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Keeping Kids at Home, in School, and Out of Trouble:  
Funding Home and Community-Based Care for Non-Medicaid Eligible Youth with Complex  
Behavioral Healthcare Needs

By

Genevieve Elizabeth Graaf

A dissertation submitted in partial satisfaction of the

requirements for the degree of

Doctor of Philosophy in

Social Welfare

in the

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of the

University of California, Berkeley

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Dr. Sophia Rabe-Hesketh

Spring 2018



## Abstract

### Keeping Kids at Home, in School, and Out of Trouble:

#### Funding Home and Community-Based Care for Non-Medicaid Eligible Youth with Complex

#### Behavioral Healthcare Needs

By

Genevieve Graaf

Doctor of Philosophy in Social Welfare

University of California, Berkeley

Professors Lonnie Snowden and Susan Stone, Co-Chairs

It is estimated that approximately 8 to 12% of all youth can be classified as severely emotionally disturbed (SED) (Costello, Egger, & Angold, 2005; Kessler et al., 2012). These youth exhibit a wide range of mental health disorders and symptoms (e.g., depression, anxiety, difficulty with emotion regulation or executive functioning) (Costello et al., 2005), and the extent to which their functioning is impaired by these symptoms and challenges varies widely (Williams, Scott, & Aarons, 2017). Only 25% of any of these children and adolescents ever access any outpatient mental health treatment (Costello et al., 2005; Costello, Messer, Bird, Cohen, & Reinherz, 1998) and even fewer obtain the intensive Home and Community-Based Services (HCBS) needed to keep youth with the most significant impairments safely in their home and communities (Owens et al., 2002; Spiker, 2017). Home and Community-Based Services (HCBS) often include in-home therapy, case management, or therapeutic behavioral support services (Kernan, Griswold, & Wagner, 2003; Marcenko, Keller, & Delaney, 2001). Without HCBS, youth with the most significant behavioral healthcare needs are at greater risk for chronic or long-term placement in a residential setting in either a psychiatric, correctional, or foster placement (Hansen, Litzelman, Marsh, & Milspaw, 2004; Knitzer & Olson, 1982; Narrow et al., 1998).

Many families cite expense and lack of sufficient health coverage as barriers to service use (Owens et al., 2002; Spiker, 2017). The only type of health coverage that routinely covers HCBS is Medicaid (Howell, 2004), leaving these services mostly inaccessible to families whose incomes are above the Medicaid means-test limits. In order to access public health insurance to fund the intensive mental health care needed for their child, many parents relinquish custody to the state—either through the child welfare or juvenile justice system (U.S. Government Accountability Office, 2003).

States use a variety of policy interventions to reduce income barriers to HCBS for these youth, including Medicaid waivers, the TEFRA provision, and State Plan Amendments (Friesen, Giliberti, Katz-Leavy, Osher, & Pullmann, 2003; Ireys, Pires, & Lee, 2006). However, little is known about these strategies or state motivations for choosing one policy over another. Limited

evaluation also exists regarding their relative effectiveness at meeting the needs of these youth and their families. Having knowledge of the variety of policy tools available to states and how states utilize these tools, as well as the factors that increase the likelihood that a state will opt to use a particular tool, will allow future research to control for such variables, and better discern the effects of the policy on state level mental health system outcomes.

This two-part mixed methods study aims to discern state policies that are more and less effective at reducing access barriers to home and community-based mental health care for non-Medicaid eligible youth with SED. The first, qualitative portion of the study aims to 1) identify policy mechanisms utilized by states to deliver HCBS to youth with SED and their families, particularly for youth whose family income disqualifies them for Medicaid and 2) understand what motivates State Mental Health Authorities and Medicaid Agencies to utilize current policy tools and structures for HCBS delivery for both Medicaid and non-Medicaid eligible youth with SED. The second, quantitative analysis seeks to 1) assess the relationship between a state's use of a Medicaid waiver and the odds that a youth with SED will have public health coverage, 2) assess the relationship between public health coverage and unmet mental health care needs and cost barriers to care for youth with SED, and 3) assess the direct relationship between a youth's residence in a state with a Medicaid waiver, and the odds that the youth will have unmet mental health care needs and cost barriers to care.

Part I of this study gathered qualitative data through semi-structured interviews with officials from 32 state mental health systems about policy tactics for funding and delivering HCBS to Medicaid and non-Medicaid eligible youth with SED in their state. Interviews also gathered information about each state administration's motivation and history that shaped the use of current HCBS policies for this population. Part II of the study utilized data created from information and observations in Part I in conjunction with data from the National Survey for Children with Special Health Care Needs from 2009/2010. Multi-level, random-intercept logistic regression models assessed the relationship between Medicaid waivers and unmet mental health care needs and cost barriers to treatment for youth with SED.

Results indicate that states use many strategies for funding and organizing care for the non-Medicaid eligible population of youth with SED, but that strategies generally involve the allocation of state general revenue funds or the use of a policy that expands the financial eligibility limits of Medicaid for children. Reasons for the use of each approach are most related to the size and flexibility of Medicaid budgets, political prioritization of children and families, and political ideology related to the role of the state in providing for the welfare of children and families. The quantitative analysis found that policies expanding financial eligibility for Medicaid were related to reductions in cost-related barriers to treatment, even controlling for the mediating effect of these policies in changing the insurance status of children. However, the use of these policies and a child's coverage under public health insurance was not significantly predictive of reduced odds of having unmet mental health care needs. By controlling for the severity of a child's mental health care needs, and the interaction between their level of need and type of health insurance coverage, this analysis also highlighted the role of clinical severity in unmet treatment needs and barriers to care and the ways in which public insurance moderated this relationship.

This study concludes that, though states have many means of funding care for non-Medicaid eligible youth with complex behavioral healthcare needs and have various reasons specific to state environments for choosing a particular approach, states with policies that allow children to more easily access Medicaid appear to have fewer families experiencing cost barriers

to mental health services. However, these state policies do not address other, unknown barriers to obtaining mental health services for families in their states. Expansion of Medicaid eligibility for children can help to reduce unmet need due to financial obstacles but does not solve all problems related to service accessibility. Additional barriers to treatment access must be identified at the individual, organizational and policy levels for children with all levels of clinical need. Policies and practices aimed at reducing these must be identified and implemented in the manner most suitable and applicable to the unique political, fiscal, and structural concerns of each state and community. Then, these practices and policies must be rigorously evaluated for effectiveness in achieving equitable access to high quality and effective mental health treatment for all children with behavioral health concerns.

## **Dedication**

To my husband, John,

And my three children—

Grace, Henry, and Clark—

For their unending patience and support.

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## CHAPTER 1: INTRODUCTION

On December 14, 2012, twenty-year-old Adam Lanza walked into an elementary school in Newton, Connecticut and opened fire, killing 20 children and six adults before taking his own life. Two days later, a post entitled, “I am Adam Lanza’s Mother” went viral on social media. The post, first appearing on the blog The Anarchist Soccer Mom, was a mother’s personal account of her family’s struggle with her son’s significant behavioral healthcare needs and their difficulties in getting the help they needed. The author describes an incident in which her son threatened her with a knife, saying he would kill himself and her. Then she states,

*“When I asked my son’s social worker about my options, he said that the only thing I could do was to get Michael charged with a crime. ‘If he’s back in the system, they’ll create a paper trail,’ he said. ‘That’s the only way you’re ever going to get anything done. No one will pay attention to you unless you’ve got charges.’ I don’t believe my son belongs in jail.”* (The Anarchist Soccer Mom, October 14, 2012, [http://anarchistsoccermom.blogspot.com/2012\\_12\\_01\\_archive.html](http://anarchistsoccermom.blogspot.com/2012_12_01_archive.html))

Violence against others, or threatening harm towards oneself, is a not uncommon among youth with serious emotional disturbance (SED) who experience global impairments (Achenbach, 1966; Narrow et al., 1998; Williams et al., 2017). It is estimated that approximately 8 to 12% of all youth can be classified as SED (Costello et al., 2005; Kessler et al., 2005), but only approximately 5 to 6% of youth experience such significant symptoms and challenges (Williams et al., 2017). Such children are distinct from the general population of youth with mental health concerns; In addition to a psychiatric diagnosis, the severity of their symptoms impairs their functioning in school, home, or the community. Often, their potential to harm themselves or others places them at risk for chronic or long-term placement in a residential setting in either a psychiatric, correctional, or foster placement (Hansen et al., 2004; Knitzer & Olson, 1982; Narrow et al., 1998). Children and adolescents with this level of impairment need more than outpatient therapy and medication management to remain stable in their communities. Often, intensive Home and Community-Based Services (HCBS)—including in-home therapy, case management, therapeutic behavioral support services—can help to maintain them safely in the home (Kernan et al., 2003; Marcenko et al., 2001).

However, only 25% of youth with SED ever access any outpatient mental health care (Costello et al., 2005, 1998), and even fewer obtain in-home support (Spiker, 2017). Many families cite expense and lack of sufficient health coverage as barriers to service use (Owens et al., 2002; Spiker, 2017). Private insurance usually only provides limited coverage for outpatient therapy and medication management. While these may be sufficient for children with mild to moderate mental health concerns, uninsured families and families with private insurance are often unable to access the home and community-based treatment needed for youth with more severe behavioral concerns (Bailey & Davis, 2012; Howell, 2004). In fact, the only type of health coverage that routinely covers HCBS is Medicaid (Howell, 2004), leaving these services mostly inaccessible to families whose incomes are above the Medicaid means-test limits. In order to access public health insurance to fund the intensive mental health care needed for their child, many parents relinquish custody to the state—either through the child welfare or juvenile justice system (U.S. Government Accountability Office, 2003).

This is why the Anarchist Soccer Mom, whose son was significantly impaired by his emotional disorder, was advised that her son would only receive the level of care he needed if

he became involved with the justice system; such involvement would place him into state custody, which would allow him to access Medicaid and mental health coverage it provides. However, if she had walked into a community mental health center anywhere in the state of Kansas and described her son's behaviors, she would have been connected to intensive, community-based mental health services within a week – at no cost, and with no request for her to have her son arrested or to relinquish custody. Because his behavior was posing a danger to himself and others, his impairments would have been considered significant and global. As such, he would have easily qualified for a form of Medicaid, called the 1915(c) Home and Community-Based Services SED Waiver (Friesen et al., 2003). The Kansas HCBS SED Waiver provides coverage for all community-based mental health services covered under Medicaid such as targeted case management, community psychiatric support treatment, attendant care, therapy, and psychiatry. It also provides additional services for youth with SED and their families: respite care, parent support, wraparound facilitation and independent living skill development.

Medicaid waivers are a policy intervention used in many states that reduce income barriers to care for youth with complex behavioral health care needs by allowing families to qualify for Medicaid based solely on the clinical need of the child and not on the families' income levels. Some waivers also provide coverage for additional services, not available to the rest of the Medicaid population, specific to the needs of youth with SED. Because such policies can reduce cost-related barriers to needed services for youth at high risk for outcome home placement, the Centers for Medicare and Medicaid Services (CMS) and the Substance Abuse and Mental Health Services Administration (SAMHSA) issued a joint informational bulletin in 2013 directing state policymakers to consider a variety of Medicaid policy options, including waivers, to design and implement a comprehensive benefit package for youth or young adults with complex behavioral healthcare needs (Mann & Hyde, 2013).

Though such policies are formally promoted by the federal government, limited evaluation exists regarding the use of Medicaid waivers to deliver HCBS to non-Medicaid eligible youth with SED and the extent to which these policies improve service access or treatment outcomes. A recent study comparing State Mental Health Authority reported outcomes between states that do and do not utilize Medicaid waivers demonstrated that a state's use of Medicaid waivers is linked to higher public mental health penetration rates (Graaf & Snowden, 2018). Limitations associated with this study include the potential for reverse causality—the possibility that states with higher penetration rates were opting to utilize Medicaid waivers to share the cost burden of having more youth with complex needs in their systems with the federal government. This study also did not account for non-waiver strategies states may use that are equally or more effective in delivering care to the SED population. Further, because penetration rates only capture the portion of youth who have come in contact with the public mental health system, this study's findings do not evaluate children's level of need or if those needs were being met more effectively in states with Medicaid waivers.

Such findings point to the need for a deeper understanding of the methods states use to structure and fund HCBS for non-Medicaid eligible youth with SED, and why state mental health administrations and Medicaid agencies use one particular strategy over another. Because outcome variables in any state may be affected by specific organizational, structural, and financial differences across state systems, as well as variance in the missions and service priorities of each state, disparities in outcome measures across states likely also reflect the complex systems surrounding those measures (Lutterman et al., 2003). Having knowledge of the variety of policy tools available to states and how states utilize these tools, as well as the factors

that increase the likelihood that a state will opt to use a particular tool, will allow future research to control for such variables, and better discern the effects of the policy on state mental health system outcomes. Highly targeted studies comparing state behavioral health policies are currently limited in number but are essential in identifying best practices in state mental health policymaking.

To more precisely assess the relationship between a state's use of a Medicaid waiver for youth with SED and access to mental health care, this two-part mixed methods study aimed to achieve the following:

Part I

- 1) Identify policy mechanisms utilized by states to deliver HCBS to youth with SED and their families, particularly for youth whose family income disqualifies them for Medicaid
- 2) Understand what motivates State Mental Health Authorities and Medicaid Agencies to utilize current policy tools and structures for HCBS delivery for both Medicaid and non-Medicaid eligible youth with SED

Part II

- 3) Controlling for variation in clinical severity of youth, assess the relationship between a state's use of a Medicaid waiver and the odds that youth with SED will have public health coverage
- 4) Controlling for variation in clinical severity of youth, assess the relationship between public health coverage and unmet mental health care needs and cost barriers to care for youth with SED
- 5) Controlling for variation in clinical severity of youth and for the mediating effects of public health coverage, assess the relationship between a youth's residence in a state with a Medicaid waiver and the odds that the youth will have unmet mental health care needs and experience cost barriers to care

Part I of this study gathered qualitative data through semi-structured interviews with officials from 32 state mental health systems about policy tactics for funding and delivering HCBS to Medicaid and non-Medicaid eligible youth with SED in their state. Interviews also gathered information about each state administration's motivation and history that shaped the use of current HCBS policies for this population. Part II of the study utilized data drawn from information and observations in Part I in conjunction with data from the National Survey for Children with Special Health Care Needs from 2009/2010. Multi-level, random-intercept logistic regression models assessed the relationship between Medicaid waivers and unmet mental health care needs and cost barriers to treatment for youth with SED.

## **Literature Review**

This study departs from most existing research on child mental health policy and service systems, which is primarily atheoretical research, by embedding this argument within system-oriented perspectives of mental health policymaking. To provide a conceptual framework for the study described above, the following section will review current knowledge and views of severe emotional disturbance in youth, the mental health service systems that serve the youth most significantly impaired, and the barriers to accessing needed services for this population. The role of Medicaid in funding and organizing home and community-based care for these youths will be reviewed, highlighting financial barriers to these services for non-Medicaid eligible youth.

Medicaid waivers, which help families of all income levels access Medicaid and its rich mental health benefits, will be introduced and described in detail. Using an open systems and resource dependent view of community mental health organizations, and political economic theories regarding state motivation for policy choices, the next section argues that the accessibility of intensive community-based services for youth with SED is influenced by the state level policies that support and shape mental health service delivery—and that these policies are shaped by complex historical, political, and economic factors specific to each state environment.

### **Severely Emotionally Disturbed Youth and their Families**

The majority of youth who utilize mental health services are not classified as severely emotionally disturbed (SED) (Mark & Buck, 2006). Severe or serious emotional disturbance (SED) is a term is used in a variety of federal statutes in reference to children under the age of 18 or 21 years with a psychiatric diagnosis who exhibits impaired functioning in at least one domain -- home life, school or vocational life, or community life (Costello et al., 1998). The term “SED” does not signify any particular diagnosis. Rather, it is “a legal term that triggers a host of mandated services to meet the needs of these children” (U.S. Department of Health and Human Services, Center for Mental Health Services, National Institutes of Health, & National Institute of Mental Health., 1999, p.46). Youth with SED can exhibit domain-specific impairment—which indicates “substantial disruption in role functioning secondary to a psychiatric disorder in at least one functional domain of family, peers, educational settings, or the community” (Williams, Scott, & Aarons, 2017, p. 2). Children with more severe SED may be impaired globally—which means their impairment is significant and manifests in two or more domains (Williams et al., 2017). Though exact definitions and criteria for determining SED vary across settings and locations, and estimates of SED can fluctuate as definitions change (Narrow et al., 1998; Ringeisen et al., 2016), it is believed that youth with SED represent approximately 8 to 12% of all youth in the United States (Costello et al., 2005; Kessler et al., 2005; Williams et al., 2017). Youth with SED with global impairments represent approximately 5 to 6% of the population.

This study is concerned with youth who have global impairments because they have the most substantial specialty mental health treatment needs (Kernan et al., 2003; Marcenko et al., 2001). For these youth, the inability to function in the home, school, or community environment is often seen in the form of problems related to impulse control, resulting in negative externalizing behaviors such as getting into fights, destroying property, or using illegal substances (Achenbach, 1966; Marcenko et al., 2001). Internalizing behaviors can also create clinical impairment in youth with SED who engage in self-mutilation, social withdrawal and somatic complaints due to depression or anxiety, or disordered or bizarre thinking, including hallucinations or delusions (Achenbach, 1966; Marcenko et al., 2001). These youth often have histories of physical or sexual abuse (Fields & Ogles, 2002) and are at high risk for hospitalization (Teich, Buck, Graver, Schroeder, & Zheng, 2003), self-harming, and delinquency (Fields & Ogles, 2002; Greenbaum et al., 1996; Vidal, Steeger, Caron, Lasher, & Connell, 2017). Youth with SED are more likely to drop out of school (Garcia et al., 2017; Porche, Fortuna, Lin, & Alegria, 2011; Rylance, 1997), may have difficulty achieving stability in secondary education and vocational settings (Rylance, 1998; Zigmond, 2006), and have increased risk of substance use (Greenbaum & Dedrick, 2007; Wu et al., 2008) and criminal justice involvement (Greenbaum et al., 1996; Mordre, Groholt, Kjelsberg, Sandstad, & Myhre, 2011). For these reasons, such youth at much greater risk of being placed outside of the home through placement



in the child welfare or juvenile justice system, or in a psychiatric residential treatment facility (Greenbaum et al., 1996; Hansen et al., 2004; Hill, 2017; Narrow et al., 1998).

Families of these youth are also impacted by their child's struggles with SED. Parents and caregivers report great strain, especially in the form of grief, depression, and anxiety (Corliss, Lawrence, & Nelson, 2008; Heflinger & Taylor-Richardson, 2004; Richardson, Cobham, McDermott, & Murray, 2013). They express concerns for their own safety and that of other siblings in the home (Corliss et al., 2008; Friesen, 1989). Parents identify emotional support to be a key resource (Friesen, 1989), but many families with children with SED report few social supports (Kernan & Morilus-Black, 2010). Caregiver stress for these parents seems to diminish as parents gain more social support and a greater sense of efficacy in their ability to provide structure, enforce limits and use basic behavioral modification skills (Corliss et al., 2008; Preyde et al., 2015).

### **Home and Community-Based Services (HCBS)**

Historically, youth with global functional impairments--cognitive, physical or behavioral—were served primarily in public or private institutions (Lourie & Hernandez, 2003). But, residential care has been found minimally effective at long-term reduction of symptoms, is more costly than community-based care (Barth et al., 2007; Hoagwood & Cunningham, 1992; Sovereign, Van der Helm, & Stams, 2013), and many critics raise concerns about iatrogenic effects (Dishion, McCord, & Poulin, 1999; Pumariega, 2007) and the lack of family involvement in treatment (Molin & Palmer, 2005; Sharrock, Dollard, Armstrong, & Rohrer, 2013).

In 1973, the passage of the Rehabilitation Act required that Medicaid and State Mental Health Authorities overseeing federally funded programs cease segregating individuals with disabilities when delivering services. Though this mandate included behavioral health service delivery, problems in the isolation of mentally ill youth did not come under scrutiny until 1982, when a critical report from The Children's Defense Fund garnered national attention. The report asserted that "that public agencies with responsibility for disturbed children and adolescents are spending money on these children too late and often inappropriately. Preventive or intensive community-based services are in scarce supply. Overreliance on costly institutional and residential care is the norm" (Knitzer & Olson, 1982, p. vii).

Today, because confinement is disruptive, expensive, and rarely meets the standard of "least restrictive alternative" set out by the Education for Handicapped Children Act (1975), residential interventions are less favored by mental health professionals and families. But children with SED—especially those with severe impairments—need access to intense services and supports to be maintained in the home (Kernan et al., 2003; Marcenko et al., 2001). Research has demonstrated that intensive community-based care alternatives can have equal or greater outcomes than residentially provided services, at a lower cost to governments (Barth et al., 2007; Shepperd et al., 2009; Snyder, Marton, McLaren, Feng, & Zhou, 2017; Urdapilleta et al., 2013). For children exiting institutional care, family engagement in post-discharge treatment planning and other community-based mental health services has been linked to reduced risk of hospital readmission (James et al., 2010; Romansky, Lyons, Lehner, & West, 2003; Trask, Fawley-King, Garland, & Aarons, 2016) and increased functioning in home, school or community settings (Barbot et al., 2015; Hoagwood & Cunningham, 1992; McNulty, Williams-Deane, & Evans, 1995).

Because impairment for the most complex youth manifests in multiple domains—school, home, community—a child may receive community-based interventions through many service

sectors at one time. This can include the child welfare system, the juvenile justice authority, or in special education settings (Garcia et al., 2017; Grape, Plum, & Fielding, 2014; Hansen et al., 2004). For this reason, the Knitzer and Olsen conclude the 1982 report, asserting, “It is not enough to develop a range of nonresidential, residential, and case advocacy services for children. These services must be organized so individual children can move easily from one to another depending on their age and needs, and so multiple services can be delivered to children, adolescents, and families in a way that is helpful rather than confusing or overwhelming. We have called such coordinated services ‘systems of care’” (Knitzer & Olson, 1982, p. 48).

Federal agencies responded to Knitzer and Olson’s report by establishing the Child and Adolescent Service System Program (CASSP) in 1984. This legislation provided funding and technical assistance to all 50 states to begin the establishment of systems of care in communities across the country. Under CASSP, national efforts also established a clear description of what Knitzer and Olsen’s proposed system of care should look like: “A system of care is a comprehensive spectrum of mental health and other necessary services which are organized into a coordinated network to meet the multiple and changing needs of severely emotionally disturbed children and adolescents” (Stroul & Friedman, 1986, p. iv). Technical assistance specified that a system of care should seamlessly surround a family with a variety of services across sectors, including mental health, education, healthcare and social services. Among many other services described, services for SED families might include any or all of the following interventions: assessment, outpatient treatment, home-based services, day treatment, emergency services, therapeutic foster care, therapeutic group care, therapeutic camp services, independent living services, residential treatment services, crisis residential services, inpatient hospitalization, case management and respite care.

When implemented fully, the systems of care framework for services has been found to be an effective way of improving clinical functioning and stabilizing the child in their home (Anderson, Wright, Kelley, & Kooreman, 2008; Barbot et al., 2015; Painter, 2012; Vidal et al., 2017). A widely cited study examined the effects of participating in a comprehensive system of care for military families in Fort Bragg, using military families in accessing usual care as a control group. Families receiving services through a continuum of care had gains in clinical functioning and reductions in family burden equal to the control group, and received services faster, in less restrictive settings, stayed in treatment longer, and expressed greater overall satisfaction with services than families and youth in usual care (Bickman, 1996; Bickman et al., 2004).

Wraparound is one specific model for treatment planning and coordinating services within a system of care. Emerging in the 1980s as a model for serving youth with SED at high risk for institutionalization (Winters & Metz, 2009), wraparound is a strengths-based “collaborative process for developing and implementing individualized care plans for children with severe disorders” (Walker & Bruns, 2006, p.1580). The process focuses on relying on the perspectives of the client and their family in determining the needs of the youth and the appropriate goals included in the plan of care. Engaging natural support systems in the family’s environment to participate in the goals and activities of the treatment plan is also emphasized. The evidence base for wraparound, though still emerging, is optimistic. In scholarly examinations of wraparound interventions, youth with SED involved in community-based wraparound services demonstrated improved role performance in school and the community, reductions in externalizing problem behavior and thought problems, and an improvement in overall functioning (Clark et al., 1998; Evans, Armstrong, & Kuppinger, 1996; Evans,

Armstrong, Kuppinger, Huz, & McNulty, 1998). Families also report high levels of satisfaction with services (Martin, Petr, & Kapp, 2003). A meta-analysis of 7 wraparound evaluations, all of which compared the treatment group with a control group, found an overall moderate positive effect for wraparound participants, based on improvements in functioning in multiple domains, improvements in youth living placements and juvenile justice involvement, as well as mental health outcomes (Suter & Bruns, 2009). A recent examination also concluded that youth participation in wraparound was associated with reduced public spending for outpatient and inpatient mental health care (Snyder et al., 2017).

Other services often provided within a system of care for children with significant and global behavioral health impairments include case management, therapeutic behavioral support services, respite care, and youth and peer support services. Case management has been demonstrated to be instrumental in maintaining youth in mental health services and reducing their use of crisis and emergency services (Bender, Kapp, & Hahn, 2011; Burns, Farmer, Angold, Costello, & Behar, 1996; Snowden, Masland, Wallace, & Fawley, 2009; Wagner, Mildred, Gee, Black, & Brann, 2017), and therapeutic behavioral support can help to reverse increasing trends in mental health crises (Cordell, Snowden, & Hosier, under review). Working with peer support has been demonstrated to increase youth and parent engagement in treatment planning and satisfaction with services (Gopalan, Lee, Harris, Acri, & Munson, 2017; January et al., 2016; Radigan, Wang, Chen, & Xiang, 2014; Simmons, Batchelor, Dimopoulos-Bick, & Howe, 2017), and use of respite can relieve stress and increase coping for parents and caregivers of children with complex healthcare needs (Strunk, 2010; Welsh, Dyer, Evans, & Fereday, 2014).

### **Barriers to Home and Community-Based Services**

Though the federal government and states have invested heavily in developing community-based mental health systems over the last 35 years (Cooper et al., 2008), approximately 70 to 80% of youth with SED go without any mental health treatment (Costello et al., 2005, 1998; Merikangas et al., 2011; Sheppard, Deane, & Ciarrochi, 2017). Further, even if youth with SED are accessing basic outpatient services (e.g., medication management, outpatient therapy), it is common for families to be unable to access additional needed services such as parent support or case management (Jenson, Turner, Amero, Johnson, & Werrbach, 2002; Owens et al., 2002; Sheppard et al., 2017). Youth with more severe impairments, especially externalizing problems, are more likely to obtain care (Banta, James, Haviland, & Andersen, 2013; Smith, Kyle, Daniel, & Hubbard, 2017; Watson, Carlson, & Magen, 2017), but Black and Latinx children are less likely to access services (Banta et al., 2013; Lu, 2017; Zimmerman, 2005). Closer proximity to mental health services increases the chances that a child will access treatment (Cherry et al., 2017; Cohen, Calderon, Salinas, SenGupta, & Reiter, 2012; Pullmann, VanHooser, Hoffman, & Heflinger, 2010).

Obstacles to accessing mental health care for children stem from the continuing existence of various sources of uncoordinated care. Getting mental health services for a child might involve consulting doctors, psychiatrists, community-based therapists, schools specialists, or occupational therapies – all of which may or may not be covered by public or private insurance (Cooper et al., 2008; Farmer, Burns, Phillips, Angold, & Costello, 2003; Grape et al., 2014; Smith et al., 2017). Specialty mental health services such as care coordination and parent support can help families to navigate these complex systems and increase family engagement in care (Bender et al., 2011; K. Miller, 2014; Whittaker, Cox, Thomas, & Cocker, 2014).

Unfortunately, care coordination or case management is often inaccessible, especially for families with commercial insurance which limits access to specialty mental health care (Burns et al., 1997; Cherry et al., 2017; Kataoka, Zhang, & Wells, 2002; Robinson et al., 2017; Zimmerman, 2005). After the advent of mental health parity legislation, private insurance now provides moderately adequate coverage for outpatient therapy or psychiatric medication management, but these carriers still provide limited to no coverage for home and community-based services, including case management, respite, behavioral support or parent peer support (Bailey & Davis, 2012; Barry & Busch, 2008). While outpatient services may be sufficient youth with mild to moderate SED—those experiencing impairment is only one life arena—youth with global impairments may be less able to meet their mental health care needs through outpatient care alone. Because costs for specialty care are significant for those with private health coverage (Rowan, McAlpine, & Blewett, 2013; Walter, Yuan, & Cabral, 2017), a recent study found that children with no insurance and public insurance were more likely than those with private insurance to receive care (Lu, 2017). Ringel & Sturm (2001) find that “adolescents on public insurance plans have higher rates of mental health service use than their privately insured peers.” (p. 321). In fact, only 18% of children with private insurance, and 10% of youth with no insurance access any mental health services, compared to 44% of children with Medicaid coverage who access mental health care (Howell, 2004).

### **Public Funding for Home and Community-Based Mental Health Treatment**

Because of the limits placed on specialty mental health care by private insurers, children with significant, globally impairing SED can more easily access intensive community mental health services through Medicaid coverage. “Through a combination of mandated benefits (inpatient care; outpatient care; and Early and Periodic Screening, Diagnosis, and Treatment, or EPSDT) and optional benefits (inpatient psychiatric care, prescription drugs, rehabilitation, and various types of case management), Medicaid provides very comprehensive coverage for mental health services, especially compared with most private insurance plans.” (Howell, 2004, p. 2). In fact, Medicaid is now the fastest growing source of funding for mental health services (Shern, Surles, & Waizer, 1989; White & Draper, 2004); Between 1997 and 2001, state match and federal Medicaid funds for mental health programs increased by 69%, while state budgets alone only increased approximately 19% (National Association of State Mental Health Program Directors Research Institute [NRI], 2004).

Further, because state and local governments often shape their mental health policies to maximize the draw-down of Medicaid dollars, federal support for the wraparound and systems of care model has encouraged many states and counties to use this Medicaid mandate and funding to shape and finance the provision of community-based systems of care (Bazelon Center for Mental Health Law, 1999; Ireys et al., 2006). This has resulted in many states creating Medicaid billing codes for services such as Wraparound Facilitation, respite care, independent living skill development or case coordination (Ng, Stone, & Harrington, 2015; Schlenger, 1992), and shaping the managed care programs that enable access to these services around systems of care principles (Stroul, Pires, Armstrong, & Zaro, 2002; Wright, Kooreman, & Anderson, 2014)

As the role of Medicaid expands in financing and shaping public community-based mental health services, the original model of community-based, block-grant funded mental health care is fading. Increases in the use of Medicaid dollars to fund and organize mental health

care systems have been accompanied by a decline in state-funded mental health safety net programs, especially those for the uninsured or non-Medicaid eligible population (Cooper et al., 2008; Frank, Goldman, & Hogan, 2003; Howell, 2004). "...Medicaid is increasingly absorbing costs from other state and locally financed sectors that had provided mental health services to children. The education, child welfare, and public mental health sectors, in particular, have enrolled more of their client children in Medicaid programs, to bring federal as well as state and local money into the financing for mental health services" (Howell, 2004, p. 2). The resources Medicaid is absorbing from the other public mental health programs that provide service for free or on sliding scale, combined with its cumulative prominence and influence in public mental health policy, may be increasing consumers' reliance on it to obtain services.

**Non-Medicaid eligible youth with SED.** Though Medicaid coverage is more common among youth classified as SED compared to mental health service users who are not SED, only about one third of children with SED are covered by Medicaid; 30 to 40% are covered by private insurance (Mark & Buck, 2006), and private coverage remains deeply inadequate (Howell, 2004; Ringel & Sturm, 2001). In 1998, over eleven billion dollars was spent on mental health-related costs for children, and a relatively large portion of specialty mental health care costs, such as HCBS, were not covered by private insurance (Ringel & Sturm, 2001).

Because 1) HCBS is costly and not covered by private insurance, 2) the household income of many families is too high to qualify them for Medicaid, and 3) waitlists are long for the shrinking supply of safety net mental health services (Bazelon Center for Mental Health Law, 1999; Ireys et al., 2006), many families are faced with difficult choices. After exhausting their private insurance plans and discovering that they do not qualify for public insurance or can't access appropriate safety net programs, some turn to the child welfare or juvenile justice system to obtain Medicaid coverage for their children, sometimes relinquishing custody of their child in this process (Friesen et al., 2003; Hill, 2017). In 2003, the General Accounting Office reported that in 2001 over 12,000 children in 19 states were transferred into state custody when families could not qualify for Medicaid and were desperate to obtain mental health services for their child. Such a practice can have damaging consequences for families, as parents give up the right to participate in decision making regarding their child's well-being, care and treatment (Giliberti & Schulzinger, 2000; McManus & Friesen, 1986).

## **Mental Health Systems as Open Systems**

For most community mental health organizations (CHMCs), questions of who receives how much of which services, and how much they will cost are shaped profoundly by agency funding streams—which are greatly dictated by state and local Medicaid and mental health policy. The influence of funding mechanisms and governance policies on a mental health organizations' ability to provide accessible mental health interventions to all youth with SED suggests the use of systems and resource dependent views of organizations when investigating questions of service access.

Mental health organizations are resource dependent, in that their actions are shaped by their level of dependence on external resources (Pfeffer & Salancik, 2003). As such, the greater an organization's dependence on external forces, the less autonomy the organization has. Public mental health organizations are entirely dependent on external organizations for resources. Thus, they have limited autonomy in deciding how they will provide mental health services to their community. In particular, because they rely on external sources of funding to pay for the services

they provide to most of their consumers (Buck, 2003), they must provide access to specific services in a manner consistent with the expectations and guidelines set forth by their funders.

The reality of this complexity suggests the use of an open systems perspective of community mental health organizations. The open systems perspective calls for the examination of the organization in the context of the multiple systems surrounding it, and how all relevant systems interact at multiple levels. An open systems view considers the organization to be made up of multiple levels of interdependent and interactive parts, which self-regulate in response to stimuli and input from its environment (Scott & Davis, 2006). Thus, to understand how and why mental health organizations deliver services in a particular way, and how that shapes consumer access to services, one must also examine the political, fiscal and administrative systems that exist at the local, state and federal level. "In essence, the rationale for adopting a systems perspective is that competing variables in multilevel systems often account for program failure. Identification and manipulation of these implementation variables from a systems perspective is, therefore, a prerequisite for program success" (Bernfeld, Blase, & Fixsen, 1990). Because 1) CMHCs are particularly resource-dependent on third-party payers, and 2) most services for youth with SED are financed by Medicaid or the State Mental Health Authority (SMHA), 3) and Medicaid and the SMHA is administered and governed by state officials, it is essential to examine the governing structures and funding mechanisms that surround public services for youth with SED at the state level. Critical policy levers affect a CMHC's ability to allow access to HCBS for all youth with SED—HCBS policies and Medicaid or SMHA policies regarding eligibility for services, funding and fee structures, and access and credentialing standards that affect the community-level supply of mental health providers and wait times for services.

### **Medicaid HCBS Policies**

Over the last 40 years, developing federal legislation has played a key role in developing multiple policy options for states to use to increase access to home and community-based services for individuals with a variety of complex care needs. Specifically, growing concerns about the exorbitant costs of long-term care has prompted revisions of Medicaid to fund fewer residential and institutional services and increase funding for Home and Community-based Services (HCBS). One strategy has been to establish HCBS Medicaid waivers or State Plan Amendment (SPA) options that allow states to expand their Medicaid plans for special populations. These policies, aimed at individuals with complex medical needs, allow states to provide Medicaid coverage for intensive in-home support services such as personal care services, case management, or in-home therapies, to prevent the disabled from needing institutional care. Several types of Medicaid waivers and plan options have been used, across many states, to deliver intensive community-based services to youth and adults with complex medical or mental health needs. States offer waivers and option participation to individuals with limiting physical, cognitive and psychological disabilities, including autism, developmental delays, traumatic brain injuries, and severe mental health disorders so that they can access intensive support services while living in the community, rather than in a residential setting. Qualification for most of these waivers rests on the recipient demonstrating a level of clinical need that would otherwise require long-term residential care.

In an effort to keep families together, many states have enacted HCBS Medicaid waivers and state plan amendment options to increase access to community-based public mental health services for youth with SED. Such policies waive or expand the means tests for parents' income and use a combination of an assessment of the child's clinical need and a means test based on the

child's personal assets alone to determine eligibility for publicly funded HCBS. Some waivers and SPAs also allow states to deliver additional specialized, Medicaid-funded services specific to the needs of the target population, including wraparound, respite care, or youth and parent peer support for youth with SED and their families.

Though all types of waivers and some state plan options eliminate or expand the traditional means tests for parents attempting to access publicly funded community-based mental health care for their child, notable differences across these waivers and plans exist. Significant differences can be observed in participant eligibility, services provided, the capacity of the waivers (how many "slots" or participants allowed at one time), and the level of state burden in implementing each type of waiver. These are reviewed in more depth in Table 1 below (Graaf & Snowden, 2017).

**Table 1. Medicaid Waiver Description and Comparison**

Medicaid Waiver Type (Year Effective)	Brief Description	Medicaid Eligibility Criteria	Requires Institutional Level of Care?	SED/Mental Health as Disability	Provides specialized SED Services?	Requires Federal Application and Approval?	Limited Number of “slots”?
TEFRA Waiver (1982)	The Tax Equity and Fiscal Responsibility Act (TEFRA), also known as the Katie Beckett Option, created the TEFRA Medicaid Eligibility Option which allowed states to expand Medicaid coverage to children with severe disabilities, regardless of parental income.	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.	Yes	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	No	No	No
1915(c)HCBS Waiver (1980)	In order to offer this program to their residents, States must apply to CMS for approval, and 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.	The HCBS SED waiver bases eligibility for services and coverage 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. The means test for parental income eligibility is waived or expanded. Some states include a special income group of individuals with income up to 300% of SSI,	Yes	Yes	Yes	Yes, State must demonstrate comparable or lesser costs for HCBS services than for institutional services.	Yes



		and some states waive the means test altogether.					
1915(c) HCBS PRTF Waiver (2005-2012)	In 2005, Congress authorized a 5-year demonstration project to examine whether youth normally served in psychiatric residential treatment facilities (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.	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.	Yes	Yes	Yes	Yes - Federal Demonstration	Yes

Section 1115 (1990)	Under this section of the Social Security Act, the Secretary of Health and Human services can approve “experimental, pilot, or demonstration projects that promote the objectives of the Medicaid and CHIP programs. The purpose of these demonstrations, which give States additional flexibility to design and improve their programs, is to demonstrate and evaluate policy approaches”	Currently, six states are implementing approved state-wide healthcare reforms under Section 1115 waivers, and all of these demonstration projects include some means of expanding publicly funded home and community-based services to disabled children and adults. The state defines eligible categories and may expand eligibility but may not add new Medicaid eligibility group(s).	No	Yes	Varies Across States	Yes	Varies Across States
1915 (i) State Plan HCBS (2007, Revised 2012)	Provides HCBS to individuals who require less than institutional level of care and who would therefore not be eligible for HCBS under 1915(c). May also provide services to individuals who meet the institutional level of care. Does not require proof of cost-neutrality.	All individuals eligible for Medicaid under the State plan up to 150% of Federal Poverty Level can participate. Additionally, the plan can include special income group of individuals with income up to 300% SSI. However, these Individuals must be eligible for HCBS under a §1915(c), (d), or (e) waiver or §1115 demonstration program.	No	Yes	No	No, but state plan amendment must be submitted to CMS. Also, does not require that the state demonstrate an equal or lesser cost for HCBS than for institutional services.	

1915(k) Community First Choice Option (2011)	Provides a new State plan option to provide consumer-controlled home and community-based attendant services and supports. Provides a 6% FMAP increase for this option. Does not require proof of cost-neutrality.	Individuals eligible for Medicaid under the State plan up to 150% of Federal Poverty Level may participate. Families with income greater than 150% of the FPL may use the institutional deeming rules (usually 300% of SSI income), but such participants must already be receiving at least one §1915(c) HCBS waiver service per month. All participants must need an institutional level of care.	Yes	Yes	No	No, but state plan amendment must be submitted to CMS.	
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*From Graaf & Snowden, 2017. A more detailed comparison of Waivers can be found in a chart by Cooper, Flanagan & Crisp's (2014) Comparative Analysis of Medicaid HCBS (1915 & 1115) Waivers and State Plan Amendments, which can be found at [http://www.nasdds.org/uploads/documents/Medicaid\\_Authorities\\_Comparison\\_Chart\\_1.pdf](http://www.nasdds.org/uploads/documents/Medicaid_Authorities_Comparison_Chart_1.pdf).*

**1915(c) Medicaid waivers.** Following the Rehabilitation Act of 1973, requiring that Medicaid and State Mental Health Authorities overseeing federally funded programs discontinue segregation of individuals with disabilities through service delivery, including through institutionalization, Congress amended Medicaid law to incent states' provision of home and community-based services. In the Omnibus Budget Reconciliation Act of 1981, the Social Security Act was amended through section 1915 to allow states several new policy mechanisms for keeping youth with SED in their homes and families intact. Section 1915(c) allows the Center for Medicaid and Medicare Services (CMS) to waive specific Medicaid statutory limitations, allowing states to provide home and community-based services for individuals with disabilities that would otherwise require an institutional-level of care.

**The SED waiver.** The 1915(c) HCBS waiver has been used extensively by states to increase home and community-based services for children with developmental disabilities, but far less often for children with serious mental health treatment needs (Ireys et al., 2006). This waiver allows states to waive the "limits on the amount, duration and scope of Medicaid services, thereby enabling the state to offer specialized intensive HCBS not available through mandatory or optional Medicaid services or through other state or county programs" (Ireys et al., 2006, p. 12). Less than ten states have applied for and been approved to use a Medicaid waiver program under 1915(c) for children with SED (Centers for Medicaid and Medicare Services, 2013). In these states, the HCBS SED waiver allows families of middle income to access Medicaid-covered, intensive community-based services for their mentally ill children, as well as additional specialized services specifically for the most severe SED children.

In order to offer the 1915(c) HCBS program to their residents, states must apply to CMS for approval, and 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 (Friesen et al., 2003). Applications also include a state's proposal of the additional specialized services that will be offered only to youth on the waiver, as well as the number of "slots" available at any given time and over the course of each year. Information from state applications is used in Table 2 to describe differences in HCBS 1915(c) SED Waiver programs across states (Graaf & Snowden, 2017).

**Table 2. 1915(c) HCBS SED Waivers by State**

State	Year started	Total Waiver Families on Waiver at 1 Time	Total Waiver Families Served in 1 Year	Income Eligibility	Services Provided
Iowa IA Children's Mental Health (0819.R01.00)	2010	1237	1570	Income Level Up to 300% of SSI	Provides family and community support service, respite, environmental mods and adaptive devices, in-home family therapy for children w/SED ages 0 – 17
Georgia Community-based Alternatives for Youth (01.R02.00)	2012	NA	Year 1- 450 Year 2 – 225 Year 3 – 0 Year 4 – 0 Year 5 - 0	Waives means test for parents	Provides behavioral assistance, care management, clinical consultative services, respite, supported employment, community transition, customized goods and services, expressive clinical services, family peer support, financial support, waiver transportation, youth peer support for individuals w/mental illness ages 18-21 and w/SED ages 4-17
Kansas KS SED (0320.R03.00)	1997	NA	Year 1- 7192 Year 2 – 8486 Year 3 – 10014 Year 4 – 11816 Year 5 - 13943	Waives means test for parents	Provides attendant care, independent living/skills building, short term respite care, parent support and training, professional resource family care, wraparound facilitation, for individuals w/SED ages 4-21
Louisiana LA Coordinated System of Care - SED Children (0889.R00.00)	2012	NA	Year 1- 1200 Year 2 – 1200 Year 3 – 2400* Year 4 – 2400 Year 5 - 2400	Income Level Up to 300% of SSI	Provides crisis stabilization, independent living/skills building, parent support and training, short-term respite, youth support and training for individuals w/SED ages 0-17 and mental illness 18-21
Michigan MI Waiver for Children with Serious Emotional Disturbances	2005	NA	Year 1- 804 Year 2 – 969 Year 3 – 969 Year 4 – 969 Year 5 - 969	Waives means test for parents	Provides respite, child therapeutic foster care, community living supports, community transition, family home care training, family support and training, home care training-non-family, therapeutic activities, therapeutic overnight camping, wraparound for individuals w/mental illness SED ages 0-21
New York NY OMH SED	1999	Year 1- 1506 Year 2 – 1551 Year 3 – 1598 Year 4 – 1646	Year 1- 2259 Year 2 – 2327 Year 3 – 2397 Year 4 – 2468	Child must be on SSI, low income or be receive Title IV adoption assistance, foster care or kinship care, or non-Title IV adoptions assistance	Provides for crisis response, family support, individualized care coordinator (case management), intensive in-home, respite, skill building for individuals w/mental illness SED ages 5 – 21

		Year 5 - 1695	Year 5 – 2543		
New York Bridges to Health for Children with SED	2007	Year 1- 2619 Year 2 – 2619 Year 3 – 2619 Year 4 – 2619 Year 5 – 2619	Year 1- 3929 Year 2 – 3929 Year 3 – 3929 Year 4 – 3929 Year 5 – 3929	Child must be on SSI, low income or be receive Title IV adoption assistance, foster care or kinship care, or non-Title IV adoptions assistance	Provides day hab, health care integration, skill building, special needs community advocacy and support, accessibility mods, adaptive and assistive equipment, crisis avoidance and management and training, crisis respite, family/caregiver supports and services, immediate crisis response services, intensive in-home supports and services, planned respite, vocational services for individuals w/mental illness ages 19-20 and w/SED ages 0-18
Texas Youth Empowerment Services (YES)	2009	Year 1- 400 Year 2 – 400 Year 3 – 400 Year 4 – 400 Year 5 – 400	Year 1- 400 Year 2 – 800 Year 3 – 800 Year 4 – 800 Year 5 – 800	Income Level Up to 300% of SSI	Provides respite, adaptive aids and supports, community living supports, family supports, minor home mods, non-medical transportation, paraprofessional services, specialized therapies, supportive family-based alternatives, transitional services for individuals w/SED ages 3-18
Wisconsin Children's Long- Term Support SED Waiver	2003	NA	Year 1- 450 Year 2 – 225 Year 3 – 0 Year 4 – 0 Year 5 – 0	Waives means test for parents	Provides consumer education and training, day services, respite, support and service coordination, supported employment, supportive home care, consumer and family directed supports, FMS, adaptive aids, adult family home, children's foster care/treatment foster care, communication aids, community integration, consultative behavioral intervention, counseling and therapeutic services, daily living skills training, early intensive behavioral intervention, home mods, housing counseling, housing start up, mentoring, nursing, PERS, specialized transportation, specialized medical and therapeutic supplies for individuals with SED ages 0- 21
Wyoming WY Children's Mental Health	2006	75, each year	135, each year	Income Level Up to 300% of SSI	Provides family care coordination, respite, youth and family training and support for individuals w/mental illness ages 18-21 and for individuals w/serious emotional disturbance ages 4-17

From Graaf & Snowden, 2017. Centers for Medicaid and Medicare Services (2013). 1915(c) *Waivers by State*. Retrieved from <http://www.cms.gov/Outreach-and-Education/American-Indian-Alaska-Native/AIAN/LTSS-Roadmap/Resources/State-Federal-Relationships/1915c-Waivers-by-State.html>, July 22, 2015.

\* Numbers served reflect those proposed on the most recent application or amendment or renewal application, most of which are dated from 2009 onward

**The PRTF waiver.** Under 1915(c), states can only apply for SED waivers to serve youth that would otherwise be served in hospitals, not psychiatric residential treatment facilities (PRTFs), even though “PRTFs have become a major provider for children and youth with mental illness and serious emotional disorders requiring an institutional level of care. PRTFs are not recognized as hospitals, nursing facilities, or intermediate care facilities for individuals with intellectual disabilities under the Medicaid statute. Therefore, states have been unable to use the 1915(c) waiver authority to provide home and community-based alternatives to institutional care, which would keep children and youth in their homes and with their families or in the community” (Urdapilleta, et al., 2013, Executive Summary p. 1). In 2003, the New Freedom Commission on Mental Health highlighted this barrier for states attempting to expand community-based mental health systems. In response, in 2005, Congress authorized a 5-year demonstration project to examine whether youth normally served in psychiatric residential treatment facilities (PRTFs), those with the most severe symptoms, could be served more effectively and at a lower cost through community-based services. In this demonstration, PRTFs were deemed as facilities authorized in section 1915(c) of the Social Security Act, which allowed up to 10 participating states to receive matching Medicaid funds for services provided in the community as an alternative for youth that would qualify for PRTF admission. As such, the project used 1915(c) waiver authority, amending it slightly, to target youth who would not have been eligible for Medicaid-funded, intensive community-based services.

Similar to the HCBS SED waiver, the types and intensity of services varied broadly across the ten participating states. Three out of the ten states offer no formal case management or care coordination as part of the PRTF waiver, and only four of the demonstration states had formal wraparound services. While all states utilized some form of the wraparound approach, some states implemented wraparound services with high fidelity to the original model and other states implemented a version of wraparound, adhering only to the Core Principles set out by Bruns and colleagues in 2004. A few states offered peer support to parents and youth, while several states declined to include this in PRTF waiver services, and the type of respite offered to families was on an hourly basis only in some states while other states provided planned out of home respite placement.

A report to the President and Congress in 2013 regarding the PRTF demonstration project, outlined the details of the project, and highlighted promising outcomes: “Using a ‘systems of care’ approach, the Demonstration successfully enabled participants to either improve or maintain their functioning status at less than a third of the cost of serving them in an institution.... However, the children and youth with the highest levels of need consistently showed improved mental health status, less frequent interaction with law enforcement, better performance in school, reductions in substance abuse and better relationships with peers and family throughout periods measured during the project” (Urdapilleta, et al., 2013, p. 1). Since the end of the demonstration project, some states maintained their PRTF waiver as a “bridge” waiver, offering it only for those youth enrolled before the demonstration project ended. However, seven states expressed interest in pursuing a permanent waiver if the regulations under 1915(c) were expanded to include residential treatment facilities. At this time, one demonstration state, Mississippi, has sought and been approved for continuation under this program through 1915(c) authority. Two other states, Indiana and Maryland, have used SPAs to sustain the array of services developed under the demonstration program.

**Section 1115 waivers.** Another method states use to waive or amend the means test barrier to Medicaid is to seek approval from CMS for a Section 1115 waiver, which was also

included in the Social Security amendments approved in the Omnibus Budget Reconciliation Act of 1981. Under this section of the Social Security Act, the Secretary of Health and Human services can approve “experimental, pilot, or demonstration projects that promote the objectives of the Medicaid and CHIP programs. The purpose of these demonstrations, which give states additional flexibility to design and improve their programs, is to demonstrate and evaluate policy approaches” (Medicaid.gov, 2015). Projects can include expanding Medicaid eligibility, providing new services under Medicaid, or creating innovative health systems that can streamline service delivery. As of 2013, only six states had been approved for state-wide healthcare reforms under Section 1115 waivers, and all of these demonstration projects include some means of expanding publicly-funded home and community-based services to disabled children and adults. Brief descriptions of these plans are included in Table 3.



**Table 3. Examples of Section 1115 Waiver Demonstrations**

Hawaii	Hawaii's QUEST Integration program is a statewide section 1115 demonstration. The demonstration enables the state to operate QUEST, which provides Medicaid coverage for medical, dental, and behavioral health services through competitive managed care delivery systems. The QUEST program was designed to increase access to health care and control the rate of annual increases in health care expenditures. The demonstration also allowed the State to expand coverage beyond its Medicaid State plan. Through the demonstration, the state provides coverage to children and adults who are eligible under the Medicaid state plan as well as additional children and adults (including former adoption assistance children, certain parents, and certain individuals who receive home and community-based (HCBS) services). All beneficiaries are eligible for state plan benefits (or, in the case of the Affordable Care Act childless adult group, approved benefits under the alternative benefit plan) as well as additional services based on medical necessity and clinical criteria (including HCBS), provided through an integrated managed care delivery system.
New Jersey	New Jersey's new section 1115 demonstration entitled New Jersey Comprehensive Waiver (NJCW) is a statewide health reform effort that will expand existing managed care programs to include long-term services and supports and expand home and community-based services to some populations. This Demonstration builds upon existing managed acute and primary care programs and established provider networks. The 1115 Demonstration also combines under a single demonstration authority several existing Medicaid and CHIP waiver and demonstration programs, including two 1915(b) managed care waiver programs; a title XIX Medicaid and a title XXI CHIP section 1115 demonstration and four 1915(c) programs.
New Mexico	Centennial Care seeks to modernize the New Mexico Medicaid program to assure that the state is providing the most effective, efficient health care possible for its most vulnerable and needy citizens and to create a sustainable program for the future. This new demonstration creates a comprehensive service delivery system for the New Mexico Medicaid program that is as unique as the State and designed to provide beneficiaries the right care, delivered at the right time, in the right setting. The state seeks to develop and implement a service delivery system that not only integrates care now but ensures that the State can afford to continue the program in future years. The demonstration will enroll most New Mexico Medicaid beneficiaries and New Mexico Medicaid expansion Children's Health Insurance Program (CHIP) beneficiaries in managed care for a full range of services, including physical health, behavioral health and long-term services and supports (home and community-based services and institutional care). The demonstration consolidates [most] existing delivery system waivers into a single comprehensive managed care product.
Pennsylvania	This state-based program grants Medicaid coverage to more than 60,000 children of all incomes in Pennsylvania, including children with autism, developmental disabilities, and complex medical needs. As defined by Disability
Rhode Island	Target Population: All adults and children; provides additional services for children with special needs. Description: Replacement program for Rhode Island's Medicaid program. Includes home and community-based services as possible benefits.

Medicaid.gov ([http://www.medicaid.gov/medicaid-chip-program-information/by-topics/waivers/waivers\\_faceted.html](http://www.medicaid.gov/medicaid-chip-program-information/by-topics/waivers/waivers_faceted.html)), 2015

### **The Tax Equity and Fiscal Responsibility Act (TEFRA) Medicaid Eligibility Option.**

The Tax Equity and Fiscal Responsibility Act (TEFRA) Medicaid Eligibility Option is another Medicaid waiver, employed in 20 states. TEFRA, also known as the Katie Beckett Option, was created in response to the plight of a 3-year-old girl with complex medical needs. The family's income was too high to qualify for Medicaid, and the family could not otherwise afford to care for her at home. In 1982, The Tax Equity and Fiscal Responsibility Act (TEFRA) was passed by Congress and created the TEFRA Medicaid Eligibility Option which allowed states to expand Medicaid coverage to children with severe disabilities, regardless of parental income. Under TEFRA, 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. States are authorized to determine whether applicants meet the level of care requirement and cannot single out individual disabilities. TEFRA has an unlimited number of "slots" (i.e., the number of youth allowed to be receiving services under this waiver) for consumers that qualify, and provides the same coverage that Medicaid provides to income-based participants with no additional specialized services.

According to a 2004 survey, out of the 20 states using TEFRA options, only ten states allowed children to qualify based on a mental health disability diagnosis. 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 & Koyanagi, 2004). To implement other types of Medicaid waivers, states must seek and receive approval from the Centers for Medicare and Medicaid Services (CMS), must be monitored by CMS, and must apply for renewal every three to five years. In contrast, because TEFRA is a Medicaid option and not a waiver, states need only inform a regional CMS office that the option has been selected.

**State Plan Options.** The passage of the American with Disabilities Act in 1990, followed by the 1999 Supreme Court decision in the *Olmstead vs. L.C.* case spurred further legislative developments of options for states to receive federal support in developing and expanding community-based alternatives to institutional care for their most disabled populations. In 2005, under the Deficit Reduction Act (DRA) of 2005, the Social Security Act was amended to offer states a few more options for structuring HCBS for medically needy persons under the 1915(i) state plan benefit option. This option was amended under the Affordable Care Act (ACA) in 2010. The ACA also added the option for states to provide HCBS under the 1915(k) Community First Choice option. Though both options were not designed specifically for youth with behavioral or emotional disturbances—and both are so recently created that programs under these policies are just beginning to be implemented and evaluated—several states are in the process of expanding HCBS services for youth with SED under these options.

**1915(i) State Plan Option.** In 2005, the 1915(i) amendment enabled states to offer HCBS services to individuals without having to prove cost neutrality to CMS, and these services could be offered to individuals who are not at risk of institutionalization. Using 1915(i) plan amendments, which must be renewed every five years, states can delineate their own needs-based criteria, such as impairments in daily living activities or other risk factors, and eligibility can be limited to specific geographic areas, to categorically needy, and to specific services. This legislation was limited by the inability to target specific populations, and income eligibility limits of 150% of the federal poverty level—which is lower than the 300% of the SSI allowed in some 1915(c) waivers and for publicly-funded institutional care. Further, it did not require that states

offer the same benefit to all individuals in the state that are eligible for it, and states were allowed to impose enrollment caps.

Some of these restrictions were lifted under revisions enacted in the Affordable Care Act (ACA). After 2010, states were able to offer HCBS services under 1915(i) to individuals with incomes up to 300% of the FPL, but those individuals have to also be eligible for an existing 1915(c) or 1115 waivers, with similar income guidelines dictating the cost-sharing amounts for consumers receiving HCBS. The state could now target specific groups, establishing needs-based eligibility criteria for each specified group, as long as the state could demonstrate that they are less stringent than the requirements for institutionalization. Enrollment caps were lifted and required that HCBS be offered to eligible populations statewide. Under ACA, participants in 1915(i) plans can include categorically eligible individuals (e.g., those who qualify for SSI programs), and participants can receive full Medicaid benefits, expanding the type, amount, duration or scope of services offered, and specialized benefits could be offered to specific populations. Under this revision, services for the mentally ill can include case management, respite care, day treatment, partial hospitalization, psychosocial rehabilitation and outpatient clinic services, as well as additional services the state requests.

The Centers for Medicaid and Medicare Services does not currently provide a comprehensive listing of states utilizing 1915(i) options. However, some states report utilizing 1915(i) options to broaden the reach of HCBS for youth with SED on their websites. Among these states, though, significant differences exist. Indiana's program, Child's Mental Health Wraparound Services, is for youth ages 6 to 17 years of age who are eligible for Medicaid and present with at least two DSM diagnosis and severe impairments in functioning. If youth meet these criteria, they can receive additional Medicaid-funded services, including Wraparound Facilitation, Habilitation (aimed at enhancing youth functioning in life and social skills), Respite Care and Family Support and Training. In contrast, Maryland's Targeted Case Management: Care Coordination for Children and Youth program only includes the additional services of extensive targeted case management, but access to these services does not require prior Medicaid eligibility, and rests instead on the level of clinical need of the child and expanded means-test limits.

**1915(k) Community First Choice (CFC) State Plan Option.** Effective in 2011, under the ACA, the CFC option incents states to offer HCBS services to disabled individuals by offering an addition 6% in federal matching funds for Medicaid services. However, eligibility for these services requires that recipients be eligible for medical assistance under the state plan and have an income at or below 150% of the FPL. For those with incomes above that limit, eligible individuals must also meet the state's criteria for institutional services or be eligible for Medicaid under the state's HCBS 1915(c) waiver criteria and receive at least one waiver service per month. "The CFC scope of services allows for the acquisition, maintenance, and enhancement of skills necessary for the individual to accomplish tasks. Services may include the transition costs for moving from an institution to the home or community and other services to increase independence or substitute for human assistance" (Harrington et al., 2012, p. 173). Under CFC, the state must offer these services to all individuals who meet the eligibility criteria, with no geographic or specific target group limits. Again, The Centers for Medicaid and Medicare Services does not provide a comprehensive listing of states utilizing 1915(k) options, and though this option could be utilized to expand community-based services for youth with SED, the author does not currently know of any state utilizing this option for this population.

## The Medicaid Waiver Knowledge Base

Though 1915(c) waivers and TEFRA Medicaid options have existed for over thirty years, evidence is limited about their use for youth with complex behavioral health needs. Studies of TEFRA programs are almost non-existent. A singular study of children with special needs served under TEFRA in Minnesota observed 959 families with diverse special needs (almost 8% of the sample had a child with severe emotional disturbance) and represented wide demographic variation. These families incurred out-of-pocket health care costs nearly five times greater than families with no children with special health care needs. The study found that the TEFRA policy was instrumental in helping families finance acute and long-term care supports, which were normally either not covered under private insurance, or for which coverage came with high co-pays and deductibles. The study concluded that TEFRA was instrumental in Minnesota for reducing cost barriers to needed healthcare services (Chan, Jahnke, Thorson, & Vanderburg, 1998).

1915(c) waivers have been researched more broadly, perhaps because they are used extensively by states to increase access to HCBS for older adults, and individuals with physical, cognitive, or developmental disabilities. Across these programs, large variation exists across states in spending (Friedman, Lulinski, & Rizzolo, 2015; Kitchener, Ng, Miller, & Harrington, 2005), type and intensity of services provided to particular target populations (Friedman & Rizzolo, 2016; Harrington, Carrillo, Wellin, Norwood, & Miller, 2001; Ng et al., 2015; Rizzolo, Friedman, Lulinski-Norris, & Braddock, 2013), and the number of waiver participants, eligibility criteria, the use cost control measures (Kitchener, Ng, & Harrington, 2004; Ng et al., 2015), resulting in HCBS access disparities across states (Harrington, LeBlanc, Wood, Satten, & Tonner, 2002) and making evaluation and comparison of state programs challenging.

In spite of these complexities, 1915(c) waivers have been studied vigorously for the past two decades. In a study of a Colorado HCBS waiver program for individuals with traumatic brain injuries, participants had significantly fewer mental health and substance use problems, but poorer occupational and functional outcomes (Cusick et al., 2003). A study of HCBS waivers for elders found that participation in Medicaid HCBS waiver programs was related to reductions in inpatient hospital stays and nursing home stays (Mitchell, Salmon, Polivka, & Soberon-Ferrer, 2006). Several studies have also found that positive effects of participation in HCBS waiver programs are magnified by an increased volume of services and associated state spending (Cidav, Marcus, & Mandell, 2014; Mitchell et al., 2006; Sands et al., 2012). 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). Further, this review found that cost increases may be contained through capitated care and consumer-directed care models. More recently, and more relevant to children with complex behavioral or emotional needs, studies 1915(c) autism waivers demonstrated that participants were less likely to utilize inpatient or residential services, demonstrated improved daily functioning, and reduced caregiver burdens (Cidav et al., 2014; Eskow, Chasson, & Summers, 2015; Leslie et al., 2017). Further, a 2017 study of waiver programs for youth with autism found that Medicaid waivers decreased unmet care needs, especially for those who would not otherwise have qualified for Medicaid (Leslie et al., 2017).

Limited evaluation exists, however, regarding HCBS 1915(c) waivers specifically for youth with SED. A federal report suggests that, for several states, adopting an SED waiver has

expanded the array of community-based services available to youth with SED and their families, has allowed more families to access intensive mental health care in the community, and has fostered a level of interagency collaboration that supports a flexible and comprehensive system of care (Ireys et al., 2006). One state reported that youth on the HCBS 1915(c) SED waiver showed better outcomes than youth with Medicaid who were only receiving basic case management services; waiver recipients were more likely to maintain placement in the home, avoid contact with law enforcement and had better school attendance rates and grades than Medicaid youth (Friesen et al., 2003). A small 2007 study of New York state's HCBS waiver examined a sample of youth in the program from 1996 to 2002, using the program waitlist as a comparison group, and found that youth in waiver services were more likely to be maintained in the home, have lower hospitalization rates, and were less frequently removed from parents' custody or placed in institutional settings (Solhkhah, Passman, Lavezzi, Zoffness, & Silva, 2007).

In existing research, studies are loosely designed and focused primarily on identifying how participation in Medicaid waiver programs helped to improve functional outcomes for youth with SED. But Medicaid HCBS waiver policies were developed in order to increase access to intensive home and community-based care for individuals with complex medical needs, to provide care outside of residential facilities—with the expectation that functional outcomes would be similar or better than those achieved in residential care, and that quality of life would be better for program participants (Miller, Ramsland, Goldstein, & Harrington, 2001). And while some studies have examined the ways in which these policies increase access to HCBS for other medically complex populations (Cidav et al., 2014; Leslie et al., 2016; Ng et al., 2015), no research has examined the extent to which these programs increase access to intensive home and community-based mental health care for youth with SED.

Recent findings suggest that Medicaid waivers may increase access to mental health care for this population; a 2017 study examined the use of TEFRA options and 1915(c) waivers for youth with significant mental health care needs in relation to state-level public mental health penetration rates for children. This research found that a state's use of a Medicaid waiver or TEFRA option was associated with significant increases in public mental health system penetration rates, particularly for adolescents and teens, suggesting that such policies may be associated with increased mental health care access for these youth (Graaf & Snowden, 2017).

But this exploratory study was limited in several ways. First, this study does not specify the clinical needs of the youth in the study or if those needs are being met; it utilized statewide public mental health penetration rates as the dependent variable indicating system accessibility which only indicates if a youth touched the mental health system in a given year. Further, because this study did not control for individual family income levels or type of insurance coverage, it was not able to discern the differential effects of a Medicaid waiver for the families most likely to experience increases in access to HCBS from them: families with incomes above Medicaid eligibility limits and possibly with private insurance. Also, the positive relationship between use of Medicaid waivers and increases in penetration rates may have been muted because the study relied on publicly available information about a state's use of TEFRA or a 1915(c) waiver, and it did not account for other non-waiver state strategies for funding and organizing community-based mental health treatment for non-Medicaid eligible youth that may equally increase access for these families. Finally, these findings were limited by the potential for reverse causality: states with higher youth mental health system penetration rates may be more likely to seek a Medicaid waiver or TEFRA option as a means of shifting some of the cost

burdens of serving these youth to the federal government by expanding the use of Medicaid in funding their care.

**HCBS waiver adoption.** State motivation for adopting a waiver—or for choosing to use one particular HCBS policy over another—may relate to latent variance across states, in policy creation or implementation, which is unobservable at the policy level but may influence outcomes of state programs for youth with SED. For example, in a state in which political ideology favors ideas of self-reliance and authoritative approaches to youth development, behavioral or emotional disorders in children may be de-emphasized. In such states, community-based systems of care for children may exist but be under-funded and under-developed, but juvenile justice systems may be financially robust and policies may support harsher sentencing for juvenile offenders. Thus, the allocation of funding and the related infrastructure and policies for youth public programs—which may stem from historical precedents and political deal-making—may have an equal or greater impact on youth outcomes than behavioral health or Medicaid policy itself.

Several scholars have made efforts to understanding state variation in Medicaid policy choices. Most recently, drawing from the work of several prior studies examining Medicaid investment in the context of the supply and demand of funding and consumer markets (Barrilleaux & Miller, 1988; Grogan, 1994; Jacoby & Schneider, 2001), researchers have attempted to understand the factors that influence a state's level of investment in HCBS and their propensity to accept the expansion of Medicaid under the Affordable Care Act. Several conclude that the decentralization of Medicaid decision making has placed greater influence on the demands of key local stakeholders and the desires of legislators. These policymakers, seeking to maximize their utility by responding to the demands of voters and interest groups, increase the supply of services as much as possible while minimizing state spending (Grogan, 1994; Merryman, Miller, Shockley, Eskow, & Chasson, 2015; Miller et al., 2005; Miller & Kirk, 2016; Thompson, Cantor, & Farnham, 2016). Other demand-side factors, such as high economic need, the professionalism of policymakers, and low initial investment in Medicaid spending are influential (Barrilleaux & Miller, 1988; Jacobs & Callaghan, 2013; Miller et al., 2005; Miller & Kirk, 2016; Vanneman & Snowden, 2014), but supply response is critically inhibited by dominant political ideologies at the policy-making level (Barrilleaux & Miller, 1988; Grogan, 1994; Miller & Kirk, 2016). Political orientations associated with reduced investment in Medicaid are also associated with less spending on the infrastructure and administration of Medicaid services (Barrilleaux & Miller, 1988). These findings highlight the possibility that specific HCBS policies within a state, for both Medicaid and non-Medicaid eligible populations, may have more or less impact on the state's target population, depending on the political will to support and sufficiently fund those policies. For example, many states have a Medicaid HCBS waiver in place, but maintain long waiting lists for services due to insufficient funding for services and administration (Kitchener et al., 2004).

### **The Current Study**

Medicaid waivers and state plan options may be a critical policy mechanism for ensuring that children with the most significant behavioral or emotional impairments receive the most intensive and targeted community-based services. As such, these policies are receiving more attention and greater support from the federal government. In 2013, at the conclusion of the PRTF Federal Demonstration Project, the Centers for Medicaid and Medicare Services (CMS)

and the Substance Abuse and Mental Health Services Administration (SAMHSA) issued a joint informational bulletin directing state policymakers to consider a variety of Medicaid policy options, including waivers, available to assist in them in the design and implementation of a comprehensive benefit package for youth or young adults with complex behavioral healthcare needs. The bulletin asserted that, according to evaluations of similar programs (primarily the PRTF Waiver Demonstration), such mental health plans would allow states to deliver care that is equivalent or superior in intensity and effectiveness to residential treatment but allows for greater quality of life for youth and their families. "While the core benefit package for children and youth with significant mental health conditions offered by these two programs included traditional services, such as individual therapy, family therapy, and medication management, the experience of the CMHI and the PRTF demonstration showed that including a number of other home and community-based services significantly enhanced the positive outcomes for children and youth. These services include intensive care coordination (often called wraparound service planning/facilitation), family and youth peer support services, intensive in-home services, respite care, mobile crisis response and stabilization, and flex funds. (Mann & Hyde, 2013, p. 3)"

Since waivers and SPAs have begun to be formally promoted by the federal government, it is imperative that the knowledge base about these policies is expanded. Both Medicaid waivers and State Plan Amendments allow states to offer an enhanced service array specific to the needs of youth with complex behavioral health concerns, but only Medicaid waivers have the potential to expand access to these services to families and youth regardless of income level. This is because 1915(c) and TEFRA waivers allow states to expand or omit the parental means test for Medicaid if the child's clinical needs are significant; Medicaid SPAs expand the means test minimally or require that youth financially qualify for Medicaid or another existing 1915(c) waiver in the state.

Because Medicaid waivers hold a unique potential to eliminate financial barriers to care for uninsured or privately insured families—and because they target youth with the more significant mental health care needs and at the greatest risk for out of home placement—rigorous of examination of these policies in relation to service accessibility is vital. But, as noted previously, the research base about Medicaid waivers for youth with complex behavioral healthcare needs is limited, and the studies that do exist are roughly planned and focus primarily on the relationship between participation in waiver programs and changes in participant clinical symptoms and individual functioning. Further, existing research assessing the relationship between the use of Medicaid waivers and treatment access for youth with SED does not account for variation in the clinical needs of youth and if those needs are being met, and it does not account for youth insurance status and income levels. Because youth with the most significant impairments who have private health coverage and who are not financially eligible for Medicaid are likely to benefit most from Medicaid waiver policies for youth with SED, family income, insurance status, and clinical severity are important factors to consider in fully assessing the reach of these policies. Further, because access outcomes in any state may be affected by specific organizational, structural, and financial differences across state systems (Lutterman, et al., 2003), an assessment also needs to account for variation in state policies and other latent ideological, fiscal, or system-specific variables that may also explain variations in access to mental health care for youth with SED.

## **Study Aims**

Building upon the 2017 Graaf and Snowden study, and to more specifically comprehend the role, this study focuses on understanding and controlling for variance in state motivation for waiver adoption, states' non-waiver HCBS funding approaches, and youths' income, insurance status, and clinical severity. Through a two-part, mixed methods design, utilizing youth and family data from the 2009 National Survey of Children with Special Healthcare Needs (NSCSHCN), this study has the following aims:

Part I:

- To identify policy mechanisms utilized by states (in 2009 and today) to deliver HCBS to youth with SED and their families, particularly for youth whose family income disqualifies them for Medicaid
- To understand what motivates State Mental Health Authorities and Medicaid Agencies to utilize current policy tools and structures for HCBS delivery for both Medicaid and non-Medicaid eligible youth with SED

Part II:

- Controlling for variation in clinical severity of youth, to assess the relationship between a state's use of a Medicaid waiver and the odds that youth with SED will have Medicaid coverage
- Controlling for variation in clinical severity of youth, to assess the relationship between Medicaid coverage and unmet mental health care needs and cost barriers to care for youth with SED
- Controlling for variation in clinical severity of youth and for the mediating effects of Medicaid coverage, assess the relationship between a youth's residence in a state with a Medicaid waiver, and the odds that the youth will have unmet mental health care needs and experience cost barriers to care

Part I of this dissertation uses qualitative methods to identify state strategies to fund and organize home and community-based mental health treatment for youth with significant behavioral health needs who are financially ineligible for Medicaid. Because the quantitative analysis in Part II uses national data from 2009, this portion of the study focuses on understanding strategies used in 2009, as well as today. Research is also aimed at understanding the state level political, fiscal, or historical reasons behind state mental health administrators' decisions to utilize these approaches. Qualitative methods are required to uncover this information because it is not publicly available data and can only be discerned through interviews with state child behavioral health policymakers who participate in behavioral health policy decisions. Further, information about non-waiver strategies for providing mental health care to non-Medicaid youth is not readily available or discernable from behavioral health division websites and requires description and explanation from state-specific subject matter experts.

Analysis of qualitative data will generate knowledge of alternative policies for serving non-Medicaid youth with SED and will assist in building hypotheses regarding the relationships between organizational contexts, state policies, and youth and family unmet mental health need and their experience of cost-related barriers to treatment. To most specifically assess this relationship, Part II aims to understand the role of these policies in expanding access to Medicaid coverage, and the role of Medicaid coverage in reducing unmet mental health care needs and cost



barriers to care—especially for children with significant emotional or behavioral impairments. By understanding the relationship between Medicaid-expanding policies and youth’s public health coverage, as well as the relationship between public health coverage and unmet mental health care needs due to cost concerns, this analysis can control for the mediating role of public health coverage and assess the direct relationship between a state’s use of a Medicaid-expanding policy and the cost-related unmet mental health care needs of youth with the most complex behavioral healthcare needs. Specifically, Part II asks the three following questions, which are illustrated in Figure 1 below. A hypothesis regarding each question is also provided.

- 1) RQ1: Controlling for variation in clinical severity of youth, do youth with SED who reside in states with Medicaid-expanding policies have higher odds of having public health coverage?

*Hypothesis RQ1: Because of the means test expansion associated with Medicaid-expanding policies, it is expected that youth living in states with such policies will have greater odds of having public insurance. Because these policies specifically target youth with greater impairments, it is expected that clinical severity will be a significant control variable.*

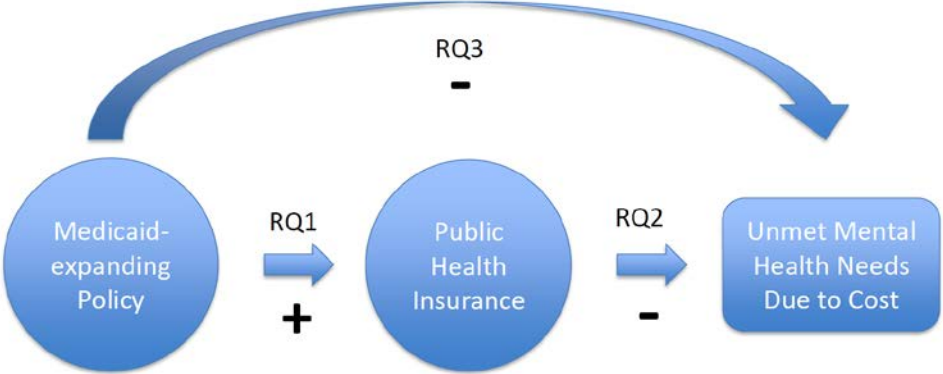
- 2) RQ2: Controlling for variation in clinical severity of youth, do youth with SED with public health coverage, have lower odds of having unmet treatment needs and encountering cost barriers to care?

*Hypothesis RQ2: Because of the greater service array available for HCBS available under public insurance, it is expected that youth with public insurance will have lower odds of unmet mental health needs and encountering cost barriers to care. Because HCBS is particularly important for youth with more significant mental health concerns, it is believed that odds of unmet mental health needs and encountering cost barriers to treatment will be even lower for youth with functional impairments.*

- 3) RQ3: Controlling for insurance status and clinical severity of youth, do youth with SED residing in states with Medicaid-expanding policies have lower odds of having unmet treatment needs and encountering cost barriers to care?

*Hypothesis RQ3: Due to the ability of Medicaid-expanding policies to extend public health coverage to families whose incomes are above the tradition means test and to expand the HCBS service array under Medicaid, particularly for youth with complex behavioral healthcare needs, it is expected that youth living in states with Medicaid-expanding policies will have lower odds of having unmet mental health care needs and experiencing cost-barriers to care. These odds will be even lower for youth with more severe clinical impairments.*

Figure 2. Part II Research Questions & Hypothesis



## CHAPTER 2: PART I METHODS AND FINDINGS

### Part I Aims

Part I of this dissertation uses qualitative methods to identify methods used by states to fund and organize home and community-based mental health treatment for youth with significant behavioral health needs who are financially ineligible for Medicaid –both today and in 2009. Research is also aimed at understanding the political, fiscal, or historical reasons behind state mental health administrators' decisions to utilize these approaches. Qualitative data was collected through semi-structured interviews with officials from 35 state mental health systems, identified through the National Association of State Mental Health Program Directors roster of the Children, Youth and Families Division. The interviews were aimed at uncovering state-specific information about key factors that contribute to the state's decision to utilize a Medicaid waiver policy or not: what alternative policy interventions they have considered, the state's experience in administering and evaluating the effectiveness of the waiver in their state, and the current administration's thinking about the state's future use of the waiver.

Analysis addressed the following questions:

- 1) What are the historical, political, fiscal, and systemic factors that influence a state's adoption of a Medicaid waiver to organize and fund HCBS delivery for non-Medicaid eligible youth with SED?
- 2) In the absence of Medicaid waivers, what mechanisms do states use to deliver HCBS services to youth with SED who do not qualify financially for Medicaid?

### Part I Methods

#### Sampling

Using the National Association of State Mental Health Program Directors' (NASMHPD) roster for the Children, Youth, and Families Division, state mental health authority representatives from all 50 states were contacted via email with a brief description of the study and an invitation to participate in an interview. State officials were also invited to identify a small group of state administrators from the state mental health authority or the Medicaid agency (1 to 3 additional people) to participate in the phone-based interview, scheduled at the convenience of the participants. Many initial respondents did not participate in interviews but did refer the researcher to other potential informants that were able to participate. These referrals were followed up on, and invitations to participate in interviews were sent to potential participants suggested by the initial contact. Non-responsive state contacts were emailed again within 10 to 14 days. States continuing to be unresponsive received follow up phone calls 10 to 14 days after the second email.

#### Data Sources

**State mental health administrators.** Data were collected through interviews with public mental health authority and Medicaid officials in all participating states. A total of 32 states

agreed to participate in interviews. Five additional states participated by answering key interview questions via email. However, because responses from these states were not in-depth, they were excluded from in-depth qualitative analysis.

Because of variation in the size and structure of state child mental health and Medicaid administrations, participants within each state ranged from one to four respondents participating in one interview. A total of 59 state officials participated in the study from across 37 states. The majority of participants (30) held administrative positions within state departments of behavioral health, which were often subdivisions within the states' health departments. However, four participants were housed in the healthcare finance or state Medicaid division, and several sat within state departments for children and families (child welfare). With the exception of two participants, all participants had been working within states' mental health, children, and families, or Medicaid programs for over five years. Many participants had been working in their state for over ten years, and a few participants had been in this career for over 20 years.

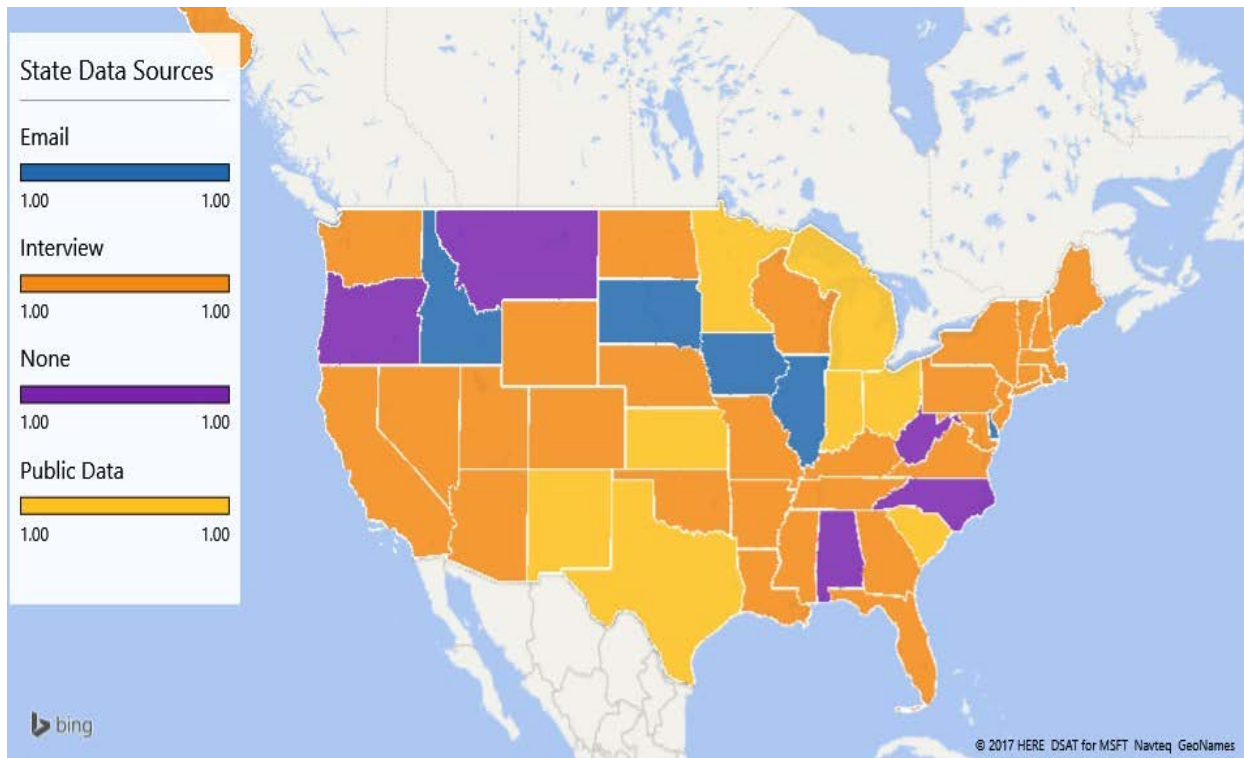
The majority of respondents (22) held program manager positions, overseeing programs within departments of children and families or children's behavioral health. One program manager was from their Medicaid division, three managed policy and/evaluation programs, and two managers were in highly specialized areas: integrated care and systems of care coordination. More detailed description of the participants' organizational role and location within state administration is included in Table 4.

**Table 4. Participant Roles and State Departmental Location**

<b>Role (State Department Location)</b>	<b>Total No. Participants</b>
Director of Children's Services (BH)	14
Assistant/Deputy Director of Children's Services (BH)	8
Assistant/Deputy Director of MH (BH)	1
Asst. Director Children's Behavioral Health (DCF)	2
Director of Children's Services (DCF)	3
Assistant/Deputy Director of Children's Services (DCF)	3
Director of Office of Medicaid Coordination	2
Program Manager (BH & DCF)	22

**Policy documents.** State policy documentation was also used to enhance and support data analysis. The majority of documents were publicly available and included proposals for legislation changes, provider manuals, family handbooks, lawsuit settlement documents, strategic plans, memos, provider contracts, PowerPoint presentations, and service brochures. Publicly available data and policy documents from states declining to participate were also gathered in relation to Medicaid waivers, State Children's Health Insurance Programs, and programming specifically targeted for youth with SED. This data was used to identify or confirm a state's use of a particular HCBS funding policy when possible. Figure 2 displays the level to which each state participated in the study.

**Figure 2. Modes of State Participation\***



\*Alaska & Hawaii (not pictured here) participated in interviews.

## Data Collection

**Interviews.** Interview protocols were built around identifying how each state provides HCBS to youth and families who do not qualify financially for Medicaid and how those services are structured (services offered, reimbursement rates, fees structures, service limits, eligibility criteria, intake, assessment and screening processes, etc.). Questions also assessed the state historical, political and strategic factors that influenced state policymakers to utilize their current system and policies. To provide context for analysis, interviews additionally asked how services for youth with SED on Medicaid are structured, and to what extent they are similar to services for similar youth who do not qualify financially for Medicaid. Finally, if states were in a time of policy and service system change at the time of the interview, as many state systems were in the wake of the Affordable Care Act, interviews aimed to capture an image of the state's HCBS system for youth with SED in prior years, as well as the state's plans and vision for what the system will look like in the future.

Interviews were conducted via phone and were recorded and transcribed. All interviews were semi-structured but guided by a comprehensive interview protocol. Interviews ranged from approximately 40 minutes to 90 minutes in length, depending on the time participants had available in their schedule. This format allowed for the interview to be comprehensive in covering topics relevant to this study but enabled flexibility to uncover aspects of state mental health policy, governing structures, and motivations not specifically asked about. Appendix A

includes the interview protocol that guided interviews. Before each interview, the researcher reviewed publicly available policy and practice documents from each state's website, and those provided by informants in advance, to gain a preliminary understanding of the state's community-based mental health system. This enabled the researcher to make the best use of interview time by allowing the interview to focus on clarifying and gathering facts not clear from public documents.

In several interviews, particularly those with only one participant, respondents reported that they did not feel knowledgeable enough on a given topic to answer it adequately. In these cases, the respondents referred the interviewer to other individuals in the state administration that could better answer the question. The researcher then followed up with the provided contact via email for clarification on the question. The email exchange was then recorded and added to the qualitative dataset for that state.

One interview participant declined to be recorded, so detailed manual notes were used to record the interview. Written notes were saved and stored digitally with transcripts from recorded interviews. Further in five states, due technical failures, only partial interviews were recorded. For these five states, the researcher relied on partial recordings, notes taken during the interviews, and policy documents to answer study questions. State answers to questions were summarized by the interviewer in writing. Summaries were shared via email with participants for verification and clarification. Summaries and participant responses were saved and stored digitally with transcripts, policy documents, and interview notes for later analysis.

**Brief email surveys.** After interviews were concluded, each of the 17 non-participating states was contacted via email and asked to answer the two key research questions via email, rather than participate in an interview. The questions were:

1. Does your state have a means of funding community-based services for youth with serious emotional disturbance (SED) who do not qualify financially for Medicaid – who are uninsured or privately insured? If so, how does your state accomplish this – through what funding source or policy? Was this policy in place in 2009? If not, what policy was in place in 2009?
2. What are the factors—historical, financial, political, or theoretical—that have shaped the state's decision to fund community-based services for non-Medicaid eligible youth with SED in this way-- Or to not fund services for this population?

Five additional states responded via email to this inquiry. Their responses were recorded and stored with interview transcripts for later analysis.

**Policy documents.** As stated above, the researcher engaged in web-based data collection of publicly available documents related to the state's child mental health policies and service systems. Documents included proposals for legislation changes, provider manuals, family handbooks, lawsuit settlement documents, strategic plans, memos, provider contracts, PowerPoint presentations, and service brochures, and were collected from state child and family service division websites, child behavioral health division websites, and the website of state Medicaid or Medicaid-contracted managed care organizations. Informants were also asked in advance of the interview to provide copies of documentation that articulates or codifies policies or processes key to SED mental health service delivery, specific to Medicaid waivers in states that utilize them. During or after interviews, informants also shared key documents

electronically. If copies were not readily available at the time of the interview, informants were asked for suggestions for where the researcher could access such documents via the internet or through making contact with other personnel. These documents were sorted and stored, and organized by state, for review before interviews with each state, and to support later analysis of interview transcripts.

Also stated previously, publicly available data and policy documents were also gathered from states declining to participate, but this type of data collection focused exclusively on data sources specifically related to eligibility and services available under Medicaid waiver programs or CHIP programs for youth with private insurance or whose family incomes were above traditional Medicaid means tests.

## **Data Analysis**

Interview audio recordings and policy documentation were stored digitally in Dedoose, a cloud-based qualitative analysis software program. These data were analyzed for content regarding specific state mental health Medicaid and Mental Health Authorities' HCBS policies, processes, and service delivery structures. The analysis included four coding cycles focused on the interview, email, and policy document content regarding specific state mental health policies funding home and community-based services (HCBS) for youth with SED who do not qualify financially for Medicaid. Because Part II of the study utilizes 2009 data, this data was gathered from states about their 2009 systems and policies, as well as their systems and policies in the fall of 2016. The analysis also focused on content revealing state processes or factors that enhanced or discouraged the adoption of Medicaid waivers or influenced policymakers to enact current policies and funding mechanisms for HCBS for this population.

Coding schemes were developed by the author through familiarization and descriptive coding accomplished by listening to interviews and reading through notes and policy documents, in consultation and collaboration with the dissertation chair. After this stage, a thematic framework was created and used in pattern coding transcripts for the second round of coding for each state. An index including five approaches to funding HCBS for non-Medicaid eligible youth and several policy-influencing factors was created and applied in the third round of coding. In a fourth and final round of coding, charting was used to condense HCBS funding approaches into four categories, and influencing factors into five factors influencing states in favor of HCBS policy adoption and three factors influencing against adoption (Miles, Huberman, & Saldaña, 2013; Saldaña, 2013).

The first three cycles of coding were carried out manually, while the fourth cycle of coding was conducted in Dedoose. Following the fourth and final coding cycle, Dedoose was used to validate theme recurrence within and across cases, confirming the frequency of the themes discussed by participants and verifying the key concepts described in the findings. Once coding and analysis were complete, findings were presented to participants to gauge accuracy and consider implications of the findings. Feedback from this process was collected and recorded, and highlights were incorporated into the final reporting of the data.

State policy documents were reviewed for participating states, as well as for states who did not participate. These documents were not coded in software but notes about state policies and programs were stored in state-related memos in the qualitative software. These memos were layered into final analysis of the data and construction of findings.

## Part I Findings

### Decision Factors in State Adoption of Medicaid Waivers

Over thirty states participated in forty to ninety-minute interviews that explored state approaches to funding home and community-based mental health care for children with complex behavioral healthcare needs whose family income was beyond the Medicaid means test for eligibility. Interviews also captured state political, historical, or fiscal factors that were weighed in decision making around approaches to funding care for this population. For additional context for data interpretation respondents also provided information about the organization of home and community-based care for youth with SED, for both Medicaid and non-Medicaid youth. Findings reported here reflect general themes that emerge more strongly in waiver versus non-waiver states, and thus there are likely to be states where exceptions to these general observations exist. This section will describe issues cited by state administrators that shaped decision-making in favor or against using a Medicaid waiver. The following section will lay out approaches used by states to fund appropriate levels of care for this population through either the expansion of eligibility for Medicaid or through state general revenue allocations.

**Factors influencing Medicaid waiver rejection.** A key factor for states choosing not to adopt a Medicaid waiver is financial constraints in the Medicaid budget. States declining to adopt Medicaid waivers also report views that the current Medicaid program structure is sufficient for meeting needs of families and youth in the state, though respondents also expressed concern about the role of private insurance in funding HCBS. Many states have generous state general revenues allocated to serve non-Medicaid eligible youth and thus have no need to move these families to Medicaid. Finally, though states that provide generous general revenue allocations for children and families report strong political support for caring for children and families, participants also indicated that political ideology related to the role of the state in providing for indigent populations may contribute to a strong state focus on delivering mental health treatment primarily to families living at or below the federal poverty line (FPL).

*Budgetary constraints.* Many states not utilizing Medicaid waivers reported that budgetary concerns were a primary driver. States referred to being in a “budget neutral environment” in which a proposed policy or program change cannot create any changes in the state budget. This can be particularly difficult to achieve in a fee-for-service Medicaid structure. One non-waiver state explained the decision-making process about adopting a Medicaid waiver: “*We’ve discussed it in the past. Our advocates’ families have discussed it with our Medicaid administration. It was really budget. It was opening up the door to more families than we thought we had the state match for. I think Medicaid felt that it would be hard to limit it, and so they never went for it, even though it makes some sense. So, it really was the match requirement and overall Medicaid budget, which is usually in the red in a fee-for-service state.*” And, as one state pointed out, in some states, there is strong voter-support for maintaining a balanced budget. “*We’re a state that every year we have to balance the budget; we can’t be in the red at all at any time. It’s kinda the running joke—or the Governor will be placed in jail.*”

A couple of states also acknowledged that the administrative burden of 1915(c) waiver applications, and the need to reapply every five years, was a deterrent. “*Those C-waivers have a lot of administrative baggage involved with them. There are a lot of things that you have to take on if you do a C-waiver...So mainly, we avoid them because of the administrative burden of a C-*



*waiver. Like, we will pursue 1115 waivers. We're working with several of those right now. The C-waivers, we tend to avoid right now."*

**Current Medicaid program is sufficient.** Several non-waiver states also report the view that their current Medicaid program is meeting the majority of the behavioral healthcare needs of the state's child population. Because one function of adopting a 1915(c) Medicaid waiver is to expand the Medicaid service array to include additional, population-specific services such as wraparound facilitation, peer support for parents or youth, and respite care. For several participating states, these or similar services are already included in their general state Medicaid plan. *"Actually, we have one of the best, if not the best, Medicaid menu in the country...the children's menu of service under Medicaid pretty much offers you everything and anything that you could want."* A couple of states contemplated adopting a Medicaid waiver in order to expand their benefit package for youth with SED but decided to capitalize on the opportunities provided through the Affordable Care Act to simply revise their state Medicaid behavioral health plan for all youth, so that enhanced benefits would not be limited to youth who clinically qualified for a Medicaid waiver program. *"I mean, we were doing a lot of research and talking to other states, and that's when we decided to rewrite our Medicaid state plan and expand services there, and also open the provider network. So, at that point, they kind of abandoned the waiver idea because we were going to get everything that we wanted at that time through Medicaid expansion."*

Further, some states were not concerned about a gap in the population that could not be served through Medicaid, because they reported having very high Medicaid penetration rates; a larger proportion of the children in their state qualified for Medicaid. *"In our state, the majority of our kids are eligible for Medicaid."* Other states pointed to their status as a Medicaid-expansion state under the Affordable Care Act, which further reduced the number of uncovered children, particularly in low-income families. *"So really, I guess the whole point being is that there's really not a lot of children, low-income children that aren't eligible for Medicaid."*

**The role of private insurance.** In many non-waiver states, however, even those that have generous allocations for serving non-Medicaid youth and families, administrators acknowledged privately insured youth were in what one state called a "donut hole." *"If you have means or commercial insurance, there were many plans that didn't have the same level of coverage as Medicaid in the state and/or you just didn't even have an eligible door to go through to, to access, even if you wanted to pay cash, for example. So much of our service array is driven by either system involvement on child welfare or juvenile justice or by financial need of Medicaid."* Many of these states are actively seeking solutions for addressing these youth that are *"in the cracks."* *"One other thing that I want you to understand statewide: local communities from local authorities are—need to be better, and we need to close the funding gap and the insurance gap."*

One state said they relied on their education system to provide the behavioral healthcare services needed for non-Medicaid or privately insured youth. *"There are some mental health services and other services that the education system is required to provide to kids that need them—regardless of payor source, in order to receive a free, to benefit from a free and public education.... And you have to go through the IEP process, the individual education plan. And have that service identified in the IEP—and if that's the case, whether it's a mental health service or whether it's occupational therapy, or something else...it becomes Education's responsibility to provide it."*

A few states are looking at ways to push responsibility for privately insured youth with SED onto the private insurance providers in their state, because *"government really is doing a*

*better job with children's mental health than the private sector."* One state spoke about directly encouraging families to advocate on their own behalf with their insurance provider. *"Now if we hear on a state level, or an accounting level, that an individual child and family really could use something under their private insurance plan, we've always advised them to talk with the medical director in their private insurance plan about a one-person agreement. And frequently we find that some of the private insurance companies will pay for a service that is not in their regular package of services. We also have encouraged families to talk to the [our state's] insurance commissioner, around a wish that they have."* In another state, *"what we've been focusing in on is trying to get the commercial insurers to step up."* This respondent asserts that currently there is a divide between what private insurers say they cover officially and what they actually end up approving for reimbursement:

*"I think there's a philosophical question there because you have probably dealt with this too, is whether the commercial insurers are, in fact, holding up their side of the bargain...all the insurance carriers told us that they cover intensive in-home for example. Well, the reality is that was not a false statement ... on the surface they would say, yes, we cover that service, but in reality, families, if they got approval, you're talking they would get approval for a day or two of what should be a six-month course of treatment or three months or whatever that would be."*

This informant also alludes to behavioral health administrators in other states engaging in similar conversations with their private insurance carriers as well—and that eventually, these insurance companies know that they will have to cover more comprehensive behavioral health services, but that they are delaying that reality as long as possible. *"...and if you're in any of states in the know, that this is the conversation that's going on everywhere...There are some states that are doing a better job pushing back but the commercial insurance. My opinion of that is, they are just so much more sophisticated, and they're able—I think they see the day coming and the pressure for parity on the mental health side is certainly closing in on them, but they're still pretty sophisticated at dodging and weaving from paying out on a number of these."*

**Political ideology.** The desire of many states to push responsibility for funding appropriate levels of mental health care to commercial insurance carriers may reflect some ideological values dominant in these states' policymaking. Many non-waiver states reported that the mandate of their organization is to serve only the Medicaid population. *"We are primarily designed for service delivery to the Medicaid eligible population. That is our main book of business."* In several of these states, there appear to be strong philosophical views about the role of the state in providing care for youth and families, and that such funding should only be for those who cannot help themselves. *"It's very important to point out that the state system funds those who cannot support themselves. It doesn't fund the ones who have private resources or options."*

Related to this ideology about the role of the state in providing care for its residents, is the notion that Medicaid waivers could be viewed as a type of Medicaid expansion—and as such, they were not politically viable in the state legislature. *"With our General Assembly climate, if we mention any waiver they always think we're expanding programs or eligibility for programs, and so we kind of avoid that for a variety of reasons."* Another state noted, *"At one point we requested in 1915(i), and even though the 1915(i) was not developed as part of the ACA, it was perceived as Medicaid expansion. In [our state] that is not palatable. That request was denied."*

Another reason cited by a few states for not pursuing Medicaid waivers is that they were unpopular with advocacy groups in their state because they were perceived as potentially

excluding specific groups of individuals, and they placed limits on the number of individuals who could be served on them at any given time. *“We have shied away from the waivers for a couple of reasons. Mostly it's because we have a very active and loud advocacy community here in [our state] and we've been under a couple of lawsuits and various subpoena. The advocates don't like waivers because they feel that they are discriminatory and they only target a certain select population, which of course is what they were designed to do.”*

**General revenue funds.** Among states not utilizing waivers, for many of the reasons cited here, several allocate varying amounts of general revenue funds to fund needed services to youth who are not covered under Medicaid. Some of these states report strong political will in their legislatures to support children and families as well. In these states, there is agreement that children are best served in their homes and communities and not in residential settings. *“For our current administration...the focus is to get kids out of high-end congregate care settings with a high degree of commitment. And as money was saved there, there were some shifts to the community-based system.”* Further, there was agreement that families should not have to give up custody of their child in order to access the services they needed. *“I think that the issue largely that drove it was the idea that parents should not have to give up custody of their kids to get care.”* To support families with children with complex needs, these states maintain their commitment to Medicaid programs being exclusively for the economically needy by providing funding through the Department of Children and Families, through the Juvenile Justice Authority, or through state-funded behavioral health programs. *“The state, our commitment to state funds is still continuing, and so we continue to create some of the kid bypasses to cover those young people with pure state money, unfortunately. But we're committed, and we have the child and adolescent funds to do it.”*

One state which does not offer a Medicaid waiver despite political prioritization of child and family well-being and plentiful fiscal resources for Medicaid uses general revenue funds to provide HCBS to youth with SED, regardless of insurance status. This state explains that a unique Medicaid funding policy in their state prevents their division from reaping the benefits of federal cost-sharing for HCBS. In an illustration of the ways in which similar states still may not enact similar policies due to complex internal political and administrative variables, it explains that *“...all federal reimbursable dollars in [our state] go back to the general fund. They don't come back to us. If we save money, we don't get it back. It doesn't come directly back to where it could be used for reinvestment.”*

For these states, however, using general revenue funds does create vulnerabilities for the sustainability of these programs. One state designed a comprehensive community-based behavioral health program for non-Medicaid youth, but the expense of it was not sustainable in the state budget. *“It was a very flexible system, and we could design what we specifically needed for the kid. It was a very, I think, robust plan—so robust that they decided to redesign it because it was a little too rich for the state system.”* Additionally, though such programs may be successful and funding may continue for a time, state priorities for funding change over time, resulting in reductions in funding or discontinued investment. *“We had a fair amount of new resources that had been invested in the system. We had run our political will out for the ability to use that as a way to leverage resources. That's when the state decided to discontinue it as an initiative.”* Such programs are especially vulnerable because the general revenue in a state is often determined by state or national economic ebbs and flows. Strong economies result in new investments in social services. *“In the last three years, our legislature has funded what we call special projects, or proviso projects, with general revenue funds—in part because [the state] has*

*been in a good place financially.” But when the state economy falters, economic support for needed programs is jeopardized. This is particularly true in states whose economies are strongly linked to the energy markets. “Grant dollars—because of the cost of oil now per barrel—our budget is significant peril. The general fund dollars that used to support those grants are shrinking.”*

***Factors influencing Medicaid waiver adoption.*** Many states that have had Medicaid waivers in place for a long time often had difficulty speaking to the reasons for state adoption, due to the fact that they had been in place for so long. In many states, the TEFRA/Katie Beckett option has been in place since the 1980s, and a few 1915(c) waivers have been in place since the mid-to-late 1990s. Further, a few states did not offer a Medicaid waiver in 2009 (the year examined in Part II of this study) but have adopted one since that time. Because these states did decide in favor of waivers, and because those decisions happened relatively recently, these states' responses contributed to the analysis of reasons that states chose to adopt a waiver. Among participants that were able to speak to reasons for waiver adoption, influencing factors included 1) state administration aims to reduce reliance on residential care and associated costs, 2) a historical precedent of federal cost sharing for behavioral health services through the existing Medicaid program and participation in the PRTF Federal Demonstration project, 3) a political prioritization of children and families, and 4) generous Medicaid budgets. No state reported motivation to adopt a Medicaid waiver due to unusually high proportions of high needs youth in their existing mental health system.

***Over-reliance on residential care.*** The most frequently cited reason for seeking a 1915(c) Medicaid waiver was the desire of policymakers and administrators to reduce the state's reliance on residential care for youth with complex behavioral healthcare needs—for both fiscal and philosophical reasons. *“We also have a high rate of use of restrictive settings, historically, for mental health folks. Certainly, a part of the push around the [waiver] program was, okay we need to really deliberately work on expanding access and intensity of home and community-based services.”* In some states, the move to increase investment in home and community-based alternatives to residential care involves changing deeply embedded ideological and structural precedents. *“[Our state] is a red state, it's kind of a law-and-order, ‘Pull yourself up by your bootstraps’ state. Kind of thinking sort of like the Darwinian calling of the herd, ‘if somebody didn't make it, well maybe they weren't meant to,’ kind of thing. We arrested more kids than any other state except for [another state], and when I say kids, I mean 10 to 18 [years old]. So that was another way kids were being handled that had extraordinary needs. They were being put in detention.”*

Even when robust HCBS systems were established in states, administrators focused efforts on educating other child-serving systems about alternative ways for addressing the needs of youth that they served. *“But there has been a huge effort—but essentially with the judges, I believe that there's a continuing need to provide education and help them to understand that there are community-based resources that could be used.”* As a result of these efforts, several waiver states emphasized the success these HCBS programs have had in their states in reducing the use of residential care. *“[We consider] our waiver program to be quite successful and it's hard to prove prevention, but we believe that we're keeping kids, we're preventing kids from going to inpatient beds and preventing them from residential services. In fact, we've seen a decline in demand for those services. So, it's easy for us to attribute at least a portion of that reduction to the availability of home and community-based services.”* States also point to the financial savings that have resulted from diverting youth from these settings and serving them in

the community. *“So, then we're a little less reliant on RTCs (Residential Treatment Centers), and in fact, over the last gosh 5, 6, seven years, we've continually lowered our expenditures for RTCs ...”*

**Primarily Medicaid-funded systems.** All of the states using Medicaid waivers rely heavily on Medicaid funding to support and structure their children’s mental health service systems. As one state asserts, *“We are pretty much a Medicaid system. All of our services are basically based on... Medicaid.”* In such states, once a youth is determined to be eligible for Medicaid, a rich array of mental health services—outpatient or community-based—becomes available to them. *“So, once that eligibility is determined, then it opens up all kinds of doors for all kinds of behavioral health services.”* The services available under Medicaid are comprehensive and are aimed at keeping kids in their homes and communities. One state discusses the number of services their Medicaid managed care organization is contracted to do in order to meet this goal: *“We're asking them to do a lot of stuff. Medications, we have very specific timing and requirements around high fidelity wraparound—like how soon after a family is enrolled they have to contact them. We have crisis, also, planning enrolled in there, and building of a crisis response system. We require them to make sure that all children have a primary care practitioner and to analyze their use of primary care and other ancillary services and to track EPSDT well-child checks for the population. There's just all kinds of things because we wanted to do a total integrated look at what do kids need to be—our bumper sticker is, ‘To keep kids in home, in school, and out of trouble.’”*

This reliance on Medicaid is likely driven by the state’s desire to maximize cost-sharing of mental health care with the federal government. Since cost-sharing reduces the state’s financial burden in meeting the care needs of the families in the state, many of these systems are economically incented to structure all expansions of services for these youth through Medicaid mechanisms. *“We had financing struggles, so a lot of need to make sure that there was maximization of Medicaid funding.”* One state that currently does not offer any Medicaid waiver programs for youth with SED, but generously funds HCBS through state revenue, is under a new state mandate to do the same—which is spurring administrators to examine various policy options that allow them to maximize their federal draw-down. *“It requires us, and that's actually what we're doing right now, and we have a report that's due to the legislature...on opportunities for us to maximize our federal revenue, it's revenue maximization. We're looking at different options to do that.”*

In these states, the primacy of Medicaid—combined with the variety of federal policies that allow for Medicaid to cover a broad service array for specialized populations (e.g. the EPSDT mandate, 1915(c) waivers, Medicaid state plan amendment options)—drives policymakers to seek Medicaid-related solutions when looking to expand HCBS in an effort to divert youth away from residential settings. As one administrator states, *“I knew that there's power in Medicaid for the kids we're talking about, and they're kind of landing in Medicaid because of all these other, ya know kind of coming or falling off the cliff and the ambulance is Medicaid (because youth end up in child welfare or justice settings which enables Medicaid coverage), and so why can't we use Medicaid to do some things?”*

**Participation in 1915(c) PRTF Waiver Demonstration.** Through participation in the PRTF Federal Demonstration project, a few states experienced the power of Medicaid in shifting costs away from institutional care through the provision of home and community-based care that is partly funded by the federal government. *“Now, again, because of the waiver, it afforded families a diversion from the residential setting or an option to transition out of the residential*

*setting sooner than they normally would, and still meet that level of care and get that same service in our [waiver] program.” Several states acknowledged that their current approach to organizing and funding care for youth with complex behavioral healthcare needs was heavily influenced by the state’s participation in this demonstration project. “And that got us to go off the family-to-family, peer-to-peer support and expressive therapies and really helped us grow even more robustly our targeted case management system and providers. So, we used it to get our system of care going a little bit more.”*

A portion of the states participating in the demonstration went on to apply for and adopt at 1915(c) for this population, and a few that didn't use other Medicaid policies (e.g., Money Follows the Person, 1915(i) State Plan Amendments) to continue to fund the enhanced HCBS service array they began under the demonstration. One state that did not continue their program developed under the PRTF demonstration through Medicaid now uses state general revenue funds to finance the non-Medicaid home and community-based mental health care. Administrators in this state can't explain policymakers' decision to refuse opportunities to continue the federal cost-sharing available under Medicaid options. *“I'd call it a little less than wise because it's a lot cheaper to use more federal dollars, but we still keep spending a lot of state dollars where we don't really have to.”*

***Political prioritization of access to care for children and families.*** Several states that currently offer Medicaid waivers spoke clearly to an administrative commitment to supporting families and youth and keeping families together, which they reported was supported by dominant partisan leaders in their state. In one state, powerful political figures took on the cause and influenced legislative action. *“It was the Governor's wife, that was her platform, I guess-So she did a statewide listening tour, and that was one of her pieces, so we always credit the Governor's wife for getting him to allocate that funding towards that.”* Another state pointed to the possibility that the religion of early state founders, and faith of current political leaders, may influence the state’s social justice and family values. *“I think there are historical factors that are really present in [the state] and kind of typical of the bent in New England.... I think there is this sort of tradition that I think goes back to the Congregationalists who were the first white people in the state. I think there are sort of historical values.... I think there are a lot of Irish Catholics in [the state] and there are some who are very prominent in the healthcare leadership world, and I think those values have really influenced the state.”* In another state, adoption was driven by one highly concerned Medicaid administrator. *“I feel like kids have gotten the short end of the stick. They're sort of our canary in the mineshaft of when things aren't going well for everybody in general, like our older and vulnerable adults are. So, I just realized, nobody's going to step up and do this, so I just took it and ran with it.”*

Other states point to the prioritization of youth and families possibly being rooted in the advocacy of parents of children with significant disabilities. *“The only thing I discovered was that parents of children with intellectual disabilities ... It was very hard back in the 70's for their children to be covered by medical assistance for a variety of reasons. So somehow it started with children with intellectual disabilities and then progressed to children with any kind of disability.”* Focusing on the enhanced access enabled through the service coordination inherent in the wraparound and targeted case management processes, which are a common Medicaid benefit under 1915(c) waivers or TEFRA/Katie Beckett options, another state points out the upgrades in the quality of care available through the adoption of a waiver. *“I think more essential to healing and recovery is how people connect with others and how systems work together and that has just really been one of our big commitments in [the state].”* Protecting the

availability of the services that supported the level of care and service coordination these youths need was also cited as a reason for waiver adoption by one long-time 1915(c) waiver state. *"If it were not for the waiver, sure we could provide some of those services with state dollars because we do have, you know we have a 50% match, right? So, we come up with half of it, but we know that then it would be very susceptible to cuts or what vulnerabilities, right, in any given budget year. So, somehow we muster up the fortitude to deal with the administrative burden."*

**Generous state Medicaid budgets.** A few states which rely on Medicaid to provide a rich array of mental health services to youth, regardless of family income or insurance status, also acknowledge unusually generous state Medicaid budget. *"There is that difference, as you know, between private insurance plans and Medicaid plans, and Medicaid plans are always richer... 'because we've been shaping it, and we have the money to do it."* As another state points out, these places them in a fortunate position from a policy perspective. *"I mean, you also have to say we're a pretty reasonably wealthy state, so we have that freedom to make those choices."*

### **State Approaches to Funding Home and Community-Based Services for Non-Medicaid Eligible Youth**

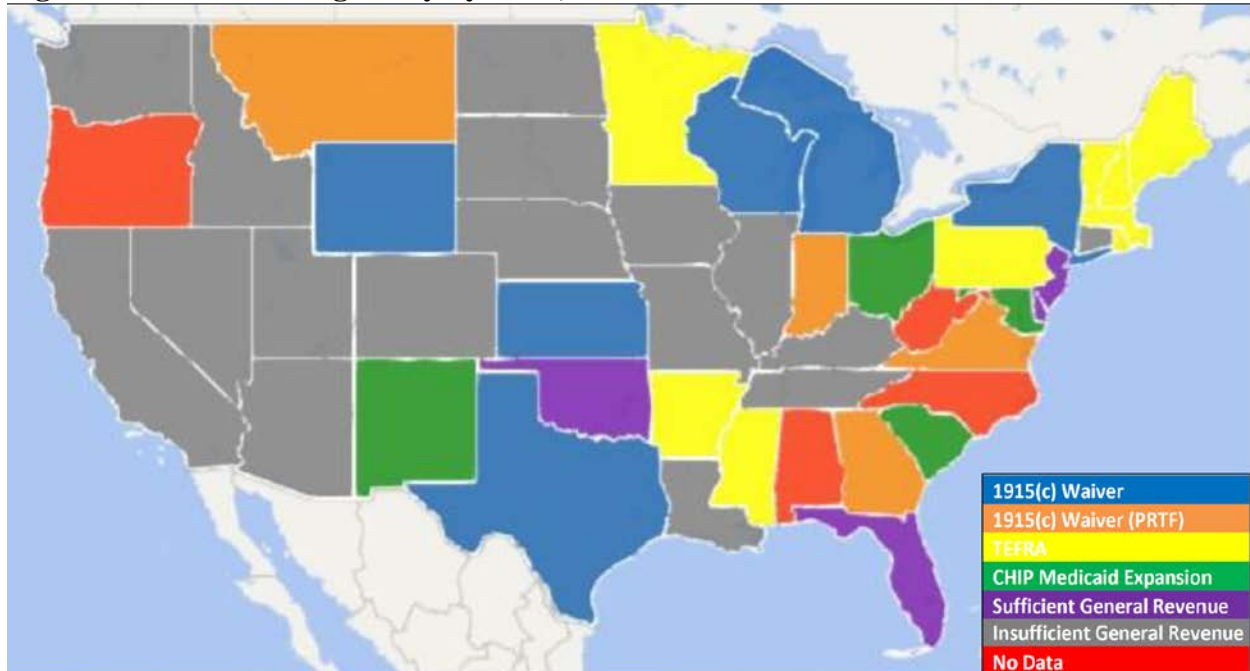
States' reasons for adoption or rejection of Medicaid waivers as a policy tool for funding and organizing home and community-based care for children and adolescents with complex behavioral healthcare needs reveal a new way to understand Medicaid policies that can enhance access to HCBS for these youths. Informants reported that Medicaid waivers could be viewed in their state as Medicaid expansions—which are unfavorable politically, particularly in states with dominant political ideologies supporting the use of public funds exclusively to serve the indigent. Findings also indicate that states use other Medicaid-expansion tactics; Some states expand the Medicaid benefit service array to youth above the traditional Medicaid means-test limit through the Children's Health Insurance Program (CHIP). These states do not adopt a Medicaid waiver because they feel that the Medicaid penetration rate in the state is high enough, and the services available under the Medicaid program are sufficient to meet the needs of the majority of the youth needing behavioral health HCBS. Integrating these key points in the findings for Research Question 1 frames how the results for Research Question 2 will be presented.

The strategies used by state administrators fund home and community-based care for youth with SED and their families can be distilled into two basic categories: 1) Expanding Medicaid-eligibility through state policies or 2) Using state general revenue funds to pay for medically necessary home and community-based services for non-Medicaid youth. Primary means of expanding Medicaid are through a TEFRA Medicaid option, a 1915(c) Medicaid waiver, a state-authorized look-a-like program, or through the expansion of the full Medicaid benefit package to youth up to 319% of the FPL through the Children's Health Insurance Program (CHIP). States using general revenue funds either allocate generous or limited portions of state general revenue funds—often activated through specific child mental health legislation—combined with state community mental health block grants to fund services for non-Medicaid children and families.

Figure 3 illustrates which states utilized each of these mechanisms in 2009. This figure includes states that were participating in the PRTF Federal Waiver Demonstration—and several of these states do not offer a Medicaid waiver today. States that are marked as having a 1915(c) waiver in 2009 that do not offer one today include Montana, Georgia, Indiana, South Carolina. Hawaii and Alaska are not pictured in this figure, but both states offer CHIP Programs that expand Medicaid up to 203% of the FPL (Alaska) and 308% of the FPL (Hawaii). However, in

both states, due to differences in cost of living, the dollar values that represent the FPLs in Alaska and Hawaii are higher than in the other 48 states. As of 2016, 100% of the FPL for a family of four is equal to \$30,380 in Alaska and \$27,950 in Hawaii, compared to \$24,300 in the other 48 states (Medicaid.gov, 2017, <https://www.medicaid.gov/medicaid/program-information/medicaid-and-chip-eligibility-levels/index.html>).

**Figure 3. HCBS Funding Policy by State, 2009**



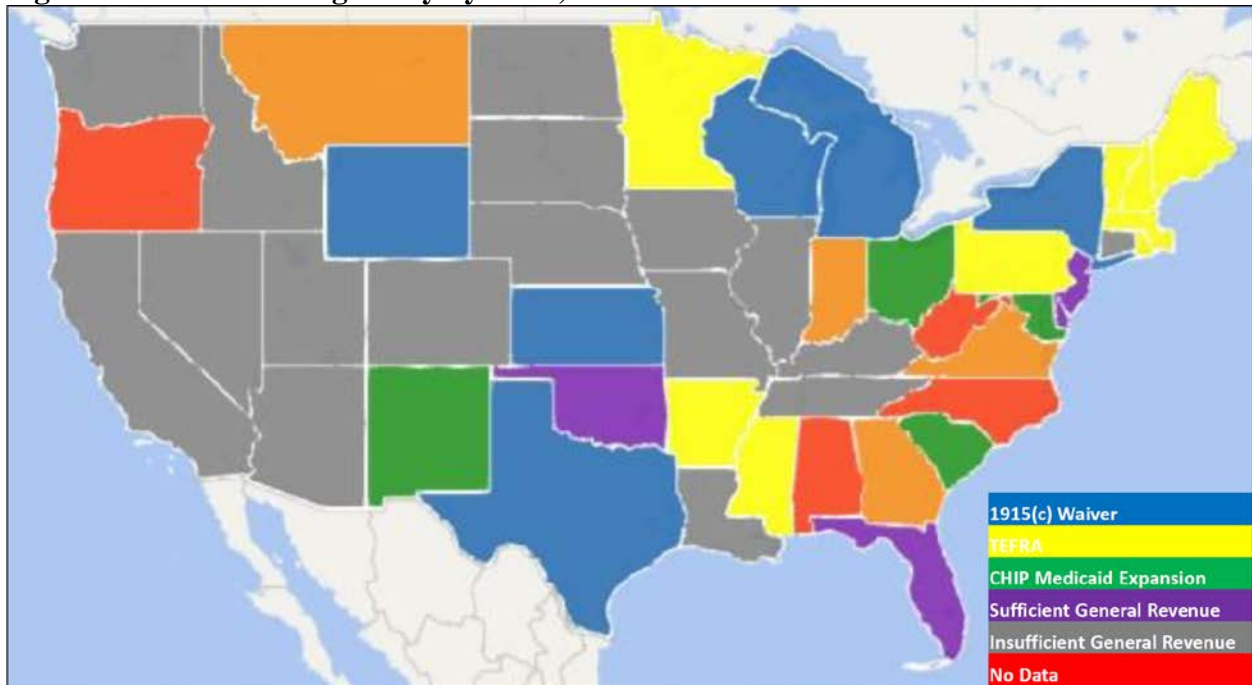
\*Alaska and Hawaii are both Chip Medicaid Expansion States

### **Medicaid-expanding policies.**

**Medicaid waivers.** Many states fund home and community mental health care for youth with complex behavioral healthcare needs through the use of 1915(c) Medicaid waivers, TEFRA or Katie Beckett options, or state-authorized look-alike policies. During the years of the study, 2009-2010, nine states were participating in the federal PRTF waiver demonstration project: Kansas, Virginia, Georgia, Alaska, Maryland, Mississippi, South Carolina, Montana, and Indiana. Kansas, whose PRTF waiver was targeted specifically at youth exiting Psychiatric Residential Treatment Settings, also had been utilizing an additional 1915(c) for this population since 1999, and thus was operating under two 1915(c) waivers in 2009-2010. Of these states, Mississippi went on to establish a 1915(c) for youth with SED after the conclusion of the demonstration projects. Indiana did not continue a 1915(c) but did adopt a 1915(i) state plan amendment (SPA) to expand their home and community-based service array specifically for the youth population with SED. States using established and on-going 1915(c) waivers outside of the federal PRTF demonstration project included Kansas, Michigan, Wisconsin, Wyoming, New York, and Texas. Iowa adopted a 1915(c) waiver in 2010, and Louisiana adopted this policy in 2012. These changes are reflected in Figure 4, which illustrates which states use each of these mechanisms at the time of data collection, in the fall of 2016.



**Figure 4. HCBS Funding Policy by State, 2016**



\*Alaska and Hawaii are both CHIP Medicaid Expansion States

Many states reported offering a TEFRA Medicaid or Katie Beckett option. Wisconsin, Vermont, Rhode Island, New Hampshire, Mississippi, Arkansas, Maine and Massachusetts all reported routinely relying on youth qualifying for Medicaid through the TEFRA option and stated that families applying for Medicaid would routinely be screened for eligibility for the program at local or regional public benefits offices. They also point out that providers at the local level would be incented to educate families about the option and ensure they know how to go about applying for the benefit to ensure that their agency would be paid for services provided. *"I would say it's pretty standard if you are going to a county system or county agency that they are going to work for insurance options because they want to be able to bill."* Two states that did not participate in interviews for the study, West Virginia and Minnesota, also have public information available confirming their use of a TEFRA option. Pennsylvania offers a state-authorized program, referred to as PH95, which functions identically to the TEFRA option—expanding Medicaid eligibility through determination of the child's need for an institutional level of care and disregarding parental income altogether. States refer to this process, in which parental income is disregarded, and income-related eligibility is based solely on the child's personal assets, as "deeming" or considering the child as a "family of one."

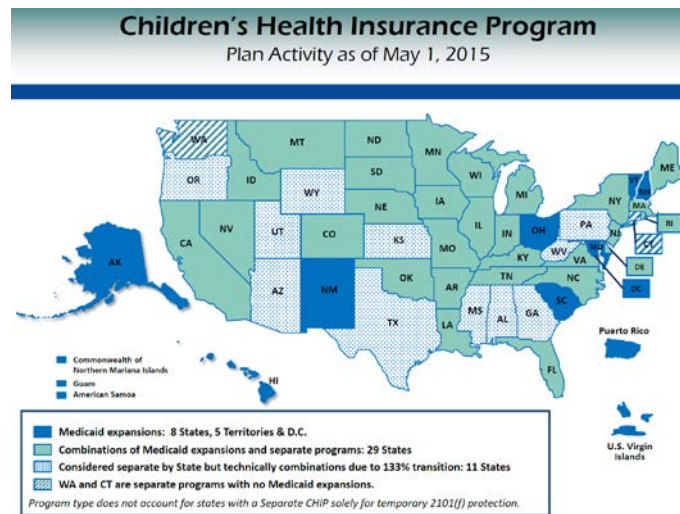
Three states use a TEFRA-like policy for funding care for these youth, but only to cover residential care. Alaska uses the federally authorized TEFRA option to "deem" children who need placement in long-term residential care. This allows the youth to transfer to Medicaid coverage while in the residential setting. Colorado and Arizona both also have a similar state-authorized policy which allows a child to be considered as a "family of one" in accessing Medicaid coverage when they have qualified for placement in a psychiatric residential treatment

facility. This allows the family avoid incurring the cost of the treatment and allows the state to share the cost with the federal government without requiring the family to transfer custody to the state. However, when the child is discharged from the residential setting, they become ineligible for Medicaid coverage once again. Colorado, however, appears to be slowly extending this policy to include coverage for home and community-based care. "Over time our whole state, as many others states, has really been trying not to rely on residential care, so we have now kind of loosened up the requirements for that so the community-based services can also be provided, paid for, for kids who don't meet the Medicaid income (limits)."

**Expanding Medicaid through CHIP.** Eight states extend Medicaid to a large number of children and adolescents with complex behavioral healthcare needs simply by expanding the eligibility for their state Medicaid plan through the Children's Health Insurance Program (CHIP), formerly the State Children's Health Insurance Program (SCHIP). The CHIP program is a federally authorized program that provides matching funds to states for the provision of health insurance to children in families whose incomes are too high to qualify for traditional Medicaid, but who are uninsured and whose incomes are too low to afford private health coverage. Whereas several other states operate a fully separate CHIP program that is structured similarly to a private insurance plan, these eight states offer identical benefits and services to youth eligible for Medicaid through CHIP. Income eligibility limits for Medicaid in these states, then, range from about 200% to over 300% of the federal poverty line (FPL). "Now, in [our state], under CHIP...the Child Health Insurance Program, the CHIP program, we go to 300% of the poverty level for Medicaid. So, our Medicaid, general state plan services, go up to 300% of the poverty level.... So, they all would be viewed as just Medicaid kids."

The majority of states have structured their CHIP programs to be a combination of both an expansion of the state plan for certain regions, populations, or income levels, with a separate CHIP plan that is structured similarly to private health coverage. Two states (Washington and Connecticut) have fully separate CHIP programs that offer no type of Medicaid Expansion. The eight Medicaid-expanding CHIP states are Alaska, Hawaii, New Mexico, Ohio, New Hampshire, Vermont, South Carolina, and Maryland. Figure 5, below, illustrates how states differentially structure their CHIP programs (Medicaid.gov, 2017).

**Figure 5. CHIP Program Structures Across States**



Accessed October 26, 2017, at <https://www.medicaid.gov/chip/downloads/chip-map.pdf>

***States with multiple Medicaid-expanding policies.*** Eight states had more than one Medicaid-expanding policy in 2009. Alaska, Maryland, and South Carolina were all operating the PRTF 1915(c) waiver, while also expanding the Medicaid benefit package up to 203% of the FPL (Alaska), 317% of the FPL (Maryland), and 208% of the FPL (South Carolina) through CHIP. As noted above, Kansas operated two 1915(c) waivers—both the PRTF demonstration waiver as well as their “SED Waiver” for all youth with complex behavioral healthcare needs. Mississippi was participating in the 1915(c) PRTF demonstration waiver project, while also offering the TEFRA/Katie Beckett option. New Hampshire and Vermont offer both a TEFRA/Katie Beckett option and expand the regular Medicaid benefit package through the CHIP program to all children up to 318% of the FPL (New Hampshire) and 312% of the FPL (Vermont). Wisconsin regularly operates both the TEFRA/Katie Beckett option as well as a 1915(c) Medicaid waiver specifically designed for youth with SED.

***Medicaid-expanding states supplement with general revenue and block grants.*** Several states with Medicaid-expanding policies also use block grants and some general revenue funds to fill the gaps in their systems by contracting with providers to provide safety net services. In addition to offering the TEFRA option to allow youth at risk for institutionalization to access Medicaid, Vermont also uses a Medicaid billing code (3560, the same code New Jersey uses) to help streamline the process for agencies to draw down state general funds for youth not covered by Medicaid. Alaska, though it expands its Medicaid benefits through the CHIP program, also supplements community-based care with limited amounts of general revenue funds. *“There’s a small amount of grant funding to our providers, but that’s not going to provide much because the system is being driven to use Medicaid more than grant dollars.”* Rhode Island uses the TEFRA option but also uses general revenue funds funneled through the Department of Children and Families for youth that remain ineligible for Medicaid and whose presenting problems place the youth and family at risk of child welfare involvement. New Hampshire also uses the TEFRA option but relies on special funds to cover care costs that are not included in the Medicaid program benefit array. *“We have instances where the youth participating identified what could help him avoid a crisis, and maybe a trip to the ER, to be assessed for hospitalization. Long story short, he really liked to sew, his sewing machine was broken, we bought him a sewing machine.... He was able to avoid a hospitalization during the Christmas season, for the first time in six years. That’s really sort of a good example of those services, in the system of care service array, that weren’t available either, so then we had to create that pathway to do that.”*

## **General Revenue Policies**

***Generous state general revenue funds.*** Five states provide generous funding from state general revenue to provide needed home and community-based services to youth and families who demonstrate medical necessity for these services due to a severe emotional disturbance. Oklahoma, Florida, Georgia, New Jersey and Connecticut all reported generous state budgets allocated to the funding of intensive home and community-based care for non-Medicaid eligible youth and their families. One state reported, *“Since 2000, we’ve been able to gain state-level finances that have actually helped us sustain the systems that we put in place once our federal dollars were gone. What that does is it allows us as a state to be able to support those kids in the communities that 1) maybe their insurance only pays a portion of what the service will provide, or 2) they don’t have a payment source at all. Regardless if they’re Medicaid or they don’t have a payment source or they have private insurance, we have some state dollars that would allow us to cover their expenses.”* Similarly, another administrator stated, *“If the service is clinically*

necessary. For a child who had Medicaid, it's provided. For a child that doesn't have Medicaid, it's provided." Also, "...in [our state] we have committed, our legislature, governor and our department, that we will offer the identical package to fee-for-service Medicaid for all children and youth who are not covered by Medicaid." Florida's Community Action Teams (CAT) "can serve a young person regardless of if they're Medicaid eligible or not because...the general revenue was allocated specifically by the legislature..." In another state, "basically, if you've got a kid with extraordinary needs and you just can't get them met, the State of Connecticut will help support the treatment costs."

**Creative Strategies for Funding.** In New Jersey, the provision of non-Medicaid funded services is streamlined for providers through the use of a single billing code, "3560" for non-Medicaid covered children and their services. "We said to every provider you're going to bill like it's Medicaid. We have what we call 3560 number, which is a Medicaid look-alike number that allows seamless billing for providers, so it doesn't matter to them whether a child has Medicaid or not. There are caveats to that because the 3560 doesn't cover any medical benefits. It covers all the behavioral health supports and services within the context of the Children's System of Care. From a provider perspective, it makes billing easy." Georgia uses a complex patchwork of general revenue combined with several lesser-known home and community-based services Medicaid policies to ensure funding of needed services for youth. After the conclusion of their participation in the federal PRTF demonstration project, the state sought creative ways to maintain the service array and accessibility established under the demonstration program. Using Money Follows the Person (MFP) and the Balancing Incentive Program (BIP) which were both "a short-term CMS plan to rebalance institution versus community-based care" the state continued to be able to fund the enhanced service array available under the PRTF waiver for many families. These programs provide grant money to states to enable them to provide HCBS to individuals transitioning out of institutional settings (Medicaid.gov, 2016).

**Braided funding.** These states were also able to leverage state revenue from other state child and family-serving agencies such as juvenile justice and child welfare divisions, to broaden the reach of their dollars. "It's all sort of jumbled up in our regular budget because it's gonna come out of the same pot as the pot for our kids in child welfare and juvenile justice.... You need residential, and you're voluntary, okay, we'll pay for that. If you need home-based, okay, you're voluntary, we'll pay for that, but it's coming out of the same overall buckets." Further, if a child has private insurance, and needs services not covered by their plan, states leverage those insurance sources to pay for all possible services in order to conserve state general funds. This allows the state to only fund services not covered by their private plan. "For a child who doesn't have Medicaid, doesn't meet the criteria for Medicaid, and they have a commercial insurance plan—we have to utilize all the components of the commercial insurance plan that are available to us."

**Limited general revenue funds and Community Mental Health Block Grants.** Several responding states acknowledged limits in their abilities to serve non-Medicaid families—and particularly privately insured youth. "For that population, we are trying to figure out how we manage care for them. They're not Medicaid; they're in the cracks." These states report the use of general revenue funding and other sources to help cover the cost of services for youth with SED who are not eligible for Medicaid or whose private insurance does not cover needed services—but admit that funding is insufficient to meet ongoing needs. "We contract our state general fund dollars to them. In our contracts with the mental health centers, we ask them to provide a continuum for youth that is un- or under-insured that matches the services in our

*current state Medicaid plan.... Those dollars are somewhat limited though. They usually, historically have run out of state general funds....*" A good many of these states name Community Mental Health Block Grant funding as a significant and relied-upon resource for serving these youths. *"We also have our Block Grant funding, and it goes out to the Human Service Centers. There's eight in the state. All located throughout to try and hit the major regions. They provide services for youth that are diagnosed with a severe emotional disturbance."* Again, however, block grants are not sufficient to meet the need. *"For the non-system involved, I would say that generally speaking, we have waiting lists everywhere."*

Because these allocations are often not enough to meet all the needs of all families seeking services, many organizations have tactics for stretching their allocation to provide services to more youth and families. One strategy is that organizations serve all youth that need care, regardless of payor source, but they may provide a more limited array of services for youth not covered by Medicaid. *"For people who really have really pressing and serious disorders, they're more likely to get something, but then something is going to be limited because the grant funds are really limited."* Additionally, some of these safety net services are structured on a sliding scale and come with a family co-pay. *"If they don't qualify for Medicaid, they might still get some services, because some (Community Service Boards) CSBs will do a payment based on income, or there'll be a parental co-pay, but that's pretty individual.... we're a very locally administered state, so it varies from different CSBs."*

*Local funding sources.* Many states using general revenue to serve non-Medicaid eligible youth and their families also rely on the contribution of local funds to enlarge the allocation for this population. *"Right now, there is the amount of state general fund that we put out, and the amount the counties are obligated to match is the limiting factor."* States like Washington and Virginia report relying heavily on local funding for safety net mental health services but understand that regional differences exist in both the level of additional funds available and local political will to use it to fund non-Medicaid eligible youth. *"So, in some localities, they just really don't choose, or they choose not to serve kids and not utilize monies for kids who might have severe emotional needs but aren't in one of those other populations [foster youth or youth with Individualized Education Plans]. So, even with this system that was designed to kind of enable localities to serve all kids, we do still have gaps where some kids might go without services."* Regional variation is particularly problematic for this group of states. States like Virginia, California, and Utah report significant levels of funding allocated for serving non-Medicaid eligible youth and their families. However, these states have highly decentralized administrative structures in which counties or local administrators have a good deal of autonomy. *"It's left up to the local level with input from us."* This allows for these funds to be used differentially across regions. *"While we're talking about the public mental health providers, the only thing that they're really mandated to do, or the only services that they're mandated to do, are the case management and the emergency services or the deciding on whether a client should be hospitalized or not ... So, there are places where that is all they do. But most places do more than that. They have other services."* These child mental health administrators acknowledged that regional disparities in access result from this level of autonomy, and many are seeking ways to address that. *"One other thing that I want you to understand is that statewide, local communities and local authorities... Need to be better, and we need to close the funding gap and the insurance gap."*

*Other Medicaid policies.* A few of these states also seek to fill service system gaps through the use of non-waiver Medicaid policies. Both Utah and Colorado offer "b3" services,

which are a specialized set of home and community-based services authorized under section 3 of a 1915(b) Medicaid waiver. *“But the other one that the B waiver allowed was to do was to offer some alternative, flexible services as well. We call them the B3 services.”* 1915(b) Medicaid waivers allow states to waive the federal Medicaid requirement for offering a choice of managed care providers to Medicaid recipients and allows the state to use only one managed care company for this population and restrict service provision only to providers within that network. Under section (3) of this policy, financial savings from restricting the provider network can be channeled into additional home and community-based specialized services for beneficiaries (Medicaid.gov, 2017). Both Utah and Colorado use this waiver to structure behavioral health care for Medicaid recipients to expand the HCBS service array. Similarly, as stated earlier, a few states rolling off of the PRTF Demonstration project have adopted 1915(i) waivers which allow states to expand the service array for youth with SED. *“So, we’d be working on 1915(i) for kids who’ve had multiple psychiatric hospitalizations across the child lifespan, and we’re currently working on a 1915(i) for young children, birth to 8, so we do a specialized service package for them.”* And another state reported using the Money Follows the Person (MFP) and Balancing Incentive Program (BIP), both alternative Medicaid policies allowed through CMS initiatives, to expand and pay for services.

Several states were in the process of designing or implementing Section 1115 Demonstration waivers as a means of transforming their behavioral health systems, and some of these states were aiming specifically to use these policies to comply with the mandate under the ACA in 2012 to create integrated systems that addressed the physical health and behavioral health needs of their residents. A few states were currently operating under such policies at the time of data collection. However, though such policies allow for creative structuring and financing of behavioral healthcare for adults and children, no state reported that these policies impacted behavioral health systems for children in any significant ways or that they were used to extend Medicaid coverage for children who were not financially eligible for Medicaid. While Section 1115 waivers, 1915(i) SPAs, MFP and BIP are Medicaid policies that help states to expand the service array available in homes and communities, they only enhance services for individuals and families who are financially eligible for Medicaid do not extend coverage to youth or families above the Medicaid means test.

## **Part I Conclusions and Implications for Part II**

Part I of this study aimed to understand factors that influence state policymakers' decision-making regarding the use of a Medicaid waiver to organize and fund home and community-based mental health care for children with SED. Additionally, the study aimed to uncover alternative state strategies for funding and delivering HCBS to these youths who are not financially eligible for Medicaid. For states utilizing a TEFRA or 1915(c) Medicaid waivers, the decision to do so was based on the desire of policymakers and administrators to reduce the state's reliance on residential care for youth with complex behavioral healthcare needs—for both fiscal and philosophical reasons. Almost all of these states spoke to political priorities that support children and families—keeping families intact and keeping youth in their homes and communities. All of the states using Medicaid waivers relied heavily on Medicaid funding to support and structure their children's mental health service systems. The majority of these states also acknowledged that resources within the state, due to dominant political values in the legislature, allowed for generous state Medicaid budgets. These budgets enable these states to

absorb excess costs that may result from serving youth with complex medical needs through the public system.

States not using Medicaid waivers most frequently cited budgetary constraints as a key reason that Medicaid waivers were not utilized. A few non-waiver states also stated that they felt their current Medicaid program was sufficient; Their state had high Medicaid penetration rates, and there was a rich home and community-based service array available under their Medicaid program—which is available to children whose family income is up to 300 or 400% of the FPL through the Children’s Health Insurance Program (CHIP). Other states felt there was no need for a Medicaid waiver because there were generous state general revenue funds that enabled the state to meet the needs of all youth and families, regardless of insurance status or income level. These states clearly expressed collective values that support serving youth and families and keeping families together in their homes, which was well supported by the legislature.

Within these decision-making contexts, two general strategies for funding HCBS for non-Medicaid eligible youth emerge in study states: states either utilize state general revenue to fund services as needed or they expand Medicaid benefits to families whose incomes are above the traditional means test. States using general revenue funds either allocate generous or limited portions of state general revenue funds—often activated through specific child mental health legislation—combined with state community mental health block grants to fund services for as many children and families as possible. Some states felt this strategy was meeting the need, and other states acknowledged unmet need resulting from limited funds for this population. Eight states relied on their expansion of the Medicaid benefit package to youth with SED (up to three or four hundred percent of the FPL) through their CHIP policy. The remaining states expanded their Medicaid benefits to youth whose family incomes were beyond traditional means test limits through a TEFRA Medicaid option, a 1915(c) Medicaid waiver, or a state-authorized look-a-like program (e.g., PH95 in Pennsylvania).

These findings cast a new light on the aims of Part II of this study; Rather than examining the relationship between a state’s use of a Medicaid waiver and the unmet mental health needs and cost barriers to care for youth living in that state, results suggest expanding the focus on Medicaid waivers to include all state policies that expand financial eligibility for Medicaid. This new perspective is suggested by statements from state children’s behavioral health administrators that Medicaid waivers were viewed in their state as Medicaid expansions.

The use of the CHIP program to expand Medicaid benefits to more children functions similarly to a TEFRA/Katie Beckett Medicaid waiver, with the exception that such a program is only available to families whose income is at or below 300% of the FPL (or lower in some CHIP Medicaid expansion states). Because of the similar functions achieved through CHIP Medicaid expansions, and because their existence in a state may preclude the use of another type of Medicaid waiver, Part II of this study must be revised to reflect this new information. Rather than aiming to understand the role of Medicaid waivers in enhancing access to home and community-based care for youth with complex behavioral healthcare needs, Part II now aims to understand the role of *any type of Medicaid-expanding policy* in reducing unmet mental health care needs, particularly in relation to cost-barriers to care. In light of Part I findings, a Medicaid-expanding policy can include a Medicaid waiver specifically aimed at children and adolescents with SED or an expansion of the full Medicaid benefit array to all children through the CHIP program.

It is important to clarify, here, that Medicaid-expanding policies in this study do not equate to a state's acceptance of Medicaid expansion under the Affordable Care Act (ACA) of





Though non-Medicaid expanding states (many of whom accepted Medicaid Expansion for non-elderly, non-disabled adults under the ACA) utilize state general funds to offer an enhanced service array specific to youth with complex behavioral health concerns whose family incomes are beyond the means test limits for Medicaid (and some states fund such programs very generously), 1) the clinical and financial eligibility for these services, 2) the services provided under these programs, and 3) the capacity of states to meet the needs of the population may vary greatly from state to state. Though such discrepancies exist across states in Medicaid-expanding policies as well, 1) the federal EPSDT and rehabilitation mandates under Medicaid, 2) the federal match provided to support these services, and 3) the entitlement status of the Medicaid program suggest that such programs may be more comparable across states and that they may have broader service arrays and greater reach than state general revenue-funded programs. For these reasons too, programs within states utilizing general revenue funds to provide services to non-Medicaid eligible youth with SED may differ greatly from Medicaid-based programs. Thus, examining states with Medicaid-expanding policies as a group may be more theoretically justifiable than attempting to compare state general revenue states with each other, or including general revenue-funded states in the predictor group along with states utilizing Medicaid-expanding policies.

Accordingly, Part II of this study will be revised to reflect an examination of the relationship between *a state's use of Medicaid-expanding policies for children* (with and without SED) and a family's experience of unmet mental health care needs and cost-related barriers to care. This will be accomplished by comparing the relationship between these outcomes in states that utilize any policy allowing the full Medicaid benefit package to be accessed by children whose incomes are beyond 100% of the FPL (1915(c) waivers, TEFRA waivers or state look-alikes, CHIP Medicaid expansions) and that in states relying on varying levels of state general revenue to fund home and community-based mental health care for non-Medicaid eligible youth with SED.

## CHAPTER 3: PART II METHODS & FINDINGS

### Part II Aims

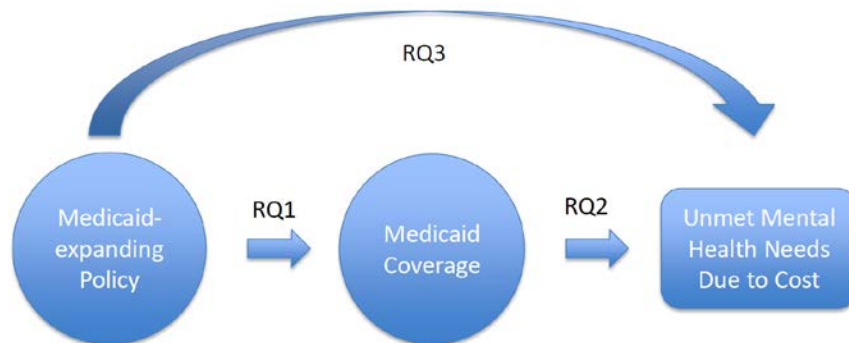
Part II of this study aims to discern a relationship between a state’s use of Medicaid-expanding policies, either through Medicaid waivers or CHIP, and unmet mental health care needs and cost barriers to care for youth with SED, using multi-level logistic modeling with random intercepts. To most specifically assess this relationship, Part II also aims to understand the role of these policies in increasing access to public health coverage, and the role of public health coverage in reducing unmet mental healthcare needs and cost barriers to care. By understanding the relationship between Medicaid-expanding policies and youth’s public health coverage, as well as the relationship between public health insurance and unmet mental health care needs due to cost concerns, this analysis can control for the mediating role of public health coverage and assess the direct relationship between a state’s use of a Medicaid-expanding policy and the cost-related unmet mental health care needs of youth with complex behavioral healthcare needs. The concern is to ascertain direct effects and indirect effects—via increased chances of having public health insurance—of Medicaid-expanding policies on having unmet treatment need and encountering cost barriers to care. Specifically, Part II asks the three following questions, which are illustrated in Figure 8 below:

*(RQ1) Controlling for variation in clinical severity of youth, do youth with SED who reside in states with Medicaid-expanding policies have higher odds of having public health coverage?*

*(RQ2) Controlling for variation in clinical severity of youth, do youth with SED with public health coverage, have lower odds of having unmet treatment needs and encountering cost barriers to care?*

*(RQ3) Controlling for insurance status and clinical severity of youth, do youth with SED residing in states with Medicaid-expanding policies have lower odds of having unmet treatment needs and encountering cost barriers to care?*

**Figure 8. Part II Aims**



### Part II Methods

### Part II Data Sources

**Findings from Part I.** The predictor variable for Research Question One (RQ1) and Research Question Three (RQ3) in Part II of this study is derived from the findings of Part I of this study. Based on these findings, states are coded as Medicaid-Expanding Policy states or non-Medicaid-expanding states.

**National Survey of Children with Special Health Care Needs (NS-CSHCN).** The predictor variable for Research Question Two (RQ2), the response variables, and many control variables for this analysis were drawn from the National Survey of Children with Special Health Care Needs, conducted in 2009 to 2010. This survey was conducted by the National Center for Health Statistics at the Centers for Disease Control and Prevention, under the direction and sponsorship of the federal Maternal and Child Health Bureau (MCHB). The survey used the State and Local Area Integrated Telephone Survey (SLAITS) technology for sampling and administration, taking independent random samples in all 50 states and the District of Columbia. The survey was administered in English, Spanish, Mandarin, Cantonese, Vietnamese and Korean. A total of 40,242 detailed interviews were collected, with at least 750 interviews in each state and the District of Columbia.

This sample was achieved by screening 372,698 children 0-17 years old living in 196,159 households nationwide, using a survey tool developed and validated specifically to identify children who meet the federal MCHB health-consequences-based special health care needs definition (CSHCN Screen). The Screener asks parents about the presence of five different health consequences: 1) need for or use of prescription medications; 2) elevated need for or use of medical, mental health, or educational services; 3) functional limitations; 4) need for or use of special therapies; or 5) emotional, developmental or behavioral conditions that require treatment. Parents of children 0-17 years old who experience one or more of these health consequences are then asked whether the specific health consequences are attributable to a medical, behavioral, or other health condition and whether this condition has lasted or is expected to last for at least 12 months. Any child with an affirmative response to one or more of the five consequences and its follow-up questions is considered to have special health care needs. In this way, 59,941 were identified with special health care needs. For households with more than one child with a special health care need, one child was randomly chosen to be the subject of the final interview.

The 2009/10 NS-CSHCN provides detailed state- and national-level parent-reported information on the health status and health care system experiences of children and youth with special health care needs (CSHCN) and their families. Topics covered by the survey include health and functional status, insurance coverage and adequacy of coverage, access to health care services, medical home, impact of children's special needs on their families, family-centeredness of services and care coordination.

**CMHS Uniform Reporting Systems (URS).** Total State Mental Health Authority Expenditures from 2009 is used as a state level control variable. This data is drawn from the Centers for Mental Health Services (CMHS) Uniform Reporting System. CMHS provides "guidance and technical assistance to decision makers at all levels of government on the design, structure, content, and use of mental health information systems, with the ultimate goal of improving the quality of mental health programs and services delivery." It describes federal Uniform Reporting System as "uniform, comparable, high-quality statistics on mental health services." The URS has been used by State Mental Health Agencies (SMHAs) to aggregate and report annual data for each state as part of the Federal Community Block Grant. Beginning in 2001, the URS was developed to enable the use of data in decision support and planning for public mental health systems and to promote program accountability.

Created in collaboration with SMHAs, the dataset includes 21 tables that include the number and sociodemographic characteristics of people served, outcomes from services, state's use of specific evidence-based practices, consumer assessments of care, and state expenditures and revenues. SAMHSA regularly used these data to calculate and report on ten identified National Outcome Measures for state and national reporting on mental health in the US, which capture how well service users are managing their illness and functioning in their daily lives, as well as indicators of access and stability of living placements.

**The Substance Abuse and Mental Health Data Archive's (SAMHDA) National Mental Health Services Survey (N-MHSS), 2010.** Part II analysis also includes a state level control variable capturing the total number of mental healthcare facilities that serve children in each state. This data is drawn from The Substance Abuse and Mental Health Data Archive's (SAMHDA) National Mental Health Services Survey (N-MHSS), conducted in 2010. The N-MHSS is a point-prevalence survey, providing a "snapshot" of information about the U.S. mental health treatment system and the consumers it serves on a pre-selected reference date of April 30, 2010. Data was collected between June 2010 and January 2011 from all known public and private mental health facilities in the US. The dataset includes information about the location, characteristics and use of formal mental health service providers throughout all 50 states, the District of Columbia and the U.S. territories. Data was collected via computer-assisted phone interviews, mail in surveys, or a secure web-based questionnaire.

The codebook for these data includes detailed method descriptions of data collection, data cleaning, item response rates, quality assurance procedures and imputation processes. Missing data were imputed (10 times) for the total number of clients (by gender, age and legal status) services for each service setting (inpatients, residential and outpatient), as well as for the total number of beds and number of admissions reported by each facility. The sample for the survey initially included over 16,000 facilities, but only approximately 12,100 were found to be eligible to participate. The survey excluded the following facilities: military treatment facilities, Indian Health Service-administered or tribally-operated facilities, private practitioners or small group practices not licensed as a mental health clinic or center, and jails or prisons. Though an attempt was made to obtain data from all eligible facilities, the data set includes a non-response rate of 8.8%, for which the data is not adjusted. However, among responding facilities, the item response rate averaged 98%.

**State and Local Public Policies Database, 2011** (Sorens, Muedini, & Ruger, 2008). A variable capturing state political ideology was utilized from the State and Local Public Policies Database of 2011. This database identifies and codes over 200 public policies for each American state as of December 31<sup>st</sup>, 2011. Occasionally, local policies are coded at the state level as well. The database is stored virtually and is available publicly at [www.statepolicyindex.com](http://www.statepolicyindex.com).

**U.S. Religion Census: Religious Congregations and Membership Study, 2010.** Designed and executed by the Association of Statisticians of American Religious Bodies (ASARB) from 2009 to 2011, data on the number of congregations and adherents for 236 religious groups in each county of the United States is compiled. The sponsors invited all religious bodies that could be identified as having congregations in the United States to participate. Special effort was made to identify and include data from several religious bodies that are traditionally excluded or are underrepresented in similar past studies. These included independent or non-denominational churches, Jewish synagogues, historically African American churches, Hindus, Buddhists, and Muslims. Data was collected from participating congregations directly (80% response rate of 296 congregations invited), and research staff employed standard

procedures for checking the accuracy of data submitted. This included checking state and national totals against county data and adjusting discrepancies (reviewing adjustments with the informant) and, when appropriate, applying the estimating procedure for adherents. Data collected from each participating congregation included membership data, adherents (including members, their children, and non-member participants), and average and weekly attendance data.

**U.S. Census Bureau, 2010.** Data for the total state population, state median income, total child population, and total number of children living below 400% of the FPL are drawn from 2010 U.S. Census Data.

**U.S. Census Bureau, 2010 Annual Survey of State Government Tax Collections.** The Annual Survey of State Government Tax Collections provides a comprehensive look at state governments and contains statistics on the tax collections of all state governments (no local government collection data), including receipts from compulsory fees.

**Henry Kaiser Family Foundation, State Health Facts.** Total Medicaid expenditures per child for each state was pulled from the Kaiser Family Foundation State Health Facts, “Medicaid Spending per Enrollment Group,” which is publicly available on their website.

## **Part II Data Set**

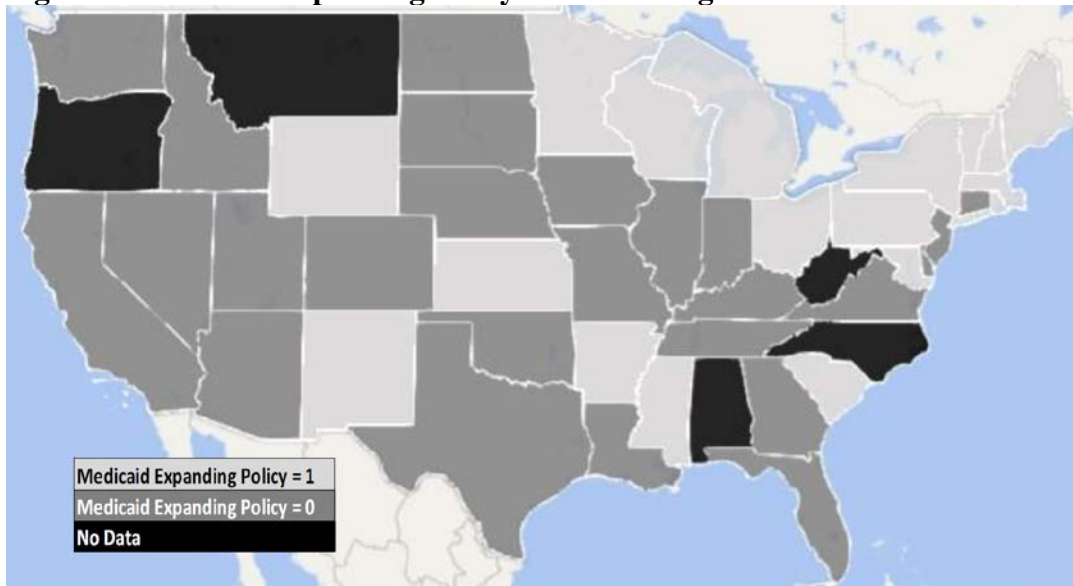
**Independent variables.** To achieve the aims of Part II, and to answer all three research questions, two independent variables were used across three stages of modeling. Whether or not a state had a Medicaid-expanding policy specific to children was used as an independent variable in Research Question 1 and Research Question 3 models. The type of health insurance a youth was covered under was used as a dependent variable for the Research Question 1 model, as an independent variable for Research Question 2 models, and as control variable in Research Question 3 models.

**Medicaid-expanding policy.** The independent variable in the analysis for Research Question 1 and Research Question 3 in Part II of this study is the presence of a Medicaid-Expanding Policy in the state. As stated above, this data was drawn from findings in Part I of this study. This is a binary variable. A state is classified as a state with a Medicaid-Expanding Policy if interview data or publicly available documents indicate that a state uses one of the following Medicaid policies to expand Medicaid HCBS benefits to children or specifically to youth with SED: a 1915(c) Medicaid waiver, a TEFRA/Katie Beckett Medicaid option or a state-level look-alike (e.g., PH-95 in Pennsylvania), or Medicaid expansion through CHIP. If a state offered one or more of these policies in 2009, it was coded as a “1” for this variable. If a state did not offer such a policy in 2009, it was coded as a “0.”

Due to the ever-changing nature of Medicaid and mental health policy, some analytic decisions were made about coding this variable. For this analysis, states must have had an established and on-going policy in 2009 that expanded Medicaid eligibility beyond the traditional means-test limits to fund home and community-based care. This excludes states involved only in the PRTF federal demonstration, using section 1115 waivers, 1915(b) services, or states using the TEFRA option only to fund residential care. Three states that currently offer 1915(c) waivers for youth with SED did not offer them in 2009 or were just adopting them. Texas adopted one in 2009, Iowa adopted in 2010, and Louisiana adopted this policy in 2012. Because Texas and Iowa were just implementing these programs in 2009/2010, it was unlikely the impacts of them would be discernable for that year. For this reason, these states were coded as a “0,” a non-Medicaid-Expanding Policy state. Additionally, in 2009, nine states were

participating in the federal PRTF Demonstration Project, under which they were offering a 1915(c) Medicaid waiver for youth with SED. Because the program was started in 2007, and was still in the early stages of implementation, and because many of these programs in participating states were very small in scale, states only offering the PRTF Demonstration 1915(c) waiver were also coded as a “0,” a non-Medicaid-Expanding Policy state (Montana, Georgia, Virginia, Indiana). States participating in the PRTF Demonstration which also offered another 1915(c) waiver for youth with SED (Kansas), or which offered a TEFRA Medicaid option or Medicaid expansion through SCHIP (Maryland, Mississippi, Alaska, South Carolina) were coded as “1”, Medicaid-expanding states. Additionally, the two states that only use a TEFRA-like policy for funding only residential care (Arizona and Colorado) were coded as “0,” non-Medicaid-expanding policy states. Finally, states that are using Section 1115 waivers, 1915(i) or other Medicaid policies for expanding Medicaid services were coded as “0”, non-waiver states. This is because these policies are aimed primarily at expanding the service array under Medicaid, and not expanding the means-test limits for eligibility. Final coding of states as Medicaid-Expanding Policy States is illustrated below in Figure 9.

**Figure 9. Medicaid-Expanding Policy States Coding**



\*Hawaii and Alaska are both coded as Medicaid-expanding States

**Public health insurance.** A variable accounting for the type of health insurance covering a youth was also utilized as an independent variable for Research Question 2. This variable captures the type of coverage a child in the data set is covered under. As a predictor variable, this was coded as a categorical variable where children with private insurance act as the reference group. Other categories for this variable include 1) “public insurance” for children with Medicaid or CHIP coverage only, 2) “dual insurance” for children with both private insurance and Medicaid or CHIP coverage, and 3) “uninsured” for children without any type of health coverage.

**Dependent variables.** This analysis assessed the relationship between a state’s use of a Medicaid-expanding policy and the odds of a youth with SED residing in that state having public health coverage. Additional models assessed the relationship between public health coverage and

unmet mental health care needs and cost barriers to care. To specifically address the cost barrier to mental health care that the expanded HCBS benefits under Medicaid may reduce, an additional model assessed the relationship between a state's use of a Medicaid-expanding policy and the odds of a family residing in that state experiencing unmet mental health care needs and delays or challenges in obtaining care due to cost concerns.

**Reports unmet mental health care need.** Drawn from NS-CSHCN data, Unmet Mental Health Care Need is a binary variable. The survey included the questions, "During the past 12 months was there any time when [your child] needed mental health care or counseling?" and "Did [your child] receive *all* the mental health care or counseling that [he/she] needed?" If the respondent answered "yes" to the first question and then "no", to the second question, this variable was coded as "1" for the observation. Otherwise, it was coded as "0".

**Reports delays or challenges in obtaining services due to cost.** Also drawn from NS-CSHCN data, Delays or Challenges in Obtaining Services Due to Cost is a binary variable as well. The survey included the question "In the past 12 months, did you experience any difficulties or delays in accessing care because of issues related to costs?" If the family answered "yes" to this question, the observation was coded as a "1" for this variable. If the family answered "no," it was coded as a "0."

**Reports public insurance.** A variable accounting for the type of health insurance covering the youth was also utilized as a dependent variable for Research Question 1. This variable captures the type of health insurance a child in the data set is covered under. As a response variable, this was coded as a binary variable where a child with only Medicaid or CHIP coverage or with Medicaid/CHIP coverage in addition to private health insurance was coded as a "1." A child with no insurance or only private insurance was coded as a "0."

**Control variables.** Control variables were drawn from the NS-CSHCN, the Centers for Mental Health Services (CMHS) Uniform Reporting System 2009 data, and from the Substance Abuse and Mental Health Data Archive's (SAMHDA) National Mental Health Services Survey (N-MHSS), 2010.

**Child level variables.** Control variables at the child level include the SED status of the child, the type of insurance the child is covered under, and whether or not the child qualified as a Child with Special Health Care Needs due to functional impairment, elevated service use, or due to use of prescription medications.

**SED status.** The identification of a child in the dataset as Severely Emotionally Disturbed is derived from a variable in the NS-CSHCN data that labels the child as having qualified as a child with special health care needs due to ongoing emotional, developmental, or behavioral health conditions. In the survey, this was determined by the respondent's answer to the screening question in the CSNCN screening tool. The screening tool asks "Does your child have any kind of emotional, developmental, or behavioral problem for which (he/she needs/'they need') treatment or counseling?" and "Has this emotional, developmental or behavioral problem lasted or is it expected to last 12 months or longer?" If a parent answered "yes" to both of these questions, this variable was coded as a "1." If they answer "no" to one or both questions, then this variable was coded as a "0."

**Insurance type.** A variable accounting for the type of health insurance covering the youth was also utilized as a control variable for Research Question 3. This variable captures the type of coverage a child in the data set is covered under. As a control variable, this was coded as a categorical variable, where children with private insurance act as the reference group. Other categories for this variable include 1) "public insurance" for children with Medicaid or CHIP

coverage only, 2) “dual insurance” for children with both private insurance and Medicaid or CHIP coverage, and 3) “uninsured” for children without any type of health coverage.

*Severity variables.* Variables capturing the severity of a child’s mental health needs were included to control for variation in the level of services needed by children in the sample.

Functional impairment. A variable capturing the severity of a child’s needs was included as a control variable in models for all three research questions. The Functional Impairment variable is derived from a variable in the NS-CSHCN data that labels the child as having qualified as a child with special health care needs due to impairments in functioning. In the survey, this was determined by the respondent’s answer to the screening question in the CSNCN screening tool. The screening tool asks “Is your child *limited or prevented* in any way in (his/her/their) ability to do the things most children of the same age can do?”; “Is this limitation in abilities because of ANY medical, behavioral, or other health condition?” and “Is this a condition that has lasted or is expected to last 12 months or longer?” If the parent responded “yes” to all three questions, this variable was coded as a “1.” Otherwise, the child was coded as “0,” having no functional impairments.

Prescription medication use. Another variable capturing the severity of a child’s needs was included as a control variable in models for all three research questions. The Prescription Medication variable is derived from a variable in the NS-CSHCN data that labels the child as having qualified as a child with special health care needs due to use of prescription medication. In the survey, this was determined by the respondent’s answer to the screening question in the CSNCN screening tool. The screening tool asks “Does your child currently need or use medicine prescribed by a doctor, other than vitamins?”, “Is their need for prescription medicine because of ANY medical, behavioral, or other health condition?” and “Is this a condition that has lasted or is expected to last 12 months or longer?” If the parent responded “yes” to all three questions, this variable was coded as a “1.” Otherwise, the child was coded as “0,” have no need for prescription medication.

Elevated service use or use of special therapies. For observations in the sample who qualified as a Child with Special Health Care Needs (CSHCN) due to an emotional, developmental or behavioral concern, the Functional Impairment and Prescription Medication Use variables captured the severity of SED in each observation. For observations who qualified as a CSHCN due to use of prescription medication, while Functional Impairment was “0” are likely children whose needs could be addressed primarily through medication management. Remaining observations who qualified as a CSHCN due to use of Functional Impairment, whether or not Prescription Medication Use was “0”, are likely children who have higher needs for intensive or more complex services. Remaining observations who did not qualified as a CSHCN due to Prescription Medication Use or Functional Impairment (both variables are “0”) are children who likely have moderate needs, and who may have qualified as a CSHCN due to elevated service use or use of specialized therapies.

*Race.* In initial analysis and model building, it became clear that including a race variable masked the main findings due to collinearity, and separate analyses are required to untangle patterns of association behind these correlations. Though race is linked to mental health care access (Aratani & Cooper, 2012; Lu, 2017; Snowden, Masland, Fawley, & Wallace, 2009), due to high poverty rates, being Latinx or African American is also strongly linked to having Medicaid coverage (Snowden & Graaf, in progress). Thus, an individual’s race is likely more strongly predictive of Medicaid coverage than their state of residence. This is particularly true because Medicaid-expanding policies are more likely to change the insurance status of youth



with higher family incomes and who are less likely to be Latinx or African American. Because insurance status is the significant variable of interest in this analysis, and it is used as a predictor variable, a response variable and a control variable, and because including race as a control introduced analytic problems related to multicollinearity with insurance, race was omitted from the final models.

***Family level.*** Control variables at the family level include the income level of the family, and the education level of the child's parents.

***Poverty level.*** The income level of the family, which impacts the family's insurance status, was controlled for with the use of a Poverty Level variable. This categorical variable accounted for the income of the family by assigning codes for four income categories: 0% - 99% FPL (1), 100% - 199% FPL (2), 200% - 399% FPL (3), and 400% FPL or greater (4). The reference group was 0%-99% FPL.

***Parent education level.*** The education level of the parents, which may relate to the ability of the parent to navigate complex mental health service systems, was controlled for with the use of a Parent Education Level variable. This categorical variable accounted for the education level of a child's parents by assigning codes for three education categories: Less than high school (1), High school graduate (2), and More than high school (3). The reference group was "Less than high school."

***State level.*** Two additional variables were included in models to control for state-level factors that could be linked to increase access to mental health care for children with SED and their families.

***Total State Mental Health Authority expenditures and ambulatory revenues.*** Qualitative findings demonstrate that state's budgets and the status of the state economy influenced state decisions to utilize a Medicaid-expanding policy. Further, state investment in mental health care has been linked to total mental health care access in previous studies (Ng et al., 2015; Snowden, Masland, Wallace, Fawley-King, & Cuellar, 2008). To control for the relationship between variation in state budgets as well as state investment in public community-based mental health care, Total State Mental Health Authority Expenditures and Ambulatory Revenues were included in models for Research Questions 2 and 3. This data, for each state, was drawn from the 2009 Centers for Mental Health Services (CMHS) Uniform Reporting System reports.

***Total state child mental health facilities.*** Though not explicitly stated by Part I participants as a factor in waiver-adoption decision making, the number of mental health practitioners in a given region has been linked to mental health care access. To control for the relationship between the number of providers and mental health service accessibility, the total number of mental health providers and facilities was included in the model for Research Question 2 and 3. This data was derived from The Substance Abuse and Mental Health Data Archive's (SAMHDA) National Mental Health Services Survey (N-MHSS) from 2010. The total number of mental health facilities and providers who served children was counted for each state and included in the dataset.

***Political ideology: Civil Libertarianism.*** From the State and Local Public Policies Database, 2011 (Sorens et al., 2008), this variable captures one of the first two components from principal component analysis (PCA) on the variables in the database. The third component extracted from PCA was capturing distinctive aspects of Alaska, and therefore was not usable. The two principle components represent two dimensions of state policy ideology: liberalism-conservatism and civil libertarianism-authoritarianism (what Sorens et al. (2008) called "policy urbanism"). The civil libertarianism variable reflects policy trends, loading heavily onto smoking

bans and same-sex marriage. This variable was included to capture possible influence of liberal political ideology that favors Medicaid expansions and greater public spending on safety net services revealed in the qualitative portion of the study. These values may also increase service accessibility via higher reimbursement rates, greater public spending, and the larger provider network that may result.

*Religiosity.* Drawn from the U.S. Religion Census: Religious Congregations and Membership Study of 2010, this variable represents the total adherence rate (per 1,000 population) in each state across all surveyed religious congregations. Adherence is the average number of individuals attending worship regularly. This variable was included to account for the potential of dominant religious views within a state that may influence child and family policy revealed in Part I of this study—possibly resulting in greater investment in services for this population and thus greater service accessibility.

*Total state revenue.* Drawn from the U.S. Census Bureau, 2010 Annual Survey of State Government Tax Collections, this variable represents total tax revenue collected by states in 2010. Data does not account for employer and employee assessments for retirement and social insurance purposes, or collections for the unemployment compensation taxes imposed by each of the state governments. No local taxes are included in estimates.

*Total State Population, State Median Income, Total State Child Population and Number of Children living at or below 400% of the FPL.* Drawn from 2010 U.S. Census data, these variables are included to control for variation in state demographics which may driver greater investment in public healthcare for children and the accessibility of services to average family consumers.

*Total Medicaid Expenditures per Child.* Drawn from the Kaiser Family Foundation State Health Facts, these estimates are based on analysis of data from the 2014 Medicaid Statistical Information System (MSIS) and the Urban Institute estimates from CMS-64 reports. They include both state and federal payments to Medicaid for services provided to children in each state, ages 18 years and under, in the 2014 fiscal calendar year. This variable was included to further control for state investment in children’s healthcare, which may impact accessibility to services via enhanced reimbursement rates and the larger provider networks that may result.

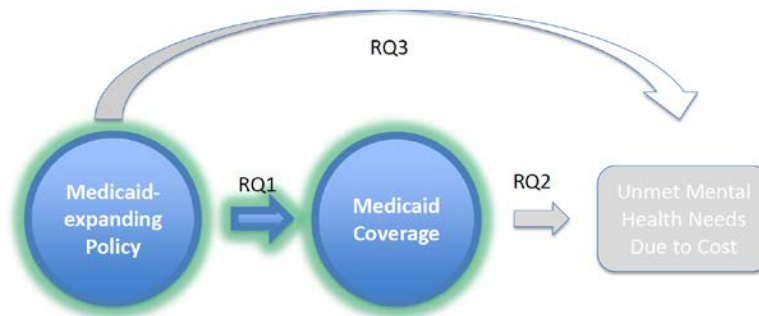
## **Sample Preparation**

To create the data set for this analysis, a dataset including states and state-level variables was merged with the 2009/2010 data from the NS-CSHCN. This process applied all state level variables associated with a given state to each child identified as living in that state. The total sample size for the merged data set was 39,491. Observations which did not qualify as a CSHCN due to an emotional, developmental, or behavioral concern were dropped. This left 12,392 observations. Finally, observations were dropped in five states for which there was no data for the predictor variable, Medicaid-Expanding Policy. These five states are pictured in Figure 9 (Oregon, Montana, North Carolina, Alabama, and West Virginia) and are states that declined to participate in Part I interviews, and for which there was no publicly available information about their use of Medicaid-expanding policies. After dropping observations in these states, the final sample size was 11, 215. Once the data set was finalized, variables and relationships between variables were assessed to identify any problematic multicollinearity. As stated previously, race covaried so strongly with public health insurance, that the race variable was left out of final analytic models.

## Data Analysis

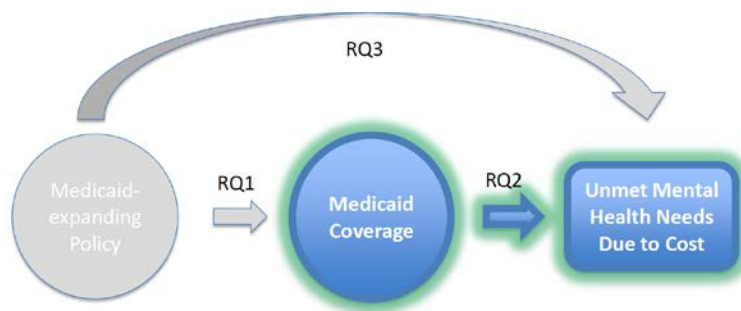
Descriptive analysis identified insurance coverage type and level of severity across all children in the sample, and assessed differences in child insurance coverage and clinical severity between states that do and do not offer Medicaid-expanding policies for children and youth with SED. This stage of analysis also assessed variation in child severity and unmet treatment needs by four types of insurance coverage. Five random-intercept logistic regression models were fit, where child and family observations were nested within states.

**Figure 10. (RQ1) Controlling for variation in clinical severity of youth, do youth with SED who reside in states with Medicaid-expanding policies have higher odds of having public health coverage?**



The model for Research Question 1, “Do youth with SED who reside in states with Medicaid-expanding policies have higher odds of having public health coverage?” (Illustrated in Figure 10 above) estimated the relationship between a state’s use of a Medicaid-expanding policy and the odds that a youth would have Medicaid, controlling for family income, and the severity of the youth’s clinical needs. The model also controlled for state political ideology (civil libertarianism) and religiosity, total state revenues, total state population and child population, the number of youth living at or below 400% of the FPL, and state median income.

**Figure 11. (RQ2) Controlling for variation in clinical severity of youth, do youth with SED with public health coverage, have lower odds of having unmet treatment needs and encountering cost barriers to care?**

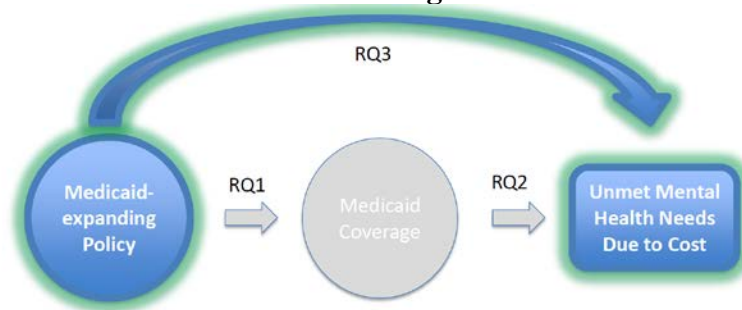


Two models were used to answer Research Question 2, “Do youth with SED with public health coverage, have lower odds of having unmet treatment needs and encountering cost barriers to care?” (Illustrated in Figure 11 above). One model estimated the relationship between a child’s type of insurance coverage and the odds that the youth would have unmet mental health

needs. The second model estimated the relationship between a child’s type of insurance coverage and the odds that the youth would encounter cost-barriers to care. Both models controlled for family income, parent education level, the severity of the youth’s clinical needs, and state total SMHA expenditures and ambulatory revenues as well as the total number of mental health providers serving children in the state. The models also controlled for state political ideology (civil libertarianism) and religiosity, total state revenues, total state population and child population, the number of youth living at or below 400% of the FPL, and state median income.

Both models also controlled for an interaction between type of health insurance and the severity of a child’s clinical need. These interaction variables combined a child’s type of health insurance coverage (public, private, dual or no insurance) with Functional Impairment, for a total of four interaction variables. These variables were created to observe the effects of Medicaid-expanding policies and type of health coverage on unmet mental health care needs, and cost-barriers to care specifically for children who have the most significant mental health care needs. This variable accounts for the possibility that children with more intensive mental health care needs might have more unmet needs when covered by private insurance than by public insurance, due to the richer home and community-based mental health service array available under Medicaid.

**Figure 12. (RQ3) Controlling for insurance status and clinical severity of youth, do youth with SED residing in states with Medicaid-expanding policies have lower odds of having unmet treatment needs and encountering cost barriers to care?**



Two models were used to answer Research Question 3, “Controlling for insurance status, do youth with SED residing in states with Medicaid-expanding policies have lower odds of having unmet treatment needs and encountering cost barriers to care?” (Illustrated in Figure 12 above). One model estimated the relationship between a state’s use of a Medicaid-expanding policy and the odds that a youth with SED living in that state would have unmet mental health needs. The second model estimated the relationship between a state’s use of a Medicaid-expanding policy and the odds that a youth with SED living in that state would encounter cost-barriers to care. Both models controlled for family income, parent education level, the severity of the youth’s clinical needs, and state total SMHA expenditures and ambulatory revenues, as well as the total number of mental health providers serving children in the state. Both models also controlled for an interaction between type of health insurance and the severity of a child’s clinical need. The model also controlled for state political ideology (civil libertarianism) and religiosity, total state revenues, total state population and child population, the number of youth living at or below 400% of the FPL, and state median income.

States differ widely in many aspects integral to this study, and random intercept modeling is implemented here, as is often done when individuals are nested in states, counties, or other groupings because it accounts for the between-state variation. Between-state variation leads to correlations between observations within the same state which violates assumptions of standard regression approaches. Hierarchical modeling accounts for this non-independence and provides an estimate of between-state variance and within-state correlation.

**Part II Findings: The Role of Medicaid-Expanding Policies in Increasing Access to Home and Community-based Mental Health Care for Youth with SED**

**Descriptive Findings**

The demographic variables from the NS-CSHCN sample are presented in Table 5. The majority of youth in the sample are covered by private insurance or public insurance, and the majority of families in the sample have a parent with more than a high school education. More children qualified as a CSHCN due to prescription medication use than due to functional impairments, and many more families experienced cost barriers to care than unmet mental health care needs.

Table 6 shows the mean number of mental health facilities and total State Mental Health Authority Expenditures for both states that offer Medicaid-expanding policies for children and youth with SED, and for states that do not. States with Medicaid-expanding policies on average have higher total spending on public mental health care and total number of mental health providers.

**Table 5. Descriptive statistics of the analytic sample of children participating in the 2009-2010 NS-CSHCN**

Insurance Type	N	%
Private	4,965	46%
Public	4,221	39%
Both	1,304	12%
Uninsured	337	3%
FPL Range	N	%
0-100%	2,478	22%
100-200%	2,406	21%
200-399%	3,319	30%
400% and up	3012	27%
Parent Education Level	N	%
Less than high school	765	7%
High school	1,891	17%
More than high school	8,559	76%
Child Clinical Severity	N	%
Qualified on Functional Impairment	4,201	37%
Qualified on Prescription Medication Use	7,186	63%
State of Residence	N	%

No Medicaid-expanding policy	5,790	53%
Medicaid-expanding policy	5,174	47%
<b>Mental Health Access</b>		
	<b>N</b>	<b>%</b>
Have Unmet Mental Health Needs	1411	13%
Experienced Cost Barriers to Care	2306	21%

**Table 6. Descriptive statistics of the states with and without Medicaid-expanding policies**

State Policy	Mean No. MH Facilities	Mean Total Expenditures
No Medicaid-expanding policy	214	\$669,217,800
Medicaid-expanding policy	222	\$779,378,400

Figure 13 illustrates the number of youth with each insurance type, categorized by whether or not the child lives in a Medicaid-expanding state. This figure shows that states with Medicaid-expanding policies have fewer youth that are uninsured and more youth who have both private and public insurance. Further, states with no Medicaid-expanding policy have a larger number of their youth population privately insured than comparison states.

**Figure 13. Insurance type by state Medicaid policy type**

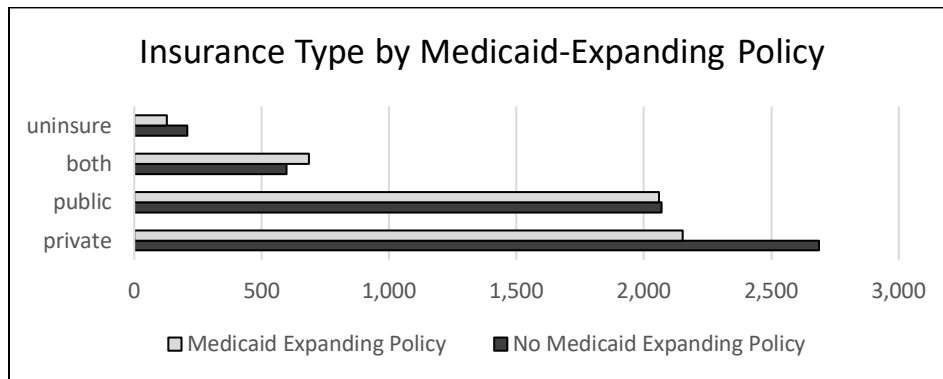


Table 8 (below) shows the proportion of youth living within each income category that has each type of insurance, differentiated by state Medicaid policy. In states with Medicaid-expanding policies, larger proportions of children are covered by both public and private insurance or by public insurance only across almost all income levels. In states with no-Medicaid-expanding policy, more youth are uninsured and privately insured across all income levels.

**Table 8. Insurance type by state Medicaid policy type and family income level**

	<b>0-99% of FPL</b>				<b>100-199% of FPL</b>			
	Private	Public	Dual	None	Private	Public	Dual	None
No Medicaid Expanding Policy	6%	78%	10%	6%	27%	55%	12%	6%
Medicaid Expanding Policy	4%	80%	12%	4%	23%	60%	14%	3%
	<b>200-399% of FPL</b>				<b>400% of FPL and above</b>			
	Private	Public	Dual	None	Private	Public	Dual	None
No Medicaid Expanding Policy	64%	21%	12%	3%	82%	8%	9%	1%
Medicaid Expanding Policy	57%	25%	16%	3%	78%	8%	13%	1%

Figure 14 demonstrates that significantly more youth with no insurance experience unmet needs and cost barriers to care than youth with any other type of insurance. Youth with private insurance experience more cost barriers to treatment than youth with public insurance but more youth with only Medicaid have unmet needs than youth with private insurance.

**Figure 14. Youth with unmet need and cost barriers by insurance type**

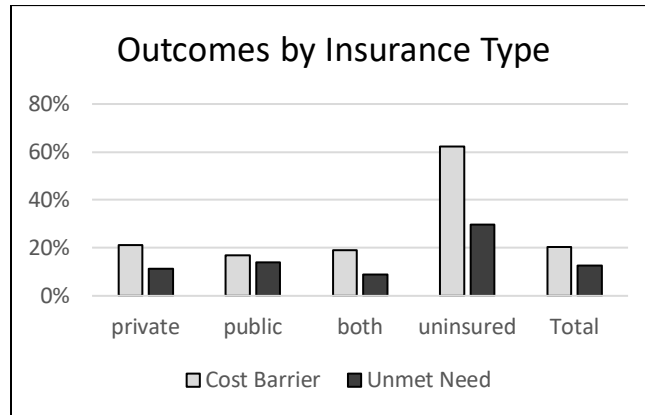


Figure 15 shows the percentage of youth with unmet needs and cost barriers to treatment for both youth with functional impairments and for youth who only need prescription medication. Greater portions of youth with functional impairments experience cost barriers to care (27%) than youth with only medication usage (20%). Unmet needs are also slightly greater for youth with functional impairments (13%) than for youth without (11%). Overall, greater portions of children, of all levels of severity, experience cost barriers to care than unmet mental health treatment needs.

**Figure 15. Percent of youth with unmet need and cost barriers by clinical severity**

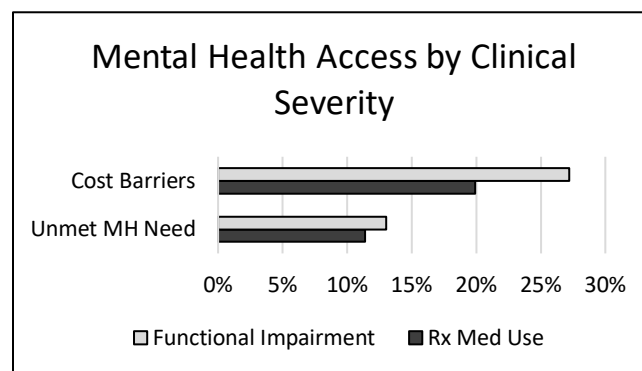


Figure 16 illustrates that a smaller portion youth living in states with Medicaid-expanding policies have cost barriers to care and unmet mental health care needs than do the portion of similar youth living in comparison states.

**Figure 16. Portion of youth with unmet need and cost barriers by state Medicaid policy**

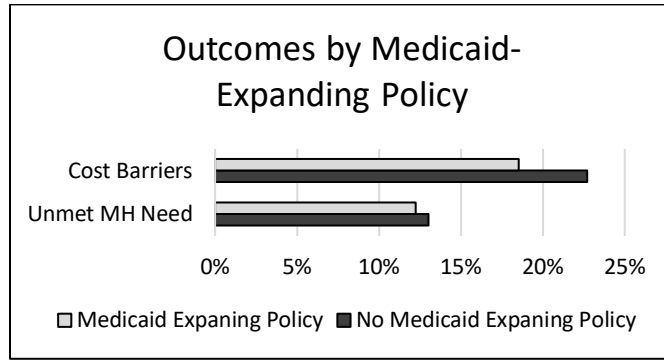
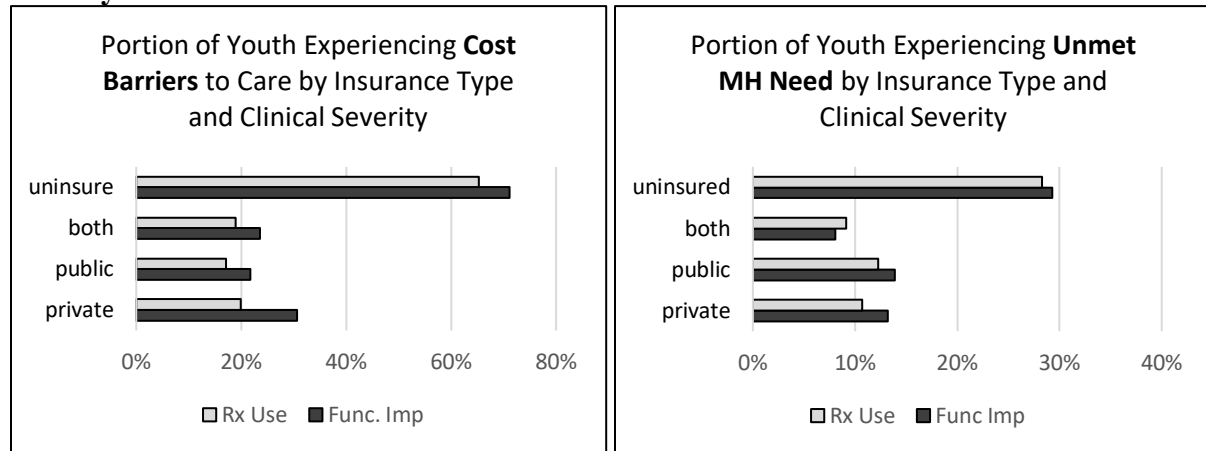


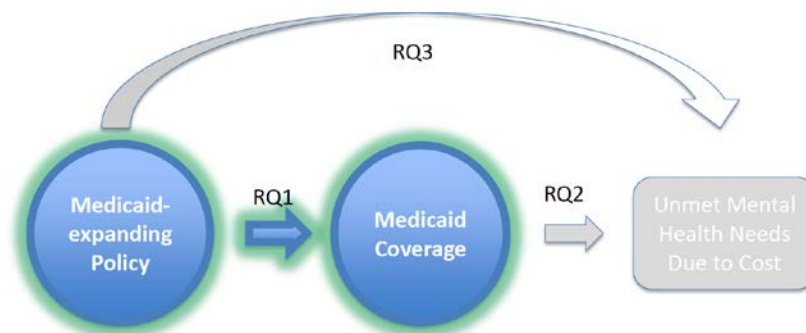
Figure 17 illustrates that children with no insurance are the largest portion of the population that have unmet mental health needs and experience cost barriers to care. However, this is particularly true for youth who have functional impairments.

**Figure 17. Children with unmet need and cost barriers by insurance type and clinical severity**



**Research Question One Findings**

**Figure 10 (revisited). (RQ1) Controlling for variation in clinical severity of youth, do youth with SED who reside in states with Medicaid-expanding policies have higher odds of having public health coverage?**





Results for Research Question 1 analysis (Do youth with SED who reside in states with Medicaid-expanding policies have higher odds of having public health coverage?) are displayed in Table 7. Findings support Hypothesis RQ1: The odds of having public insurance (dual coverage or public only) are estimated to be 1.44 greater for youth with SED living in a state with a Medicaid-expanding policy than that of a similar youth living in non-expansion policy states. Further, results indicate that, in non-Medicaid-expanding policy states, youth with functional impairments are estimated to have 85% greater odds of having public health coverage (dual coverage or public only). Several state level variables (state population, state median income, total religiosity, and total children below 400% FPL) are significant, but do not appear to impact the odds that a youth will have public health coverage. Intra-class correlations are also reported in Table 7a for this model, with and without state level covariates.

**Table 7. Do Medicaid expansion policies predict public health coverage?**

	<u>OR</u>	<u>95% CI</u>	
Medicaid-Expanding Policy	1.44**	1.16	1.79
Political Ideology	1.00	0.94	1.06
Total State Revenue	1.00	0.99	1.01
Child Population	1.00	0.99	1.01
Total State Population	1.00*	1.00	1.00
State Religiosity	1.00*	1.00	1.00
No. Children below 400% FPL	1.00*	1.00	1.00
State Median Income	1.00***	1.00	1.00
Poverty Level	0.28***	0.27	0.30
Functional Impairment	1.85***	1.68	2.04
Rx Medication Use	1.02	0.92	1.13
_cons	762.11	142.30	4081.65

\*\*\* p ≤ 0.001; \*\* p ≤ 0.01; \* p ≤ 0.05

**Table 8a. ICCs for Question One**

<u>Level</u>	<u>ICC</u>	<u>SE</u>	<u>95% CI</u>	
With State Covariates	0.03	0.01	0.02	0.04
Without State Covariates	0.05	0.01	0.03	0.08

### Research Question Two Findings

**Figure 11 (Revisited). (RQ2) Controlling for variation in clinical severity of youth, do youth with SED with public health coverage, have lower odds of having unmet treatment needs and encountering cost barriers to care?**

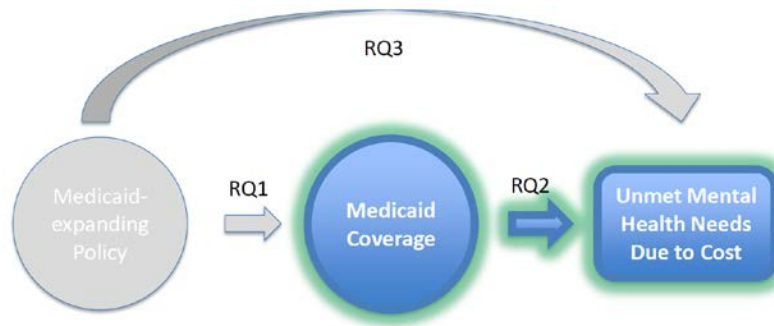


Table 8 displays results from multilevel logistic regression assessing the relationship between public health coverage and unmet mental health care need. In this analysis, private insurance in the reference group for the Insurance Type variable. Results partly support Hypothesis RQ2; There is not a significant relationship between public versus private health insurance and unmet mental health care needs (OR=1.15) when there is no functional impairment. However, the interaction between insurance type and functional impairment approaches significance ( $p \leq 0.06$ ); the odds of having unmet mental health needs are estimated to be 12% lower for youth with functional impairments who have public insurance than for youth with functional impairments who have private insurance ( $1.15 \times 0.78 = .88$ ). The estimated odds of having unmet mental health needs are 25% greater for youth with private insurance who have functional impairments (OR=1.25) than for youth with similar health coverage but who are classified as SED due to elevated service use. For youth on private insurance, the estimated odds of having unmet mental health needs are 20% lower if they only need Medication management (OR=0.80). Also, of note in this analysis, the odds of having unmet mental health needs are estimated to be almost 200% greater for youth with no insurance than for youth with private insurance (OR=2.84). State total revenues are a significant control variable, but do not change the odds that a parent whose child has private insurance will report having unmet mental health care needs.

**Table 9. Does public insurance reduce unmet mental health need?**

	<u>OR</u>	<u>95% CI</u>	
<b><u>Insurance Type</u></b>			
Public Insurance	1.15	0.95	1.40
Dual Insurance	0.84	0.62	1.14
Uninsured	2.84***	2.04	3.96
Functional Impairment	1.25*	1.04	1.51
<b><u>Insurance Type &amp; Functional Impairment</u></b>			
Public Insurance and Functional Impairment	0.78†	0.60	1.01
Dual Insurance and Functional Impairment	0.71	0.46	1.09
Uninsured and Functional Impairment	0.84	0.49	1.44
Poverty Level	0.83***	0.77	0.89
Education	1.25***	1.12	1.40
Rx Medication Use	0.80***	0.71	0.90
Political Ideology	0.99	0.95	1.04
Total State Revenue	1.01**	1.00	1.02

Child Population	1.00	0.99	1.00
Total State Population	1.00	1.00	1.00
Total Medicaid Expenditures per Child	1.00	1.00	1.00
State Religiosity	1.00	1.00	1.00
No. Children below 400% FPL	1.00	1.00	1.00
State Median Income	1.00	1.00	1.00
Mental Health Facilities	1.00†	1.00	1.00
Total MH Ambulatory Revenues	1.00	1.00	1.00
Total MH Expenditures	1.00	1.00	1.00
Intercept	0.08	0.02	0.27

\*\*\* p ≤ 0.001; \*\* p ≤ 0.01; \* p ≤ 0.05; † p ≤ 0.07

**Table 8a. ICCs for Question Two, Unmet Mental Health Need**

	<u>ICC</u>	<u>SE</u>	<u>95% CI</u>	
With State Covariates	0.00	0.00	0.00	0.02
Without State Covariates	0.01	0.01	0.01	0.03

Table 9 shows the results for analysis of Medicaid’s relationship to cost barriers to treatment. Estimates for this model suggest that, for youth with SED and no functional impairments, those with public insurance have almost 30% lower odds of experiencing delays or difficulty getting needed services due to cost barriers compared to youth with private insurance (OR=0.71). This is the same for similar youth with both Medicaid and commercial health coverage (OR=0.71). Not surprisingly, for youth with functional impairments, the odds of experiencing cost barriers to services are estimated to be almost 6 times as great for youth with no insurance as for youth with private insurance (OR=5.96). However, for youth on private insurance, those with functional impairments are estimated to have over twice the odds of experiencing delays or difficulties getting needed services due to cost barriers (OR=2.18) as similar youth with no functional impairments. For youth with functional impairments, the estimated odds of having unmet mental health care needs due to cost barriers are 46% lower for youth with public insurance versus private insurance ( $0.71 \times 0.78 = 0.54$ ). For youth with private insurance, those only needing medication have 10% lower odds of having unmet mental health care needs due to cost barriers than youth who are SED due to elevated service use (OR=0.89).

**Table 10. Does public insurance reduce cost barriers to care?**

	<u>OR</u>	<u>95% CI</u>	
<b><u>Insurance Type</u></b>			
Public Insurance	0.71***	0.60	0.84
Dual Insurance	0.71*	0.54	0.93
Uninsured	5.96***	4.42	8.05
Functional Impairment	2.18***	1.89	2.52
<b><u>Insurance Type &amp; Functional Impairment</u></b>			
Public Insurance and Functional Impairment	0.78*	0.63	0.97
Dual Insurance and Functional Impairment	1.01	0.73	1.41
Uninsured and Functional Impairment	0.87	0.52	1.44
Poverty Level	0.82***	0.77	0.87
Education	1.39***	1.26	1.53
Rx Medication Use	0.89*	0.80	0.99
Political Ideology	1.00	0.96	1.04
Total State Revenue	1.00	1.00	1.01
Child Population	1.00	0.99	1.00
Total State Population	1.00	1.00	1.00
Total Medicaid Expenditures per Child	1.00	1.00	1.00
State Religiosity	1.00	1.00	1.00
No. Children below 400% FPL	1.00	1.00	1.00
State Median Income	1.00	1.00	1.00
Mental Health Facilities	1.00	1.00	1.00
Total MH Ambulatory Revenues	1.00	1.00	1.00
Total MH Expenditures	1.00	1.00	1.00
Intercept	0.11**	0.04	0.37

\*\*\*  $p \leq 0.001$ ; \*\*  $p \leq 0.01$ ; \*  $p \leq 0.05$

**Table 9a. ICCs for Question Two, Cost Barriers to Care**

	<u>ICC</u>	<u>SE</u>	<u>95% CI</u>	
With State Covariates	0.01	0.00	0.00	0.02
Without State Covariates	0.01	0.00	0.01	0.02

**Research Question Three Findings**

**Figure 12 (Revisited). (RQ3) Controlling for insurance status and clinical severity of youth, do youth with SED residing in states with Medicaid-expanding policies have lower odds of having unmet treatment needs and encountering cost barriers to care?**

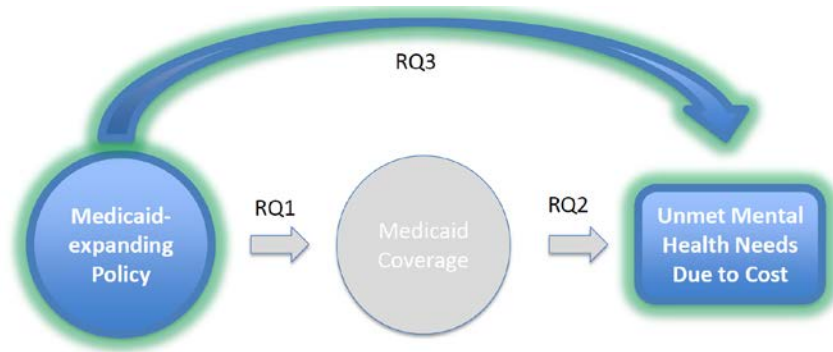


Table 10 displays analysis results for models assessing the relationship between Medicaid-expanding policies and unmet mental health care needs for youth with SED, controlling for the mediation of Insurance Type and its interaction with Functional Impairment. Results shows that for youth with SED, the relationship between living in a state with a Medicaid-expanding policy and the odds of having unmet mental health needs approaches significance ( $p \leq 0.06$ ), and that odds are reduced in states with Medicaid-expanding policies ( $OR=0.87$ ). Because this model is identical to the model for Research Question 2, with the addition of one new predictor variable (Medicaid-Expanding Policy), it follows that the odds ratio estimates for other variables in the model are very similar to those seen in findings for Research Question 2.

**Table 11. Do Medicaid Expansion Policies Reduce Unmet Mental Health Need?**

	<b>OR</b>	<b>95% CI</b>	
Medicaid-Expanding Policy	0.87†	0.74	1.01
<b><u>Insurance Type</u></b>			
Public Insurance	1.16	0.96	1.40
Dual Insurance	0.84	0.62	1.14
Uninsured	2.84***	2.04	3.96
Functional Impairment	1.25*	1.04	1.50
<b><u>Insurance Type &amp; Functional Impairment</u></b>			
Public Insurance and Functional Impairment	0.78 †	0.60	1.01
Dual Insurance and Functional Impairment	0.71	0.46	1.09
Uninsured and Functional Impairment	0.83	0.49	1.42
Poverty Level	0.83***	0.77	0.89
Education	1.25***	1.12	1.40
Rx Medication Use	0.80***	0.71	0.90
Political Ideology	0.99	0.95	1.04
Total State Revenue	1.01***	1.01	1.02
Child Population	1.00	0.99	1.00
Total State Population	1.00	1.00	1.00
Total Medicaid Expenditures per Child	1.00	1.00	1.00
State Religiosity	1.00	1.00	1.00
No. Children below 400% FPL	1.00	1.00	1.00
State Median Income	1.00	1.00	1.00

Mental Health Facilities	1.00	1.00	1.00
Total MH Ambulatory Revenues	1.00	1.00	1.00
Total MH Expenditures	1.00	1.00	1.00
Intercept	0.07***	0.02	0.23

\*\*\* p ≤ 0.001; \*\* p ≤ 0.01; \* p ≤ 0.05; † p ≤ 0.07

**Table 10a. ICCs for Question Three, Unmet Mental Health Need**

	<u>ICC</u>	<u>SE</u>	<u>95% CI</u>	
With State Covariates	0.00	0.00	0.00	0.04
Without State Covariates	0.01	0.01	0.01	0.03

Table 11 reports findings for the second portion of Research Question 3, which assesses the relationship between a state’s Medicaid-expanding policy and cost-barriers to services. This model shows that, when living in states with Medicaid-expanding policies, families are estimated to have 18% lower odds of experiencing delays or difficulty getting needed services due to cost barriers (OR=0.82). Again, as in Table 8, the remaining findings are very similar to findings reported for Research Question 2.

**Table 12. Do Medicaid Expansion Policies Reduce Cost Barriers to Care?**

	<u>OR</u>	<u>95% CI</u>	
Medicaid-Expanding Policy	0.82**	0.71	0.95
<b><u>Insurance Type</u></b>			
Public Insurance	0.71***	0.60	0.84
Dual Insurance	0.72*	0.55	0.93
Uninsured	5.97***	4.43	8.05
Functional Impairment	2.18***	1.89	2.52
<b><u>Insurance Type &amp; Functional Impairment</u></b>			
Public Insurance and Functional Impairment	0.78*	0.62	0.97
Dual Insurance and Functional Impairment	1.01	0.72	1.41
Uninsured and Functional Impairment	0.86	0.52	1.43
Poverty Level	0.82***	0.77	0.87
Education	1.39***	1.26	1.53
Rx Medication Use	0.89*	0.80	0.99
Political Ideology	1.00	0.96	1.04
Total State Revenue	1.00	1.00	1.01
Child Population	1.00	0.99	1.00
Total State Population	1.00	1.00	1.00
Total Medicaid Expenditures per Child	1.00	1.00	1.00
State Religiosity	1.00	1.00	1.00
No. Children below 400% FPL	1.00	1.00	1.00
State Median Income	1.00†	1.00	1.00
Mental Health Facilities	1.00	1.00	1.00
Total MH Ambulatory Revenues	1.00	1.00	1.00

Total MH Expenditures	1.00	1.00	1.00
Intercept	0.10***	0.03	0.30

\*\*\* p ≤ 0.001; \*\* p ≤ 0.01; \* p ≤ 0.05; † p ≤ 0.07

**Table 11a. ICCs for Question Three, Unmet Mental Health Need**

	<u>ICC</u>	<u>SE</u>	<u>95% CI</u>	
With State Covariates	0.00	0.00	0.00	0.01
Without State Covariates	0.01	0.00	0.00	0.02

## CHAPTER 4: DISCUSSION AND CONCLUSION

### Practice, Policy, and Research Implications

This two-part, mixed methods study has multiple aims and findings. After discussing study limitations, this chapter will summarize and present key findings from Part I of the study, followed by a summary and discussion of results from Part II of the study.

#### Study Limitations

These findings need to be considered in the context of several limitations in the study design with respect to sampling strategy, the timing of data collection and interview design. First of all, the study did not include all 50 states. In-depth interviews were only conducted with 32 states, and only 45 states were included in the quantitative analysis. Additionally, the sample of interviewees was selected through the use of the roster of child and family behavioral health administrators across all fifty states, which may not have been accurate or complete in listing possible informants and their contact information.

Further, because participation in interviews, or even via email, was voluntary, sample bias may affect findings; Similarities may exist across non-participating states that would lead to non-random missing data, making findings here less generalizable to these states. For example, participants who responded to requests for interviews may feel especially proud of their state mental health systems and policies and be particularly interested in sharing their processes. Conversely, administrators who feel that their state does not offer innovative or generous services to youth with SED may feel that do not have much information to provide the researcher and decline to participate. As a result, dissenting views and the perspectives of these administrators may be inadequately represented. However, in this study, a number of states that do offer HCBS Medicaid waivers declined to participate in interviews, and several states that have limited funding for non-Medicaid eligible youth did participate.

The timing of data collection may also have influenced participation, as many state budget cycles and legislative sessions were ramping up during the fall of 2016 when data was collected. This may have constrained participation from some states that did not have the capacity to participate in a research study and prepare for the upcoming legislative session. States with legislative sessions or fiscal deadlines in the spring may have been more available for participation. However, such timing is unlikely to be indicative of any underlying state variable that may relate to the outcomes of interest. Finally, although the semi-structured interview format promoted depth and detail in responses, it may have contributed to missing data. Unless an interview question directly addressed a particular topic, it may or may not have been deemed relevant by the respondent

Other limitations in qualitative data exist due to variation in respondents across states. While the majority of participants had worked in their field at the state level for some time, a few respondents were relatively new to the position and did not have as much historical knowledge of legislative and behavioral health policy making decision processes. Also, though many participating states involved more than one informant in small group interviews, in some states only one respondent participated, thereby providing only one perspective regarding key questions. Further, coding was completed by a single coder which creates opportunities for bias



and subjectivity. However, this risk is minimized to some degree because the codes were created in consultation with a research supervisor and verified with research participants.

The analytic design was also aimed at exploring relationships between state policies and youth and family experiences of unmet mental health need and cost barriers to treatment; quantitative findings, then, suggest associations between policies and youth experience of treatment access and do not specify a causal relationship. Further, response variables, while obtained from a random sample, are based on parent self-report and rely on the parent recalling service access experiences over the prior twelve-month period. Though it is an acceptable proxy for utilization or access measures in the absence of administrative data, extensive studies have evaluated agreement between consumer self-report of utilization and consumer medical records. Such research demonstrates that self-report can be anywhere from 30 to 60 % inaccurate and that inaccuracy is much greater when recalling over a 12 month period compared to a monthly time frame (Beckles et al., 2007; Palmer et al., 2012; Short et al., 2009).

Additionally, findings in Part I of this study indicate that significant regional variation exists within states, especially those with more decentralized administrations and decision making. Because this study is examining a state-level policy, and thus data is pooled at the state level, regional variation within states is not captured and accounted for. This limits the conclusions that can be drawn from these findings, particularly for states with more localized mental health policy authority. By compiling data from regions that facilitate exceptional accessibility and service delivery with data from surrounding counties that have less well-funded, accessible, or comprehensive community-based mental health care, the effects of successful local strategies may be absorbed or washed out in analysis.

Concerns with modeling in Part II also exist in the omission of race as a control. Though concerns about collinearity exist for this study, race is an important predictor of mental health care access and utilization. However, for children with significant mental health needs, a higher likelihood of holding Medicaid coverage for Latinx and African American children may create complex associations between public health insurance and unmet need and cost barriers to care; populations with higher rates of poverty and thus higher rates of Medicaid coverage may also have a higher likelihood of having a payor source for the intensive home and community-based services this population often needs, resulting in lower rates of cost barriers or unmet needs. As such, race and other determinants of unmet need and cost-barriers may be salient, and future explanatory models should be assessed in subsamples of each race category to evaluate how differences emerge in unmet need and cost for each population.

To evaluate the potential impact of several possible limitations, a full sensitivity analysis was performed. This included 1) examining variation in findings with various additional controls included in the model, 2) performing the analysis with all 50 states as well as with missing data states excluded, 3) with states coded differently based on PRTF participation in 2009, and 4) modeling approaches including random coefficients and random slopes, and modeling level-one variables as both a fixed effect and random effect. Throughout this process, key findings presented here remained, and non-significant controls were dropped from final models for parsimony. Consistency in findings throughout the sensitivity analysis and model building process suggests robust quantitative findings.

## **Part I Summary of Findings**

Part I of this study aimed to understand factors that influence state policymakers' decision-making regarding the use of a Medicaid waiver to organize and fund home and community-based mental health for children with SED. Additionally, the study aimed to uncover alternative state strategies for funding and delivering HCBS to these youths who are not financially eligible for Medicaid. For states utilizing a TEFRA or 1915(c) Medicaid waivers, the decision to do so was based on the desire of policymakers and administrators to reduce the state's reliance on residential care for youth with complex behavioral healthcare needs for both fiscal and philosophical reasons. Almost all of these states spoke to political priorities that support children and families and keeping families intact and keeping youth in their homes and communities. All of the states using Medicaid waivers relied heavily on Medicaid funding to support and structure their children's mental health services systems. Reliance on Medicaid is likely motivated by the state's desire to maximize cost-sharing of mental health care with the federal government. In these states, the primacy of Medicaid—combined with the variety of federal policies that allow for Medicaid to cover a broad service array for specialized populations (e.g. the EPSDT mandate, 1915(c) waivers, Medicaid state plan amendment options)—drives policymakers to seek Medicaid-related solutions when looking to expand HCBS in an effort to divert youth away from residential settings. One state asserted that embedding mental health care in Medicaid was a deliberate strategy to protect funding for HCBS for youth with SED from the ebbs and flows of state budgets and economies. The majority of these states acknowledged that resources within the state, due to dominant political values in the legislature, allowed for generous state Medicaid budgets. These budgets enable these states to absorb excess costs that may result from serving youth with complex medical needs through the public system.

Unsurprisingly, states not utilizing Medicaid waivers most frequently cited budgetary constraints as a key reason that Medicaid waivers were not utilized. These states often stated that policy changes in their states must be budget neutral, and the level of need that may be presented to the state by youth on a Medicaid waiver would make projecting and balancing the budget difficult. A few non-waiver states also stated that they felt their current Medicaid program was sufficient; Their state had high Medicaid penetration rates, and there was a rich home and community-based service array available under their Medicaid program. This finding is consistent with a recent study examining state adoptions of Medicaid waivers for youth with autism which found a commonly reported reason for non-adoption was the state perception that current resources and policies were meeting the public need (Merryman et al., 2015). In some of these states, the Medicaid benefit package was expanded under the Children's Health Insurance Program (CHIP). As such, the full Medicaid service array is available to all children up to over 300% of the Federal Poverty Line.

A few states felt there was no need for a Medicaid waiver because there were generous state general revenue funds that enabled the state to meet the needs of all youth and families, regardless of insurance status or income level. These states expressed collective values that support serving youth and families and keeping families together in their homes, which was well supported by the legislature.

A couple of states, however, noted that Medicaid waivers were politically unfavorable in their state; either advocates did not like them because these policies allowed for the targeting of specific populations and for limiting the number of youth that could be served under them, or legislators did not like Medicaid waivers because they were viewed as a type of Medicaid expansion. Embedded in a dislike of Medicaid expansion might be the oft-cited concern in non-waiver states that state public mental health systems were mandated only to serve the indigent

population, and waivers allowed for other non-poor populations to access the public mental health system.

Some non-waiver states managed the concern that privately insured youth were not able to access the public mental health service array by expressing a plan or desire to push responsibility for coverage of needed HCBS onto commercial insurance carriers in their states. Some of these states also pointed to the ways that other child-serving systems, such as the juvenile justice authorities or public schools, were also responsible for serving non-Medicaid eligible populations.

Two general strategies for funding HCBS for non-Medicaid eligible youth are apparent in the study states: states either utilize state general revenue to fund services as needed or they expand Medicaid benefits to families whose incomes are above the traditional means test. States using general revenue funds either allocate generous or limited portions of state general revenue funds—often activated through specific child mental health legislation—combined with state community mental health block grants to fund services to as many children and families need them. Some states felt this strategy was meeting the need, and other states acknowledged unmet need resulting from limited funds for this population. Further, even states with large mental health budgets reported regional disparities in unmet need in states where counties, regions, or local authorities had significant autonomy in allocating funding and structuring services. Eight states relied on their expansion of the Medicaid benefit package to youth with SED, up to three or four hundred percent of the FPL through their CHIP policy. The remaining states expanded their Medicaid benefits to youth whose family incomes were beyond traditional limits through a TEFRA Medicaid option, a 1915(c) Medicaid waiver, or a state-authorized look-a-like program (e.g., PH95 in Pennsylvania).

## **Part I Discussion: Contextualizing Findings**

Part I findings provide additional insight into the role of political ideology in policy making regarding Medicaid and other funding allocations for behavioral healthcare, particularly for children. Results also suggest the need for consideration and closer examination of the role that the Children’s Health Insurance Program (CHIP) may play in organizing, funding, and expanding access to needed HCBS for youth with complex behavioral health needs. Finally, the qualitative portion of the study provides specific guidance in future quantitative modeling to assess relationships between states’ use of waivers and measures of consumer access.

**The role of political ideology in policy making for youth with SED.** The results highlight the importance of political ideology in understanding state behavioral health policies and associated outcomes. Variation in the funding mechanisms used to serve this population may belie dominant political philosophies. This is emphasized by the fact that some states report Medicaid waivers being viewed as a type of Medicaid expansion—thus positioning them in an unfavorable light politically. This observation prompts a reconceptualization of these policy tools and places them within a larger context of controversy that reflects the underlying ideology of partisan politics. Rather than Medicaid waivers being viewed as a policy that enables access to needed care that will help to preserve family structures and keep children out of institutions, this finding reveals that choices around the use of Waivers are laden with philosophical concerns about the role of state versus federal government in welfare provision, questions of deservingness and need, and the responsibility of private industry versus government in providing for public well-being.

The discrepancy between states that expand Medicaid for children, especially those with complex healthcare needs, and states that accepted ACA Medicaid expansion, may be an indicator of underlying ideological politics shaping state Medicaid waivers decisions. This is particularly noticeable in Southeastern states. States that rejected the ACA Medicaid expansion, but who provided expansions targeted at children may value state’s autonomy and believe in limiting the role of government in providing welfare. However, such states may also have leanings towards particularistic spending (Caughey & Warshaw, 2015), which may be driven by a dominant protestant value related to the deservingness of children and family values. There is greater consistency between ACA Medicaid expansion acceptance and Medicaid-expanding policies for children in Northeastern states. This is unsurprising as these states have strong histories of political support for social justice-oriented policies (Caughey & Warshaw, 2015; Thompson et al., 2016)

Over the last few decades, much research has emerged which attempts to uncover state-level factors that may be associated with state investment in Medicaid and other safety net programs. Findings point to the importance of special interest groups (Callaghan & Jacobs, 2015; Grogan, 1994; Merryman et al., 2015), state affluence, administrative capacity, the trajectory of healthcare spending and prior policy making (Jacobs & Callaghan, 2013; Lukens, 2014), as well as political ideology and party control in legislative bodies (Grogan, 1994; Jacobs & Callaghan, 2013; Jacoby & Schneider, 2001). However, across this research, and particularly in more recent studies looking specifically at factors influencing state adoption of the recent ACA Medicaid expansion, it is clear that investments in healthcare does not fall neatly across party lines. Other factors within state circumstances and political environments appear to be creating "cross-pressures" on legislatures which moderate the effects of partisan politics (Grogan, 1994; Jacobs & Callaghan, 2013, p. 1023; Lukens, 2014).

Given the divergence between states that expand Medicaid for children through waivers or CHIP Medicaid expansions, and the states that rejected Medicaid expansion, it is likely that such “cross-pressure” factors may vary in relation to the social problem being addressed. For example, many states that rejected Medicaid expansion have expanded Medicaid for children through waivers or CHIP: Kansas, Texas, Wyoming, Mississippi, and Wisconsin have rejected Medicaid expansion under ACA but offer, in some cases, multiple Medicaid expansion options for youth with complex behavioral healthcare needs. Additionally, many states that accepted Medicaid expansion have no Medicaid-expanding policies for children (California, Oregon, Washington, Connecticut, New Jersey, Delaware). This observation, combined with dynamics observed in levels of local autonomy and authority, suggests that a complex combination of ideologies and state administrative factors shape waiver adoption decision-making differentially for children and adults. One possible approach to understanding one facet of these “cross pressures” is illustrated in Table 12.

**Table 13. Political Ideology in State Approaches to HCBS policy for Youth with SED**

<b>HCBS Funding Policy for Youth with SED</b>	<b>Politics that prioritize Children and Families</b>	<b>Politics that prioritize Local Autonomy</b>
Insufficient General Revenue	Weak	Weak
Sufficient General Revenue	Strong	Strong
Medicaid-expanding Policy	Strong	Weak

Findings suggest that states utilizing generous amounts of general revenue have strong political support for funding services for children and families, combined with politics dominated by ideologies supporting local autonomy (e.g., Florida, New Jersey). A good portion of states using general revenue to fund HCBS for these families also report significant local autonomy in shaping services and fund allocation, contributing to regional disparities in mental health care access across their states. Also, many states utilizing non-Medicaid funds to serve these youths do so by pooling funds from other child-serving agencies such as child welfare and juvenile justice authorities, thus diffusing responsibility for these families across systems. While this may encourage desirable cross-system collaboration, it may also reflect a more punitive view of children with behavioral or emotional disorders and their families.

In contrast, a second classification includes states providing minimal general funding for behavioral health care for children and minimal access to Medicaid for children with SED may have less political support for serving this population, combined with politics that favor local governmental control (e.g., Nevada, Utah, Washington, California). In the sample of participating states (32 total completed in-depth interviews), the majority of participants reported commitment to serving children and families. However, this was reported less repeatedly or not at all in a few states in which no Medicaid waivers were used and in which respondents reported insufficient general revenue for funding non-Medicaid eligible youth with SED. Among the remaining states, all respondents indicated a political commitment or values-based prioritization of children and supporting families.

Lastly, a third category emerges: states that use a Medicaid waiver or expand Medicaid through CHIP, intentionally relying on the federal government to share the cost burden for serving youth with SED and their families. Such choices may reflect a dominant political view in the state that is less hostile toward federal involvement in welfare provision and more favorable to the more stable funding streams and policy protections that accompany such involvement. Further, the use of Medicaid waivers may also indicate political support for funding and policy structures that support permanent community integration of populations with disabilities and the desire to serve children primarily through the behavioral healthcare system in non-residential settings.

#### **The role of CHIP in organizing and funding HCBS for non-Medicaid eligible youth.**

A significant finding that may further reflect the role of political ideology in the use of Medicaid to fund HCBS for youth with SED is that some non-waiver states expand their Medicaid benefits through other means; though a notable portion of states utilize CHIP to accomplish this, a few other states use other non-waiver Medicaid policies to deliver and fund these services (e.g., Money Follows the Person, 1915(i) state plan amendments). This highlights the need to consider the role of CHIP and other non-waiver Medicaid policies in enhancing access to HCBS for this population, as well as for other populations with complex healthcare needs. Currently, scholarship examining the role of these policies in delivering care to this population is almost non-existent. Elevating this finding may be particularly important in the current national political climate, in which federal funding for CHIP was discontinued for over three months. For states that rely on this program to expand youth access to funding for HCBS, future discontinuation of federal funds may prompt youth behavioral health system redesign as youth in these states begin entering care through other institutional pathways (e.g. Child Welfare, Juvenile Justice) once federal funding for community-based care diminishes and limits state-wide access to these services.

**Implications for quantitative analysis.** These findings suggest that concerns raised about reverse causality underlying relationships between a state's use of an SED-focused Medicaid waiver and state-level public mental health penetration rates for children in Graaf & Snowden (2018) may be unfounded. Across 37 participating states, no respondent indicated that the state's decision to use a Medicaid waiver was prompted by perceptions of an overburdened mental health system, or a plan to reduce that financial burden through the adoption of a Medicaid waiver. Rather, such decisions were motivated by a desire to shift service modalities away from residential care and to community-integrated care in order to improve quality of life for children and families and to realize cost-savings associated with community-based versus residential care. While sharing these costs with the federal government was cited as a bonus in using a waiver, the use of Medicaid funding to achieve these goals was also seen as a more permanent solution, as it protected funding allocations for this population from variations in state-level politics and economics that may affect mental health budgets. Consistent with prior Medicaid investment research (Jacobs & Callaghan, 2013), waiver states acknowledged robust Medicaid budgets, due to political prioritization of healthcare, children and families, and strong state economies.

## **Part I Discussion: Implications for Policy and Future Research**

**Part I Policy Implications.** Findings from Part I suggest a few policy-relevant implications. Results reveal a variety of strategies to fund HCBS for non-Medicaid eligible youth, including the possibility of putting responsibility for this commercial insurance carriers. Additionally, these results point to specific strategies that supporters of mental health access may be able to use to advocate for policy change in non-Medicaid waiver states.

**HCBS funding strategies.** First, it is evident that states have many ways of funding HCBS for non-Medicaid youth, beyond the use of a Medicaid waiver. Though respondents acknowledge that relying on community mental health block grants and other limited general state fund sources is not sufficient to meet the need of this population, states can be creative in their use of funding from other state child-serving divisions. Braiding funding in this way may encourage cross-system collaboration, as these agencies have "skin in the game." However, general revenue funding can be allocated in various ways by local decision makers, which respondents believe contributes to regional disparities in states with strong levels of local authority. For states using non-Medicaid approaches to delivering care to these youth, particularly those states that acknowledge the insufficiency of current financing, asking other state departments to contribute to serving these youths and innovating how these funds can be integrated to yield greater resources and broader stakeholder involvement. But, states must weigh this with the level of discretion local decision makers hold and the extent to which this factor will create further disparities across county lines.

Qualitative findings also reveal another potential non-Medicaid strategy for delivering care to non-Medicaid youth and their families. Though no state has successfully engaged in this endeavor at this time, the possibility of holding commercial insurers more accountable for delivering the care that is medically necessary for its beneficiaries holds philosophical and theoretical promise. Given the changing climate of the health insurance markets and industry as these organizations manage to navigate the implementation and impacts of new mandates under the ACA, the next five to ten years may change the accountability landscape for private insurers and open new opportunities for states to change the conditions of licensing and contracting for

insurance carriers in their state. Much like the federal mandate under EPSDT in Medicaid, states might have room to start enforcing requirements for insurers to provide coverage for the newly defined essential benefits through penalties or consumer- or advocate- driven lawsuits.

**Approaches to advocacy.** Finally, results in Part I suggest a few factors for advocates and policymakers to consider when seeking legislative change to increase access to Medicaid-funded HCBS for youth with complex needs. First, political party control of the governor's office or the legislature, as well as precedents for investments in Medicaid exemplified by acceptance of Medicaid expansion under the ACA, is not indicative of the political viability of expansions of Medicaid to these youths. Promoting waivers as a cost-reduction strategy that can have impacts across several sectors of child-serving agencies due to reductions in long-term care costs and federal cost-sharing may help to influence adoption. Further, advocating for increased HCBS access as means of maintaining family unity and keeping children in their homes and schools may appeal to the conservative, family-values of lawmakers on the right. However, in states that require budget neutral approaches to policy change, advocacy approaches may need to include identification of new revenue sources that can fund increases in state Medicaid match dollars that might be generated by Medicaid-expanding policies aimed at children—particularly children with complex health care needs.

**Part I further research.** Findings from the qualitative portion of the study also point to several important directions for future research. The analysis reveals the significance of political ideology in shaping Medicaid plans across states, and that these factors may differentially impact the services available under Medicaid and eligibility for those services for adults versus children, for special populations, as well as for primary health care and behavioral health care. Further qualitative work aimed specifically at unpacking political ideologies and their relationship to health care versus behavioral health care policy making for children versus adults, would provide more specificity about the nature of this relationship and how it differentially shapes access to care for various populations. Differences in state plans, which may be rooted in views of deservingness, federalism, and concerns about the role of government in welfare provision, should be examined in the context of these possible variables. Explicit examination and revelation of the role of ideology in health care policy decisions, combined with examination of the impact of those policy decisions upon key populations, may highlight new ways to engage in legislative debate and suggest new language and approaches that can be successfully used to advocate for more inclusive HCBS policies for all populations with significant disabilities.

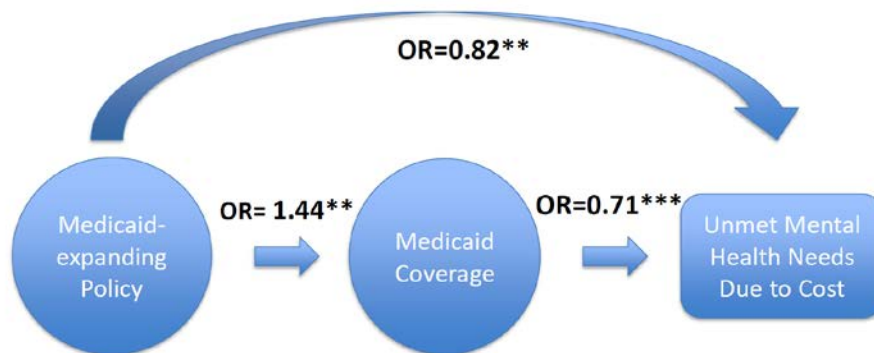
## **Part II Discussion: Summary of Findings**

Findings from Part I of this research informed analytic decisions for the quantitative portion of the study and provided data for variables to be used in Part II. By modeling and controlling for state-level factors influencing waiver adoption and states' use of non-waiver funding strategies for non-Medicaid eligible populations, the second part of the study assessed interrelationships among states' Medicaid-expanding policies, individuals' public health coverage, and the unmet treatment needs and cost barriers to care experienced by families whose children have complex behavioral healthcare needs. Specifically, for reducing the odds that youth will experience (a) unmet mental health care needs and (b) cost barriers to care, the study examined direct effects of a state's use of a Medicaid-expanding policy and the indirect effects of this variable via the odds of a youth having public insurance coverage. Does a state's use of a Medicaid-expanding policy drive greater likelihood that an individual will have public insurance

coverage, which in turns drives individuals having lower odds of having unmet need and encountering cost barriers to care? Is a state’s Medicaid-expanding policy linked to reduced odds of having unmet need and cost barriers to treatment through other means? Analysis controlled for the differential effects of youths’ clinical severity, income, and insurance status on these relationships.

Results demonstrated a positive relationship between a state's use of a Medicaid-expanding policy and the odds that youth with SED in that state will have public health coverage (OR=1.44\*\*). Thus, as expected, state’s employment of Medicaid-expanding policies translated into more individuals with Medicaid coverage. However, the study did not find evidence that Medicaid-expanding policies translated into having mental health needs met, either indirectly via more public health coverage (OR=1.15) but suggests that these policies may reduce odds directly by other means (OR=0.87†). On the other hand, the findings did demonstrate that in states with Medicaid-expanding policies, youth with SED have significantly lower odds of encountering cost barriers to mental health care (See Figure 17). This occurred both by way of increasing public health coverage (OR=0.71\*\*\*) and by other direct means (OR=0.82\*\*). Thus, it appears that Medicaid-expanding policies may reduce financial barriers to care but may not increase the odds of youth being able to access all needed services—as indicated by no significant association with reduced odds of unmet need. This suggests that many other, non-cost-related barriers to needed services exist for youth with complex behavioral healthcare needs that Medicaid-expanding programs across most states don’t address. It may be that in these programs 1) services are physically or temporally less accessible, 2) that needed services are not offered or have long waiting lists, or 3) that regional variation in how programs are executed within these states is so great that it diminishes the ability of the Medicaid-expansion to impact unmet need state-wide. Further, there are likely non-structural barriers to accessing needed care that Medicaid policies cannot address (e.g., lack of parental awareness of how to obtain care, public stigma, fear of medication usage, the preference to manage the child’s disability through informal social networks and support systems, etc.).

**Figure 18. Summary of Part II Analysis Findings: Cost Barriers to Care**



Research findings also provide insight about the extent to which clinical severity affects patterns of association between Medicaid-expanding policies and public health coverage, as well as families' experience of unmet mental health care needs and cost barriers to treatment. When youth with functional impairments have public insurance, whether they live in a state with a Medicaid-expanding policy or not, their odds of experiencing unmet mental health care needs are significantly reduced (OR= 1.15 x 0.78†=0.89). The same is true for the odds that such youth will encounter cost barriers to care (OR=0.71\*\*\*x 0.78\*=0.55).



For youth with functional impairment, the odds of having public insurance are much greater (OR=1.85\*\*\*) than the odds of having private insurance. This is good because, if they have private insurance, their odds of having unmet mental health care needs are greater (OR=1.25\*), and they have much greater odds of encountering cost-barriers to care (OR=2.18\*\*\*). Thus, since Medicaid-expanding policies are linked to higher odds that a youth will have public insurance, it is possible that families with private insurance in non-Medicaid-expanding states whose children have global impairments—who are more likely to experience unmet need due to cost barriers—may seek public coverage through other means, perhaps by relinquishing custody of their children to the state.

To highlight the importance of public health coverage for youth with functional impairments, it is helpful to observe results for youth who only need prescription medication to manage their disorder. In stark contrast to youth whose functioning is impaired, regardless of the Medicaid policy of the state, having private insurance significantly reduces the odds of having unmet mental health care needs (OR=0.80\*\*\*) and encountering cost-barriers to care (OR=0.89\*) for youth who only need medication management.

## **Part II Discussion: Contextualizing Findings**

These outcomes advance knowledge of the interactions between state policy and access to mental health care by considering both macro (state policy) and micro variables (insurance status and clinical severity), which reveals complex relationships between insurance type, clinical mental health needs, and indicators of service access. Results also call attention to continuing disparities in access to care for uninsured youth and the role that Medicaid-expanding policies may play in reducing these disparities.

**Expanding access and policy research.** Part II findings support the study assumption that the more limited service array available through private insurance is more likely to be adequate for youth with moderate mental health needs, who may benefit greatly from outpatient therapy and medication management. However, these findings also suggest support for hypotheses for Research Questions 2 and 3: that youth with more complex behavioral health needs are less likely to have their needs met through private insurance coverage due to greater cost barriers to services not customarily covered by commercial health plans. Youth with more significant needs (and the population usually targeted through Medicaid waivers) have lower odds of experiencing cost barriers to needed treatment when they have Medicaid or other public insurance and can access the broader home and community-based service array funded through these insurance programs. Together, these findings highlight the extent to which the relationship between health coverage type and a family's experience of unmet need and cost barriers can vary in relation to the clinical needs of the youth.

Though much research currently exists examining factors related to access barriers, including studies looking at the role of insurance coverage in access to care (Miller, 2014; Owens et al., 2002; Popescu, Xu, Krivelyova, & Ettner, 2015; Stiffman et al., 2000; Varda, Hardy, & Talmi, 2016; Walker, Cummings, Hockenberry, & Druss, 2015; Wilson, Hirschi, Comeau, Bronheim, & Bachman, 2014), and scholarship regarding the role of Medicaid waivers in organizing and funding HCBS for individuals with complex needs is robust (Cidav, Marcus, & Mandell, 2014; Kitchener, Ng, & Harrington, 2004; LeBlanc, Tonner, & Harrington, 2000; Leslie et al., 2016, 2017; Miller, Merryman, Eskow, & Chasson, 2016; Miller, Ramsland, Goldstein, & Harrington, 2001), there is virtually no current knowledge regarding the role that

Medicaid waivers can play in overcoming cost-related barriers to care specifically for children with complex behavioral healthcare needs. This study bridges both literatures and calls attention to the role of state Medicaid policy in shaping mental health access, particularly for non-Medicaid eligible youth. By highlighting the geographic variation associated with youth-specific Medicaid policy and its differential relationship with insurance, unmet need, and cost-related challenges in obtaining care for youth with the most complex needs, these findings also contribute to the developing body of knowledge regarding alarming geographic disparities that exist in mental health service access (Cummings, Wen, Ko M, & Druss, 2013, 2014; Dinwiddie, Gaskin, Chan, Norrington, & McCleary, 2013; Kim et al., 2017; Sturm, Ringel, & Andreyeva, 2003). These findings provide additional evidence supporting the need to consider county or regional location and policy in national assessments of unmet need.

Further, by identifying differences in unmet need for youth of varying levels of clinical severity, these findings make a significant contribution in the body of research identifying unmet needs for youth with SED and their families and the role of insurance coverage in treatment access. This study highlights the ways in which financial barriers differ by clinical severity, and variation in how commercial insurance versus public insurance can address these challenges more or less effectively, based on disparities in the clinical severity of the youth being served. Though prior studies have demonstrated that youth with more significant impairments are at greater risk for poorer outcomes (Costello, Angold, & Keller, 1999; den Dunnen et al., 2012; Reed, Jakubovski, Johnson, & Bloch, 2017) and evaluation of the federal Medicaid PRTF waiver demonstration project found that youth with the greatest clinical need benefited the most from participation in publicly-funded, intensive community-based mental health treatment (Urdapilleta et al., 2013), few studies consider the role of clinical severity in unmet mental health care needs and families' experience of difficulties in accessing care due to cost concerns, particularly in relation to health insurance coverage. Because Medicaid HCBS services exist for the purpose of providing community-based alternatives to out-of-home placement for individuals with the most significant needs, findings here demonstrate the need to consider variation in clinical need when assessing treatment access and barriers to care in future Medicaid waiver evaluations.

**Insurance-related disparities.** Study outcomes also call attention to disturbing disparities in mental health care access for youth with SED who lack any health coverage. Though it is well known that lack of health insurance is linked to mental health service utilization (Burns et al., 1997; Kataoka, Zhang, & Wells, 2002; Rowan, McAlpine, & Blewett, 2013; Wilson et al., 2014), the disparities in unmet need and cost-related barriers to treatment demonstrated in this study are vast. Uninsured youth with SED, regardless of their level of clinical need, have almost three times greater odds of having unmet mental health care needs and almost six times greater odds of encountering cost-barriers to treatment, when compared to similar youth with private insurance. Though the percentage of youth with no health insurance represents a small portion of children and adolescents in the United States due to Medicaid and the CHIP program, these youth are likely to be at much greater risk for out of home placement due to their inability to access adequate outpatient or home and community-based supports (Barbot et al., 2015; Greenbaum et al., 1996; Tarren-Sweeney, 2017). Medicaid-expanding policies may be a key strategy in reducing rates of uninsured youth with SED and preventing these youth from going without care. By funding needed home and community-based mental health treatment for youth with complex behavioral healthcare needs—through the extension of comprehensive health coverage regardless of family income levels—Medicaid waivers or

Medicaid-expansion CHIP plans may be an important step to meeting the perceived needs of these youth. This hypothesis is supported by descriptive findings here that demonstrate fewer uninsured youth in Medicaid-expanding policy states.

## **Part II Discussion: Implications for Policy and Future Research**

**Part II policy implications.** Given the robustness of study findings, there are several important implications for policy making including the importance of public health coverage in increasing access to HCBS, especially for youth with more significant needs. Findings also suggest the need to continue and more specifically assess unmet mental health care needs and non-cost-related barriers to services. Finally, results underscore the importance of Medicaid expansions under the ACA and under CHIP programs for increasing access to needed mental health care for adults and higher income families.

**Insurance, clinical severity and access to care.** Findings from Part II suggest that the use of a Medicaid-expanding policy, either through CHIP or a waiver targeting youth with SED, is associated with increased access to Medicaid for youth with SED. However, though access to Medicaid is associated with reduced cost barriers to services, it does not relate to unmet mental health needs. This is *particularly true for youth with functional impairments*, suggesting that families are encountering other significant barriers to care, beyond cost barriers, and that barriers may vary based on the clinical need of the child. Further, barriers may vary across states in relation to distinctions in state Medicaid and mental health policy. When integrating this finding with results from Part I's qualitative analysis, it is likely that variation also exists regionally throughout states, particularly in states where local governments have more autonomy and discretion around service provision and spending. Due to the potential for this level of variation, state and local policymakers need to do thorough assessments of their populations, using regionally stratified random sampling, to fully understand the needs that are not being met, how those vary based on the clinical need of the child, the barriers families experience in trying to access needed services (backlogs, proximity or transportation concerns, limited service array). Policymakers must then utilize local survey findings in service planning and budget allocations while accounting for regional habits of service structure and fiscal allocations.

Additionally, though findings here imply that cost barriers are not the only factor preventing families from accessing care, they also suggest that many families are still experiencing cost barriers to care (particularly families with youth with more complex needs). However, states that have Medicaid-expanding policies have far fewer families experiencing cost barriers. For states without such policies, study results suggest that utilizing some policy that enables access to public health coverage will help to reduce cost barriers to needed services for youth and families living in that state.

**ACA and CHIP.** This study also has implications related to two key federal policies: Medicaid expansion under the Affordable Care Act (ACA) and CHIP. In regard to the ACA, results demonstrate that expansions of Medicaid reduce cost barriers to needed care for many children, which suggests that a state's acceptance of Medicaid expansion could have the same effects for millions of low-income adults—especially those with mild to moderate mental health care needs. Under current federal disability policy, the majority of adults with significant mental health concerns (those that impair their daily functioning) can qualify for Medicaid and the HCBS funded under it by applying for disability benefits. However, findings here also indicate that, due to variation across states in the mental health benefits available through each state plan

and local variation related to service provision and funding, reducing cost barriers does not ensure that all mental health needs of low-income adults will be met through their public health coverage—whether their behavioral health needs are mild, moderate, or significant.

Results here also underscore the stark disparities in mental health care access between individuals with health coverage and those without. When compared to similar adults who lack any insurance, public health coverage is likely to increase the odds of having mental health treatment needs met for all low-income adults. Thus, moving adults from no health coverage to full health coverage through a Medicaid expansion is likely to have a significant effect on mental health care access for many low-income adults.

Study outcomes are also particularly salient in light of recent federal changes in the CHIP program; CHIP federal funding was discontinued as of September 30<sup>th</sup> of last year, and only recently reinstated after almost four months of inadequate funding. Several states anticipated exhausting their funds by the end of 2017, and as a result, some states with separate CHIP programs (CHIP programs that are *not* expansions of Medicaid and are more similar to a commercial health plan) planned to close or cap enrollment or discontinue coverage for enrolled children. A few states have state statutes that require them to close the program or discontinue coverage if federal funds for the program decrease (Kaiser Family Foundation, 2017). Results from this study provide evidence that CHIP may play a pivotal role in funding home and community-based services for children and adolescents with SED in at least eight states. Capping enrollment or ending this program is likely to leave many families without a funding source for critical HCBS and may result in many children moving back into institutional settings through Juvenile Justice, Child Welfare, and PRTFs—potentially incurring much greater costs for states.

**Part II future research.** Findings from this study also point to several important directions for future research, including the need for 1) more specific understanding of unmet mental health care needs and barriers to treatment, 2) closer examination of the role of CHIP in expanding access to mental health care, and 3) deeper investigation of the direct and causal effects of Medicaid-expanding policies on unmet treatment needs and clinical outcomes for youth.

***Unmet mental health needs.*** Quantitative findings suggest the need to examine unmet mental health care needs more specifically. Large national datasets such as the National Survey of Children with Special Health Care Needs might be utilized to discern other structural sources of unmet mental health need, using principal component analysis or factor analysis. Such analysis might inform the construction of a national survey that might more clearly discern causes for unmet need—specifically for children and youth with complex behavioral healthcare needs. Such research has yet to be conducted on a national level but is critical for understanding the accessibility of our mental health system for children and families on a global level. Such endeavors would enable consumers and other stakeholders some public transparency in how their regions or states compare to systems in other locations and assist in holding state policymakers and administrators accountable in meeting the needs of their constituents.

Descriptive findings also reveal that more families experience delays or challenges in accessing treatment due to cost concerns than families experience unmet mental health care need, suggesting that cost barriers are a more common problem for families than not getting needed services. This also suggests that cost barriers are likely to be temporary or overcome for a portion of these families, and they are eventually able to access what is needed. Further qualitative or survey-based research would be useful to more clearly understand the specific circumstances of cost-related delays or challenges and how these are or are not resolved. To

support these endeavors, descriptive research is needed to uncover specific services that are required but not being accessed and the barriers existing for families in obtaining these services. Results from this project also suggest that these concerns should be observed in the context of families' health coverage, youths' clinical severity, and state and county of residence.

***Children's Health Insurance Program.*** This investigation also suggests the need to study the role of CHIP and other non-waiver Medicaid policies in enhancing access to HCBS for this population, as well as for other populations with complex healthcare needs. Because this study indicates that having any public health coverage does not relate to a reduction in unmet need, it would be useful to conduct an additional analysis which parses between Medicaid coverage and CHIP coverage. Because many CHIP programs are structured similarly to commercial insurance with associated limits in HCBS coverage, it is possible that a similar analysis utilizing a variable specifically capturing Medicaid coverage would yield stronger associations and larger effects, particularly for youth with functional impairments. Having greater clarity about the relationships between the richer service array offered under most Medicaid programs and unmet mental health care needs, compared to those under more limited CHIP programs, can provide evidence to guide the design of HCBS offered under separate CHIPs.

To further these efforts and provide more context for these examinations, the variations between CHIPs that expand Medicaid, CHIPs that are structured as a combination of a Medicaid expansion and a separate health coverage program, and CHIPs that are designed as fully separate benefit packages need to be specified. The services, eligibility for services, and service limits under CHIPs across states need to be observed, codified and categorized. This data can then be used in conjunction with specific data about unmet need and barriers to care to understand the population-level relationship between CHIP program design and access to mental health care. Such endeavors can assist policymakers in shaping their Medicaid and CHIP benefit array and eligibility standards and may help to bolster arguments in favor of sustaining federal funding for CHIP.

***Medicaid-expanding policies.*** Finally, further study is needed to fully understand the specific ways in which Medicaid-expanding policies may be reducing cost-barriers to services. The final model in Part II, which controls for the mediating effect of public insurance, suggests that Medicaid-expanding policies have a direct effect on cost-barriers to care—beyond the effects of these policies in helping youth to access public health coverage. This implies that there are non-insurance related effects or latent factors across Medicaid-expanding policy states that are also associated with reducing cost-barriers to care. It may be that these states have broader service arrays, enabling access to more diverse services that exist in non-waiver states. This is particularly likely in 1915(c) waiver states, which offer additional services specific to the unique needs of youth with SED. It may also be that these states have higher Medicaid payment rates, and therefore a wider provider network, thus increasing the availability of services with lower transportation burdens. Or perhaps these states have fewer service limits associated with HCBS, particularly for youth with more complex needs. Further research is needed to address this question, and findings may point to specific policy changes that can be enacted in non-waiver or CHIP expansion states that can reduce cost barriers to care without adopting a Medicaid-expanding policy.

Continued investigation into the impacts of Medicaid waivers or Medicaid-expanding policies is needed to establish causal links between access to needed services, improvements in youth and families' outcomes, and state-level cost-savings. It is likely that a state's use of a Medicaid-expanding policy is linked with unaccounted for latent variation across states. Though

several state-level potentially confounding variables were accounted for in these models--and though these were either non-significant or relatively unimpactful on the odds of a family encountering unmet needs or cost barriers to care—future research may utilize different measures of political ideology (e.g., percentage of state registered a republican or democrat, state outcomes of elections, or party affiliation of governors or state legislators) or religiosity (percentage of population that identify as Christian versus other religions or non-religious). Further, other approaches to estimating provider supply might be utilized (e.g., provider to youth ratios, provider density), including estimates that include non-master's level mental health providers; many specialty behavioral healthcare services needed by youth with global impairments (e.g. respite care, case management, therapeutic behavioral support) are provided by staff with a bachelor's degree or less (see Kansas HCBS SED Waiver or Tennessee's Health Link provider manuals) and thus are often not included in state or county estimates of mental health providers. Unmet mental health care need for youth with significant impairments may relate to organizational capacity to provide such services if staffing levels are low. It may also be important to account for state-level measures of mental health awareness or stigma in help-seeking as well as the strength or presence of mental health or child and family advocacy organizations within a state. Given that states expanding access to home and community-based services are looking to shift service modalities and associated public costs away from residential care for these youth, the number of Psychiatric Residential Treatment Facilities (PRTFs) in a state may also be linked with state investment in community-based care, enhancing access to such services for the most impaired youth with SED.

Studies seeking to identify a causal relationship between access to care and Medicaid-expansion policies would need to be rooted in difference-in-difference designs or longitudinal approaches to regression discontinuity analyses. Such research may need to take into account regional variation in states with greater local autonomy, and variation in state waiver benefits and service limits. Possible outcome variables to utilize might be state-level outcomes, including aggregated measures of unmet need from the National Survey of Children with Special Health Care Needs, the portion of youth admitted into state custody voluntarily with emotional or behavioral disabilities from Adoption and Foster Care Reporting System (AFCARS), or hospital admission and readmission data from the Healthcare Cost and Utilization Project (HCUP).

## **Conclusion**

In a uniquely integrated mixed methods design, the first part of this dissertation sought to understand how state mental health systems fund home and community-based mental health services for youth with complex behavioral healthcare needs who are not financially eligible for Medicaid eligible, as well as state policymakers' motivation for choosing particular approaches to meeting the needs of this population. The study found that states use many strategies for funding and organizing care for this population, but that strategies involve the allocation of state general revenue funds or the use of a policy that expands the financial eligibility limits of Medicaid for children. Reasons for the use of each approach are most related to the size and flexibility of Medicaid budgets, political prioritization of children and families, and political ideology related to the role of the state in providing for the welfare of children and families.

The second part of this dissertation aimed to assess the relationship between a state's use of Medicaid-expanding policies and unmet mental health care needs and cost-barriers to care for these youth—both the direct relationship between these variables and the indirect relationship with health coverage type used as a mediator. This portion of the study found that policies that

expand financial eligibility for Medicaid were related to reductions in cost-related barriers to treatment, even controlling for the mediating effect of these policies in changing the insurance status of children. However, both the use of these policies and a child's coverage under public health insurance was not significantly predictive of reduced odds of having unmet mental health care needs. By controlling for the severity of a child's mental health care needs, and the interaction between their level of need and type of health insurance coverage, this analysis also highlighted the role of clinical severity in unmet treatment needs and barriers to care and the ways in which public insurance moderated this relationship.

Holistically, this study concludes that, though states have many means of funding care for non-Medicaid eligible youth with complex behavioral healthcare needs and have various reasons specific to state environments for choosing a particular approach, states with policies that allow children to more easily access Medicaid appear to have fewer families experiencing cost barriers to mental health services. However, these state policies do not address other, unknown barriers to obtaining mental health services for families in their states. Expansion of Medicaid eligibility for children can help to reduce unmet need due to financial obstacles but does not solve all problems related to service accessibility. Additional barriers to treatment access must be identified at the individual, organizational and policy levels for children with all levels of clinical need. Policies and practices aimed at reducing these must be identified and implemented in the manner most suitable and applicable to the unique political, fiscal, and structural concerns of each state and community. Then, these practices and policies must be rigorously evaluated for effectiveness in achieving equitable access to high quality and effective mental health treatment for all children with behavioral health concerns. Until families are no longer directed to engage in the child welfare or juvenile justice system for the sole purpose of obtaining suitable levels of mental health care, research and policy reform aimed at increasing access to all levels of behavioral health treatment must continue.

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Appendix A. Predicting State Adoption of Medicaid Waivers: Interview Protocol

Understanding the State’s Public Mental Health System  
 State Administrator Interview Protocol

Thanks so much for agreeing to contribute your time to my study today. I am very grateful.

The purpose of this interview is two fold:

- 1.) To understand the primary structures and funding mechanisms behind all community-based services available to Youth with SED in your state, those funded by Medicaid and those not funded by Medicaid.
- 2) To understand the history, rationale and motivation behind the current and or changing structures of these mental health services, with a special emphasis on the use of Medicaid Waivers or State plan options.

As many states are undergoing significant changes at this time, it would be helpful if answers regarding service structure and funding mechanisms can be answered first about how services have been structures in the last 5 or 6 years (2010 to 2013 is the data set I will be using), and then discussion how services are being changed in their structure more recently.

Respondent Contextual Information	
Interviewees:	1)
	2)
	3)
	4)
Positions held:	1)
	2)
	3)
	4)
Years in Position:	1)
	2)
	3)
	4)
Years in Organization:	1)
	2)
	3)
	4)
Youth with SED in the State Mental Health System	
What are the goals of the state mental health system for Youth with SED and their families?	

Is the mental health system state administered or county administered?	
What are the key federal mandates that shape state actions and policy?	
How do they shape state policy and procedures?	
How is a youth determined to be Severely Emotionally Disturbed? (criteria)	
What assessments are used to determine SED or eligibility for services?	
<b>Home and Community-based Services</b>	
What is the role of community-based services in serving and Youth with SED and their families?	
If determined to be SED, what services could they receive in the Community?	
How are these services financed?	
Who or What organizations can provide these services?	
What is the standard for first contact and intake for new clients?	
What Medicaid billing codes can used to provide services to Youth with SED in the community, and how are those defined?	
What is the reimbursement rate for each service? (if unknown, where could I find it?)	

Is there co-pay for Medicaid covered services?	
What does a provider need to possess in qualifications to be able to provide each of the above billing codes?	
How is the State Mental Health Plan for Youth with SED different from the services available under Medicaid?	
How is it determined who receives which services?	
About how many SED kids are served through Medicaid vs. through the SMHA?	
Does the state have a way for families to access intensive, CBS whose income is above the Medicaid threshold?	
How are these services financed?	
Was this policy in place in 2011-2012?	
Is Medical necessity defined differently each of these services? How?	
<b>Residential/Inpatient Services</b>	
What is the role of residential or inpatient care in the state mental health system for Youth with SED?	
What is the process for a child being admitted to/screened for the hospital?	
What is the criteria for residential or inpatient admission for Youth with SED?	



Acute?	
Short term?	
Residential?	
How are inpatient services paid for?	
Acute?	
Short term?	
Residential?	

Medicaid Waivers	
What is the role of CHIP and private mental health services in the mental health system? How do families access services through these programs, and what services can they access?	
Does the state utilize any policy mechanism that waives the means test for Medicaid/Medicaid funded services for Youth with SED, basing eligibility for services on the clinical severity of the youth to keep them out of long term care settings?	
Tell me about how 1915c/TEFRA/Sec 1115 works in facilitating access to community-based services for Youth with SED?	
How and to what extent do these funding mechanisms – Medicaid Waivers, or other funding streams—shape the mental health services Youth with SED and their families receive?	
Has the state ever been sued by a child/family consumer? What was the law suit about and how was it resolved?	

For states that have a Waiver: Why did the state pursue the use of a Medicaid Waiver? Why that particular type of waiver?	
For states that do not have a Waiver: Why has the state chosen not to pursue a waiver?	
What other policy/Medicaid options or structures have been considered for structuring and financing services for Youth with SED?	
How well does the state feel the current system is working? Why?	
Are there plans to change the current system? What will it look like in the future?	
How has Medicaid expansion affected services for Youth with SED in this state?	

#### Administration of HCBS

Do you operate in a fee for service model, or block grant? (Do providers get paid as they go, or have to give money back if they don't serve the right number of people? Or is capitation used?)	
What part of oversight for children's mental health services are managed by private outsourced health insurance companies? Which companies?	
Why did the state decide to work with managed care companies? How were they selected?	
Can you suggest documents that I can find that outlines policies for service providers (ex: service limits, utilization review standards, appeals processes)	
What kind of training is provided to system of care providers?	
Who provides this training, and how it is provided?	

What is the process for filing grievances against a CMHC or associated providers?	
How often do you receive these?	
How does the state respond to these?	
What is the process and structure for oversight of CMHCs or other CBS service providers in ensuring that they comply with mandates and standards? (Credentialing, utilization reviews, audits, licensure, etc.)	
What outcomes are required and reported to the state?	
How often are they observed and reported?	
What kinds of data systems are used by the state to capture CMHC data and services?	
How does this interface with CMHC data systems?	
How does the state fund the Medicaid match for mental health services?	
Which state department sets Medicaid policy related to mental health billing codes, rates, and eligibility?	
Where does the state mental health agency fall in the organizational chart of the state administration? (Is it housed in the Medicaid division? Is it a subset of a children's division? Is it part of all mental health?)	
What is the level of collaboration and coordination between the State Mental Health Authority and Medicaid?	
To what extent do Child Welfare, Juvenile Justice and Drug and Alcohol Departments collaborate at the state level in regards to children's mental health issues?	

