Consequences of Administrative Burden for Social Safety Nets that Support the Healthy Development of Children

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Abstract

Through the lens of administrative burden and ordeals, we investigate challenges that low-income families face in accessing health and human services critical for their children's healthy development. We employ a mixed methods approach—drawing on administrative data on economically disadvantaged children in Tennessee, publicly available data on resource allocations and expenditures, and data collected in purposive and randomly sampled interviews with public and nonprofit agencies across the state—to analyze the distribution of resources relative to children's needs and provide rich descriptions of the experiences of organizations striving to overcome administrative burdens and support families. We also scrutinize the place-based resource deserts and environmental contexts of resource gaps and deficiencies in public policies governing the distribution of public resources that exacerbate administrative burdens and inequities in access to public resources. Our insights into the costs imposed on individuals and organizations and how they impede or spill over into other aspects of organizational work point to specific state and local program and policy changes that could be implemented to address resource constraints and alleviate burdens on organizations and poor families. © *2021 The Authors.* Journal of Policy Analysis and Management *published by Wiley Periodicals LLC on behalf of Association for Public Policy and Management.*

INTRODUCTION

While waiting for the state worker to confirm whether his qualified children had their healthcare benefits reinstated, Mr. Garcia[1] asked, "What do they have against poor people? I submitted my applications *four* times. The last time they asked me to submit proof of income, I sent them a bank statement with four dollars in my account." Mr. Garcia, a Tennessee father of three young children in a working-poor[2] family, relies on public programs, such as Medicaid (TennCare) and the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC), for his children to receive services and supports that are critical to their healthy

[1] We use pseudonyms to protect the confidentiality of those who we interviewed or whose case information we present in this research.
[2] This term is used to describe people who spend 27+ weeks either working or looking for work and their income, regardless of employment, falls below the poverty level in one year.

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development. Yet for nearly a two-year period, Mr. Garcia's children went without these critical, health-enhancing benefits, while their eligibility for the programs was contested by state re-certification and application processes. The consequences of their denial of access to these services were both immediate and likely longer-term: The elementary-age child missed months of therapy, the younger children fell behind on immunizations and well-child checks, and the five-year-old failed his kindergarten readiness screening and was delayed a year in starting school.[3]

Unfortunately, this family's experience with the state's Medicaid and other public benefits programs was not exceptional. In 2018, the number of children with public health insurance fell sharply, and Tennessee led the nation in the decline, with 9.7 percent fewer children on TennCare, as reported in an analysis conducted by *The Tennessean* (Kelman & Reicher, 2019). Investigations of the substantial loss of public health insurance coverage for Tennessee's low-income children in recent years point to an opaque, cumbersome, and outdated process for verification and re-verification of children's eligibility for TennCare (Alker & Pham, 2018; Kelman & Reicher, 2019). Tennessee disenrolled more children from Medicaid than any other state, primarily because of late, incomplete, or unreturned eligibility forms, which often left children's coverage status undetermined. Some parents, like Mr. Garcia, did not find out that their children were without coverage until they sought healthcare for them, at times in urgent circumstances. Mr. Garcia showed a letter he received with a request for additional information about his TennCare application that arrived *after* the deadline for responding indicated in the letter. When he contacted the state agency, he was told that he would have to begin the process anew, even though this was not his first application attempt to get his children reinstated that had been lost or delayed by the state. In the literature, these types of onerous experiences or difficult encounters with bureaucracies that erect barriers to accessing public services and supports are known as administrative burden or ordeal mechanisms (Burden et al., 2012; Heinrich, 2016; Herd & Moynihan, 2018; Moynihan, Herd, & Harvey, 2015; Schuck & Zeckhauser, 2006).

This study draws on the concepts of administrative burden and ordeal mechanisms to investigate the challenges that many low-income families face in accessing health and human services critical for the healthy development of their children, as well as the constraints that individuals and organizations encounter when trying to help vulnerable children and families gain access to resources and supports. We aim to make three primary contributions with this research. First, while the administrative burdens framework focuses on *individual experiences* of policy implementation as being "onerous," and ordeal mechanisms are characterized as burdens placed on *individuals* that "yield no direct benefits to others" (Krogh Madsen, Sass Mikkelsen, & Moynihan, 2021), we illuminate how the burdens or ordeals encountered by individuals also impose broader public and societal costs on government and a range of nonprofit organizations that play a key role in sustaining the health and social services safety net. We also document how efforts by these organizations to overcome administrative burdens impede their core functions and spill over into other aspects of their organizational work.

A second objective of our research is to describe how place-based resource deserts and deficient policies governing the distribution of public resources exacerbate administrative burdens and the costs they impose on all parties. Accordingly, we scrutinize the place (e.g., urban vs. rural) and environmental contexts of resource gaps and their implications for equity in access to public resources, recognizing that they

[3] Lee and Mackey-Bilaver (2007) showed that children participating in WIC were about 36 percent less likely to be diagnosed with "failure to thrive" and 74 percent less likely to be diagnosed with nutritional deficiencies than eligible children who had not received WIC.

reflect sociopolitical factors and legacies of systemic discrimination in the South (Bell et al., 2020; Camacho & Henderson, 2020). Krogh Madsen, Sass Mikkelsen, and Moynihan (2021) argue that the concept of administrative burden allows for both objective measures and subjective interpretations of how they are experienced; our research aims to advance both qualitative and quantitative description of these experiences. To that end, we employ a mixed methods approach and draw on administrative data on economically disadvantaged children in Tennessee, publicly available data on resource allocations and expenditures, and data collected in purposive and randomly sampled interviews with public and nonprofit agencies across the state. The quantitative analyses enable the mapping of subpopulations of children in need and the distribution of resources to serve them, while the qualitative analyses provide rich descriptions of the experiences of organizations striving to overcome administrative burdens or cobble together supports that are lacking for families.

We conclude by compiling recommendations for addressing resource gaps and alleviating burdens on poor families through state and local program and policy changes that emerged from our interviews, but that also have broad relevance beyond Tennessee for those working on the front lines in health, education, and community-based organizations to serve children and families. States in the South and others that have not expanded Medicaid to adults under the Affordable Care Act have seen the largest increases in uninsured children (Alker & Roygardner, 2019), exacerbating historical inequities and making it critical to study Southern states like Tennessee in greater depth. Furthermore, all 10 states with the highest child poverty rates, including Tennessee, are in the South (Children's Defense Fund, 2020),[4] and Tennessee children have also been disproportionately affected by the opioid epidemic that places them at greater risk for a range of adverse consequences (Winstanley & Stover, 2019).[5]

ADMINISTRATIVE BURDEN AND ORDEALS AS POLICY TOOLS

In *Targeting in Social Programs*, Schuck and Zeckhauser (2006) describe "ordeals" as a policy tool in social programs to screen out potential program beneficiaries who are "bad bets"—i.e., those who benefit too little to warrant the public expenditures—and "bad apples," who are undeserving for reasons of irresponsible, immoral, or illegal behavior. The objective, they argue, is to impose costs (nonmonetary) on participation, such as queuing in long lines or other ways of requiring greater outlays of effort—that induce applicants to reveal or signal "their true preferences and needs" via their persistence through an arduous application process (Schuck & Zeckhauser, 2006, p. 105). Their underlying premise, drawing on neoclassical economics and following on Nichols and Zeckhauser (1982), is that in the context of limited public resources that have to be rationed, these types of ordeal mechanisms are effective policy tools for increasing targeting efficiency by screening out the less needy and the undeserving, or prioritizing access to benefits for the "good apples" and "good bets." Nichols and Zeckhauser (1982, p. 376) argued that "demeaning qualification tests and tedious administrative procedures" serve as a sorting function that should

[4] Children are defined as poor if they live in a family with an annual income below the Federal Poverty Line of $25,701 for a family of four, which amounts to less than $2,142 a month, or extremely poor if they are at 50 percent or less below the FPL. In 2018, Tennessee had the 6th highest poverty rate (at 26.2 percent) for children under six years old.

[5] Tennessee has one of the highest opioid prescription rates in the country as well as a high drug overdose death rate. See data dashboards at the Centers for Disease Control and Prevention and Tennessee Department of Health: https://www.cdc.gov/drugoverdose/data/index.html and https://www.tn.gov/health/health-program-areas/pdo/pdo/data-dashboard.html.

impose lower costs on the intended beneficiaries. While recognizing that social programs (that are not entitlements) are often "pitifully limited" in resources or availability relative to the eligible needy, Schuck and Zeckhauser (2006) suggest that this strengthens the argument for ordeals, which increase the chances that those who ultimately receive program benefits are "good bets."

The use of ordeals in public programs is also intended to shift some of the costs of screening and assessment from program managers to applicants. Because the costs of collecting ample and accurate information to determine who is most in need and likely to benefit from public programs are not trivial, the shifting of these burdens to the applicants serves a secondary purpose of reducing program administration costs. Another approach to reducing the screening costs would be to simplify them (e.g., the screening criteria and quantity of information collected)—making the experience less onerous, as administrative burdens theory would suggest—but Schuck and Zeckhauser (2006) argue that there is a trade-off in a likely increase in errors of classification or determination with reduced information for making these judgments. Linos and Riesch (2020) found in their experimental study of police officer recruitment that simplification of the application process reduced organizational efficiency and increased costs for some applicants, who spent a longer time in the process and otherwise would have been screened out earlier. Schuck and Zeckhauser (2006) argue that if a simplified process to screening (that could increase risk of errors) is pursued, it would be better for decisions to "tilt toward denial," because those who are denied access unfairly or wrongly to programs or other desired ends are more likely to appeal and to persist in a challenging appeals process. In fact, they suggest that a system with an appeals process will not only reduce errors, but it can also reduce operational costs as it increases targeting efficiency, "since so much is learned on the cheap" from the applicants (Schuck & Zeckhauser, 2006, p. 113). As Deshpande and Li (2019) show, however, in their study of the closing of Social Security Administration field offices that provided assistance with filing disability applications, and as we find in our research, the shifting of burdens from the state to those who apply for services or supports (and organizations that endeavor to help them) does not come cheaply.

While Schuck and Zeckhauser (2006) were primarily concerned with improving the targeting efficiency of public programs, researchers drawing on the lens of administrative burden have employed a more expansive conceptual approach to investigating how these ordeals or burdens are enacted, experienced, and distributed, with both intended and unintended consequences. For some who encounter them, as Herd and Moynihan (2018, p. 5) illustrate, "burdens are a matter of life and death," or as we saw in our research in Tennessee, they can profoundly shape one's life chances. Moreover, Moynihan, Herd, and Harvey (2015, p. 2), Heinrich (2016), and Herd and Moynihan (2018) describe how policymakers or "street-level bureaucrats" (i.e., those working on the front lines of policy implementation) can construct administrative burdens as a form of "policymaking by other means," particularly when legislation allows for procedural discretion in implementation. These and other studies (Heinrich, 2018; Soss, Fording, & Schram, 2011; Vargas & Pirog, 2016; Watson, 2014) expose how resulting delays in access to program benefits or "bureaucratic disentitlement"—in which eligible individuals or families are denied access entirely—can lead to long-term and devastating consequences that go well beyond the program administration costs that Schuck and Zeckhauser (2006) were concerned with minimizing. Below, we briefly review some of the literature on administrative burden to explicate this conceptual framing as applied in our study of low-income children and families in Tennessee and the organizations that navigate a myriad of bureaucratic, resource, and other contextual constraints in their efforts to address their needs.

Administrative Burden Conceptual Frame and Research Base

As Nichols and Zeckhauser (1982), Schuck and Zeckhauser (2006), and Herd and Moynihan (2018) point out, administrative burdens (or ordeals) can serve legitimate purposes in administering public programs, such as requiring applications that facilitate assessment of the veracity of claims on public funds and specifying rules and procedures that enable more efficient rationing of limited resources. At the same time, these objectives impose what Currie (2006) and Moynihan, Herd, and Harvey (2015) categorize as learning costs—for example, the time and effort applicants need to invest to understand whether they qualify for and will benefit from a program—as well as costs associated with complying with the rules and requirements for accessing the benefits or services (e.g., producing required documentation for applications). Schuck and Zeckhauser (2006) argued that these burdens should weigh more heavily on the applicants seeking access to public services and supports to minimize public program administration costs, and also that they should err on the restrictive side as means to single out those most deserving or in need among those who apply.

Yet the growing research base on administrative burden and ordeals, including research grounded in behavioral economics (Bertrand, Mullainathan, & Shafir, 2004), alternatively finds that more often, these costs tend to be more difficult to bear for those who are most in need of the public programs (Alvarez, Devoto, & Smith, 2008; Brodkin & Majmundar, 2010; Burden et al., 2012; Cherlin et al., 2002; Christensen et al., 2020; Deshpande & Li, 2019; Finkelstein & Notowidigdo, 2019; Heinrich, 2016, 2018; Herd & Moynihan, 2018; Nisar, 2017; Sekhon, 2011). Finkelstein and Notowidigdo (2019), for example, designed an experiment that targeted a low-income elderly population—eligible for but under-enrolled in the Supplemental Nutritional Assistance Program (SNAP)—for alternative forms of outreach (randomly assigned) that included information on their eligibility for SNAP (and how to apply), information plus phone-based assistance (if they called to apply), or no intervention (status quo). While both types of outreach increased applications, the large majority (70 percent) of elderly who did not respond were the neediest, with higher predicted benefit levels, healthcare spending and use, and chronic health conditions. They concluded that, consistent with behavioral theories, sizable numbers of high-need persons were deterred from enrolling. Indeed, there are many poor and minoritized groups for whom legacies of discrimination have exacerbated the barriers they face, given their less ready access to information, transportation, and financial resources for covering out-of-pocket learning and compliance costs (Heinrich, 2016, 2018; Nisar, 2017). As Herd and Moynihan (2018, p. 6) contend, the distribution of administrative burdens realized in policy and program implementation tends to "reinforce inequalities in access to rights" and perpetuate discrimination.

Another category of burdens or costs includes psychological costs that are experienced with the intrusiveness of application processes and requirements, such as having to turn over personal records for public scrutiny, or that may come with the denial of benefits or appeals, e.g., feelings of rejection or stigma experienced in these encounters with the public sector (Bhargava & Manoli, 2015; Currie, 2006; Moffitt, 1983; Moynihan, Herd, & Harvey, 2015). Again, these costs may weigh disproportionately more on the poor and other excluded or isolated groups in society. In a stark example from South Africa, Heinrich (2016) showed how subgroups of the poor (i.e., disproportionately negatively affected by the legacies of apartheid) faced considerably greater administrative burdens in accessing South Africa's cash transfer program. Historically marginalized by the color of their skin, those who were pushed away from urban centers and into informal settlements (often without utilities) were ostracized when their applications were rejected after being required to bring additional documentation (beyond program rules), such as proof of residence,

electricity, or water, that they were least likely to have. Although the setting of this study in Tennessee is very different from the South African context, there are parallels in regard to how barriers to program access are erected, i.e., in how they reflect longstanding racial or social hierarchies that discriminate with intent. For example, in the case of Mr. Garcia, highlighted in the introduction, he was told (discriminatorily) at the WIC office that he needed to return with a current passport in order to get his infant son connected with WIC benefits, even though he had presented his son's birth certificate and Social Security card and a passport was not officially required.

Furthermore, these burdens can also extend to individuals and organizations, even if they are not interacting directly with public agencies (Heinrich, 2016; Kahn, Katz, & Gutek, 1976). Heinrich (2018) and Nisar (2017) pointed to the roles that other public and nonprofit organizations frequently play in helping to mitigate administrative burdens, especially those that fall disproportionately on the poor and disadvantaged. Nisar (2017), for example, studied the historically marginalized Khawaja Sira of Pakistan and described how nongovernmental organizations have sought to reduce administrative burdens that prevent the Khawaja Sira from securing legal identification, such as arranging special teams of "frontline workers" to brief them about rules and regulations and guide them through the process, reducing both learning and socio-psychological costs. As we show in our current study, however, the diversion of these organizations' resources to breaking through administrative burden can detract from their core work and impose additional costs beyond those experienced by the individuals seeking services and supports. For instance, county health department staff described how diverting social workers to address paperwork problems associated with client access to public insurance strained their capacity in other areas, such as family counseling services.

RESEARCH SETTING AND POLICY CONTEXT

Before describing our research samples and data analysis, we present some important policy background and contextual information about Tennessee that has both motivated and informed our study. As Fox, Feng, and Stacyzk (2020, p. 105) point out, social welfare policy at the federal level "is governed by a labyrinthine set of rules that define program eligibility, enrollment procedures, and the cash value of benefits received," and states layer on additional rules and procedures that exacerbate the administrative burdens experienced by citizens. In this research, we focus in particular on policy and administrative actions at state and local levels that may have affected the accessibility and functioning of programs for children and families seeking health and social services supports.

TennCare Background

In the 1990s, Tennessee secured a waiver from the Secretary of Health and Human Services (under Section 1115 of the Social Security Act, 42 U.S.C. § 1315) that allowed it to replace the state's conventional Medicaid program with TennCare, a demonstration program. The waiver was subsequently repeatedly renewed, and although Tennessee did not expand Medicaid coverage under the Affordable Care Act, any laws and rules not explicitly waived still applied to TennCare. For example, the state is required to determine Medicaid eligibility within 45 days of an application submission (or within 90 days if eligibility is based on a disability, 42 C.F.R. § 435.912(c)(3)), and those found eligible are required to receive benefits "without any delay caused by the agency's administrative procedures" (*Id*. § 435.930(a)). In

addition, beneficiaries' coverage is subject to renewal and reverification of their eligibility every 12 months (42 C.F.R. § 435.916).[6]

Until January 1, 2014, individuals typically applied for TennCare in person at their local Department of Health Services (DHS) offices, assisted by social workers and DHS eligibility workers who entered their data directly into the eligibility system and could address problems with the applicant. DHS also operated the Family Assistance Service Center, a call center that helped TennCare applicants navigate the application process and resolve any issues affecting eligibility. In conjunction with the rollout of the Affordable Care Act (ACA), states received funding to develop new information technology (IT) systems or to revamp existing systems to meet ACA IT requirements by October 1, 2013. Drawing on this funding, Tennessee had contracted for the development of a new IT system, the TennCare Eligibility Determination System (TEDS) that was intended to be operational by the October 2013 target date. However, it was more than five years later (in 2019) before TEDS was finally launched to process applications, determine eligibility for TennCare, and interface with the federal government's online marketplace.

In the interim, starting on January 1, 2014, the state suspended the option that allowed individuals to apply directly to TennCare and instead required applicants to go through the federally-facilitated marketplace (healthcare.gov) for health insurance benefits.[7] The state also sought to equip each of its DHS offices in the 95 Tennessee counties with computer kiosks and telephones for applicants without access to technology. In addition, TennCare entered into a contract with the Tennessee Department of Health, which operates local health departments in 89 of the counties, to provide enrollment assistance statewide (and separately through subcontracts with the six metropolitan counties). However, as we describe below, Tennesseans applying for public health insurance during this period encountered numerous challenges, and renewals were processed primarily on hard-copy forms that had to be mailed to the state agency.

This background information also illustrates the importance of the time period in which we are examining individual and organizational experiences interacting with state agencies in Tennessee. The data we use in resource mapping are primarily from the most recent years available, 2018 and 2019, and we also use the most recently available data on children (from the 2018/2019 school year). We now turn to describe our research samples and methods of data analysis, before presenting the study findings.

RESEARCH SAMPLES

Our study focuses on the public and nonprofit infrastructure in Tennessee that is designed to make health and social services available to its economically disadvantaged children and families. The state agencies that address the needs of children and families include the Departments of Children's Services, Education, Health,

[6] To enroll in Medicaid, individuals have to meet "categorical eligibility" rules by providing evidence that they are aged, blind, disabled, or pregnant, or that they are children or parents of dependent children. They also have to meet income and asset eligibility requirements that depend on their categorical eligibility group. In addition, newborns born to mothers receiving TennCare are, under federal law, eligible to receive medical assistance under a state plan that begins on the date of the child's birth (if found eligible for Medicaid) and remain eligible for a period of one year (42 U.S.C. § 1396a(e)(4)). Tennessee has opted to extend coverage to unborn children whose pregnant mothers meet the income limitations specified by the state and who are not otherwise eligible for Medicaid.

[7] According to a class action lawsuit, the federal marketplace was not designed to process all categories of Medicaid eligibility, leaving Tennessee and its citizens without an operating system for generating eligibility decisions from the state, as was their right (Case 3:14-cv-01492 Document 1 Filed 07/23/14).

Human Services, Mental Health and Substance Abuse Services, and TennCare. Through the Policies for Action Research Hub at Vanderbilt,[8] we have a research partnership with the Departments of Education, Health and TennCare to link children's health, education, and public insurance data over time, with the goal of improving children's health and education outcomes. Among children in low-income families, we are particularly concerned with those made vulnerable by the opioid (and other drug) crises and other adverse childhood experiences, as well as children of immigrants.

In examining how low-income families (and those who assist them) navigate the public infrastructure to help them meet their children's healthcare and related needs, we constructed a sample frame and designed instrumentation to collect data from individuals working at local and regional levels in community mental health centers, county health departments, federally qualified health centers (FQHCs), school-based health centers (SBHCs),[9] community anti-drug coalitions, and opioid treatment programs across the state of Tennessee. There are 95 counties and 137 school districts in Tennessee, and we used purposive and random sampling to prioritize and select organizations within counties or school districts for interviews. In purposively sampling, we focused on indicators corresponding to the populations of vulnerable children of interest in our study: (1) distressed counties, i.e., those that rank in the bottom 10 percent in the nation based on an index that factors in poverty rates, per capita market income, and unemployment rates;[10] (2) counties with high rates of neonatal abstinence syndrome (NAS, in which babies withdraw from drugs they were exposed to in the womb before birth); and (3) the percent of Hispanic and immigrant students in the county. We also purposively selected two counties with the highest incidence of NAS, and separately, with the highest rates of Hispanic/immigrant children to interview.

In conducting the random sampling, we used administrative data to first stratify the sample based on CORE region (west, middle, east)[11] and urbanicity (town, city, suburb, rural).[12] Mahalanobis distances were calculated using the percent of students in each county that were economically disadvantaged, immigrant or Hispanic, and diagnosed with NAS.[13] Within each core-urbanicity region, the two observations closest to the average Mahalanobis score of the core-urbanicity region were selected. Table 1 describes the number and types of organizations interviewed in each county selected and the number of interview participants in each of the categories. Figure 1 presents a geographical map of the (more than 80) completed interviews and also indicates those that were conducted in counties classified as economically distressed at the time of data collection in the 2019 fiscal year.

[8] For more information on the Policies for Action Research Hub, see: https://www.policiesforaction.org/hub/vanderbilt-university.

[9] In Tennessee, school-based health centers (SBHCs) are a primary source for meeting the basic healthcare needs of many low-income children.

[10] For more information on distressed counties, see: https://www.tn.gov/transparenttn/state-financial-overview/open-ecd/openecd/tnecd-performance-metrics/openecd-long-term-objectives-quick-stats/distressed-counties.html#:~:text=The%2011%20distressed%20counties%20in,counties%20to%2010%20by%202025.

[11] CORE regions are a designation used by the Tennessee Department of Education (TDOE) to delineate areas of the state by geographic region. There are eight regions, each with its own regional field office.

[12] Urbanicity designations were obtained from NCES data. These locale designations are created using census data on the area's urbanicity, geographic size, and population. More information on these designations can be found here: https://nces.ed.gov/surveys/ruraled/definitions.asp.

[13] Ties were settled using a rank function that calculates the unique rank of the Mahalanobis distances and arbitrarily breaks ties. For core-urbanicity regions that only contained multiple observations from one county, observations were randomly ordered, and two observations were selected.

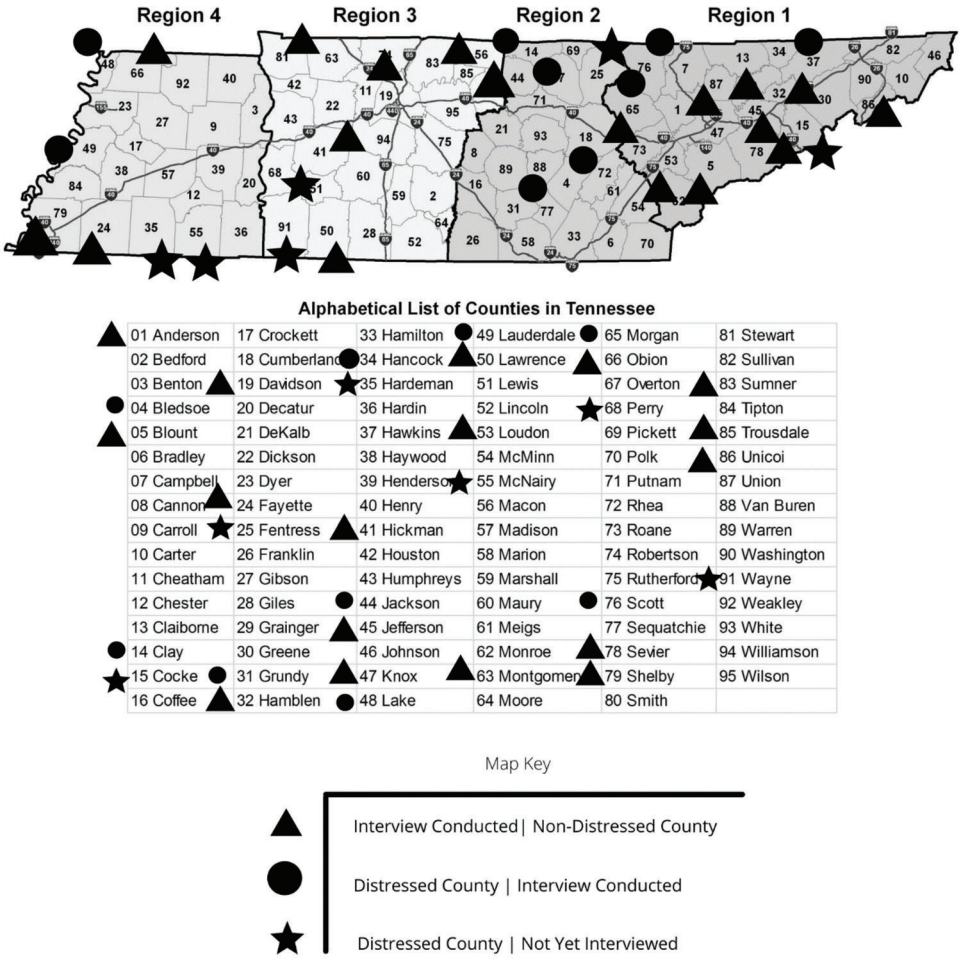
Table 1. County, number of interviews, number of participants, and types of organizations interviewed.

County	Interviews	Participants	Organization
01 Anderson	2	3	CSHD
04 Bledsoe*	1	1	CSHD
05 Blount	1	1	CAO
14 Clay*	1	3	COADC
19 Davidson	8	11	CAO (3), NHC (2), OTP (1), TEIS (1), MED (1)
24 Fayette	1	1	CSHD
31 Grundy*	1	2	SBCH
32 Hamblen	5	5	COADC (1), CMHC (1), CSHD (1), CHD (1), FQHC (1)
34 Hancock*	1	2	CMHC
41 Hickman	1	1	CMHC
44 Jackson*	1	1	CSHD
45 Jefferson	1	1	CAO
47 Knox	4	4	COADC (1), CHD (1), FQHC (1), NCH (1)
48 Lake*	1	1	CSHD (1)
49 Lauderdale*	2	11	COADC (1), CSHD (1)
50 Lawrence	1	9	COADC (1)
53 Loudon	1	1	CSHD
63 Montgomery	1	1	CMHC (1)
65 Morgan*	3	3	CHD (1), FQHC (1), SBCH (1)
66 Obion	1	3	COADC
76 Scott*	3	8	COADC (1), CSHD (1), CHD (1)
78 Sevier	1	1	CSHD
79 Shelby	2	3	COADC (1), CSHD (1)
83 Sumner	1	2	CHD (1)
85 Trousdale	1	1	CSHD (1)
86 Unicoi	1	1	CSHD (1)
Total	47	81	

Source: See https://www.tn.gov/transparenttn/state-financial-overview/open-ecd/openecd/tnecd-performance-metrics/openecd-long-term-objectives-quick-stats/distressed-counties.html.
Notes:
*Indicates economically distressed counties as of fiscal year 2019.
Community Advocacy Organization (CAO)
County Health Department (CHD)
Community Mental Health Center (CMHC)
Community Anti-Drug Coalition (COADC)
Coordinated School Health Directors (CSHD)
Tennessee Early Intervention Program (TEIS)
Federally Qualified Health Center (FQHC)
Medicaid (MED)
Neighborhood Health Center (NHC)
Opioid Treatment Program (OTP)
School Based Health Center (SBHC)

STUDY DATA AND INSTRUMENTATION

We draw on administrative data from longitudinal, statewide (Tennessee) student population data files (2006 to 2018) that include student-level information from the Tennessee Department of Education (TDOE) on enrollment, attendance,



Note: Economically distressed counties identified in fiscal year 2019.

Figure 1. Map of Interviews Completed in Tennessee.

discipline, assessments, demographics, economic disadvantage[14] and special education needs, foreign-born or migrant status, and English language learners, and publicly available, statewide TennCare population data on Medicaid enrollment. These data were used in our sample selection for interviews, as described above, and also for describing students and their supportive service needs, as well as their geographic distribution across school districts in Tennessee. For instance, we used TDOE data to identify counties or districts with high percentages of children who

[14] In the data, a student is identified as economically disadvantaged if she is eligible for federal assistance programs (TANF, SNAP, FDPIR) or if she has been identified as homeless, runaway, migrant, or in foster care.

are economically disadvantaged, homeless, or eligible for special needs services. In addition, these statewide education data files include information on school staffing that we used to construct measures of staff resources (e.g., counselors, social workers, special education teachers, etc.) relative to the size of the student population at the district or county level.

To construct additional measures of children's needs and the resources available for serving children across the state, we also extracted data from the Tennessee Department of Education's Annual Statistical Report, KIDS COUNT data (from the Annie E. Casey Foundation), the Health Resources and Services Administration, the Centers for Disease Control, Housing and Urban Development (HUD), and the Homeless Shelter Directory. These data were linked to the administrative data on children and used to develop indicators by school district or county of the resources available for serving student needs, including by relevant subgroups of children such as students with special educational needs (see Table 2). Spreadsheets with detailed information on all measures constructed using these data, including the time frame and where to access them, are available from the authors.

We began conducting interviews with individuals working in community mental health centers, county health departments, FQHCs, SBHCs, community antidrug coalitions, and opioid treatment programs in Spring 2019 to collect original data on the infrastructure intended to help children and families meet their health, mental health, and social service needs. Through the interviews, we aimed to: (1) document gaps in access to health services and supports for poor children and their families, (2) learn about administrative barriers that impede access to services and challenges that organizations face in attempting to meet the needs of children and families, and (3) identify actionable findings for policymakers to improve children's outcomes. Prior to developing our interview questions, we engaged in informational interviews with individuals from these types of organizations to aid in the instrumentation design and to ensure that we were not missing important topics. The general topics covered in the interviews include: individual roles and history in the organization; populations served; outreach and collaborations; public assistance policies and procedures; barriers to service awareness and receipt; policy levers and promising strategies for improving service access and effectiveness; resource and capacity needs; and adaptations to resource deficits. We then designed four case scenarios that guide interviewees through a case situation posed by a caregiver or other adult with a child (based on actual experiences of Tennessee residents) to probe and understand their capacity to assist in the situation and what resources they would draw on to overcome administrative burdens in serving the child or family. Interviewees were presented with a subset of the four case scenarios, distinguishing cases for clinicians and providers at health departments and FQHCs from those created for school-based personnel and SBHCs. The interview protocol (see Appendix A)[15] was also designed to allow for probes and tailoring of questions based on interviewee responses, for example, to pursue more information about an outreach strategy used by an organization or about challenges its staff experience in serving a particular subgroup, and to encourage rich descriptions of their experiences in serving children and families. Permission to tape the interviews was obtained from respondents, and the recordings were professionally transcribed.

[15] All appendices are available at the end of this article as it appears in JPAM online. Go to the publisher's website and use the search engine to locate the article at http://onlinelibrary.wiley.com.

Table 2. Data for geographical mapping of children's needs and resources.

Needs		Resources		Relationship	
Indicator	Data source	Indicator	Data source	Correlation coefficient	p-value
Child Abuse (reported cases)	**Kids count**	**Students per social worker**	TERA	**.492***	**.019**
Child Abuse (reported cases)	Kids count	Students per psychologist	TERA	.134	.304
Child Abuse (reported cases)	Kids count	Students per mental health staff	TERA	.074	.477
% Children of Immigrants	**TERA**	**Children of Immigrants per ELL teacher**	**TERA**	**.606*****	**.000**
% Special Education students (SPED)	**TERA**	**Sped students per sped teacher**	**TERA**	**.294****	**.004**
% Students econ. disadvantaged (ED)	**TERA**	**Students per mental health staff**	**TERA**	**.242***	**.018**
% Students ED	**TERA**	**Family Resource Center**	**TERA**	**−.359****	**.003**
% Students ED	TERA	Students per counselor	TERA	.173	.094
% Students ED	TERA	Students per social worker	TERA	−.046	.840
% Students ED	TERA	Students per psychologist	TERA	.164	.207
% Students ED	**TERA**	**Expenditures in community services per student**	**ASR**	**−.204***	**.047**
% Students ED	TERA	Students per school nurse	ASR	.073	.483
% Students ED	TERA	Students per health personnel	ASR	−.090	.467
% Students ED	TERA	Expenditures in health services per student	ASR	−.162	.117
% Students ED	TERA	Students per school bus	ASR	−.182	.077
% Students ED	TERA	Pct students transported 1.5M or greater	ASR	.088	.396
% SPED students	TERA	Expenditures in sped per sped student	ASR	−.123	.236
% Students in foster care	TERA	Family Resource Center	TERA	−.193	.124
Children with NAS	Kids count	Community anti-drug coalition and opioid treatment program	RWJF qualitative sampling	−.197	.561

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Table 2. (Continued).

Needs		Resources		Relationship	
Indicator	Data source	Indicator	Data source	Correlation coefficient	p-value
% Students disciplined	TERA	Expenditures in alternative programs per disciplined student	ASR	−.190	.065
% students ED	**TERA**	**Expenditures in food services per ED student**	**TERA and ASR**	**−.570*****	**.000**
Youth drug and alcohol abuse	Kids count	Community anti-drug coalition and opioid treatment program	State of TN	.157	.645
% Students who are experiencing homelessness	TERA	Homeless shelters	Homeless Shelter Directory	.040	.702
% Students who are experiencing homelessness	TERA	Emergency food programs	Homeless Shelter Directory	−.079	.445

Notes: SPED denotes Special Education. ED denotes Economically Disadvantaged. TERA denotes the Tennessee Education Research Alliance. ASR denotes the Tennessee Department of Education Annual Statistical Report. Bolded rows indicate correlation coefficients that are statistically significant.
$^{***}p<0.001$; $^{**}p<0.01$; $^{*}p<0.05$.

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METHOD OF DATA ANALYSIS

All of the analyses that we undertake are descriptive and are not intended to assert any causal relationships between state policies and experiences of administrative burden. In addition, the mapping of the distribution of resources available across the state for serving children is undertaken to illuminate gaps between need and resources for addressing need, as well as to observe what characteristics of counties and school districts are associated with those gaps.

Resource Mapping

The administrative data and data collected from publicly available sources that were used to construct measures of children's and family needs and resources available for meeting those needs were compiled in spreadsheets and categorized into domains of student needs and resources. We define need primarily by economic disadvantage (at the child and county level) but also examine educational needs, while resource domains include economic, health, education, and family or community resources. Next, we identified key indicators within these need and resource domains and generated scatterplots to depict the variation in children's needs relative to resources at the county level across the state. In Table 2, we present information on these measures, including the correlation coefficients and corresponding p-values that describe the relationships between levels of available resources and the indicators of student need.

Qualitative Analysis of Interview Data

The interviews, transcribed verbatim, were analyzed using a qualitative software program (NVivo). Categories and *a priori* themes were first derived from the interview protocol and used to frame the analysis (through the lens of administrative burden). Deductive codes emerged within the categories and in relation to the theoretical frame. The codebook for the qualitative analysis was piloted three times by two members of the research team, using the same five interviews. Codes were modified until there was a 90 percent agreement when coding a sample of responses. After establishing intercoder agreement, each interview was coded twice. (See the codes in Appendix B).[16]

STUDY FINDINGS

In presenting our study findings, we begin with insights and excerpts from our qualitative research that describe the experiences of individuals and families in accessing public benefits in Tennessee, particularly healthcare (TennCare), and primarily through the lens of public and nonprofit providers who serve them. We connect these experiences to the administrative burdens and ordeals concepts discussed above and consider the purpose and costs of the burdens imposed on individuals and organizations. We next draw on both qualitative and quantitative data to illuminate the contextual or environmental factors that exacerbate these burdens. We present the findings of our resource mapping to illustrate how resource deficits vary across Tennessee and compound the costs associated with administrative burdens for individuals and organizations.

[16] All appendices are available at the end of this article as it appears in JPAM online. Go to the publisher's website and use the search engine to locate the article at http://onlinelibrary.wiley.com.

Experiences with Administrative Burden in Accessing Public Benefits

As discussed above, learning and compliance costs are two pervasive types of administrative burden, which as we describe here, arise in the form of documentation demands and entangle individuals and organizations in protracted processes for assessing eligibility and compliance that too often result in disconnections and disenfranchisement.

Documentation

While prospective buyers are typically advised to follow the maxim "location, location, location" in choosing a residence, the corresponding aphorism for individuals beginning a quest for access to public program benefits might be "documentation, documentation, documentation." The documentation required in applying for public benefits such as Medicaid, WIC, and food and housing assistance ostensibly serves a legitimate purpose—it is used to verify eligibility for receipt (or continuation) of program benefits and to minimize the potential for fraudulent access and use. Yet a key question raised by Schuck and Zeckhauser (2006) concerns the *extent* to which the burdens of compiling the information and documentation should weigh on the program applicants or on the public organizations that will process their information and determine eligibility. Schuck and Zeckhauser (2006) argue, rather simplistically, that administrative costs to the public sector can be minimized by shifting more of the learning and information burdens to the applicants. Moynihan, Herd, and Rigby (2016) point out that public agency staff can affect the level of burden that is experienced by applicants through their decisions about how much information and assistance they provide to applicants and the amount and types of documentation they demand. Our research and prior studies suggest, however, that placing greater burdens on applicants may increase costs for all parties—the government, those in need of public supports, and other public and private organizations that play a role in sustaining the social services safety net.

In addition to documents for proof of income and residence, the birth certificate is one of the most essential documents required for accessing public benefits. The cost to obtain a copy of one's birth certificate varies across U.S. states, from a low of $7 (ND) to a high of $34 (MI), with Tennessee coming in (at $15) just under the average of $17.69 (in 2018).[17] In our interviews with staff in county health departments, FQHCs, school-based health centers and other community-based organizations, we heard over and over (as illustrated in these excerpts) about how the cost of a birth certificate was a limiting factor to accessing public benefits.

> The birth certificates, the Social Security cards… you've got to think, these families are low income, so they're always in crisis mode. They're trying to solve: Do I have enough food tonight, and do I—can I keep my electricity on? And that's the two things that they're worried about at that time. They don't care about birth certificates or Social Security cards, and they move a lot.

> We see kids all day long for, you know, immunizations, for our WIC program, people coming in for birth certificates. A lot of the problems we see with homelessness, you know, people don't have the $15 to get their birth certificates.

> They'll always need the birth certificates to register for school. We print those here [but they have to pay that fee]. You know, most—all of our fees will slide based on family size and income… [but] that doesn't slide, and that can be a barrier sometimes. They're $15.

[17] Birth certificate cost data can be obtained here: https://ballotpedia.org/Birth_certificate_costs_by_state,_2018.

When paying the fee for a birth certificate or undertaking other efforts to help a child or family secure requested documentation, sometimes a nonprofit would cover the costs from program funds or a staff member's pocket. One coordinator of school-based health described a situation where a student who was turning 18 in two days needed healthcare and a birth certificate, so school staff rushed to print a school ID for her, drove her to the county vital records office, and an outside organization paid the fee for the birth certificate. Another interviewee described how this was a problem for a local Head Start organization, because they had to take program funds to pay for birth certificates, but the fees had to be paid before a child was enrolled (coming out of someone's pocket first). For nonprofits, whose funding and missions were often stretched beyond capacity, the costs of helping their clients secure necessary documentation added up, as did the frustrations:

> …So many of the programs, you have to have documentation of residence in the county or residence in the state, and if you are like living out of your car or you're family living in a homeless shelter, you don't have a gas bill for two months to show the Department of Health and Human Services… Yesterday the director of our community access program, the one who does the eligibility, he came to my office, and he's like, "this is killing us," because he just—he's like, "I just need to vent, because there are people who just can't get on. They qualify and everything, but they can't—… you can't even apply for food stamps without proof of residency."

Protracted Processes

We also heard in a large majority of the interviews that even when the documentation for TennCare, WIC, or other public programs was submitted, the problems in processing the applicant information were often only just beginning. Sometimes documents were lost, and it was typical for TennCare, for example, to send a form requesting additional information from the applicant. With the correspondence taking place primarily via the U.S. postal service and with short timelines (e.g., 10 days) for replying or complying with the request, steps in the process were frequently missed, which could result in termination of the process.

> It seems that accessing TennCare is more difficult, navigating the system is very difficult. You know, I've heard stories that the applications go out and they send back the information to a residential address, but families move frequently, so then they miss that in the mail, and just getting hooked up with the system itself, even if you're qualified, there seems to be some barriers that are hard to overcome.

This is what happened in Mr. Garcia's case (described in the introduction), and he went through this cycle four times before he was able to get his children connected with public health insurance (even though the family's residence had not changed). This was not only a cost experienced by the father in repeatedly completing and submitting an application that is 15 pages long with instructions and addendums (that had to be completed separately for each child), but it also consumed the time of TennCare staff in processing the applications again and again, as well as staff in an FQHC that intervened to help restore his children's access to healthcare services. In fact, one interviewee in an FQHC explained that they have one employee who works solely on TennCare enrollment issues:

> And they deal with them just about insurance, and they can actually help them sit down and fill out an application with them. Or file appeals; it's really nice that we have an employee that just deals with just that… They [the clients] are having a really hard time.

Staff in county health departments, FQHCs and school-based health centers also made it clear that the use of their staff for addressing bureaucratic barriers to their

clients' access to public health insurance was time-consuming, and time away from their roles in delivering healthcare and social service supports.

> I would say that we spend a lot of time trying to manage assisting individuals with having TennCare or other, you know, payments for services, and again, there are hoops. I think the challenge for most individuals is that they don't know how to navigate those systems, and so having someone really assist them and kind of help them through that process is important. And so, we spend a lot of time administratively doing that, and we could be using those other resources in other places… we're already underfunded and utilizing a lot of resources.

Herd and Moynihan (2020), in fact, point to numerous studies that confirm application assistance is key to increasing Medicaid enrollment rates. Yet recall that in 2014, the State suspended direct applications to TennCare, sending applicants instead to "self-service" computer kiosks and telephones in DHS offices. This not only added to the learning costs of individuals, but it also placed additional burdens on the local organizations helping them:

> And like I said, the [county] department of health, we can help prenatal women enroll in TennCare, so that their pregnancy is covered and their delivery is covered, but you know, like I say, I don't think that DHS helps anyone anymore enroll. It's just those kiosks, and so that's kind of like a disservice because there's no one to assist folks when they do have problems, like in the school. So, it puts the burden back on the school system to try to help the child, because the child needs to be able to learn to get through life and things like that, and there's just such a disconnect. And so like I said, I was getting e-mail after e-mail, you know, what about this child, what about this child, and like I said, we can't see—we just see end dates or whatever, and so I can say, hey, the TennCare ended on, you know, whenever, but you know, that doesn't—that's not really that helpful.

> I don't think the local DHS office helps anyone. I think there's a computer system in their lobby, and I think you are on your own. When you're dealing with literacy rates as low as they are, and then disorders of any sort, and all those other things in there—and it's a big population of kids, you're thinking too many probably are raised by grandparents as much as anything, and—heaven forbid it's an elderly trying to navigate the system…

These barriers to applying for programs also contribute to both short-term and longer-term costs to the health and well-being of individuals who go without healthcare while trying to access benefits for which they are eligible. One interviewee in a FQHC described how critical the time lost to a bureaucratic TennCare application process was for a pregnant mother for whom they were trying to get medical treatment for her addiction to opiates:

> We have to use Subutex, because you can't use like regular suboxone for pregnant women. But guess what, you cannot use Subutex without prior approval from TennCare, from the MCO. So, you get the form, and you fill out the form… You have to go through the protocol, and then you put a note, patient is pregnant. And you send it in, and you wait, and the patient is here, and you don't hear back, you don't hear back, and then this happens—this is our standard. We just say, they're here; we will absorb the cost (and they're expensive meds). So, we start the induction, and I would say within 12 to 40 hours we get the denial, denied. Why? Did not go through other medications, did not try this first, this, this, this. But then we're like, well, we can't try it. Did you not see they're pregnant? And we send it back. And sometimes it's two and three times, and then we have to call, and then we say it's because they're pregnant. And I have begged, and we've talked to TennCare. But somehow there's this bureaucracy, whatever, convoluted whatever it is, and nothing happens. To this day, nothing has happened. This has been going on for almost three years with TennCare.

Staff in this organization were working hard to prevent a baby being born with neonatal abstinence syndrome (NAS). Children born to opioid-addicted mothers are more likely to be low birthweight, and children with a history of NAS are at greater

risk of developmental delays and educational disabilities (Jarlenski et al., 2020; Oei et al., 2017; Patrick et al., 2015).

Disconnections from Benefits

As indicated above, Tennessee recently gained notoriety for the number of children who lost their public health insurance coverage. An audit conducted by the Tennessee Comptroller of the Treasury from 2016 through 2019 found that two-thirds of the children who lost access to TennCare did so *not* because they were determined ineligible, but rather because of incomplete or unreturned paperwork.[18] While TennCare officials denied that the documentation problems signaled any systemic flaws in their work processes, a State Senator pointed out that even if TennCare was following the law, the fact that children were losing access to public insurance and healthcare because of "burdensome paperwork" and a "bureaucratic quagmire" reflected poor quality governance (Kelman, 2020). In fact, as suggested above, the costs to government and society go beyond those of administrative inefficiency; the literature on administrative burdens has empirically linked this type of "bureaucratic disentitlement," which results in the loss of access to public benefits, to worse health and education outcomes for children (Heinrich & Brill, 2015). Rigorous research also specifically relates children's receipt of public health insurance to higher reading scores, increased schooling, and improved labor market outcomes later in life (Brown, Kowalski, & Lurie, 2020; Cohodes et al., 2016; Levine & Schanzenbach, 2009). One frustrated community health coordinator described her nonprofit clinic's efforts to help a mother get her preemie baby, who qualified for TennCare, onto the program, so that they could offer specialized care to avoid a respiratory infection:

> Like I mean, we can't like allot, 30 minutes, right, to sign people up [for TennCare]. We do have people that we could schedule them to come back, but again, scheduling somebody to come back to do their TennCare…I mean, we have a baby right now that qualifies for TennCare. A preemie baby that needs Synagis. I can't figure out what her [the mother's] barrier is to not get the TennCare for the baby. So right now, we're sitting on not being able to provide Synagis to a high-risk baby that needs it because she's a preemie and she's going to end up with RSV and she's going to end up in the hospital and we're going to end up with an uninsured…

While the responses of TennCare officials appeared to ascribe fault to individuals for not submitting paperwork, the perceptions of organizational staff in county health departments, FQHCs, schools, and other community organizations was that the agency needed to take responsibility for both the disconnections and application challenges:

> You know, so that's something that I feel like should be addressed… the massive disenrollment with TennCare; there needs to be an easy pathway for schools with children who have—you know, major issues, that there is a direct line where they can assist, or help, or something like that.
>
> They're not getting them [recertification packets], and then they're automatically disenrolled—and maybe that's okay for adults, but children should not have been done that way, because now you've got these parents or they're [the children] with someone else and they can't complete the forms.
>
> It seems like within the last year they'll be on it, and then all of a sudden for, you know, no reason and kind of no even warning, all of a sudden they've lost their TennCare, and

[18] See the performance audit report at https://www.documentcloud.org/documents/6770443-TennCare-Audit.html.

> they don't—you know, it's just been—it's a very lengthy and frustrating process. And complicated. I saw that with someone getting dropped for no reason, and then them making a mistake and then taking months to get it back—and even when they fill out the application with their workers, sometimes—or you know, it either takes a really long time or all of a sudden they just don't approve it for no reason.

As suggested above, the TennCare disenrollment and barriers to reconnecting children were placing considerable strain on those working in local organizations to address the gaps in children's healthcare insurance and access to services. One rural nonprofit that serves children in five counties hard hit by the opioid crisis described what a "nightmare" it was when they tried to help an eligible child who went without TennCare for a year and a half to get services. Even a county health department employee explained that they sometimes had to ask a provider for a favor, like when an uninsured child had a fractured elbow and needed to see a specialist. "Specialists are probably the hardest thing for somebody that's uninsured," she noted. These insights resonate with the findings of Masood and Nisar (2020), who pointed to the importance of social networks in successfully navigating administrative burdens, as well as the investments of time building this type of social capital required. While some larger FQHCs were better positioned to endure these added financial and personnel burdens of serving the uninsured, others, especially in rural areas, were unable to sustain programs or services for children in families that couldn't pay and had to refer them to organizations and providers in other counties.

> What can we do? So, what ends up happening is a tremendous amount of energy trying to piece together some coverage, and then you know, there are many— I'm sure you have talked to many organizations who just—part of what they do, I mean, they just absorb it as part of their cost of care. They know that they'll have a lot of uncompensated care.

The location of service providers and lack of access to specialty care were also contextual factors that aggravated administrative burdens, as described in the next section.

Contextual and Environmental Factors that Exacerbate Burdens

We found many of the contextual and environmental factors that exacerbate administrative burdens—including economic isolation and place-based resource deficits, the opioid crisis, and family deprivation—were overlapping in communities that were being drained of resources and assets over time, compounding the costs or externalities associated with administrative burdens. The 2020 Economic Report to the Governor of the State of Tennessee (Murray, 2020) pointed out that despite the fact that the state economy had recently gone through a 10-year "unprecedented and record-breaking growth streak," Tennessee ranked 42 of the 50 states in its overall health outcomes and was also among the worst for access to clinical care, mental health providers, and preventable hospitalizations.

Place-Based Resource Deserts

Among the contextual or environmental factors that constrain the efforts of health professionals, social workers, school-based health coordinators, counselors, and others on the frontlines of serving vulnerable families in Tennessee, rural, place-based factors appeared to be some of the most challenging to overcome, in part because of their intersection with other economic, social, and population dynamics. The South has seen the largest rural to urban population transitions among

U.S. regions, leaving behind an older, poorer, and sicker populace.[19] Barriers such as the absence of public transportation options, for example, coincide with declining rural populations that are insufficient to sustain medical practices (e.g., primary care providers and pediatricians) and local hospitals and clinics. Between 2013 and 2018, nine rural hospitals closed in Tennessee, with a loss of more than 350 beds; overall, the rural South has suffered the greatest recent deterioration of healthcare capacity.[20] Combined with dwindling area employment opportunities, this requires families to travel farther to get healthcare, find work, and meet other basic household needs. Furthermore, the deepening poverty in some rural areas, particularly in those hit hard by the opioid and other substance abuse crises, means that even if a vehicle is available, gas money may be in short supply.

> I would say our biggest challenge is transportation. There is no public transportation within the county. Sometimes people will have a car, but they don't have gas money. Or they won't have gas money until the first of the month when they receive their check.

> It's a huge issue. A lot of people who are in poverty, and I'm talking about the people who are working, have just enough gas to get to work and back. And so, the problem they're having is they are not able to take a day off work for one thing, and then they can't afford the gas to pick them up, bring them back and you know, take them to get mental health services or dental health services.

Interviewees also pointed out that Medicaid rules only allowed coverage of the cost of transportation to a healthcare provider for a parent and one child.[21] For a single parent with multiple children, the parent has to find childcare for the other children when taking one child to get healthcare services; it also implies multiple trips and childcare coordination to meet the needs of each child in the family. In addition, another constraint to parents transporting their children for healthcare services was a lack of access to car seats. In multiple interviews, we heard about a program that had at one time provided county health departments and FQHCs with free car seats to give out when needed. After this program was cut, it created immediate challenges for organizations striving to connect families with healthcare services. One FQHC official described trying to locate a car seat for a baby while in a meeting out of state:

> One day, I got a phone call saying this family showed up, the mom brought the baby on the bus and there is no car seat, and—We don't want the mom to go back on the bus with no car seat…You know, so what are we going to do? And it used to be that there was that program where you, through Children's Hospital or the sheriff's department, could get free car seats. Well, that program got cut. So literally, we're like texting everybody and one of our staff… he ran home, and he got his and brought it in.

The FQHC official ordered a rideshare and the staff member rode in the car with the mother and baby and showed her how to use the car seat. "I will just tell you," she added, "there are so many holes in the safety net for children and families; it is just–we're doing our best, but we are not enough, and we don't have enough, and we can't do everything. Nobody can do everything." This plea for a stronger safety net—i.e., more public (federal and state) support for low-income families—was echoed

[19] See www.nihcm.org/categories/rural-health-in-america-how-shifting-populations-leave-people-behind.
[20] See documentation of hospital closings in Tennessee and other states here: http://www.shepscenter.unc.edu/programs-projects/rural-health/rural-hospital-closures/.
[21] The Code of Federal Regulations requires States to ensure that eligible, qualified Medicaid beneficiaries have non-emergency medical transportation to take them to and from providers. States may develop Medicaid waiver programs to provide coverage for additional transportation needs. See www.CMS.gov.

by staff in another rural FQHC, who shared this example of how they had to go well beyond their scope of services to help a family in a medical emergency:

> I mean, we just had somebody yesterday that had a newborn baby… they came in and the baby is not maintaining his temperature, his body temperature. The mom had a C section, so she didn't come… The dad came with two older children, and the baby had to be transported via ambulance to Children's [Hospital]. The dad didn't have any money, any gas money. So, everybody opened up their wallet, and we gave dad enough money to get down to the hospital, and he was able to arrange for somebody to come pick up the other children, but then, of course, we had to babysit, you know, and then that kind of puts you in a little bit of a liability issue. What if they don't come and pick up the children?

The children's hospital referenced in the above example was in a metropolitan area a long distance away from the rural FQHC. In fact, the lack of nearby healthcare providers and hospitals was an issue raised in every interview conducted in a rural area. It was not unusual to hear, for instance, that there was a single primary care doctor serving a multi-county area.

> Don't have a hospital. We don't have a 24-hour urgent care. We don't have any optometrists. I mean, we are very isolated when it comes to healthcare. So, a lot of times we do have to send students out of county.

In one interview, a doctor who was past retirement age described how he continued his primary practice in a rural county because there was no other doctor in the area. They once had a thriving hospital, but it had closed down years ago. In the most recent year, only 20 percent of his patients had commercial insurance, about half were on Medicaid, and the rest were uninsured and paid for care on a sliding fee scale. He explained that he worked part-time as a medical center director so he could draw a salary to continue supporting his family, but he was concerned about his ability (financially) to meet even the most basic healthcare needs of children (e.g., vaccinations), not to mention their growing behavioral health needs:

> If I had to say where we're definitely lacking, it's in the behavioral health issues such as childhood depression, ADHD, you know, having something other than just falling back on stimulants and medicines; very scarce here. I can't even begin to say, you know, where are we going to get help for this child? And those resources are usually more [metro area name] based, which is an hour away and getting them in sometimes takes three, four months. You get on a waiting list. I have used the [specialty name] department down there. Usually it takes about, you know, eight or nine months or so to get a child in.

Indeed, for many rural, low-income families, county health departments and SBHCs are relied on as a "medical home," even though these organizations are not funded or equipped to serve in these roles. One coordinator of school-based health pointed out that state funding (in dollars) for school-based health centers has not changed since 2006, even though the demand for and use of their services has increased exponentially.

> The need is just continuing to grow, and our school counselors, most of them are actually teaching in the classroom a portion of the day because we only have so many warm bodies to go around and so many dollars… Our school counselors feel very stressed so much of the time, because they recognize there's so many needs, and they feel that they're not meeting those in a way that they actually can go home and feel good.

In addition, the lack of transportation options has further compounded family's reliance on these local organizations for regular healthcare:

> We [county health department] just don't have the—you know, the equipment or the meds to treat these people, and we treat them the best they can, because even if we refer

> them to an ER or even to [name], I mean, people are walking to us. Around here a lot of people walk. They don't have a mode of transportation.
>
> A, there's a transportation issue, especially in your high poverty school districts, and B, if parents have a car, they're at work, and they don't have—you know, these low-paying jobs do not offer sick days and, you know, time off and all that kind of stuff. So, parents cannot really take off and take the child to therapy…

While a few school districts have been fortunate to receive federal grants such as AWARE (Advancing Wellness and Resiliency in Education) to expand school-based mental health services, a director of coordinated school health explained how three new employees hired through this grant were immediately overwhelmed with the extent of unmet student needs in the county, saying, "this is honestly the first year we have been capable of serving [mental health needs]… and their caseloads are more than they can handle."

A perceived stigma (or psychological cost) associated with being uninsured and having to use school-based health or mental health services, particularly for older children, may also limit the ability of school-based supports to compensate for the lack of access to services in the community. As one school-based health coordinator explained:

> Some of especially our older teenage kids, who know enough about the house or what's going on, they're like, I'm not going to say anything because A, we don't have insurance, or B, even if we do, I know my parents can't afford this, and so instead of trying to go and get help, they self-medicate.

For children in immigrant or mixed status families, we frequently heard about how fears related to another contextual factor, the public charge rule[22]—i.e., accepting public or social welfare assistance from any source would make family members ineligible to become a U.S. citizen in the future—were deterring them from requesting help. As one county health department interviewee described it, "There are fears, there are obstacles, and sometimes fears are the obstacle." She provided the following example:

> At the health department we have a safety net program called children's special services (CSS), which you know, allows a child under 21 who is undocumented, uninsured or uninsurable or underinsured to get on our program for chronic medical needs, an eye exam, etc. That does require a TennCare application to get on the program, and I've had parents straight up refuse that program… because of those fears, that accepting those programs for their documented citizen children would adversely affect them.

Another county health department employee likewise reiterated concerns about fears (psychological effects) of the public charge rule and their consequences for children's health:

> And normally the people that we are hearing those stories from are the families with the sickest children that need the CSS services, and so they're desperately coming in, like a child needs a surgery, and they're trying to weigh should my child get this surgery or not, and that's just a horrible predicament to be in.

[22] Immigration law in effect during our study states: "an alien who is likely at any time to become a public charge is generally inadmissible to the United States and ineligible to become a lawful permanent resident." See https://www.uscis.gov/news/public-charge-fact-sheet.

Opioid Crisis and Family Deprivation

Another important set of contextual factors that have increased burdens on public and private organizations on the front lines of serving low-income children and families stems from the ravages of the opioid and other drug crises on Tennessee families and communities. While opioid prescribing and dispensing are on a downward trend in Tennessee, the negative health and social impacts of the drug crisis continue to escalate, and in many areas, heroin, synthetic opioids (e.g., fentanyl) and meth are growing in use. Overdose deaths and cases of neonatal abstinence syndrome continue at high rates, and data from the Centers for Disease Control and Prevention show that about half of Tennessee's 51 rural counties rank in the top 5 percent of all U.S. counties for disease prevalence associated with illicit drug use (e.g., hepatitis C and HIV).[23] Numerous interviews with county health departments, community anti-drug coalitions, and other community-based organizations identified the lack of treatment facilities and recovery program supports as an ongoing barrier to helping families affected by addiction. One county prevention program coordinator explained there were no recovery beds or homes nearby, and so they relied on a "lifeline coordinator" (funded through the Tennessee Department of Mental Health and Substance Abuse Services) to help people in crisis identify treatment options, but they were often a long distance away:

> In our area there are no recovery, you know, homes or— I mean, there's nothing here. We had an A&D [alcohol and drug] ward here at our hospital, but they closed, but [lifeline coordinator name] will find somebody— you know, he finds the resources they need… You know, it's—I mean, Memphis is two hours from us. Nashville's, what, about three or four hours from us… And it depends on insurance or no insurance, whether you can get into those places that are close.

Another challenge with assisting families with treatment and recovery is parents' fear being separated from their children, as very few treatment programs are structured to allow children to reside with their parents (and they are not in close proximity). Or they fear losing custody of their children, so they do not reach out for help. Often, next of kin became the caretakers of children in these families (formally and informally), which amplified the challenges for schools and health and community organizations trying to meet the needs of the children.

In fact, we repeatedly heard in interviews that grandparents, and even great-grandparents, were assuming parental responsibilities in families troubled by addiction, which created new challenges for organizations helping to assist with children's connections to public benefits and essential supports. Grandparents and great-grandparents were less likely to use technology and to be able to complete TennCare applications or other benefit program paperwork online, and they often lacked the documentation required to apply on behalf of the children. And as indicated earlier, the self-service kiosks installed in DHS offices were challenging for them. One member of a community-based organization who worked with schools to coordinate healthcare for these children expressed frustration at how they "fell through the cracks":

> It shouldn't be that hard if somebody is having an issue and you get custody or placement, that they aren't helping you to make sure these kids are transitioning, you know, and the same thing with TennCare. It's kind of like, well, they had it, but you know, what happens, mama don't show up, grandmother, whoever—guardian isn't going to the visit, so they lost their TennCare.

[23] See cdc.gov/chronicdisease/data/surveillance.htm; University of Tennessee Institute of Agriculture.

School-based health coordinators also reported difficulties in communicating with grandparents and great-grandparents about the children's health and education needs.

> So, we just need more and we need more support for our grandparents and great-grandparents that are raising families. I mean, it would be nice if we had a way to get information to them or if we had any sort of funding that they—I don't know, we could provide transportation for them to come to school for meetings. A lot of them, they don't drive, or they don't drive at night, or they don't drive when it's raining, and I totally understand that. And unfortunately, that's when we hold most of our parent meetings or our parent involvement is in the evenings or at night.

Grandparents also struggled to understand and cope with some of the mental health and substance abuse problems that were more prevalent among children in families grappling with addiction. One school health official explained that grandparents often do not understand why children need to be given medications for mental health needs, or they do not want to acknowledge them because of the stigma they perceive is associated with mental health issues. Alternatively, a director of a community anti-drug coalition described how they have to regularly convey the dangers to grandparents—and give them lock boxes—to keep their own medications out of the hands of their grandchildren:

> …Let them know, you know, that grandparents are very important in the role of, you know, their grandchildren coming over, making sure that you're not the next drug dealer.

With the holes in the public safety net described above, along with declining per pupil funding because of population loss (it does not take into account the greater need among families left behind), community-based organizations were constantly looking to their private, nonprofit partners and networks for support (and digging into their own pockets) to meet the basic needs of children and families. The following quote is from an interview prior to the 2020 pandemic:

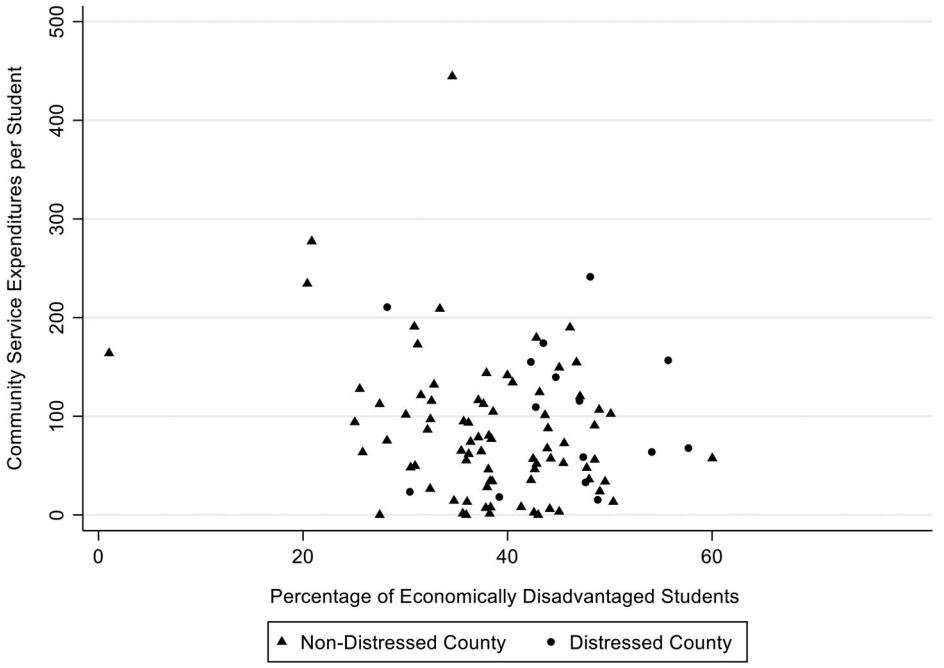
> [We] use our own money to buy new clothes and books and things of course. Of course, and I'm sure that's everywhere. We do get supplement funding from United Way of [name]. We do a lot with them throughout the year and we—and we apply for their funding and we do receive some yearly from that, and that's helpful, but like we were way over budget last year and can't even do simple things…

Below, we present the findings from our final set of analyses that use administrative and publicly available data to depict the geographical distribution of resource deficits relative to the needs of Tennessee children and families and to show how this exacerbates the burdens placed on the organizations working on the front lines to help them.

Mapping Resource Distributions Relative to Economic Need in Tennessee

The discussion of contextual factors above sheds light on the intertwining of place-based resource deficits and economic and social isolation. We undertook resource mapping to visually depict how the availability of school and community resources varies by county relative to children's needs. As described earlier, we are primarily defining children's needs by economic disadvantage,[24] although we also examine the percentage of children with special educational needs and the percentage

[24] A child is economically disadvantaged if she is eligible for federal social services (TANF, SNAP, FPDIR), or if she has been identified as homeless, runaway, migrant, or in foster care.

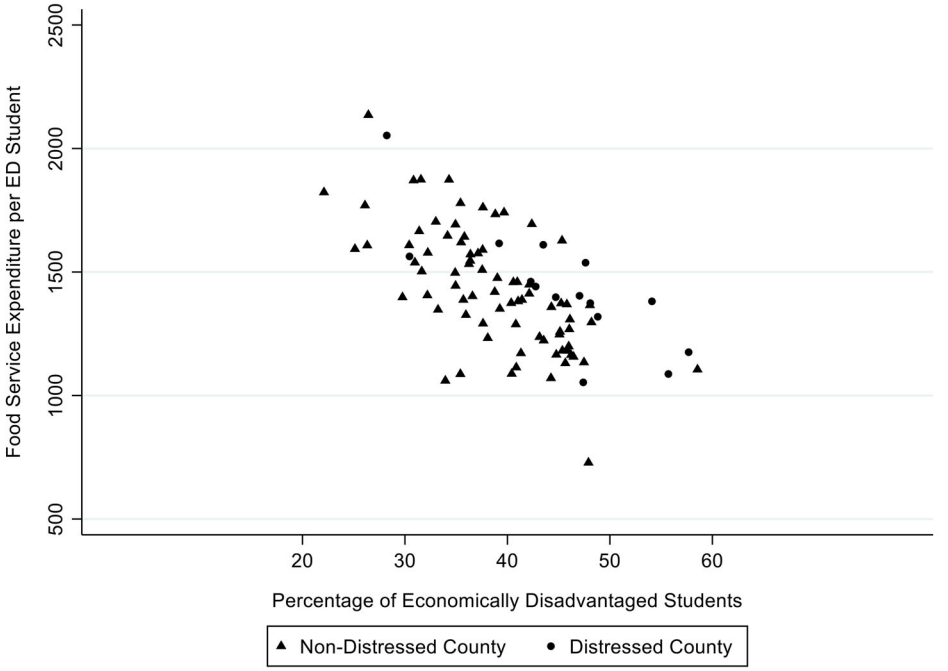


Notes: Percentage of economically disadvantaged (ED) students per county calculated using Tennessee Education Research Alliance (TERA) data on K-12 student enrollment in Fall 2018. Community service expenditures reported in total dollars per county from the 2018/2019 Tennessee Department of Education Annual Statistical Report (ASR).

Figure 2. Relationship Between Percentage of Economically Disadvantaged Students and Community Service Expenditures per Student, by County.

of children of immigrants.[25] Table 2 presents the correlation coefficients from our analyses that describe the strength and direction of the relationships between the levels of resources available to meet students' needs and the prevalence of student needs; the rows in boldface (along with p-values) indicate statistically significant relationships. The patterns in these relationships are largely all consistent, unfortunately, in showing where there are more economically disadvantaged children or children in need of services, resources are inadequate and stretched more thinly. For example, the first four statistically significant relationships shown in Table 2 are positive, indicating that there are more students per social worker where reported cases of child abuse are higher; higher percentages of immigrant children where there are more immigrant children per teacher of English language learners (ELLs); more special needs students per teacher where there are higher percentages of students needing special education; and more students per mental health staff member in communities with higher percentages of economically disadvantaged students. Alternatively, where there are higher percentages of economically disadvantaged students, community services expenditures and food services expenditures

[25] We define children of immigrants as children who have at least one immigrant parent and who speak a non-English native language in the home or are English language learners.



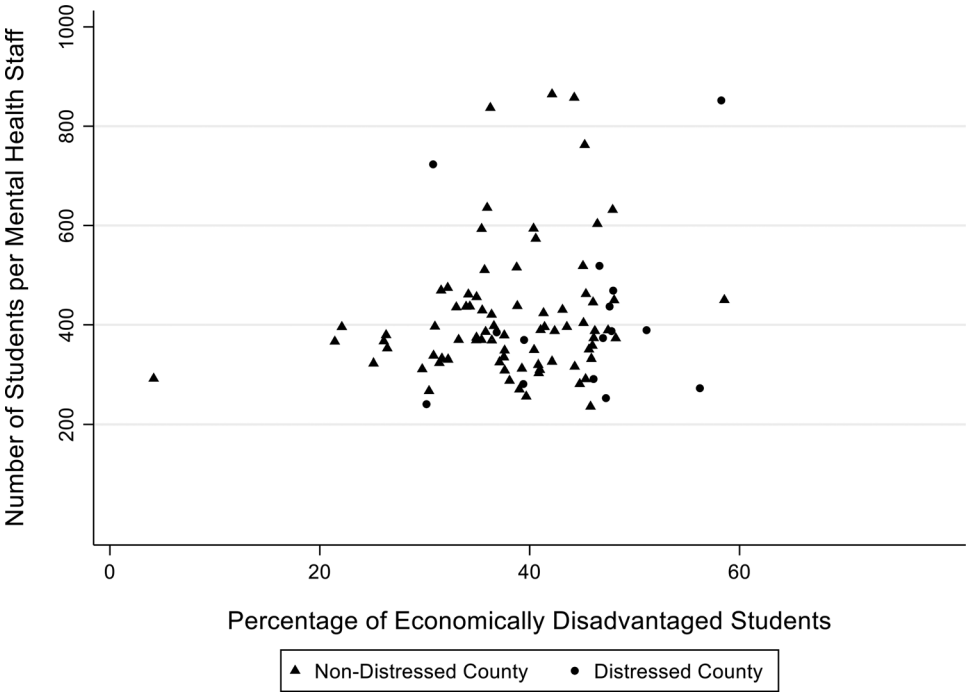
Notes: Percentage of economically disadvantaged (ED) students per county calculated using Tennessee Education Research Alliance (TERA) data on K-12 student enrollment in Fall 2018. Food service expenditures are reported in total dollars per county for the 2018/2019 school year, Tennessee Department of Education Annual Statistical Report (ASR).

Figure 3. Relationship Between Percentage of Economically Disadvantaged Students to Food Service Expenditures per Economically Disadvantaged (ED) Student, by County.

per student are significantly lower (reflected in a negative coefficient), and there are fewer Family Resource Centers.

We also depict a subset of these relationships graphically, distinguishing the distressed counties, i.e., those that rank in the bottom 10 percent in the nation based on poverty rates, per capita market income, and unemployment rates, from non-distressed counties. The resources mapped in these graphs include community service expenditures per student, food expenditures per student, number of students per mental health staff at school, the number of students with special educational needs per special education teacher, and the number of children of immigrants per ELL teacher. As indicated above, we would hope to identify linear patterns in these graphs, showing greater levels of financial and personnel resources were allocated to communities with more children identified with needs and place-based deficits that limit their capacity to meet those needs.

Figures 2 and 3 present the graphs mapping community service and food expenditures per student by the percentage of students in the county who are economically disadvantaged. While it is challenging to identify any linear association between students in economic need and the community service expenditures per student in Figure 2, in fact, the direction of the relationship is negative (correlation coefficient = -0.204) and statistically significant ($p = 0.047$), showing lower community service expenditures per student where there are greater percentages of economically



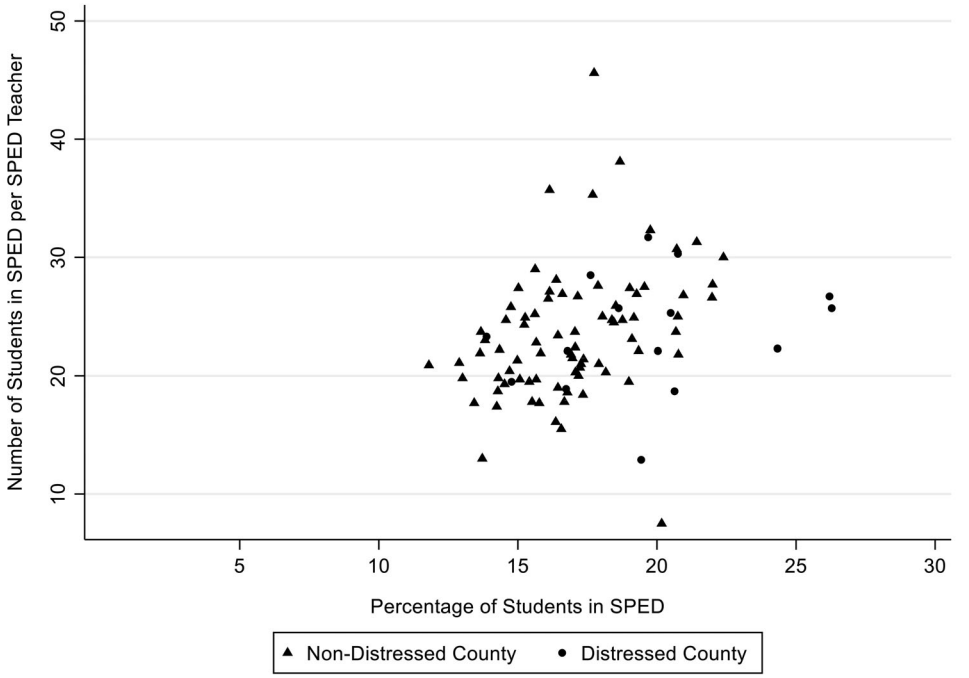
Notes: Percentage of economically disadvantaged students (ED) per county calculated using Tennessee Education Research Alliance (TERA) data on K-12 student enrollment in Fall 2018. Number of students per mental health staff calculated using TERA data on school staff and K-12 school enrollment from the 2018/2019 school year. Mental health staff in schools include counselors, psychologists, and social workers.

Figure 4. Relationship Between Percentage of Economically Disadvantaged Students and Number of Students per Mental Health Staff, by County.

disadvantaged students. The stronger negative correlation between the percentage of economically disadvantaged students and food expenditures per student (-0.570) is likewise troubling. It can also be seen that distressed counties (labeled with a circle in the figures) have some of the highest rates of economically disadvantaged students and relatively low expenditures per economically disadvantaged student.

Figure 4 focuses on mental health staffing, depicting the availability of mental health staff per student (relative to student economic disadvantage). For the correlation between student economic disadvantage and mental health staffing, a negative correlation is desirable, as it would indicate that with higher percentages of economically disadvantaged students, there are fewer students per mental health staff member. The correlation coefficient for this relationship, however, is positive (0.242), with a p-value (0.018) that indicates statistical significance. This is consistent with school-based health coordinators' perceptions that their caseloads of students with mental health needs were overwhelming SBHC resources. This was also perceived among mental health staff working in county health departments and social service organizations in these communities:

> We have a high rate of suicide and mental illness in the region…I feel like that money should be allocated to areas that are in most need. But what I'm seeing a lot of times is, oh, we're going to give it to the bigger places, and what you have there is places that have more money, they have more resources, and then of course your impoverished areas,

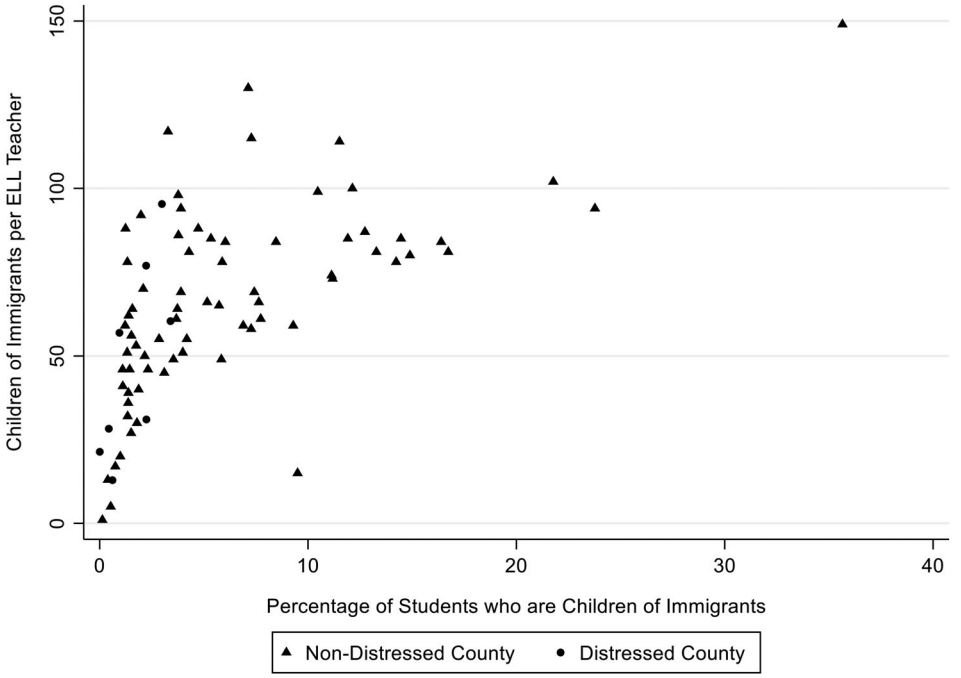


Notes: Percentage of students receiving special education services (SPED), per calculations using Tennessee Education Research Alliance (TERA) data on K-12 student enrollment in Fall 2018. Ratio of children receiving special education services (SPED) to SPED teachers calculated by aggregating counts of students receiving SPED services and SPED teachers in each county using 2018/2019 K-12 student enrollment data from TERA.

Figure 5. Relationship Between Percentage of Students Receiving Special Education Services (SPED) and Number of Students Receiving SPED per SPED Teacher, by County.

> your small rural areas where nobody wants to come, we can't even afford to hire anybody at this time because the money has been given to bigger places.

In Figure 5, we show the number of special education students per special education teacher relative to the percentage of special education students in the county. Again, a lower ratio or negative association would be desirable, indicating that there are fewer special education students per teacher where the need is greater. However, the correlation coefficient in this relationship is likewise positive and statistically significant (0.294, p-value = 0.004), suggesting that instructional resources for students with special education needs are fewer where there are more students in need of those services. Figure 6 illustrates a similar but even stronger relationship (0.606, p-value < 0.001) between the percentage of children of immigrants in counties (learning English or speaking another native language in the home) and the number of children of immigrants per ELL teacher, pointing to an acute need for more educational resources for children of immigrants. Overall, the patterns across each of the depictions of student need vs. resources (Figures 2 through 6) are consistent in showing that in counties where there are greater percentages of students likely to be needing more supports, there are fewer public and community resources available for them.



Notes: Percentage of children of immigrants per county calculated using Fall 2018 student demographic data from the Tennessee Education Research Alliance (TERA). Ratio of children of immigrants per English Language Learner (ELL) teacher calculated by aggregating counts of children of immigrants and ELL teachers in each county using 2018/2019 K-12 student demographic and school staff data from TERA.

Figure 6. Relationship Between Percentage of Children of Immigrants to Number of Children of Immigrants per ELL Teacher, by County.

Limitations

It is important to reiterate that the analyses presented above are descriptive and are not intended to imply causal linkages between federal, state, and local policies and the relationships and circumstances we observe. Our interviewees were both purposively and randomly selected, and it was our intent to understand administrative burdens encountered by individuals and organizations in areas facing especially challenging circumstances, such as economic distress and the opioid crisis. We also recognize that social safety nets in the South have been historically underfunded at state and local levels, particularly where marginalized populations reside, which intensifies the challenges of closing resource gaps and eradicating the burdens we described.

CONCLUSION

As Herd and Moynihan (2020, p. 5) point out, debates or contrasting perspectives about administrative burdens are often "fights about political values, such as access or program integrity or the deservingness of recipients." As described in the research presented here, however, administrative burdens may have far-reaching individual and systemic consequences—they generate substantial negative externalities, or harmful effects on third parties. They not only appear to impede children's

and families' access to public benefits and social service supports that affect their healthy development and well-being, but they also place additional strain on the capacity of public and private nonprofit organizations that serve as the health and social safety net for those in most need, particularly in communities with more limited resources and social service infrastructure.

The growing research base on administrative burdens and our interviews with those working on the "front lines" of health and social services delivery in Tennessee point to an array of relatively straightforward policy and program changes that could be implemented to reduce administrative burdens and their negative consequences for individuals and communities. Early in 2020, Tennessee state leaders convened to consider how they could best expend more than $700 million in unspent federal Temporary Assistance for Needy Families (TANF) program funds that the state had amassed, the highest in the nation (and $200 million more than New York, the next highest state) (Wadhwani, Reicher, & Allison, 2020). Based on our interviews, we compiled a long list of specific suggestions we shared with state officials at that time (for the use of TANF or other available state funds), including: (1) increase transportation support in rural areas (not limited by mileage to the nearest service); (2) revive programs to purchase car seats and expand car seat certification programs to increase safe transportation for children; (3) improve communications, translation capabilities, and record keeping between state agencies, the vulnerable populations they serve, and the local organizations serving them; (4) remove impediments to accessing services for those without a physical address; (5) increase assistance in enrolling in Medicaid (TennCare) through more qualified navigators who could also bolster the administrative capacity of local organizations; and (6) streamline the 15-page TennCare application and eligibility determination process. In fact, there are proven models that Tennessee can look to in streamlining its Medicaid application and eligibility determination processes, such as ACCESS (Automated Community Connection to Economic Self Sufficiency) Florida, which won the 2007 Innovations in American Government award.[26] ACCESS Florida replaced its 15-page application for assistance with a four-page, simplified application and adopted new information technology (developed "in-house")—electronic imaging, web-based eligibility determination, and linked database systems—that significantly reduced paper documentation and processing time. The resulting modernized, paperless workflow led to a decline in the average number of days to process a client from more than 40 days to 17 days, with less than one-fourth the staff required to handle the processing. In addition, re-certifications and other routine changes are now processed electronically within hours.

In addition, states should consider waiving or substantially reducing the fees for obtaining essential documents such as birth certificates for low-income families. Birth certificates are a "gateway" document to nearly every basic health and social support for children, including Medicaid, WIC, HeadStart, preschool, and K-12 education. Although $15 may appear to be a minor cost to some, research on the effects of small (e.g., $2 to $3) increases in co-pays for prescription medications have shown that they can significantly deter the ability of vulnerable populations (e.g., the economically disadvantaged) to fill their prescriptions, affecting both healthcare utilization and patient health (Sinnott et al., 2013). Furthermore, existing research on administrative burdens (Heinrich, 2018) has shown that states have enacted policies and administrative rules with politically motivated intent to restrict access to birth certificates for particular subgroups—specifically, children of immigrants—

[26] For more information on ACCESS Florida innovations, see https://www.businesswire.com/news/home/20070925005057/en/ACCESS-Florida-Honored-Innovations-American-Government-Award.

with negative consequences for their access to health, education, and social services. Indeed, Tennessee legislators (following on Texas and North Carolina) proposed a bill in 2018 that included a ban on consular identification cards commonly used by Mexican and Central American immigrants in establishing the parental-child relationship for their citizen children, but this provision was removed during the final day of the legislative session (Ebert, 2018).

The serious gaps between the level of unmet children's need and public supports, particularly in rural, high poverty counties that have also suffered the turmoil of the opioid and meth epidemics, will not be bridged by some of the straightforward policy and program changes suggested above. We heard repeatedly in our interviews about the urgent need for more healthcare providers and specialists for underserved rural populations and more resources like the federal AWARE grants to expand the number of school counselors, psychologists, and other mental health services staff to respond to the rising mental health needs among PK-12 students. Our mapping of public expenditures or resources relative to student needs across the state—including the most basic needs of children for food—suggested that current allocations are inadequate to ameliorate these gaps in the health and social safety nets. Federal and state funding formulas based on per-student or per-capita calculations that fail to recognize changes in population characteristics other than size or the intersection of social, political, and economic factors that exacerbate risks for children will likely continue to shortchange communities that are experiencing concentrations of poverty or place-based resource deficits (Camacho & Henderson, 2020). The many compounding contextual factors identified in this research, such as the lack of state-funded detox beds, the scarcity of emergency and transitional housing support, poor internet access, and more, further suggest that these resource disparities will not be readily overcome, as the COVID-19 pandemic has already worsened the chasms.[27] In the face of these new challenges, it may be even more imperative to grasp some of the clear-cut options for reducing administrative burdens, such as simplifying the TennCare application or waiving birth certificate costs. This would also lessen the load on individuals and organizations on the front lines, who are "worn out of asks" and calling on policymakers to move beyond politically fraught considerations of "good vs. bad apples" or overwrought concerns about fraud and simply remove these barriers to more effectively serving those in need.

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[27] For example, a proposed allocation of more than $6 million in state funding for a pilot program that would have extended TennCare coverage for low-income mothers from two months through one year after giving birth was cut from the state budget due to the economic crisis precipitated by the pandemic.

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APPENDIX A

FOR INTERVIEWS: ORGANIZATIONS SERVING LOW-INCOME AND IMMIGRANT FAMILIES WITH CHILDREN (April 2020 Version with COVID-19 Questions Included)

Description of RWJF Study and Objectives

The Policies for Action Research Hub at Vanderbilt is bringing together health and education data to better understand the challenges faced by children in Tennessee, especially those who are at risk of falling behind on key health and educational outcomes. Experts from Vanderbilt University's Department of Health Policy and Peabody College of Education and Human Development are combining longitudinal, statewide health and education data files to study children over time, with the aim to illuminate ways that current policies, processes, and program structures might be adapted to more effectively serve the needs of families and improve program access and child well-being. We are also interested in hearing about the experiences and ideas of organizations (public and private) that are helping to meet the needs of Tennessee children in their daily work.

Purpose in Talking to You Today and Background on Your Organization

We want to understand more about your experiences in working with low-income and vulnerable populations to navigate and overcome barriers to accessing public benefits and services. To begin:

- Could you please provide some background on your organization, your own role, and your organization's involvement in supporting access to benefits and services for the population you serve?
- What public or private organizations do you partner with in your work? Which partnerships have been the most productive?
- Does your organization rely on or are you a part of a referral network for services (publicly accessible or pro bono services?)
- Can you briefly describe how your individuals find out about your services?
    - *Probe: Do individuals come to you from formal referrals, or can they come through the door after learning about your services? Does your organization engage in any outreach efforts to help make people aware of your services?*
- Approximately what percentage of the children and families that you serve:
    - Rely primarily on TennCare or CoverKids for health insurance to access healthcare? Are uninsured?
    - Are affected by homelessness?
    - Are affected by the opioid crisis?
- In addition to opioids, are there any other types of drug problems that are currently affecting your community?
- Has the population of children and families that you serve changed noticeably in the last decade and a half? If so, how?
    - *Probe here for changes in immigrant/undocumented immigrant population*.
- Has the COVID-19 pandemic had noticeable effects on your outreach and service to the children and families you serve?
    - Have you changed any policies related to fees for services?

- Have you used or explored the use of telehealth/telemedicine or other distance service strategies (either before or since COVID-19)?

Public Assistance Policies and Support of Low-Income and Immigrant Families

We are interested in understanding public policies and recent or past policy changes that you see as most directly affecting access to benefits and services that are important for meeting the needs and improving the health and well-being of the population you serve. For example, these could be requirements (or changes in policy) that affect outreach and pertain to particular categories of eligibility (e.g., immigrant status). To help us better understand how you might experience these policies and issues in your role and daily work, we are going to ask some basic questions and then present several scenarios to you (hypothetical instances) of children and their parents presenting with needs.

- What do you do (or what steps would you take) if you encounter a client who needs healthcare but is not covered by health insurance?
- What procedures do you use to determine if the client is qualified to receive public health insurance in Tennessee?
    - Have there been any notable changes to those procedures in the last five years?
        - If yes, what were those changes, and do you know what motivated them?
- How do you advise a client who has lost public health insurance coverage?
- Are you aware of provisions to support children and families' access to public benefits under the Families First Coronavirus Response Act of 2020?
    - Have you seen changes in need or requests for public assistance supports among those you serve in the wake of the COVID-19 pandemic?

Scenario 1

Mr. Gutierrez arrives at [location] with his 7-year-old son who has autism and is treated with therapy and medication. (He has three young children, ages 1, 5, and 7). It is discovered that the child's public health insurance coverage has lapsed and needs to be renewed.

- How do you advise Mr. Gutierrez?

You find out from looking at Mr. Gutierrez's 7-year-old son's medical records that he was regularly attending appointments until about four months ago, but Mr. Gutierrez indicates that his son has not been receiving his therapy since then.

- How would you respond?

Mr. Gutierrez mentions that he has not filled his son's prescription recently because TennCare was denied and the cost of the medicine at the pharmacy was not affordable.

- Is there any action you could take?

Mr. Gutierrez inquires about services for his youngest son, who turned one year old a month ago. Mr. Gutierrez is unsure about when his son was last seen by a doctor, whether he is up to date on his vaccinations, and whether his TennCare coverage is still active.

- How could you assist Mr. Gutierrez?

- Is there anything you could do to check on Mr. Gutierrez's son's immunization record?
  - *Probe expected challenges—immunization data are manually entered, records of immunizations at WIC are not automatically transferred to TennCare.*
- How could you verify whether the youngest son's TennCare coverage is active?
  - *Probe for understanding of Newborn Presumptive Eligibility program implemented in August 2014.*

Mr. Gutierrez mentions that his 5-year-old son has registered for kindergarten, but he has not seen a doctor recently, and he is also unsure whether he is up to date on his vaccinations.

- What recommendations or referrals could you offer to Mr. Gutierrez in regard to his 5-year-old son's preparation for kindergarten?

In the course of your conversation with Mr. Gutierrez, you learn that his spouse was deported and that Mr. Gutierrez is also an undocumented immigrant, although his children under age 19 are U.S. citizens.

- Could you offer any further advice or referrals to Mr. Gutierrez to help him in meeting the health, education, and social service needs of his children, particularly in the absence of their mother?

Mr. Gutierrez explains that he had an appointment to renew the WIC benefits for his one-year-old son. At the appointment, he was told that the WIC benefits could not be renewed without his passport, a requirement that he had not faced in the past. Mr. Gutierrez's passport has expired, and he was told at the WIC office that they can't help him without a valid ID.

- Are there any steps you could take or referrals you could make to assist Mr. Gutierrez in getting his son's WIC benefits restored?

Do you know of any similar experiences from your own organization's work with low-income and immigrant families that you could share (anonymously), including examples of improvement or success in serving children and families, as well as challenges?

Barriers to Service Awareness and Participation—Policies and Strategies to Address Them

- In your geographical area, where do low-income families typically go when they seek assistance to meet the basic needs of their families?
- What would you describe as the key barriers that your clients face in accessing public benefits and services and other supports?
  - Probe for concerns about separate applications, separate offices for basic supports (WIC, TANF, SNAP, TennCare, etc.), transportation, documentation.
- Are you aware of any recent or pending changes to *national* or *state-level* laws that have affected access to public benefits or education services for the population you serve?
  - Probe for awareness of Tennessee legislation/regulatory changes on immigration enforcement (e.g., 287g or HB 2315); the Trump administration restored 287g as a tool available to state and local authorities for immigration enforcement.

- Are you aware of efforts made by *state and local program offices* to inform your clients of policy changes that may affect their access to public benefits and services (e.g., outreach to communities, eligibility screening, use of interpreters, community-level outreach)?
    - Probe for understanding of additional coverage options available for immigrants to support their access to public health insurance, welfare, and food stamp programs (e.g., coverage for "qualified" legal immigrants, for lawfully residing children or pregnant women regardless of immigration status, presumptive eligibility determinations for pregnant women).

Scenario 2

(To be completed by clinicians/providers at health departments and FQHCs)

A young, pregnant woman has come to your organization for services during the first trimester of her pregnancy. You find out that the woman had a minor surgery a few months ago, and she shares that she was given a painkiller for the surgery.

What would you do next?

- *Probe: Would you ask if the painkiller was OTC drug (e.g., aspirin) or a prescribed opioid?*

The woman has shared that she was prescribed an opioid for the pain. She explained that when her prescription ended, a friend began providing her with opioids to help with the pain. Furthermore, she has continued using the opioids and has lost her job and is experiencing withdrawal symptoms when she isn't taking them. What type of follow-up would be recommended for her?

- *Would you recommend a treatment or care plan?*
- *If the patient was publicly insured by TennCare, would the treatment plan you consider be different?*
- *If the patient was uninsured, would the treatment plan you recommend differ?*
- *Would your referral or treatment plan be different based on where the patient lives? Or language spoken?*

In general, what policies could be put in place to improve services and referrals for pregnant women who have used opioids during pregnancy, despite the possible adverse consequences?

Scenario 3

(Personnel in school-based health clinics will skip scenario 3 and complete scenario 4)

A mother comes with her infant and her two-year-old son to an appointment. Medical records show that the 1-month-old infant was diagnosed with neonatal abstinence syndrome at birth. What next steps would you take?

- *Probe: How would you screen for additional social risk factors, including those in the home environment*?
- Is there any action you could take to facilitate screening of the other (2-year-old) child for signs of opioid exposure?
- If you find out the mother is insured through TennCare, what intervention and treatment options would you advise?
- If, alternatively, the mother was uninsured, would the intervention and treatment options you would consider differ?
- *Probe: Is the provider aware of the TennCare partnership with the Department of Children's Services (DCS) and Department of Health (DOH) to provide whole*

family trauma informed care? Are they aware of the infant's ability to qualify for TN Early Intervention Services (TEIS) for infants and toddlers (birth to age 3) with disabilities and their families?
- Would you recommend screening for the infant and 2-year-old child for Hepatitis C? If you found out one of the children was exposed, how would you ensure the child received treatment?
- Are there any other steps you would take in consideration of the mother's and children's welfare given these circumstances?
- Have you encountered any similar experiences from your own work that you could share (anonymously), including examples of improvement or success in serving children and families, as well as challenges?

In the course of considering options for treatment with the mother, you find out that the 2-year-old son no longer has TennCare coverage, but it has been less than three months since the insurance was last active.

- What steps could the parent be advised to take?

The parent completes a renewal application for the child's TennCare coverage. The application instructions indicate that she should receive information on the outcome within 90 days.

Five months later, she seeks healthcare services for her son, but TennCare indicates that her son does not have insurance coverage.

- Is there any advice or assistance you would offer to the parent at this time?

The parent learns from TennCare staff that they mailed her a letter 10 weeks after her renewal application was received asking for proof of income. The letter specified that a response was required within 3 weeks, but the parent does not recall receiving the letter. Four days after the deadline for the response, the insurance coverage for her son was terminated.

Are there any steps you would take or referrals you would make to assist the parent in getting the child's insurance coverage reinstated?

Scenario 4

(For interviewees in schools or school-based health centers)

An elementary school teacher refers a child in her classroom to the school-based health center for mental health services.

- What steps would you take to better understand what mental health or other unmet health needs the student may have?
- How would you go about accessing the student's school and health records?
- If the student has an individual educational plan (IEP), what types of information in the IEP would you expect to be useful to your assessment of the child?
- Beyond the IEP, what other sources of information could you look to in determining how best to help meet the needs of this student?

Based on information in the child's school records, you find out that she has previously been referred for therapy.

- How would you determine if the child has been receiving the therapy services?
- Are particular permissions required to obtain this information, and if so, how would you proceed to secure them?
- If you could not get access to this information, what next steps could you take?

- If the recommended therapy could not be provided through the school-based health clinic, what steps could clinic staff take to connect the child with the needed services?

In the course of considering additional options for treatment referrals with the child's parent, the clinic staff find out the child no longer has TennCare coverage, but it has been less than three months since the insurance was last active.

- What steps could the parent be advised to take?

The parent completes a renewal application for her children's TennCare coverage. The application instructions indicate that she should receive information on the outcome within 90 days.

Five months later, she follows up on the treatment recommendation for her daughter, but the provider tells her that her daughter does not have insurance coverage. The parent returns to the school-based health clinic for assistance.

- Is there any advice or assistance you could offer to the parent at this time?

The parent learns from TennCare staff that they mailed her a letter 10 weeks after her renewal application was received asking for proof of income. The letter specified that a response was required within 3 weeks, but the parent does not recall receiving the letter. Four days after the deadline for the response, the insurance coverage for her daughter and her preschool-aged son was terminated.

- Are there any steps you could take or referrals you would make to assist the parent in getting the children's insurance coverage reinstated?
- Have you encountered any similar experiences from your own work that you could share (anonymously), including examples of improvement or success in supporting children and families' access to services, as well as challenges?

Policy Levers

What kinds of policy or program changes would you like to see at the state or local level that would increase low-income and immigrant families' access to benefits and services for supporting the healthy development of their children?

What do you consider to be the most effective or promising strategies your organization has adopted to reduce the barriers and increase access to health and education services for low-income and immigrant families?

Do you anticipate any long-term changes or shifts in your organization's work or who you serve resulting from the COVID-19 pandemic?

APPENDIX B

Table B1. Qualitative analysis codebook.

Name	Abbreviated Code	Brief Description
Scenario 1		
Eligibility Knowledge of Health Insurance	Eligibility KNWL HI	Knowledge that the provider has regarding the specific steps they can take to help a family determine if their child is eligible for public health insurance
Enrollment Knowledge of Health Insurance	Enrollment KNWL HI	Knowledge that the provider has regarding how to enroll the child for public health insurance
General Knowledge of State Programs	General KNWL SP	Knowledge that the provider has regarding state programs that help meet the general health and social welfare needs of children
Additional Knowledge of Resources for Immigrant Families	Additional KNWL for IMF	Knowledge that the provider has of health and social service resources available to immigrant families
Provider Responsibility Assumed	Provider Responsibility Assumed	The provider assumes responsibility for securing general health care and social assistance for children regardless of insurance status
Provider Responsibility Assumed for Immigrant Families	Provider Responsibility for IMF	The provider assumes responsibility for helping immigrant families to secure health care or social assistance for their children
Provider Responsibility Assumed for Undocumented Immigrants	Provider Responsibility for UIM	The provider assumes responsibility for helping immigrant families to secure health care or social assistance for children who may be undocumented and/or their parents are undocumented
Provider Responsibility Denied	Provider Responsibility Denied	The provider does not assume the general responsibility of providing health and/or social services resources
Provider Responsibility Denied for Immigrant Families	Provider Denied for IMF	The provider does not assume the responsibility of helping immigrant families secure health care and/or social assistance for their children

Table B1. (Continued).

Name	Abbreviated Code	Brief Description
Provider Responsibility Denied for Undocumented Immigrants	Provider Denied for UIM	The provider does not assume the responsibility of helping undocumented families secure health care and/or social services resources for their children
Provider Knowledge of Policies that Affect Access	Provider KNWL of Policies that Impede	The provider identifies a specific state and/or local policy that impedes children's access to health care and other social services
Provider Knowledge of Policies that Facilitate Access	Provider KNWL of Policies that Support	The provider identifies a specific state and/or local policy that facilitates children's access to health care and other social services
Scenario 2		
Provider Screening for Routine Visit	Routine Screening	The provider knows what to screen for in a routine prenatal visit
Provider Denied Screening for Routine Visit	Denied Routine Screening	The provider does not know what to screen for in a routine prenatal visit
Comprehensive Screening of Risk Factors	Comprehensive Screening	The provider describes/provides a comprehensive screening process that includes social risk factors
Comprehensive Screening of Risk Factors Denied	Denied Comprehensive Screening	The provider does not describe/provide a comprehensive screening process that includes social risk factors
Provider Screening for Previous Drug Use	Screening for Previous DU	The provider screens for previous drug use
Provider Denied Screening for Previous Drug Use	Screening Denied for Previous DU	The provider does not screen for previous drug use
Provider Screening for Current Drug Use	Screening for Current DU	The provider screens for current drug use
Provider Denied Screening for Current Drug Use	Screening Denied for Current DU	The provider does not screen for current drug use
Provider Distinguish between OTCD and Prescription Opioids	Provider Distinguish OTC and RX OP	The provider distinguishes between over-the-counter drugs and prescription opioids when asking patients about painkillers
Provider Does Not Distinguish between OTCD and Prescription Opioids	Provider Non-Distinguish OTC and RX OP	The provider does not distinguish between over-the-counter drugs and prescription opioids when asking patients about painkillers
Provider Knowledge of Referral for OP User	Provider KNWL of OP Referral	The provider knows how to refer pregnant patients who use opiates

Table B1. (Continued).

Name	Abbreviated Code	Brief Description
Provider Denies Referral for OP User	Provider Denies OP Referral	The provider does not know how to refer pregnant patients who use opiates
Provider Knowledge for Opiate Use Referral for Non-Insured	Provider KNWL for OP Non-Insured	The provider knows how to refer pregnant patients who use opiates and do not have insurance
Provider Denies Referral for Non-Insured OP User	Provider Denies for OP Non-Insured	The provider does not know how to refer pregnant patients who use opiates and do not have insurance
Provider Knowledge of Referral for Non-English OP User	Provider KNWL for OP Non-English	The provider knows how to refer pregnant patients who use opiates and speak another language/language barrier
Provider Denies Referral for Non-English OP User	Provider Denies for OP Non-English	The provider does not know how to refer pregnant patients who use opiates and speak another language/language barrier
Provider Knowledge of Referral for Underserved OP User	Provider KNWL for OP Underserved	The provider knows how to refer pregnant patients who use opiates and live in underserved areas
Provider Denies for Underserved OP User	Provider Denies of OP Underserved	The provider does not know how to refer pregnant patients who use opiates and live in underserved areas
Provider Policy Recommendation for Opiate Support	Policy Support for OP	Provider has suggestions for policies and/or programs that can support them in providing care for patients in their area of care
Scenario 3		
Provider Knowledge NAS Post-Delivery	Provider KNWL NAS Post-Delivery	Provider knows how to care for an infant diagnosed with NAS post-delivery
Provider Denies NAS Post-Delivery	Provider Denies NAS Post-Delivery	Provider does not know how to care for an infant diagnosed with NAS post-delivery
Provider Screening Knowledge for Risk Factors NAS	Provider Screening Risk Factors-NAS	Provider knows how to screen for social/environmental risk factors for children diagnosed with NAS
Provider Denies Screening for Risk Factors NAS	Provider Denies Screening Risk Factors-NAS	Provider does not know how to screen for social/environmental risk factors for children diagnosed with NAS

Table B1. (Continued).

Name	Abbreviated Code	Brief Description
Provider Support for OP Family	Provider Family Support OP	The provider is aware of treatment programs for other children who have been exposed to opiates, regardless of NAS diagnosis
Provider Denies Opiate Support for Family	Provider Denies Family Support OP	The provider is not aware of treatment programs for other children who have been exposed to opiates, regardless of NAS diagnosis
Provider TennCare Treatment Knowledge	Provider KNWL TennCare	Provider is aware of treatment options through TennCare for mothers using opioids
Provider Denies TennCare Treatment	Provider Denies TennCare	Provider is not aware of treatment options through TennCare for mothers using opioids
Provider Knowledge of Resources for Uninsured Opiate Users	Provider KNWL Uninsured OP	Provider is aware of treatment options for mothers using opiates if uninsured
Provider Denies Resources for Uninsured Opiate Users	Provider Denies Uninsured OP	Provider is not aware of treatment options for mothers using opiates if uninsured
Provider Knowledge of DCS Partnerships for Trauma Care	Provider KNWL DCS for Trauma	Provider is aware of DCS partnerships that can assist the family with trauma-informed care
Provider Denies DCS Partnerships for Trauma Care	Provider Denies DCS for Trauma	Provider is not aware of DCS partnerships that can assist the family with trauma-informed care
Provider Knowledge of TEIS Eligibility	Provider KNWL TEIS	Provider is aware of eligibility criteria for Tennessee Early Intervention Services
Provider Denies TEIS Eligibility	Provider Denies TEIS	Provider is not aware of eligibility criteria for Tennessee Early Intervention Services
Provider Support for Medicaid Application Process	Provider Support Medicaid Application	Provider knows how to advise the patient in the Medicaid application
Provider Denies Medicaid Application Support	Provider Denies Medicaid Application	Provider does not know how to advise the patient in the Medicaid application
Scenario 4		
S. Provider Assessment of Student	S. Provider Assessment	S. Provider describes assessment of student for health needs
S. Provider Access to Student Health Information	S. Provider Access Student Information	S. Provider describes how student health information is accessed

Table B1. (Continued).

Name	Abbreviated Code	Brief Description
S. Provider use of IEP for Care	S. Provider IEP for Care	S. Provider uses IEP information to inform their care
S. Provider Non-IEP for Care	S. Provider Denies IEP for Care	S. Provider does not use IEP information to inform their care
S. Provider use of Additional Information for Care Plan	S. Provider Info for Care Plan	S. Provider describes how they create a care plan for student
S. Provider Access for Therapy Services	S. Provider Therapy Services	S. Provider describes how to access information about therapy services
General Questions		
State Policy Changes to Increase Capacity for Service	State Policy to Increase Service	Provider identifies state policy changes they would like to see to increase their capacity to effectively serve children and families
Local Policy to Increase Capacity for Service	Local Policy to Increase Service	Provider identifies local policy changes they would like to see developed/implemented to increase their capacity to effectively serve children and families
Promising Strategies in Support of Vulnerable Families	Strategies in Support of Vulnerable Families	Provider describes strategy to work with vulnerable families that are worthwhile to share and/or scale up
Promising Practice in Support of Vulnerable Families	Practices in Support of Vulnerable Families	Provider describes developed practices to work with vulnerable families that are worthwhile to share and/or scale up