



State Approaches to Funding Home and Community-Based Mental Health Care for Non-Medicaid Youth: Alternatives to Medicaid Waivers

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Abstract

Home and Community-Based Services (HCBS) Medicaid waivers for children increase the availability of public funding for HCBS by waiving or expanding the means tests for parents' income, basing child eligibility for Medicaid coverage primarily on clinical need. But many states provide mechanisms apart from HCBS waivers to increase coverage for youth with significant mental health needs. Through interviews with public mental health officials from 37 states, this study identifies and explains non-waiver funding strategies for HCBS services for otherwise ineligible youth. Results demonstrate that states expand Medicaid-eligibility through CHIP or use state general revenue funds to pay for medically necessary HCBS for non-Medicaid youth.

Keywords Home and community-based services · Children's mental health · Mental health financing · Public mental health · Systems of care

Introduction

Approximately one in ten children can be classified as having a serious or severe emotional disturbance (SED) (Costello et al. 2005; Williams et al. 2017). SED classification denotes that a youth has a psychiatric diagnosis and impaired ability to function in at least one life domain—home, community, or education (Center for Behavioral Health Statistics and Quality 2016). Youth with SED are more likely to drop out of school (Garcia et al. 2017; Porche et al. 2011), may have difficulty achieving stability in advanced education and employment settings (Zigmond 2006), and are at increased risk of using substances (Greenbaum and Dedrick 2007; Wu et al. 2008) and criminal justice involvement (Mordre et al. 2011).

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 et al. 2008; Heflinger and Taylor-Richardson 2004; Richardson et al. 2013). They express concerns for their safety and that of other siblings in the home (Corliss et al. 2008). Parents identify peer support to be a key resource (January et al. 2016), but many of these families report few social supports (Kernan and Morilus-Black 2010).

Home and Community-Based Services (HCBS)

To address these risks, 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 home and community-based services (HCBS) can have equal or greater outcomes than residentially provided services, and at a lower cost to governments (Barth et al. 2007; Shepperd et al. 2009; Snyder et al. 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 et al. 2003; Trask et al. 2016) and increased functioning in home, school or community settings (Barbot et al. 2015; Urdapilleta et al. 2013).

Though the federal government and states have invested in developing community-based mental health systems over

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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; Merikangas et al. 2011; Sheppard et al. 2017). Further, for youth with SED who are accessing basic outpatient treatment (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 et al. 2002; Owens et al. 2002; Sheppard et al. 2017).

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 (Graaf 2018). Due to the fact that 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 the Medicaid mandate and funding to shape and finance the provision of community-based systems of care (Howell 2004; Ireys et al. 2006). Thus, financing for HCBS services is difficult to come by without Medicaid eligibility. Though not yet documented specifically for children with complex behavioral health needs, it has been demonstrated that for children with autism spectrum disorder (ASD), those with private insurance experience out-of-pocket costs that are five times greater than those of families with public health insurance (Parish et al. 2015).

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 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 (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.

Medicaid Home and Community-Based Services Waivers

To extend much needed HCBS financing to families who do not qualify for Medicaid, many states have enacted HCBS Medicaid waivers 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 assessed clinical need and a means test based on the child's assets alone to determine Medicaid eligibility. Qualification for most of these waivers rests on the recipient demonstrating a level of clinical need that would otherwise require long-term residential care. Some waivers 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 (Graaf and Snowden 2017).

Waiver research is limited but findings indicate that youth on the HCBS 1915(c) SED waiver are more likely to maintain placement in the home, experience fewer hospitalizations, avoid contact with law enforcement, and have better school attendance outcomes than other Medicaid youth. They can achieve these outcomes in the community at less than a third the cost of serving them in a residential setting (Friesen et al. 2003; Solhkhah et al. 2007; Urdapilleta et al. 2013). Recent findings also suggest that Medicaid waivers may be associated with increased mental health care access for these youth (Graaf and Snowden 2018).

Beyond HCBS Medicaid Waivers

Though initial explorations of Medicaid waivers suggest positive outcomes for children, families and service systems, these policies have continuously failed to be adopted by the majority of states. Commonly cited reasons for not adopting Medicaid waivers include administrators' perceptions that children's needs are being met sufficiently through other state programs, including the existing Medicaid program (Graaf 2018; Merryman et al. 2015). What these "other" state programs may be, which states employ them, and how effective they are at maintaining children in their homes remains unknown. Wider knowledge about specific approaches to funding and structuring HCBS for this population may provide insight for policy-makers seeking alternatives to waiver-based solutions and researchers pursuing a comprehensive understanding of HCBS financing for these youth.

Researchers can gain a better understanding of waiver effects by differentiating states providing Medicaid-based coverage from states providing no coverage for non-Medicaid qualifying youth. To date, when comparing Medicaid waiver and non-waiver states in service access assessments, researchers treat states with non-waiver funded HCBS as equivalent to states lacking any provision for funding HCBS (Cidav et al. 2014; Leslie et al. 2017; Ng et al. 2015). This approach risks underestimating the impacts of waiver participation on consumer and system outcomes. Furthermore, identifying alternative strategies for further investigation may uncover state policies that prove equally or more effective at increasing access to care and helping youth and families stabilize in community settings.

As such, the current study seeks to identify and describe waiver alternative strategies used to fund and organize home and community-based mental health treatment for youth with significant behavioral health needs who are financially ineligible for Medicaid. The investigators used qualitative

methods to gather this information, including key informant interviews, email questionnaires, and document reviews. By relying on description and explanation from state-specific subject matter experts and supplementing this with data from other sources, this study gathered previously uncollected and undocumented information.

Methods

Sampling, Data Sources & Data Collection

State Mental Health Administrators

Data were collected in the fall of 2016 through interviews with State Mental Health Authority (SMHA) and Medicaid officials in all participating states. Drawing from 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. Purposive sampling was used as 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 (Palinkas et al. 2015). Many initial respondents did not participate in interviews but referred the research team 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. A total of 32 states agreed to participate in interviews. Five additional states participated by answering key interview questions via email.

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 5 years. Many participants had been

working in their state for over 10 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 1.

Policy Documents

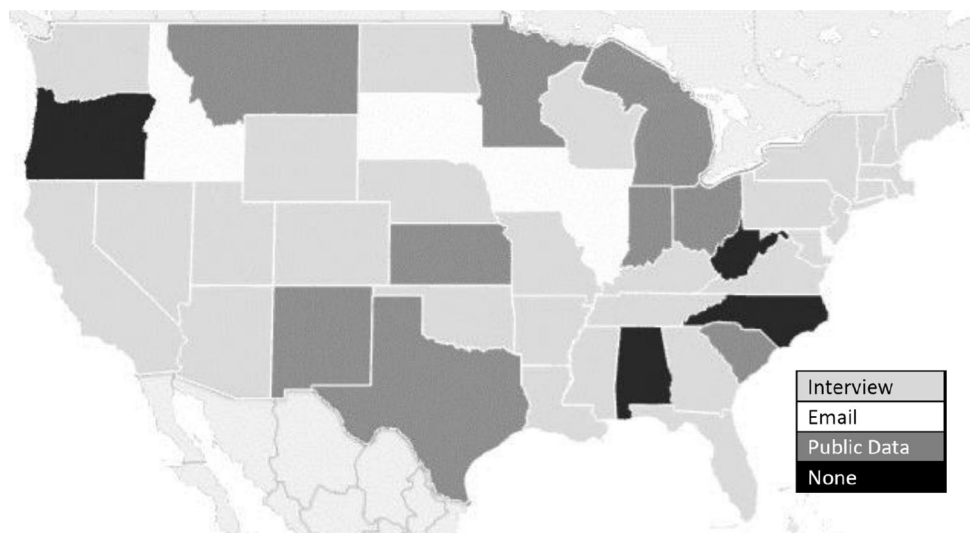
Publicly available data and policy documents were gathered in relation to Medicaid waivers, state Children's Health Insurance Programs, and programming specifically targeted for youth with SED, especially those financially ineligible for Medicaid. This data was collected from all states, including those declining to participate, and used to identify or confirm a state's use of a particular HCBS funding policy when possible. These 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. All 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. These documents were sorted, stored, and organized by state to support later analysis of interview transcripts. Figure 1 displays the level to which each state participated in the study: interview, email, public policy documents, or no participation. States that did not participate in interviews or email surveys and who did not have clearly communicated Medicaid waiver policies in public documents or websites were labeled as non-participating due to the inability to

Table 1 Participant roles and state departmental location

| Role (State Department Location) | Total no. participants |
|--|------------------------|
| 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 |

BH Department of Behavioral Health, *DCF* Department of Children and Families

Fig. 1 Modes of state participation [Alaska & Hawaii (not pictured here) participated in interviews]



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

definitively know their policies for funding HCBS for non-Medicaid eligible youth.

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. 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 comparable youth who do not qualify for Medicaid.

Interviews were conducted via phone, recorded, and transcribed. All interviews were semi-structured but guided by a comprehensive interview protocol and ranged from approximately 40 min to 90 min in length. This format allowed for the interviews to be comprehensive in covering topics relevant to this study, while enabling flexibility to uncover aspects of state mental health policy, governing structures, and motivations not explicitly asked about.

Before each interview, the interviewer 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.

For participants unable to be recorded, detailed manual notes were used to record the interview. Written notes were saved and stored digitally with transcripts from recorded interviews. 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 research question via email, rather than participate in an interview. The question was "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?" Five additional states' responses were recorded and stored with interview transcripts for later analysis.

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. Data from policy documents were used primarily in preparation for interviews and to enhance understanding of information provided in interviews. Public data was also employed to assess the use of Medicaid-related policies by states that were not interviewed. However, for states that participated in interviews, data provided by informants was prioritized over policy documents. For states with multiple informants, since interviews took place in group settings, information was delivered in consensus with all participants and was considered to be factual. For states in which respondents recommended consultation with additional informants outside of the interview, data collected from consulting state informants was prioritized over information provided by the respondent because the consultant had been recommended as an expert of that particular topic.

The analysis included four coding cycles focused on the interview, email, and policy document content regarding specific state mental health policies and funding for home and community-based services (HCBS) for youth with SED who do not qualify financially for Medicaid. Coding schemes were developed by the research team through familiarization and descriptive coding. 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 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 (Miles et al. 2013; Saldaña 2013). 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 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.

Findings

Non-waiver strategies, previously overlooked in policy analysis and research literature, come from two sources. One is 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). The second is through state-authorized programs using general revenue funds. States using general revenue funds either allocate relatively

substantial 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. These funds are subjectively identified by respondents as sufficient for meeting the need in the state or insufficient for the level of need (i.e., participants know families are going without care due to resource constraints).

Expanding Medicaid Through CHIP

Eight states extend Medicaid to a large number of children and adolescents with complex behavioral healthcare needs by merely expanding the eligibility for their state Medicaid plan through the Children's Health Insurance Program (CHIP) to *all* children in the state. 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, who are uninsured, and whose incomes are too low to afford private health coverage. Whereas several other states operate an entirely 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."*

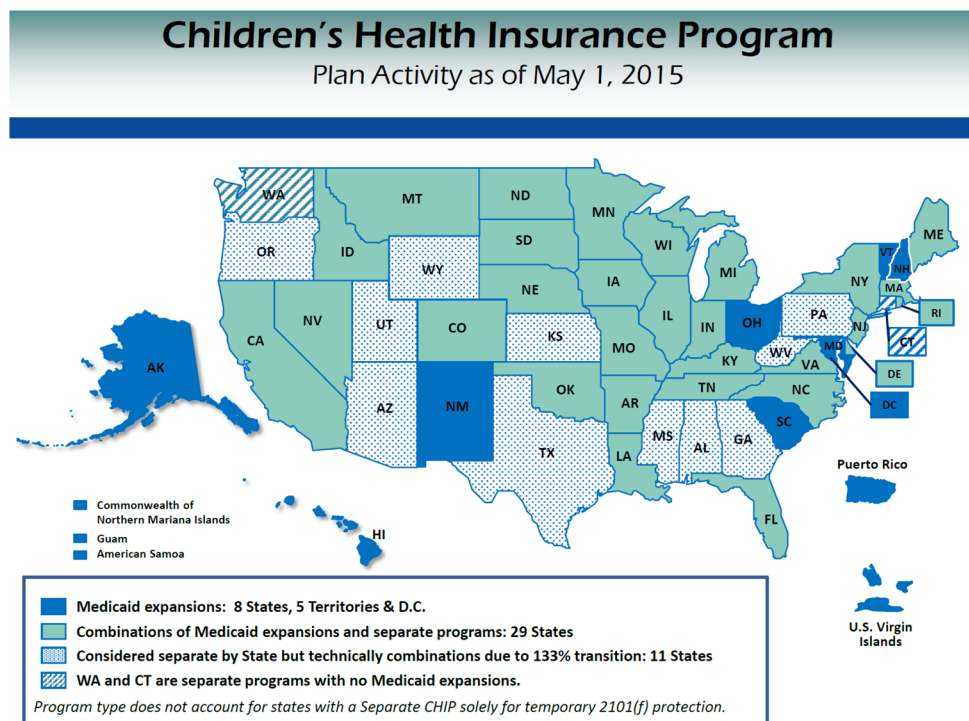
The majority of states have structured their CHIP programs to be a combination of both an expansion of the state plan for certain regions, populations, or income levels, with a separate CHIP plan that is structured similarly to private health coverage. Two states (Washington and Connecticut) have fully 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 2, below, illustrates how states differentially structure their CHIP programs (Medicaid.gov, 2017).

General Revenue Policies

Unrestricted State General Revenue Funds

Five states provide significant funding from state general revenue to finance 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

Fig. 2 CHIP program structures across states (from Medicaid.gov). Accessed October 26, 2017, at <https://www.medicaid.gov/chip/downloads/chip-map.pdf>



reported significant amounts within state budgets allocated to the funding of intensive home and community-based care for non-Medicaid eligible youth and their families. These states report that children presenting significant mental health concerns do not go without needed mental health care due to lack of health coverage or finances because the state will pay for needed services from general revenue allocated for children's behavioral health. 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." Similarly, another administrator stated, "If the service is clinically necessary. For a child who has 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..."

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." However, 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 in significant peril. The general fund dollars that used to support those grants are shrinking."

Supplementing State Allocations with Contributions from Social Services and Other Sources

Some 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 going 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.”* Furthermore, 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 for organizations to serve all youth that need care, regardless of payer source, but these agencies 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 that 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 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. *“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.”

Discussion

Based on participant responses and publicly available data, two general strategies for funding HCBS for non-Medicaid eligible youth are apparent: states extend the CHIP program, or they use state general revenue funds. Eight states relied on their expansion of the Medicaid benefit package to youth with SED, up to three hundred percent of the FPL through their CHIP policy. States using general revenue funds either allocate generous or limited portions of state general revenue funds, combined with state community mental health block grants, to fund services to as many children and families that 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.

Non-Waiver HCBS Funding Strategies

States have many ways of funding HCBS for non-Medicaid youth, beyond the use of a Medicaid waiver. For states using non-Medicaid approaches to deliver care to these youth, some respondents acknowledge relying on community mental health block grants and other limited general state fund sources. However, they often find this funding is insufficient; as a result, many states are creative in their use of funding from other state child-serving divisions to supplement their budgets. Braiding funding in this way may encourage cross-system collaboration, as these agencies have “skin in the game.” However, local decision makers retain discretion over general revenue funding, and local diversion of funding can exacerbate regional disparities in states with strong levels of local authority. Asking non-mental health departments to contribute to serving these youths and innovating how these funds can be integrated may yield greater resources and broader stakeholder involvement. However, 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.

The Role of CHIP in Organizing and Funding HCBS for Non-Medicaid Eligible Youth

A notable portion of states utilize CHIP to provide HCBS to families with incomes beyond Medicaid eligibility levels. This finding highlights the need to consider the role of CHIP

in enhancing access to HCBS to youth with SED; currently, scholarship examining the role of this policy 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 in 2017. For states that rely on CHIP to expand youth access to funding for HCBS, discontinuation of federal funds would produce unacknowledged consequences for youth with SED.

The use of the CHIP program to expand Medicaid benefits to more children functions similarly to an HCBS 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). As such, both waivers and CHIP Medicaid expansions can be conceptually classified together as policies that expand Medicaid benefits through extended income limits. Thus, examining states with Medicaid-expanding policies as a group may be a theoretically justifiable means of examining the impacts of such policies on access to mental health care for youth with SED.

In contrast, though states not expanding their Medicaid programs through CHIP may utilize significant amounts of state general funds to offer an enhanced service array specific to non-Medicaid eligible youth with complex behavioral health concerns, these programs are likely to vary significantly from state to state. Stark differences probably exist in the clinical and financial eligibility for these programs, the services provided, and the capacity of states to meet the needs of the population. Though such discrepancies exist across states in CHIP Medicaid-expanding states as well, federal directives surrounding Medicaid provide some uniformity. The EPSDT and rehabilitation mandates, the federal match provided to support these services, and the entitlement status of the Medicaid program suggest that such programs may be more comparable across states. They may also 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 serve to non-Medicaid eligible youth may not be equivalent to Medicaid-based programs.

The Role of Political Ideology in Policy Making for Youth with SED

When grouping together states that expand Medicaid for children with SED through Medicaid waivers or CHIP Medicaid expansions, opportunities also emerge to compare these states with states that expanded Medicaid for poor, non-disabled adults through the Affordable Care Act. Many states that rejected Medicaid expansion have expanded Medicaid for a limited number of children through waivers: 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). Further, all but one state (South Carolina) that expands Medicaid through their CHIP Program also accepted Medicaid expansion for adults. This observation, combined with dynamics observed in levels of local autonomy and authority, suggests that a complex combination of ideologies and state administrative factors may shape Medicaid policy differentially for children and adults—especially for children with special needs—and that this may be especially true in midwestern and southern states.

Findings suggest that states utilizing substantial 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.

Further examination of influences upon Medicaid financing decisions for children with SED may contribute to existing efforts to understand state variation in Medicaid policy choices. Political orientations associated with smaller federal government and public spending are associated with less investment on the infrastructure and administration of Medicaid and other public services (Barrilleaux and Miller 1988; Lewis et al. 2015; Miller and Kirk 2016; Zhu and Clark 2015), and recent studies have demonstrated the possible role of racial bias in Medicaid spending for disabled populations (Leitner et al. 2018; Vanneman et al. 2016; Zhu and Clark 2015). 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).

However, beyond politics and ideological drivers, other practical factors are likely at play in state decision-making

about approaches to funding and organizing HCBS for non-Medicaid eligible children, including the presence of Medicaid-spend down programs in some states and variation in the size and state allocation priorities for Title V funding for child and maternal health. Consideration of state budget size and flexibility, and the ability to ensure HCBS for non-Medicaid eligible youth through codification in Medicaid waivers or avoidance of service limits associated with some waivers also influence these state strategies (Graaf 2018). Further, though eligibility for the federal Social Security Income (SSI) program does not vary by state and the income limits for it are relatively low, participation in this program automatically comes with Medicaid in some states and may provide another avenue for non-Medicaid eligible youth to access Medicaid. Because variation in Medicaid eligibility and enrollment associated with the SSI program varies greatly across states for children with SED (Hoagwood et al. 2016), deviation in the structure and implementation of the SSI program at the state level may also influence state decisions about funding HCBS for middle-income families.

Too little is known about alternatives to Medicaid waivers used to support HCBS services for youth with SED and how these approaches compare in accessibility and clinical effectiveness to Medicaid-funded programs. Although the knowledge base about waivers is also limited, unlike alternatives, waivers are sought under nationally uniform and available rules and are monitored according to national standards. CHIP is decentralized, and waiver alternatives may be even less adherent to general rules and standards of application. The use of alternatives is entirely under state, and sometimes local, discretion. For waiver alternatives, more research is needed to document eligibility criteria and coverage, service arrays, program participation and outcomes in comparison to existing Medicaid-funded programs.

Study Limitations

These findings need to be considered in the context of several limitations in the study design concerning 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. 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. And, although the semi-structured interview format promoted depth and detail in responses, it may have contributed to missing data.

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. 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 the research team and verified with research participants.

Despite limitations, these findings provide additional insight into the variety of alternatives to waiver HCBS funding strategies available to states. 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.

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Compliance with Ethical Standards

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