Medicaid HCBS Waivers for Youth with SED

The Role of Medicaid Home and Community-Based Services Policies in Organizing and Financing Care for Children with Severe Emotional Disturbance

Genevieve Graaf, PhD
Lonnie Snowden, PhD

Abstract

Medicaid finances considerable home and community-based children’s mental health treatment, and The Department of Health and Human Services offers a variety Medicaid Home and Community Based Services (HCBS) policies that allow states to extend Medicaid coverage to special populations, including those with incomes beyond Medicaid eligibility criteria. Because waivers pay for alternatives to institutional care, and because they reach many families whose children have Severe Emotional Disturbance (SED), they hold great promise as a source of support and structure for community-based integrated systems of care for seriously mentally ill children. However, we know little about why states adopt such policies to target children with complex behavioral health needs, and the community-based alternatives funded by waivers remain largely unspecified and untested. Medicaid HCBS funded treatment programs afford unparalleled opportunities to learn more about community-based treatment for youth with SED as it currently exits, informing the knowledge base about child mental health treatment and potentially upgrading service delivery to these youth and their families.

Keywords: Severe Emotional Disturbance, Children’s Mental Health, Medicaid, Medicaid waivers, Mental Health Policy, Systems of Care
1. Introduction

Youth with severe emotional disturbance (SED) represent approximately 8 to 12% of all youth in the United States (Costello, Egger, & Angold, 2005; Costello, He, Sampson, Kessler, & Merikangas, 2014; Kessler et al., 2005). Along with personal distress, these youth struggle to meet the family, educational, and social demands required for successful community living. Stability in secondary education and vocational settings is more difficult for these youth to achieve, and they are at greater risk of using substances and harming themselves or others (Mordre, Groholt, Kjelsberg, Sandstad, & Myhre, 2011; Strompolis et al., 2012; Wu et al., 2008; Zigmond, 2006). Due to these behaviors, they have an increased likelihood of out of home placement in the criminal justice system, foster care, or in residential treatment facilities (Fields & Ogles, 2002; Mordre et al., 2011; Peiper et al., 2015).

Children with behavioral health needs of this severity require comprehensive treatment to be maintained in their homes and communities (González-García et al., 2017; Green, Twill, Nackerud, & Holosko, 2014; Painter, 2012), but many parents report barriers to such treatment (Akin, Bryson, McDonald, & Walker, 2012; Friesen, Giliberti, Katz-Leavy, Osher, & Pullmann, 2003; Owens et al., 2002). Only about 25% of families are able to arrange any mental health treatment for their child with SED (Costello et al., 2005, 2014), and many report that the expense of treatment is a factor in the inability to access needed levels of care for their child (Owens et al., 2002; Rowan, McAlpine, & Blewett, 2013). Despite parity laws, private insurance is often deeply inadequate—omitting coverage for home or community based services (Bailey & Davis, 2012; Barry & Busch, 2008). Often, the only insurer that provides coverage for the intensive level of care needed for these youth is Medicaid. Comprehensive care is expensive and financial
consequences are so burdensome that privately insured or uninsured caregivers sometimes transfer custody of their child to the state in order to obtain public financing for their children’s care (Friesen, Giliberti, Katz-Leavy, Osher, & Pullmann, 2003; Hill, 2017; U.S. Government Accountability Office, 2003).

To finance community-based treatment alternatives to confining and expensive residential or institutional care for specific high-needs populations, the Department of Health and Human Services allows state Medicaid programs to apply for and offer a variety of Medicaid HCBS waivers or state plan amendments (SPAs). These options allow states to extend coverage to persons with special healthcare needs, including those whose incomes are beyond Medicaid eligibility criteria. To date, almost every state offers one or more waivers, under several related Medicaid provisions, for numerous residents with special healthcare needs (Medicaid.gov, 2016). Approximately half of those states offer waiver programs that are specifically targeted to youth with complex behavioral healthcare needs, and some states have adopted HCBS SPAs for these youth. Because these policies expand income eligibility, and thus access, to Medicaid and the richer HCBS service array funded under its coverage, they hold great promise for widespread treatment of youth with SED, regardless of family income or insurance status. These programs may also have corresponding improvements in symptoms, social functioning, and quality of life arising from less restrictive, more effective, and less expensive treatment organization and delivery.

In what follows, we aim to bring greater scholarly attention to these Medicaid HCBS programs, particularly for policy analysts and researchers, by describing the Medicaid policy mechanisms for funding HCBS for youth with SED, reviewing the status of the knowledge base about these options, and providing suggestions for future study. We begin by discussing inpatient
and residential treatment, and the substitute community care that HCBS policies help to fund. We then provide crucial background information, discussing the Medicaid program’s role in financing children’s mental health systems of care, and laying a foundation for our presentation of Medicaid waivers and SPA options. We describe the variations in Medicaid waiver options available for states to use in financing home and community-based care, and include specific data about the structure of existing SED-specific 1915(c) HCBS Medicaid waiver programs for across nine states. We conclude by reviewing current evidence about these policies and highlighting the opportunity provided by HCBS waivers and SPAs to address key questions about service systems for youth with SED.

2. **Community-Based Care vs. Residential Care**

   Historically, youth with Serious Emotional Disturbance were served primarily in public or private institutions (Lourie, 2003). But, in 1982, a critical report from The Children’s Defense fund garnered national attention by asserting “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). Critics of residential care point out that it has been found minimally effective at long term reduction of symptoms and it is more costly than community-based care (Barth et al., 2007; Hoagwood & Cunningham, 1992). In addition, 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). Confinement is also disruptive, expensive and rarely meets the standard of “least restrictive alternative” set out by the Individuals with Disabilities Education Act (IDEA), renewed in 2004.
However, children with severe impairments may need access to intensive services and supports to be maintained in the home (Kernan, Griswold, & Wagner, 2003; Marcenko, Keller, & Delaney, 2001). A relatively small number of studies has demonstrated that such intensive community-based care alternatives can have equal or greater outcomes than residually provided services. Reviewing randomized controlled trials of intensive home treatments, and intensive home-based crisis interventions devised as inpatient treatment alternatives, one report identified a few which improved children’s problems and would prevent psychiatric hospitalization (Shepperd et al., 2009). But, in a comparison of longer term outcomes for youth served in residential settings against youth served through intensive in-home treatment programs, using propensity score matching to control for group differences, in-home services proved to be at least equally effective as residential care in producing stable outcomes (Barth et al., 2007). Because legal, political, and familial preference is for care to be provided in the least restrictive setting, equality in harm prevention, symptom reduction, and functioning improvement—not superiority—is the standard to meet.

Because impairment manifests in all domains—school, home, community—a child may need to receive these community-based interventions in many service settings at one time such as through the child welfare system, or in juvenile justice or special education settings (Hansen, Litzelman, Marsh, & Milspaw, 2004). For this reason, the Knitzer and Olsen conclude their 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 this report by establishing the Child and Adolescent Service System Program (CASSP) in 1984 which provided funding and technical assistance to all 50 State Mental Health Authorities (SMHAs) 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, treatment for families of youth with SED 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 stabilizing the child in their home, their community, and with their family and improving clinical functioning (Anderson, Wright, Kelley, & Kooreman, 2008; Bickman et al., 2004; Green et al., 2014; Painter, 2012).
2.1 Medicaid’s Role in Financing Community-Based Care

Even as systems of care were developed in communities nationwide, obtaining access to the services in these systems remained elusive for many families. Though SMHAs received federal funds to establish systems of care, much of the treatment provided through them came with a hefty price tag. In fact, families whose children have complex healthcare needs, including SED, incur costs for care that are three to five times that of families whose children do not have such needs (Chan, Jahnke, Thorson, & Vanderburg, 1998; Newacheck & Kim, 2005). Though mental health parity laws have been passed, private coverage remains deeply inadequate for the families of these youth (Barry & Busch, 2008; Bailey & Davis, 2012). Usually covering nominal inpatient care and limited amounts of outpatient services, private policies often restrict access to appropriate levels of care and the needed spectrum of home and community-based mental health services for youth with complex behavioral health needs (Kataoka, Zhang, & Wells, 2002; Rowan et al., 2013; Zimmerman, 2005).

Because states are required to provide these services through Medicaid’s Early Periodical Screening, Diagnosis and Treatment (EPSDT) mandate, the majority of the comprehensive home and community-based service array essential to a system of care is delivered by public providers and funded by Medicaid (Howell, 2004). The state-federal Medicaid program provides relatively generous mental health benefits for children, including coverage for home and community-based services essential to a system of care such as targeted case management, behavioral support services, and psychosocial rehabilitation. Moreover, as state dollars are increasingly invested in the state Medicaid match, funding for mental health safety net programs serving non-Medicaid families is declining (Frank, Goldman, & Hogan, 2003; Howell, 2004).
As a result, more children covered by Medicaid are accessing mental health services than youth under any other type of insurance (Burns et al., 1997; Ringel & Sturm, 2001; Walker, Cummings, Hockenberry, & Druss, 2015); 18% of children with private insurance and 10% of youth with no insurance access mental health services, while 44% of children with Medicaid coverage obtain treatment (Howell, 2004). Given that 30 to 40% of youth with complex behavioral health needs are privately insured or uninsured (Mark & Buck, 2006), many do not receive care due to cost barriers (Rowan et al., 2013).

Because much expensive specialty mental health care is not paid for by private insurance—and the household income of many families is too high to qualify them for Medicaid or the shrinking array of safety net mental health services—some families 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 (Cohen, Harris, Gottlieb, & Best, 1991; Friesen et al., 2003; Hill, 2017; Ireys, Pires, & Lee, 2006). In 2003, the General Accounting Office reported that over 12,000 children in 19 states were transferred into State custody when families were desperate to obtain mental health services for their child and had either maxed out their private insurance plans, found that they do not qualify for public insurance, or that local safety net programs had no openings for new clients.

3.0 Medicaid Waivers and State Plan Amendment Options

Many states have enacted policies that attempt to discourage custody transfer by increasing access to public mental health services through the establishment of a Medicaid waiver or option to expand the state Medicaid plan for special populations (Friesen et al., 2003; Hill, 2017). Medicaid waivers and SPA options allow states to “waive” many key federal Medicaid requirements in order to more effectively serve specific high-needs populations that would otherwise require institutional long-term care. States can use these waivers to provide services not covered
by the state Medicaid plan, but can limit services to specific population groups, geographic areas, and the total number of participants served (Kitchener, Ng, Miller, & Harrington, 2005).

Several types of Medicaid waivers and SPA options have been used across many states (e.g., TEFRA, 1915(c), 1915(i), 1915(k), Section 1115) to deliver intensive community-based services to youth and adults with complex medical and/or mental health needs. States offer waivers or options to individuals with limiting physical, cognitive and psychological disabilities—including autism, developmental delays, traumatic brain injuries, and severe mental health disorders—to enable their access to intensive support services while living in the community, rather than in a residential setting. Qualification for most of these programs rests on the recipient demonstrating a level of clinical need that would otherwise require long-term residential care. For those targeting children, the means-tests for parents’ income can be disregarded, and eligibility can be determined through a combination of an assessment of the child’s clinical need and a means-test based on the child’s personal assets alone.

These waivers and state plan options may be a critical policy mechanism for ensuring that children with the greatest emotional and behavioral impairments receive the most intensive and targeted services, in the least restrictive setting, regardless of their families’ level of income, and at a lower cost to states. Though all 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 found in participant eligibility (does it cover mental health disabilities?), services provided (does it provide access to additional specialty mental health services?), the capacity of the waivers (how many “slots” or participants at one time?), and the level of state burden in implementing each type of waiver (how complicated is it for a state to adopt and implement this waiver?).
describes each program varies across these dimensions (adapted from Cooper, Flanagan & Crisp, 2014).
Table 1. Medicaid HCBS Policy Description and Comparison

<table>
<thead>
<tr>
<th>Medicaid Waiver Type (Year Effective)</th>
<th>Brief Description</th>
<th>Medicaid Eligibility Criteria</th>
<th>Requires Institutional Level of Care?</th>
<th>SED/Mental Health as Disability</th>
<th>Provides specialized SED Services?</th>
<th>Requires Federal Application and Approval?</th>
<th>Limited Number of “slots”?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1915(c) HCBS Waiver (1980)</td>
<td>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.</td>
<td>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, and some states waive the means test altogether.</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes, states must demonstrate comparable or lesser costs for HCBS services than for institutional services.</td>
<td>Yes</td>
</tr>
<tr>
<td>1915(c) HCBS PRTF Waiver (2007-2012)</td>
<td>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.</td>
<td>The Demonstration served children and youth who were either “diverted” from being served in a PRTF, or were “transitioned” from a PRTF into the community. The youth must demonstrate SED severe enough to require hospital or residential levels of care in a Psychiatric Residential Treatment Facility (PRTF). In at least one state, youth transitioning out of a PRTF into the home and community were automatically eligible for this waiver.</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes - Federal Demonstration</td>
<td>Yes</td>
</tr>
<tr>
<td><strong>Section 1115 (1990)</strong></td>
<td>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”</td>
<td>Section 1115 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).</td>
<td>No</td>
<td>Yes</td>
<td>Varies Across States</td>
<td>Yes</td>
<td>Varies Across States</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td><strong>TEFRA Waiver (1982)</strong></td>
<td>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.</td>
<td>A child must demonstrate a physical or mental disability that meets standards under the federal Supplemental Social Security Income disability program, and must require the level of care provided in a hospital, nursing facility or an intermediate care facility for mental retardation. States are authorized to determine whether applicants meet the level of care requirement, and cannot single out individual disabilities.</td>
<td>Yes</td>
<td>Yes, but only in 10 out of 20 TEFRA states. Across those states, as few as 3%, and as many as 52%, of TEFRA consumers identify a mental health diagnosis as the primary disability</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td><strong>1915(i) State Plan HCBS (2007, Revised 2012)</strong></td>
<td>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.</td>
<td>All individuals eligible for Medicaid under the State plan up to 150% of FPL 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.</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>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.</td>
<td>No</td>
</tr>
<tr>
<td>1915(k) Community First Choice Option (2011)</td>
<td>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. Allows consumers to obtain services through an agency, or to hire providers directly.</td>
<td>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.</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>No, but state plan amendment must be submitted to CMS.</td>
<td>No</td>
</tr>
</tbody>
</table>

3.1 1915(c) HCBS Waivers

The Medicaid Home and Community-Based Services (HCBS) waiver program is authorized under section 1915(c) of the federal Social Security Act, and is often referred to as an HCBS waiver (Ireys, et al., 2006). HCBS waivers are used extensively by states to increase access to HCBS for the elderly, and individuals who are physically, cognitively, or developmentally disabled. 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; Harrington, Ng, LaPlante, & Kaye, 2012). Among many other factors, applications must also include a state’s proposal of the additional specialized services that will be offered only to youth on the waiver, the number of “slots” available at any given time, as well as over the course of each year, and the financial eligibility requirements for families in qualifying for the program.

States commonly use 1915(c) HCBS waivers to fund home and community-based services especially for children with physical, intellectual, or developmental disabilities, but far less often for children with serious mental health treatment needs (Ireys, et al., 2006). As of 2016, according to the State Waivers List from Medicaid.gov, only nine states have an HCBS or 1915(c) waiver specifically designed to serve youth with SED and their families. 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 by omitting or expanding the parental means-test for Medicaid eligibility, and basing eligibility for services and coverage on the severity of the child’s emotional disturbance (Friesen et al., 2003; Ireys, et al., 2006). This waiver also allows states to waive the “limits on the amount, duration, and scope of Medicaid
services, thereby enabling the state to offer additional specialized services specifically for the most severe SED children” (Ireys et al., 2006, p. 12).

Table 2 displays basic variations in SED waiver programs across these nine states, obtained through examination of publicly available 1915(c) waiver applications in 2014. In this table, the number of waiver “slots” refers to how many consumers are allowed to access the waiver over the course of a given year, as well as to how many consumers can be on the waiver at any given time. On the low end of the spectrum, Wyoming allows 75 youth on the SED waiver at one time, and can serve only 135 families over the course of the year. Kansas, however, serves the most children with the SED waiver. This state places no limits on the numbers of youth accessing the Waiver at one time, and projects serving almost 14,000 youth by the fifth year of its current waiver. The types of services offered under waivers also differ from state to state. The SED waiver in Texas, implemented in 2009, offers respite, adaptive aids and supports, community living supports, family supports, minor home modifications, non-medical transportation, paraprofessional services, specialized therapies, supportive family-based alternatives, and transitional services. Iowa, however, does not provide paraprofessional services, transitional assistance, or transportation.
<table>
<thead>
<tr>
<th>State</th>
<th>Year started</th>
<th>Total Waiver Families on Waiver at 1 Time</th>
<th>Total Waiver Families Served in 1 Year</th>
<th>Income Eligibility</th>
<th>Services Provided</th>
</tr>
</thead>
<tbody>
<tr>
<td>Iowa</td>
<td>2010</td>
<td>1237</td>
<td>1570</td>
<td>Expands Parental Means Test</td>
<td>Provides family and community support service, respite, environmental mods and adaptive devices, in-home family therapy for children w/SED ages 0 – 17</td>
</tr>
<tr>
<td>Georgia</td>
<td>2012</td>
<td>NA</td>
<td>Year 1 - 450 Year 2 – 225 Year 3 – 0 Year 4 – 0 Year 5 - 0</td>
<td>Omits Parental Means Test</td>
<td>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</td>
</tr>
<tr>
<td>Kansas</td>
<td>1997</td>
<td>NA</td>
<td>Year 1 - 7192 Year 2 – 8486 Year 3 – 10014 Year 4 – 11816 Year 5 - 13943</td>
<td>Omits Parental Means Test</td>
<td>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</td>
</tr>
<tr>
<td>Louisiana</td>
<td>2011</td>
<td>NA</td>
<td>Year 1 - 1200 Year 2 – 1200 Year 3 – 1200 Year 4 – 1200 Year 5 - 1200</td>
<td>Expands Parental Means Test</td>
<td>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</td>
</tr>
<tr>
<td>Michigan</td>
<td>2005</td>
<td>NA</td>
<td>Year 1 - 804 Year 2 – 969 Year 3 – 969 Year 4 – 969 Year 5 - 969</td>
<td>Expands Parental Means Test</td>
<td>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</td>
</tr>
<tr>
<td>New York</td>
<td>1999</td>
<td>Year 1 - 1506 Year 2 – 1551 Year 3 – 1598 Year 4 – 1646 Year 5 - 1695</td>
<td>Year 1 - 2259 Year 2 – 2327 Year 3 – 2397 Year 4 – 2468 Year 5 - 2543</td>
<td>Expands Parental Means Test</td>
<td>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</td>
</tr>
</tbody>
</table>
| New York | 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 | Specifically for children in foster care | 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,
<table>
<thead>
<tr>
<th>State</th>
<th>Year</th>
<th>Numbers Served</th>
<th>Supports Provided</th>
</tr>
</thead>
<tbody>
<tr>
<td>Texas Youth Empowerment Services (YES)</td>
<td>2009</td>
<td>Year 1 - 400, Year 2 – 400, Year 3 – 400, Year 4 – 400, Year 5 – 400</td>
<td>Expands Parental Means Test</td>
</tr>
<tr>
<td>Wisconsin WI Children's Long Term Support SED Waiver (0415.R02.00)</td>
<td>2003</td>
<td>NA</td>
<td>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</td>
</tr>
<tr>
<td>Wyoming WY Children's Mental Health (0451.R02.00)</td>
<td>2006</td>
<td>75, each year, 135, each year</td>
<td>Expands Parental Means Test</td>
</tr>
</tbody>
</table>


* Numbers served reflect those proposed on the most recent application or renewal application, most of which are dated from 2009 onward.*
Nine states also offered an HCBS waiver for five years from 2007 to 2012 under a five year federal demonstration project. In 2005, Congress used 1915(c) waiver authority to target youth who would not have been eligible for Medicaid-funded, intensive community-based services, by authorizing a 5 year demonstration project to evaluate a “PRTF” Waiver. The demonstration was intended 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 (Urdapilleta, et al., 2013).

Similar to the HCBS SED waiver, the financial eligibility requirements for families to be approved for coverage—and the types and intensity of services available under that coverage—varied broadly across the nine participating states. Distinctions across these programs, which included discrepancies in types and volume of services available, are described by Urdapilleta and colleagues’ (2013) National Evaluation of the Medicaid Demonstration Waiver Home- and Community-Based Alternatives to Psychiatric Residential Treatment Facilities.

3.2 Section 1115 Demonstration Waivers

Another, less studied method states use to waive or amend the means-test barrier to Medicaid is to seek approval from the Centers for Medicaid and Medicare Services (CMS) for a Section 1115 demonstration waiver. 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, 2016). Projects can include expanding Medicaid eligibility, providing new services under Medicaid, or creating innovative health systems that can streamline service delivery. As of July 2017, a few 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. Among others, Illinois is restructuring its entire system of care for youth with SED around the adoption of a Section 1115 waiver (Illinois Department of Health and Human Services, 2016), and Missouri is working on a 1115 aimed specifically at transitional age young adults with complex behavioral health conditions (Missouri Department of Mental Health, 2016). New York is using this policy tool to comply with directives under the Patient Protection and Affordable Care Act (2010) to integrate behavioral healthcare and primary care (Chapman, Chung, & Pincus, 2017).

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

The Tax Equity and Fiscal Responsibility Act (TEFRA) Medicaid Eligibility Option, also known as the Katie Beckett Option, is another under-examined Medicaid option, employed in 20 states (Semansky & Koyanagi, 2004). This option allows youth of middle income with mental health disabilities to access the same coverage available to all youth covered by Medicaid, including community-based interventions like case management and other home and school support services which are integral to a comprehensive system of care. 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. According to a 2004 survey, out of the 20 states now using TEFRA options, only 10 states allow 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).

The TEFRA Medicaid option is much easier to adopt than federal Medicaid waivers. To implement Medicaid waivers –1915(c) or Section 1115—states must seek and receive approval from the Centers for Medicare and Medicaid Services (CMS); they 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 (Ireys, et al., 2006). However, TEFRA also has an unlimited number of “slots” (i.e. the number of youth allowed to be receiving services under this waiver) for consumers that qualify, making it a potentially costly option for states.

### 3.4 1915(i) & (k) HCBS State Plan Amendment Options

In 2005, the Social Security Act was further amended to offer states more options for structuring home and community-based care for medically needy persons under the 1915(i) SPA option. This option was amended under the Affordable Care Act in 2010, which also added the opportunity for states to provide HCBS under section 1915(k), or Community First Choice. Both options were not designed specifically for youth with behavioral or emotional disturbances and are so recently created that these policies are just beginning to be implemented and evaluated. However, a handful of states have expanded HCBS services for youth with SED under these regulations, and report finding the 1915(i) option advantageous; it allows policy makers to offer families a full continuum of care in less restrictive settings by adding additional HCBS not within the official state plan, without the burden of proving cost neutrality (Dorn, et. al, 2016).

Since 2010, the 1915(i) SPA option has allowed states to offer HCBS services to individuals who are not at risk of institutionalization, and to do so without having to prove cost
neutrality to CMS. Participants in 1915(i) plans can include categorically eligible individuals with incomes up to 300% of the FPL, but those individuals have to also be eligible for an existing 1915(c) or 1115 Waiver. Participants can receive full Medicaid benefits, expanding the type, amount, duration, or scope of services offered, and specialized benefits can be offered to specific populations. The 1915(i) option requires that HCBS be offered to eligible populations statewide. Under this policy, state-funded 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.

1915(k), or the Community First Choice (CFC) State Plan Option, encourages 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, or 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 Waiver criteria, receiving at least one waiver service per month. Under CFC, the state must offer these services to all individuals who meet the eligibility criteria, with no geographic or specific target group limits.

Though states must submit proposals or applications for both state plan options, the Centers for Medicaid and Medicare Services does not provide a comprehensive listing of states utilizing 1915(i) or 1915(k) options. Though the 1915(k) option could be utilized to expand community-based services for youth with complex behavioral health needs, and it provides an additional federal fiscal incentive to do so, the authors do not know of any state utilizing it for this population as of July, 2017.
Some states are utilizing the 1915(i) option in various ways to broaden the reach of HCBS for these youth; Indiana’s program is for youth ages 6 to 17 years of age who are eligible for Medicaid and present with at least two DSM-IV TR 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 (Indiana Division of Mental Health and Addiction Child Mental Health Wraparound Services, Provider Reference Module, 2017). In contrast, Maryland’s Targeted Case Management: Care Coordination for Children and Youth program only includes the additional service of targeted case management, but it expands the means test, extending coverage to children whose family income is up to 300% of the federal poverty level (Maryland’s Child and Youth TCM Approved SPA, 2014).

4.0 Directions for Future Research

In 2013, following the conclusion of the Home- and Community-Based Alternatives to Psychiatric Residential Treatment Facilities Medicaid Demonstration Waiver, 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 policy makers to Medicaid policy options 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.

“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)”
Authors assert that, according to evaluations of similar programs (including the PRTF Waiver Demonstration), such mental health plans will 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 family. “These services enable children with complex mental health needs – many of whom have traditionally been served in restrictive settings like residential treatment centers, group homes, and psychiatric hospitals – to live in community settings and participate fully in family and community life. (Mann & Hyde, 2013, p. 1)” Adding such services to the state plan will help states to comply with mandates under the Americans with Disabilities act for least restrictive service settings and services required under Medicaid’s Early Periodic Screening, Diagnostic and Treatment (EPSDT) mandate.

Further, in compliance with directives under the Patient Protection and Affordable Care Act (2010) many states are seeking ways to restructure public healthcare to integrate with behavioral health systems and are considering how these policy tools can be a resource in that endeavor (Chapman et al., 2017; May et al., 2017; Jeffers, 2014). The Committee on Child Healthcare Financing for the American Academy of Pediatrics asserts that achieving such integration of healthcare requires that coverage for children include “care coordination or case management by pediatric primary and specialty medical homes to ensure excellent outpatient management of children with chronic and complex conditions and to ensure linkages to age-appropriate public, community, and employer-based programs. (Hudak, Helm, White, & Financing, 2017)”

By funding services such as wraparound, which helps to organize care into “a coordinated network to meet the multiple and changing needs of severely emotionally disturbed children and adolescents” (Stroul & Friedman, 1986, p. iv), HCBS waivers may play a pivotal role in the development of integrated systems of care across the nation, and in facilitating youth
and family access to those systems. These policies also represent opportunities for states to finance many evidence-supported ancillary services for youth with complex behavioral health needs such as respite care, parent and youth peer support, and independent living skills training (Grové, Reupert, & Maybery, 2015; January et al., 2016; Jivanjee & Kruzich, 2011; Sather & Bruns, 2016; Strunk, 2010). But perhaps most importantly, these policies may be mechanisms for relieving the financial burden on families, regardless of their income level, while structuring a “comprehensive spectrum of mental health and other necessary services” that allow youth to achieve recovery or stability in less restrictive settings.

Though tens of thousands of children receive services under HCBS waivers and SPAs, and these policies finance many critical services nationwide, little is known about these policies and the systems of care they are used to finance and organize. As of 2017, peer reviewed, non-governmental research investigating the use of Medicaid waivers to finance and deliver care to young mental health consumers is severely limited. No peer-reviewed research has examined how Section 1115 waivers, 1915(i) or (k) waivers, or TEFRA waivers are used to serve youth with complex behavioral health needs—or the success of these policies in doing so. And though a fair amount of evidence has been gained about the use of 1915(c) waivers, the majority of endeavors have focused on how this policy is used to expand access and organize services for populations with other long term, complex healthcare needs: older adults and individuals who are medically fragile or have physical, intellectual, or developmental disabilities.

Minimal evaluation exists regarding HCBS 1915(c) waivers specifically for youth with complex behavioral healthcare needs. To fully understand the part these policies play in organizing, structuring, and expanding access to the comprehensive community-based service
array critical to a full system of care, many knowledge gaps must be filled through rigorous empirical investigation.

The moderately well-developed knowledge base about the use of 1915(c) waivers to deliver publicly-funded HCBS to populations with physical and developmental disabilities may help to inform the priorities and directions for study of Medicaid waivers or SPAs for youth with SED. Examining this literature suggests that, first, we lack information as to which states seek and obtain Medicaid waivers for youth with SED, and why. Under these waivers, what kind of care is provided by whom, to which families, where, and when? How does that differ from what is standardly available under the each state’s mental health plan? Nor do we understand how successful services are in reducing symptoms and improving children’s community functioning. Ultimately, we need to determine which community-based alternatives these policies fund and whether they are effective in reducing symptoms of mental illness and improving levels of functioning in a manner that is more cost effective for states and communities than non-waiver alternatives.

4.1 Which States Apply for and Receive Waivers and Why?

Many states have not taken advantage of the waiver program or state plan options to finance and shape mental health services, despite the many advantages these policies offer for bringing more youth into the expanded service options available through a comprehensive system of care. Because Medicaid is a state-federal program which allows states to shift costs for needed mental health care, it would appear to be beneficial to state policy makers. However, many states have yet to leverage these cost-saving and system expanding opportunities; insider knowledge is needed to understand state-level factors that drive and block a state’s movement toward waiver adoption or utilizing SPA options.
Advocates for persons with mental illness in general, and youth with SED in particular, may influence a state’s use of Medicaid HCBS policies. In a survey-based study aiming to determine factors influencing state adoption of waivers to serve youth with autism spectrum disorders, Merryman and colleagues (2015) found that support from state legislators, parents, and family members were critical to the process. Further, Schmeida & McNeal (2013) found that having strong advocacy groups for civil rights was significantly associated with states adopting children’s mental health access language assistance laws. Children’s mental health advocacy groups are likely to be equally influential, as many states are spurred to invest in system of care development in response to lawsuits (e.g. Illinois, Idaho, Wyoming, California).

Merryman et al. (2015) also found that the primary barrier to state waiver adoption was insufficient funding, and policy makers’ perception that children and youth with ASD were receiving adequate care through other Medicaid benefits. Medicaid expenditures account for a significant share of states’ budgets, and debates over Medicaid spending are usually tense. Political scientists describe interplay of economic forces and interest group politics that decide the fate of tightening or loosening pre-ACA eligibility and Medicaid spending overall (Grogan, 1994; Jacobs & Callaghan, 2013; Miller & Kirk, 2016). Thus, Medicaid permits states to adopt various non-waiver optional benefits for coverage, and adopting more of these might indicate a more receptive stance toward Medicaid. Behind this more generous stance toward Medicaid may lie a state’s value-based preferences (e.g. self-reliance, primacy of family) and political leanings, including whether it is more conservative or liberal, and relatedly, its beliefs about the legitimacy of safety net spending on health and social services (Grogan, 1994; Heberlein et al., 2012; Jacoby & Schneider, 2001; Plotnick & Winters, 1985). Such ideologies may influence implementation of Medicaid policies, resulting in varying levels of resource appropriation for the
planning and infrastructure of related public mental health programs—which may result in varying service outcomes for children and families.

On the other hand, waivers and SPA options might escape some of the stigma attached to safety net spending in general and spending on Medicaid in particular, because waivers bring Medicaid coverage to non-poor families, delivering services that are simply not covered under private insurance. As such, Medicaid waivers may be viewed as supplemental to the private insurance industry. This feature of youth SED waivers is such that hypotheses about “undeserving poor” can be formulated and tested.

4.2 Who Receives What, Where, and Delivered by Whom: Descriptive Research

Much of the research on Medicaid waiver for other medically complex populations is descriptive, using surveys or content analysis of waiver applications to note large variations existing across state HCBS waiver programs. Studies of 1915(c) waivers for the older adults and individuals who are physically, cognitively or developmentally disabled report significant discrepancies in spending, and type and intensity of services provided to particular target populations (Friedman, Lulinski, & Rizzolo, 2015; Friedman & Rizzolo, 2016; Harrington, Carrillo, Wellin, Norwood, & Miller, 2001; Ng, Stone, & Harrington, 2015; Rizzolo, Friedman, Lulinski-Norris, & Braddock, 2013; Velott et al., 2016). Waiver participant limits, eligibility criteria, and the use cost control measures also vary (Kitchener, Ng, & Harrington, 2004; LeBlanc, Tonner, & Harrington, 2000; Ng et al., 2015; Velott et al., 2016), resulting in HCBS access disparities across states and making evaluation and comparison of state programs challenging (Harrington, LeBlanc, Wood, Satten, & Tonner, 2002).

Because of the autonomy the federal government provides to states in designing and administering their mental health systems, the services available and means of access for youth
with SED looks different from state to state. In county-administered states like Iowa or California, this changes from county to county. However, beyond a few federally sponsored reports, there is minimal knowledge of the extent and manner in which such programs vary. Distinctions in mental health plan eligibility, service availability, approaches to treatment planning and family engagement, and the ways in which these all vary in policy and implementation, need to be captured and evaluated.

First it is important to understand who is accessing HCBS through waivers. Where waivers have been granted, the knowledge base is missing a detailed description of who is being served under these waivers and how covered and treated populations compare in demographics, SED severity, income level, or outcomes to youth and families accessing mental health services in non-waiver funded systems. To what extent do 1915(c) and TEFRA waivers serve families that would not otherwise qualify for state-funded mental health services?

There is also a pressing need to characterize interventions delivered to consumers and supported by Medicaid across states. Without the use of Medicaid waivers, what types of services would be available to these families under their private insurance or through the mental health safety net? What components of existing systems of care and other community-based alternatives are available under Medicaid, and how do these HCBS policies enhance that service array? How, where, and by whom are they delivered at the organizational and family level? What are the required qualifications for providers of these services, and what type of training do they receive? Also, to what extent are these services supported by best evidence? Many states offer wraparound and respite care under waivers, both of which are supported by an emerging research base, but states may fund other empirically supported therapies through their basic state Medicaid plan. For example, the state of Delaware has Medicaid service codes that reimburse for
specific ESTs, including Dialectical Behavior Therapy, Multi-Systemic Therapy, and Family Functional Therapy (Delaware Division of Prevention and Behavioral Health Services Treatment Provider Manual, 2016). Across all states, what empirically supported treatments (ESTs) are supported by Medicaid, or through the additional services funded under waivers?

A close inspection of the interventions provided—the intervention strategies as well as organizational or environmental factors that shape what is observed—is a critical next step in mental health service knowledge building. In attempt to go “inside the black box” of residential treatment, one study examined a typical day of treatment across several residential settings to gain an understanding of what “treatment” really entailed (Libby, Coen, Price, Silverman, & Orton, 2005). A similar approach needs to be applied to all aspects of community-based services, observing different types of interventions across the whole range of service settings: in the home, in the school, in the community, and at the mental health center. This type of research will help to define, categorize, and qualify what is done on behalf of children with SED within Medicaid HCBS programs, and how it differs from services in non-waiver private and public settings. Such research may uncover additional points of leverage for quality improvement in children mental health systems.

4.2 Effectiveness of Waivers and SPAs

4.2.1 Access to care. Theoretically, Medicaid waivers increase access to a wider array of home and community-based services by alleviating the financial burden of treatment costs for families of all income levels. However, evaluations of how effective these policies are in increasing access to care for average mental health consumers are uncommon. A study of children with special needs served under TEFRA in Minnesota found that the policy was instrumental in helping families finance acute and long term care supports, which is normally
either not covered under private insurance, or coverage comes with high co-pays and deductibles. Though the 959 families observed in this study had diverse special needs (almost 8% of the sample had a child with severe emotional disturbance) and represented wide demographic variation, the study concluded that TEFRA was instrumental in Minnesota for reducing cost barriers to needed healthcare services (Chan et al., 1998). In another study, Leslie and colleagues (2017) used longitudinal national data in a quasi-difference-in-difference regression design to assess the capability of 1915(c) waivers to address unmet treatment needs for children with autism spectrum disorders. Results indicated that, though cost limits per child, enrollment limits, and household income level impacted the outcome, waivers significantly decreased the unmet need for care among families, especially for those who would not otherwise qualify for Medicaid (Leslie, Iskandarani, Dick, et al., 2017).

It is also important to understand is how waivers can help states to achieve greater system-level outcomes for public mental health care. What effect do variations in financial or clinical eligibility criteria and the number of available “slots” have in limiting or expanding access to coverage for families of all income levels under these policies? Some answers can be captured through closer scrutiny of waiver applications—how is income eligibility structured, and how is clinical severity measured, and what standards is it evaluated against? Other information can be gained through secondary analysis of administrative data of state-wide services of families served in the public mental health system. Assessing system-wide access to care for youth with mental health concerns, a recent exploratory study compared state-level public mental health penetration rates for youth in states with SED-specific Medicaid waivers to states with no such waivers. Multilevel regressions also captured any changes related to whether a state waived the parental means test or simply expanded it. Researchers found that Medicaid
waivers were significantly associated with increased system penetration rates, but that completely waiving income limits did not contribute to penetration rate increases (Graaf & Snowden, 2017, in press).

4.2.2 Treatment outcomes. Learning exactly what constitutes waiver or SPA-financed HCBS interventions is a key first step in evaluating the interventions’ successes in reducing SED clinical symptoms and improving social functioning of consumer youth and their families. A few effectiveness studies of 1915(c) waivers for other populations suggest some positive outcomes. Recent studies of 1915 (c) autism waivers used regression methods and difference-in-difference designs with national datasets to determine that participants were less likely to utilize inpatient or residential services (Cidav, Marcus, & Mandell, 2014), experienced improved independent living skills and family quality of life (Eskow, Chasson, & Summers, 2015), and that caregivers were less likely to be required to cease working to care for their loved one (Leslie, Iskandarani, Velott, et al., 2017). An evaluation 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 increased volume of services and associated state spending (Cidav et al., 2014; Eskow et al., 2015; Leslie, Iskandarani, Dick, et al., 2017; Mitchell et al., 2006; Sands et al., 2012). A 2006 review of these studies concludes that, though most studies were based in research designs with unresolved potential confounders, 1915(c) waiver programs were generally associated with increased public costs, but greater client and care provider welfare (Grabowski, 2006). However, this review concluded that cost increases may be contained through capitated care and consumer directed care models.
Though findings of effectiveness are promising for waivers targeting other populations needing long term care, few researchers have attempted to discern if the additional HCBS provided under Medicaid, waivers, or SPAs result in similar or better outcomes compared to usual outpatient services or care in more restrictive environments. For youth with complex behavioral health care needs, a few studies suggest that waivers help them maintain placement in the home, avoid contact with law enforcement, have lower hospitalization rates, and have better school attendance rates and grades than Medicaid youth (Friesen et al., 2003; Solhkhah, Passman, Lavezzi, Zoffness, & Silva, 2007). For states, adopting an HCBS waiver expanded the array of community-based services available for youth with SED, allowing more families to access intensive mental health care in the community, and helped to foster a level of interagency collaboration that supports a flexible and comprehensive system of care (Ireys, Pires & Lee, 2006).

These beginning efforts at evaluating SED-specific waiver programs are limited in methodology and scope, but provide a basis for undertaking larger evaluations with more sophisticated analytic methods (e.g., regression discontinuity, difference-in-difference designs, in-depth qualitative analysis) and longitudinal state administrative data. Studies of ongoing programs and practices—those that are and are not informed or supported by evidence—can provide feedback for improving interventions to better meet the needs of children with SED and their parents. Information sharing from these efforts can encourage “best practice” dissemination among clinicians and administrators facing common clinical and functional problems across diverse implementation environments.

4.2.3 Cost effectiveness. Because federal policy mandates—and families often prefer—that appropriate levels of treatment take place in the most integrated settings, and because state
per-child costs for residential treatment can be staggering, community-based alternatives to inpatient placement are high priority targets for economic evaluation studies. The high cost of inpatient and residential care, relative to other mental health treatments, has led critics to assume that community-based alternatives are more cost-effective. Though a limited number of studies have examined this, results have been mixed (Barbot, et al., 2015; Barth et al., 2007; Bickman et al., 2004; Green et al., 2014; Urdapilleta, et al., 2013), leaving it a hypothesis to be tested more rigorously in future research.

Key questions beckon from wider perspectives because failure to obtain effective mental health services can have high costs for communities and governments. Mental health treatment for children costs approximately more than $8.9 billion per year in the United States (Soni, 2015). When the cost of special education and juvenile justice services are added to that, the cost of mental disorders in youth in the United States has been estimated at over $247 billion annually (Boat & Warner, 2009). The cost effectiveness of Medicaid HCBS programs’ ability to reduce system and societal burdens is important to determine. Such research can precisely value any savings from community-based treatment, observed across all child-serving public sectors, helping administrators and policy makers to better understand budgetary consequences of Medicaid HCBS policies. This knowledge may also drive collaboration across state administration divisions, broadening stakeholder support of Medicaid HCBS waivers or SPA options.

5.0 Conclusion

Inability to access needed and effective mental health care can have deleterious effects on individuals and families. Youth with SED suffer personal distress and cause strain for members of their families (Leon, 2014; Richardson, Cobham, McDermott, & Murray, 2013; Tahhan, St.
Access to the comprehensive, community-based service array within a system of care can be a means of preventing or lessening the need for inpatient or residential services for youth with SED (Barbot et al., 2015; Preyde et al., 2010). Intensive home and community based treatments can reduce family stress while improving quality of life and functioning for youth with complex behavioral health needs (Henggeler & Schaeffer, 2010; Whittaker, Cox, Thomas, & Cocker, 2014).

Medicaid HCBS policies like waivers and SPA options may increase access to needed home- and community-based mental health services for families of all income levels. These services, which may deliver equivalent or superior care outcomes for youth in less restrictive settings and at lower costs to states that residential care, may help to keep youth with complex behavioral healthcare needs in their homes and with their families. However, definitive success remains to be documented. Research of similar Medicaid programs for youth with other types complex healthcare needs, often funded by the National Institutes of Health, are beginning to demonstrative tentatively positive outcomes. Building on these efforts, and in the current political environment in which 1) expansions of Medicaid are coming under scrutiny, 2) CMS is formally encouraging states to adopt waivers as a means of expanding HCBS, and 3) funding for care coordination supports national mandates to integrate behavioral health with primary care, study of Medicaid waivers and SPAs should be an emerging federal priority for funding. Child mental health researchers may be able to access such funding to engage efforts to demonstrate the impacts of Medicaid expansion upon mental health service access and treatment effectiveness for youth with SED.

Findings from evaluative studies could yield robust knowledge regarding insurance expansion and its relationship with health care access and care integration for privately insured
or uninsured children with special healthcare needs. Increased understanding of the relative effectiveness of multiple policy approaches in expanding access to a comprehensive, community-based service array for these youth will equip policy makers in state children’s mental health systems—and policy makers in all systems serving populations with special healthcare needs requiring HCBS (e.g., individuals with brain injuries, physical or developmental disabilities, or designated as medically fragile)—with more evidence about more and less effective means of expanding access to HCBS for individuals of all income levels and insurance status.

More study of the services, interventions, and programs making up state system of care, administered through Medicaid HCBS policies or not, may help to identify yet-unexamined components in those systems that could be strengthened through closer scrutiny and the application of evidence into all service modalities in continuums of care. Further examination of the state mental health administrations that support these services and providers, and the effects of these policies on youth, families, communities, and organizations, is needed to better understand the potential that Medicaid waivers and state plan options—and the comprehensive service array they support—may hold for families and youth with complex behavioral health needs in the United States.
References


Dorn, S., Peters, R., Cheeks, M., Casanova, P., Eckart, G., & Lutterman, T. (2016). *The Use of 1915(I) Medicaid Plan Option for Individuals with Mental Health and Substance Use*


https://doi.org/10.1016/j.dhjo.2015.03.003

Missouri Department of Mental Health (2016). *Missouri Section 1115 Waiver – Mental Health Crisis Prevention Project*, retrieved on July 27, 2017 at

https://doi.org/10.1080/08959420.2016.1111729


https://doi.org/http://dx.doi.org/10.1037/0002-9432.75.1.152


https://doi.org/http://dx.doi.org/10.1186/1471-244X-11-57


https://doi.org/http://dx.doi.org/10.1007/s00127-015-1017-2


https://doi.org/10.1007/s10826-010-9442-z


https://doi.org/http://dx.doi.org/10.1080/0886571X.2013.751807

https://doi.org/10.1002/14651858.CD006410.pub2


