities to voluntarily participate in data collection, and of the 12,186 facilities eligible for participation, 93% responded to the survey. In the dataset, the provider count for each state reflected the state-specific sum of all facilities in the N-MHSS which both serve youth and accept State Mental Health Authority (SMHA) funding. Because state public sector penetration rates for youth were drawn from SMHA-funded organizations, it is critical that the provider count for each state include only SMHA funded providers that serve youth.

**Time trend.** A time trend variable was created for each state, to control for any normative expansion in public sector penetration rates over time. For this variable, a state was assigned a “1” for the year 2007, and continued to count upward for each year of the study, concluding with a “6” assigned for the year 2012.

### Dependent Variables

**Public sector penetration rates.** Public sector penetration rates are commonly used as an indicator of service access (Stiles, Boothroyd, Snyder, & Zong, 2002). The National Association of State Mental Health Program Directors has defined it as the total number of unduplicated persons served in specialty public mental health treatment per year, divided by the number of people in the state population. State-level public sector penetration rates were gathered from SAMHSA’s URS reports for each year.

Because levels and types of mental health need, modes of expression, and treatment opportunities vary with age, public sector penetration rates for youth are reported in URS reports by ages: 0-12 years of age, 13-17 years of age, and 18 to 20 years of age. A variable was created for each penetration rate age range, for a total of three penetration rate variables for each state, for each year. It is expressed as the number of youth in the age range served per 1,000 individuals in
that age range living in the state. The penetration rate for 18 to 20 years of age was included because some HCBS SED and PRTF waivers serve youth up to the age of 21 years.

**Sample Preparation and Sample Size**

Researchers compiled secondary data from the sources listed above for all fifty states for the years 2007 through 2012 \((n = 300)\) and systematically cleaned and assembled these data. Because the years of the study aligned with the Great Recession, variables and relationships between variables over the six years of the study were assessed graphically to determine if the timeframe violated linear assumptions; the relationship between variables in any given year remained fairly linear. Response variables were also assessed for normality and skew, and most response variables appeared to be generally normally distributed. Some variables also had a few extreme outliers which were removed for final analysis. Correlation analysis demonstrated no problematic multicollinearity between variables other than an expected close relationship between total state expenditures and ambulatory revenues.

**Data Analysis**

Descriptive analysis identified differences across states with Full Waivers, Partial Waivers, and No Waivers in relation to penetration rates in all three age groups, and all control variables. Statistical analysis estimated three random-coefficient linear regression equations, where time-varying observations of state penetration rates were nested within states. Each equation estimated relationships between predictor and control variables and penetration rates for each age group (0-12 years, 13-17 years, and 18-20 years), assessing the contribution of “Any Waiver” and “Full Waiver.”

States vary widely in many respects crucial to the study, and random intercept and slope modeling is implemented here, as in much state, county, or other area level research, because it
minimizes many of these background differences. Furthermore, observations within the same state over time are correlated, likely substantially so, which violates assumptions of standard regression approaches. Hierarchical modeling—with random intercepts, random slopes, and unstructured covariance—accounts for non-independence between within-state observations as it adjusts for key between-state and within-state differences. The random intercepts control for average difference between states on response variables. Random slopes allow state-specific regression lines, capturing individual state patterns of predictor-response association and more accurately controlling for within-state correlations among observations, thereby ensuring more precise standard errors and confidence intervals (Schielzeth and Forstmeier, 2009).

RESULTS

[Insert Tables 3 & 4]

Table 3 displays descriptive statistics for states with Full Waiver, Partial Waiver, and No Waiver, aggregated across the six years of the study. Both Partial Waiver and Full Waiver states served notably more youth in all age groups. Partial Waiver and Full Waiver states spent more per capita on mental health treatment, had less per-capita income, and higher proportions of youth with SED. Partial Waiver states had the largest number of public sector providers serving youth, and Full Waiver states had by far the lowest number of such providers.

Results from random-coefficient analysis are presented in Table 4. Any Waiver states had significantly higher public sector penetration rates for 0 to 12 year olds than states with no Medicaid waiver ($\beta=4.42$, SE= 1.83). Full Waiver states demonstrated no significant additional increase in penetration rate when considered on their own. Similarly, for 13-17 year olds, Any Waiver states increased public sector penetration rates at significant levels ($\beta=7.44$, SE= 3.16), but Full Waiver states demonstrated no significant additional change in public sector penetration.
rates. For 18 to 20 year olds, no significant results were found either for Any Waiver or Full Waiver states.

This analysis also reveals intriguing relationships between state-level public sector penetration rates and control variables in the model. Especially worthy of note is that treatment need and wealth matter in their connection to higher public sector treatment rates. The proportion of youth within a state who have SED is associated with very significant (p<0.01) increases in penetration rates (ages 0-12: β=2.94, SE= 0.91; ages 13-17: β=3.35, SE= 1.45; ages 18-20: β=8.04, SE= 1.39). Also noteworthy is a strong effect for financial resources: for every $10,000 increase in a state’s median income, an additional 4.9, 8.5, and 2.7 per 1000 youth were served in public sector treatment for each age group, respectively. Higher penetration rate states were also significantly associated with higher ambulatory revenues, and with smaller populations and population densities.

**DISCUSSION**

After controlling for state variation in treatment need and other factors, findings reveal that the presence of a Medicaid waiver either relaxing or eliminating income limits for coverage is linked with higher public sector penetration rates for youth. This suggests that states offering any kind of Medicaid waivers for youth with SED are serving a portion of the population otherwise lacking access to a full spectrum of community-based services. The finding that public sector penetration rates are not increased for 18 to 20 year olds in states with any type of waivers may reflect the fact that disabled youth are likely to qualify for Medicaid as a “family of one” based on their income and disability after turning 18 years of age. This status change would enable them to access publically-funded mental health services without Medicaid waivers, minimizing differences in public sector penetration rates between Any Waiver and No Waiver states.
No additional increase in public sector penetration rates was evident from waiving the means test considered on its own, suggesting that little would be gained from sacrificing the policy’s flexibility by restricting states seeking waivers to eliminating income limits for eligibility altogether. There may be little difference in practice between relaxing and eliminating parental income limits for Medicaid coverage if few parents earn enough to exceed relaxed eligibility criteria, leaving relatively few families in need without coverage. If so, this implies that families with resources that place them above 300% of the Federal Poverty Level (FPL), which is the income limit for waivers in most Partial Waiver states, may have enough resources to pay for some level of services on their own, either through private payment or insurance coverage. Because this study only examines overall public sector penetration rates, it is unknown if represented families are able to access the intensity of services needed—those usually only covered by Medicaid. Further research is needed determining the extent to which eligibility restrictions in Partial Waiver states affect access to appropriate levels of care for youth with SED.

The interpretation presented above proposes that the presence of Medicaid waivers leads to higher public mental health public sector penetration rates rather than the reverse direction of influence—that states with higher public sector penetration rates are more likely to seek and be granted waivers. Several considerations argue against the latter interpretation. First, previous studies have demonstrated that those with public insurance coverage are more likely to access mental health care that those with private insurance (Burns et al., 1997; Walker et al., 2015), suggesting that families seeking Medicaid waivers are attempting to gain more efficient access to public sector specialty treatment and its wider array of specialized services for youth with SED. While some waiver-qualified Medicaid parents might have previously received public sector treatment by relinquishing custody, or financed on a stopgap basis from personal finances or
from special local programs, it is considerably more likely that previous mental health intervention for these non-poor youth has occurred in pediatric, school-based, and other non-specialty sectors—where most mental health care is provided, especially to families lacking Medicaid coverage (Costello et al., 2014; Farmer, Burns, Phillips, Angold, & Costello, 2003). Medicaid waivers would allow families to move from treatment in private or educational settings—not funded by state mental health block grants or Medicaid—to the home- and community-based services only available in public treatment systems. This is reflected in larger public sector penetration rates in states with waivers.

A control variable significantly related to increased penetration rates is the percentage of youth in a state who meets the criteria of SED. This finding suggests that states may be succeeding in structuring services to meet the needs of their populations. Conversely, it could be the reverse relationship: states with high penetration rates are serving a greater proportion of youth, and are therefore able to identify and report higher numbers of youth with SED. Further research focused explicitly on untangling the nature and direction of this relationship is needed.

This study also finds that a state’s median income significantly predicts state mental health penetration rates. This is particularly surprising when combined with the observation that a state’s total SMHA expenditures on public mental health services are not related to penetration rates. This suggests that a common assumption—that wealthier states have more money to spend on services and therefore can reach more families—may not be at the root of the relationship. It is possible that states with higher median incomes have a greater amount of private individual or foundation giving that can fund a wider mental health safety net. A second possibility is that, though results here suggest that SMHA expenditures are not related to increases in public penetration rates, states with higher median incomes may have greater tax revenues. Some of these
more solvent state general funds may be funneled to children’s mental health care through state agencies other than the State Mental Health Authority, and these funds may expand the reach of SMHA-funded agencies—which would be reflected in public sector penetration rate data. Finally, it is possible that a state with a higher median income may have more privately insured families, and penetration rates for publically funded mental health services are higher because families in these states are more able to access services through the use of private insurance or by paying out of pocket for these services through SMHA-funded agencies.

The role of private insurance in increasing state mental health penetration rates for youth may have particular relevance in understanding the effectiveness of the Mental Health Parity and Addictions Equity Act of 2008. This federal policy took effect partway through this study, in late 2009, and requires that private insurance provide coverage for mental health and substance use concerns equal to the coverage provided for medical care. Parity is especially useful for enhancing private sector mental health coverage whose inadequacy gave rise to Medicaid waivers. Yet available literature, although limited, suggests that parity coverage has continued to be insufficient to meet the treatment financing needs for many children with mental illness (Bailey & Davis, 2012; Barry & Busch, 2008). Despite parity’s enhancement of private coverage, there is likely a continuing need for Medicaid waivers’ comprehensive coverage to enable families’ access to the wider array of home- and community-based treatment available primarily through public sector services.

Because Medicaid waivers are essentially an expansion of Medicaid for targeted high-need populations, continuing investigation into the relationship between these waivers and state-level penetration rates may also be especially relevant in the light of the Affordable Care Act (ACA) of 2010. Medicaid expansion, which was authorized under the ACA and began in 2014,
extends full Medicaid coverage to individuals and families up to 138% of the Federal Poverty Line (FPL). As such, it is a controversial but key component of the ACA. Because Medicaid coverage was more readily available for children than adults before the ACA, and because children’s Medicaid coverage has been expanded in many states through the State Children’s Health Insurance Programs (SCHIP) since 1997, the Affordable Care Act only slightly reduced children’s uninsurance rates, from an already low 7% to 5% (The Henry J. Kaiser Foundation, 2017). In terms of sheer numbers, on the other hand, many new children and families gained coverage.

However, when considering the role of SCHIP in financing HCBS for youth with SED, it is important to note that states vary widely in the extent to which SCHIP covers home- and community-based services for youth needing long-term care. While SCHIP in all states provides publically funded insurance coverage to children whose family’s income is up to 250% to 400% of the FPL, some states provide coverage under SCHIP that is identical to Medicaid (e.g. Maryland, Rhode Island) while other states have more restricted benefits under SCHIP (e.g. Tennessee, Hawaii, Kansas). In more restrictive states, SCHIP is similar to private insurance coverage and limits access to community-based care (Medicaid.gov, 2017). Medicaid expansion allows many families whose income is below 138% of the FPL, but above the Medicaid threshold previously set in their state, to move their child with SED from a limited benefit package under SCHIP to the more comprehensive service array covered by full Medicaid. On the other hand, for nineteen states declining Medicaid expansion, movement from less generous SCHIP coverage to more generous Medicaid does not exist as an option. Findings from this study suggest that Medicaid expansion, where it occurred, may increase mental health service access for many families. For this reason, there is a need to engage in carefully constructed state-level research, com-
paring public mental health penetration rates of Medicaid expansion states with those of non-expansion states, while controlling for other Medicaid-expanding policies for youth with SED (e.g. waivers) that may exist in non-expansion states (e.g. Kansas).

The study’s findings must be understood in relation to several additional limitations. Although the study did include the entire population of states, the sample size is relatively small, limiting the statistical power of the analysis, and decreasing the chances of the study detecting a true effect (Button et al., 2013). Another limitation stems from the use of public sector penetration rates as a measure of access. Focus on public sector penetration rates in the study exclude examination of the level of intensity of the services received by individuals, the mental health needs of those being served, or the income levels and insurance status of families most likely to be affected by states’ Medicaid waiver adoption. Finally, this exploratory study is limited in causal inference. Because most states did or did not have waivers throughout the entire study period, pre-post waiver observations or difference-in-difference study designs were not possible.

Directions for Future Research

These limitations notwithstanding, the study’s findings represent an initial step toward understanding states’ adoption of Medicaid waivers, and the mechanisms within them, to promote delivery of community-based services to youth with SED. Findings suggest that state policies like Medicaid waivers, which promote easier access to state funded community-based care, may be associated with higher public sector penetration rates, but that the hypothesized mechanism for doing so—the elimination of means-testing for Medicaid eligibility—may not be a reason for this association. Subsequent inquiry can profitably illuminate potentially confounding variables embedded within the sociopolitical and historical processes by which waivers come to the attention of state decision makers and are regarded as a viable option—which may also con-
tribute to broader mental health access within that state. What roles are played, for example, by states’ sophistication and receptivity to the Medicaid program as well as advocacy for meeting the needs of at-risk youth? Additionally, non-waiver related policies may be utilized by states to deliver services to the youth with SED not financially eligible for Medicaid which, when not observed and included in analysis, mute the effects of waivers upon treatment accessibility.

Nationwide state policy research, using more specific data about the characteristics of families needing and accessing mental health care—and how they enter the public sector mental health service system—may help to illuminate alternative policy mechanisms for delivering services to this population, allowing comparison of the relative reach and accessibility of these methods with waiver-based mechanisms. Future national HCBS Medicaid waiver research may also further unpack how 1915 (c) HCBS waivers are structured across states, and what Medicaid community-based services are available to TEFRA-qualifying youth with SED. Such inquiry may clarify how Medicaid waivers influence service delivery to youth with SED, and with what result. More should be learned about what services waivers fund, who receives them and how, and what differences are attained in the lives of youth with SED and their families as a result.
References


Family Social Work, 8(1), 27–45.
https://doi.org/http://dx.doi.org/10.1300/J039v08n01_02


Medicaid Waivers and Public Sector Penetration Rates


<table>
<thead>
<tr>
<th>Medicaid Waiver Type</th>
<th>Brief Description</th>
<th>Eligibility Criteria</th>
<th>SED/Mental Health as Disability</th>
<th>Provides specialized SED Services?</th>
<th>Requires Federal Application and Approval?</th>
<th>Limited Number of “slots”?</th>
</tr>
</thead>
<tbody>
<tr>
<td>TEFRA Waiver (The Tax Equity and Fiscal Responsibility Act Medicaid Option)</td>
<td>The Tax Equity and Fiscal Responsibility Act (TEFRA), also known as the Katie Beckett Option, created the TEFRA Medicaid Eligibility Option allowed states to relax Medicaid coverage to children with severe disabilities, regardless of parental income.</td>
<td>A child must demonstrate a physical or mental disability that meets standards under the federal Supplemental Social Security Income disability program, and must require the level of care provided in a hospital, nursing facility or an intermediate care facility for mental retardation. States are authorized to determine whether applicants meet the level of care requirement, and cannot single out individual disabilities.</td>
<td>Yes, but only in 10 out of 20 TEFRA states. Across those states, as few as 3%, and as many as 52%, of TEFRA consumers identify a mental health diagnosis as the primary disability (Semansky &amp; Koyanagi, 2004)</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>1915(c) HCBS Serious Emotional Disturbance Waiver (HCBS SED Waiver)</td>
<td>To receive Medicaid’s Home and Community-Based Services waiver for SED states must show that they can serve children that require a hospital level of care with intensive services at home and in the community at a cost equal to or less than a hospital level of care.</td>
<td>The HCBS SED waiver bases eligibility for services and coverage only on the severity of the child’s emotional disturbance, usually assessed using standardized scales such as the Child Behavioral Check List or the Child and Adolescent Functional Assessment Scale.</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>1915(c) HCBS Psychiatric Residential Treatment Facilities Waiver (HCBS PRTF Waiver)</td>
<td>In 2005, Congress authorized a 5 year demonstration project to examine whether youth normally served in PRTFs, those with the most severe symptoms, could be served more effectively and at a lower cost through community-based services than in a PRTF. The project used 1915(c) waiver authority to target youth who would not have been eligible for Medicaid-funded, intensive community-based services.</td>
<td>The Demonstration served children and youth who were either “diverted” from being served in a PRTF, or were “transitioned” from a PRTF into the community. The youth must demonstrate SED severe enough to require hospital or residential levels of care in a Psychiatric Residential Treatment Facility (PRTF). In at least one state, youth transitioning out of a PRTF into the home and community were automatically eligible for this waiver.</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes - Federal Demonstration</td>
<td>Yes</td>
</tr>
</tbody>
</table>
Table 2. Waiver Type by State

<table>
<thead>
<tr>
<th>Type of Waiver</th>
<th>Means Test Treatment</th>
<th>States</th>
<th>Years</th>
</tr>
</thead>
<tbody>
<tr>
<td>TEFRA</td>
<td></td>
<td>Alaska</td>
<td>2007-2012</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Arkansas</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Delaware</td>
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<tr>
<td></td>
<td></td>
<td>Maine</td>
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<td></td>
<td></td>
<td>Minnesota</td>
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<tr>
<td></td>
<td></td>
<td>Mississippi</td>
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<tr>
<td></td>
<td></td>
<td>New Hampshire</td>
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<td></td>
<td></td>
<td>Vermont</td>
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<tr>
<td></td>
<td></td>
<td>West Virginia</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Wisconsin</td>
<td></td>
</tr>
<tr>
<td>1915 (c)Waiver – SED (SED)</td>
<td></td>
<td>Kansas</td>
<td>2007-2012</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Michigan</td>
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<tr>
<td></td>
<td></td>
<td>Wisconsin</td>
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<tr>
<td></td>
<td></td>
<td>Iowa</td>
<td>2010-2012</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Texas</td>
<td>2009-2012</td>
</tr>
<tr>
<td></td>
<td></td>
<td>New York</td>
<td>2007-2012</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Wyoming</td>
<td>2007-2012</td>
</tr>
<tr>
<td>1915 (c) Waiver – PRTF (PRTF)</td>
<td></td>
<td>Alaska</td>
<td>2007-2012</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Virginia</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>South Carolina</td>
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<tr>
<td></td>
<td></td>
<td>Kansas</td>
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<td></td>
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<td>Maryland</td>
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<td>Mississippi</td>
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<td>Montana</td>
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<td>Georgia</td>
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<td></td>
<td></td>
<td>Indiana</td>
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<tr>
<td></td>
<td>0-12 yrs</td>
<td>13-17 yrs</td>
<td>18-20 yrs</td>
</tr>
<tr>
<td>--------------------------------------</td>
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<td>-----------</td>
<td>-----------</td>
</tr>
<tr>
<td><strong>Full Waiver</strong> (States that Waive the Means Test for Medicaid)</td>
<td>26.41</td>
<td>54.34</td>
<td>30.37</td>
</tr>
<tr>
<td><strong>Partial Waiver</strong> (States that Expand the Means Test for Medicaid)</td>
<td>22.27</td>
<td>41.91</td>
<td>24.43</td>
</tr>
<tr>
<td><strong>No Waiver</strong> (States with No Medicaid Waiver)</td>
<td>16.66</td>
<td>35.13</td>
<td>21.25</td>
</tr>
</tbody>
</table>
### Table 4. Estimates of Predictors of State Level Youth Mental Health Public Sector Penetration Rates

<table>
<thead>
<tr>
<th></th>
<th>Penetration Rate 0-12</th>
<th>Penetration Rate 13-17</th>
<th>Penetration Rate 18-20</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>β</td>
<td>SE</td>
<td>p</td>
</tr>
<tr>
<td>Public Sector Providers</td>
<td>0.06</td>
<td>0.05</td>
<td>0.24</td>
</tr>
<tr>
<td>Ambulatory Revenue a</td>
<td>0.01</td>
<td>0.00</td>
<td>0.02</td>
</tr>
<tr>
<td>Total SMHA Expenditures</td>
<td>-0.01</td>
<td>0.00</td>
<td>0.17</td>
</tr>
<tr>
<td>State Population b</td>
<td>-0.09</td>
<td>0.04</td>
<td>0.05</td>
</tr>
<tr>
<td>Population Density c</td>
<td>-0.01</td>
<td>0.01</td>
<td>0.02</td>
</tr>
<tr>
<td>% of Pop. SED</td>
<td>2.94</td>
<td>0.91</td>
<td>0.00</td>
</tr>
<tr>
<td>Median Income d</td>
<td>4.91</td>
<td>1.16</td>
<td>0.00</td>
</tr>
<tr>
<td>Any Waiver</td>
<td>4.42</td>
<td>1.83</td>
<td>0.02</td>
</tr>
<tr>
<td>Full Waiver</td>
<td>-0.69</td>
<td>2.49</td>
<td>0.78</td>
</tr>
<tr>
<td>Time trend</td>
<td>0.22</td>
<td>0.18</td>
<td>0.21</td>
</tr>
<tr>
<td>Intercept</td>
<td>-31.20</td>
<td>9.67</td>
<td>0.00</td>
</tr>
</tbody>
</table>

a in millions; b in tens of thousands; c in hundreds of thousands; d persons per square mile