## THE UNIVERSITY OF CHICAGO

# ASSESSING REAL-WORLD ACCESS TO COMMUNITY-BASED MENTAL HEALTH SERVICES FOR ADOLESCENTS: A MIXED METHODS MYSTERY SHOPPER STUDY

# A DISSERTATION SUBMITTED TO THE FACULTY OF THE CROWN FAMILY SCHOOL OF SOCIAL WORK, POLICY, AND PRACTICE IN CANDIDACY FOR THE DEGREE OF DOCTOR OF PHILOSOPHY

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## Dedication

This dissertation is dedicated to the families who persevere in their search for highquality mental health services despite multiple obstacles, the navigators who help them traverse the tangled web that is the mental health system, and the providers who offer hope in a time of despair. Nevertheless, we persist.

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#### Abstract

One in five adolescents in the United States have a mental health (MH) disorder, yet less than half receive any MH care. Given the potential lifelong effects of MH problems in adolescence, it is vital that youth with MH disorders are offered timely access to effective treatment. Safety-net health agencies, such as community mental health centers (CMHCs) and Federally Qualified Health Centers (FQHCs), are key points of access for families with adolescents in need of care, especially those enrolled in Medicaid. However, significant barriers exist which may reduce accessibility, including a paucity of qualified specialty providers, lack of insurance acceptance, onerous paperwork requirements, and long wait times. The overall objective of this mixed-methods study is to identify ways to increase timely access to effective MH services delivered in safety-net health agencies that serve adolescents enrolled in Medicaid.

Paper 1 uses survey data to describe the availability and accessibility of outpatient MH services for children and adolescents at safety-net health agencies in Cook County, Illinois, a year after the COVID-19 pandemic began in the United States. Findings reveal that approximately 12% of agencies in the initial sample were closed. Roughly 20% of agencies reported not offering outpatient MH services to adolescents. These findings indicate that online directories are often inaccurate or out-of-date. The median wait time for virtual services was 60 days at CMHCs and 15 days at FQHCs.

Paper 2 uses a mystery shopper methodology to assess how access to trauma-informed MH services delivered in safety-net outpatient health agencies varies by insurance status (Medicaid vs. private insurance), the race of the caller (White, Latina, or Black), and organizational type (CMHC vs. FQHC). Data indicate that barriers to access are high as less than 20% of pseudo-mothers could schedule an appointment. The primary reasons for appointment

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denials were a lack of appointment availability at CMHCs and the implementation of administrative burdens at FQHCs. Insurance type did not predict the ability to schedule an appointment, but the caller's race did predict access, indicating discrimination may be occurring at the point of scheduling.

Paper 3 follows up on the findings from Papers 1 and 2 to help determine the administrative burdens that exist in safety-net health agencies and how they act as barriers to accessing MH services. Findings reveal that FQHCs implement a variety of administrative burdens on prospective clients, such as a requirement to designate their primary care physician into the FQHCs network through their insurance prior to scheduling, and frequently engage in other organizational practices that create burdens on families, such as difficult-navigate phone trees, voicemails that are never responded to, and rude or discriminatory interactions with schedulers. These administrative burdens act as barriers to families accessing care due to the psychological, learning, and compliance costs associated with them.

#### **Introduction to Dissertation**

Adolescence is a time of heightened stress where the majority of lifetime mental health (MH) disorders arise (Kessler et al., 2005). While the COVID-19 pandemic certainly exacerbated MH concerns among American youth, rates of anxiety, depression, trauma exposure, and suicide have been on the rise since 2009 (Office of the Surgeon General, 2022). Untreated MH disorders occurring early in life are predictors of poorer academic outcomes (Woodward & Fergusson, 2001), substance use (Winstanley et al., 2012), and higher rates of avoidable hospitalization and use of emergency room services (Bardach et al., 2014). Untreated MH disorders are a major risk factor for suicide, which is the second leading cause of death for those aged 15–24 (U.S. Department of Health and Human Services, 2017). Fortunately, early intervention has been shown to lower the risk of these negative outcomes (Wolk et al., 2015). While multiple evidence-based treatments have been developed (Weisz et al., 2006), only 30– 50% of youth can access the treatment they need (Merikangas et al., 2011). There is a significant gap between the extent of the need for MH services and the percentage of youth who can access them. Furthermore, this gap disproportionately impacts the racial and ethnic minority and lowincome youth who have higher levels of unmet MH needs than White, higher-income youth (Alegria et al., 2010; Cunningham & Freiman, 1996; Satcher, 2001; Yeh et al., 2003).

While the majority of MH services in the United States are financed by public or private insurance (Frank & Glied, 2006; Office of Inspector General, 2019), evidence of an association between insurance type (private vs. public) and an adolescents' access to, and utilization of, MH services is mixed. Due to major shortages in providers and disparities in reimbursement rates, having private insurance may improve access to services that are in high demand, such as child and adolescent psychiatrists (Bisgaier & Rhodes, 2011; Steinman et al., 2012). On the other

hand, because Medicaid offers better coverage for a wider array of youth MH services than many private insurance plans (MentalHealth.gov, 2020), it may provide greater access to nonpsychiatric MH services (e.g., individual psychotherapy; Busch & Barry, 2009; Nageswaran et al., 2011; Walker et al., 2015; Yu et al., 2008).

Beyond the ability to schedule an appointment, timely access is an another essential element of MH care access and quality (Agency for Health Research and Quality, n.d.). While languishing on a wait list, MH symptoms may worsen, placing youth at increased risk of harm and/or hospitalization (Westin et al., 2014). Furthermore, there is a clear relationship between wait list placement and disengaging from engaging in treatment (Stallard & Sayers, 1998; Westin et al., 2014). The longer families have to wait between a referral and a first appointment, the more likely it is they will fail to attend their initial appointment (Foreman & Hanna, 2000; Schraeder & Reid, 2015)—an occurrence that wastes valuable agency resources and clinician time and makes wait times longer for other clients (Harrison et al., 2004). Wait times have been associated with organizational characteristics, such as the proportion of youth and Medicaid clients served (Sirkin et al., 2017). Given the impact of waitlist placement on treatment engagement and outcomes, strategies to improve scheduling and waitlist procedures, key gateway points of access for youth, are important avenues for research.

#### Safety-net Health Agencies

Safety-net health agencies, such as community mental health centers (CMHCs) and Federally Qualified Health Centers (FQHCs), hold the promise of improving access to care for adolescents with MH disorders. Throughout this study, safety-net health agencies are defined as community-based providers that accept at least one Medicaid Managed Care Plan. CMHCs began in 1963 when President John F. Kennedy's administration passed the Community Mental

Health Act, which aimed to reduce the population in the nation's psychiatric institutions by half. Beyond deinstitutionalization, the Community Mental Health Act aimed to create a system of CMHCs that would "reduce the price of community-based MH services, thereby encouraging access to care" (Frank & Glied, 2006, p. 59). Initial federal funding incentivized states and municipalities to create a robust system of CMHCs throughout the United States, yet these federal funds were not reallocated to sustain the CMHC system. Today, CMHCs rely primarily on funds from Medicaid and Medicare, with a small amount of funding also coming from state MH agencies, private health insurance companies, and foundations (Frank & Glied, 2006).

The Illinois Department of Public Health defines a CMHC as an "entity that provides the following services: Outpatient services, including specialized outpatient services for children and adolescents, the elderly, and individuals who are chronically mentally ill" (Illinois Department of Public Health, n.d., p. n.p.). To be classified as a CMHC, a facility must meet applicable licensing or certification requirements where it is located (Substance Abuse and Mental Health Services Administration, 2018b). Whether CMHCs have achieved their stated goal of "reducing the price of community-based MH services … encouraging access to care" (Frank & Glied, 2006, p. 52), especially for special populations (e.g., children and adolescents), remains an open question.

Championed by President Lyndon B. Johnson under the Office of Economic Opportunity, FQHCs began as "community health centers" in 1965. With just two clinics in the mid-60s the program has grown into the nation's largest safety-net health provider today. Community health centers officially transitioned to the FQHC program in 1989 under new legislation (Lefkowitz, 2005) and expanded their reach in underserved communities through Medicaid and Medicare dollars.

Located in medically underserved areas, FQHCs are a critical component of the health care safety-net, serving client populations that are predominantly low-income, uninsured, underinsured, or rely heavily on public insurance (i.e., Medicaid). Further, FQHCs are required to offer "enabling services" to address access-related barriers, such as transportation, translation and interpretation, and insurance enrollment (Substance Abuse and Mental Health Services Administration, 2013). A 2010 assessment of behavioral health services in FQHCs found that approximately 70% of FQHCs offer on-site MH services (National Association of Community Health Centers, 2011). Given the significant funding funneled to FQHCs over the past decade this percentage has likely increased (Myong et al., 2020). FQHCs provide MH services by employing or contracting licensed psychologists or social workers to treat clients with mild to moderate behavioral health disorders (Nardone et al., 2014). By "co-locating" physical and MH services, FQHCs hope to reduce childcare and transportation costs associated with making trips to multiple locations to receive health services and better coordinate care between providers.

In Cook County, Illinois, the second-most populous county in America and the location for this research, FQHCs provide the largest percentage of MH services to Medicaid populations (Chicago Department of Public Health, 2016). Medicaid is the largest source of revenue for FQHCs, accounting for about 44 percent nationally in FY 2015 (Kaiser Family Foundation, 2021a). In the calendar year 2016, nearly half of FQHC patients had Medicaid as their primary source of insurance, approximately 37% were uninsured, and 13% had private insurance (Health Resources and Services Administration, 2020).

FQHCs use a prospective payment system (PPS) that supports the integration of MH care in primary care settings. This funding model allows FQHCs to include the costs of licensed behavioral health practitioners in the calculation of their prospective rates (MACPAC, 2017).

Moreover, the integration of Medicaid funding for physical and behavioral services in the FQHC context contrasts with Medicaid fee-for-service payments, where primary care and behavioral health providers are reimbursed separately (Nardone et al., 2014). The ability to bundle payments and receive an enhanced reimbursement rate from Medicaid makes FQHCs an ideal location to integrate MH services for the most marginalized. Despite their promise, however, evidence suggests that FQHCs have a paucity of staff trained to serve youth with severe MH disorders (Bonilla et al., 2021; Cummings et al., 2013, 2020), potentially limiting the accessibility of MH services for this population.

In contrast, CMHCs offer a comprehensive array of services for youth with severe MH disorders, including specialized and evidence-based services. Still, CMHCs may be less accessible than FQHCs as they are not mandated to serve youth enrolled in Medicaid or offer similar enabling services such as a sliding fee scale (Substance Abuse and Mental Health Services Administration, 2013). Given that nearly half of youth in the United States are insured by Medicaid (42%; Cohen et al., 2018), it is imperative to analyze the availability and accessibility of MH services at these safety-net health agencies, which serve as a cornerstone for low-income adolescents and their families. As each organizational type (FQHC vs. CMHC) experiences different funding streams, mandates, and incentives (e.g., FQHCs can receive enhanced reimbursement rates for accepting Medicaid clients; Centers for Disease Control and Prevention & Office for State, Tribal, Local and Territorial Support, 2014), it's essential to understand how the availability and accessibility of outpatient MH services for youth varies by organizational type.

This study addresses a Healthy People 2030 objective to increase the proportion of children and adolescents with symptoms of trauma who get treatment. It does so by advancing

our understanding of how to increase timely access to effective MH services delivered in safetynet health agencies that serve low-income adolescents. Concrete policy and practice recommendations at the organizational level include reducing or eliminating administrative burdens, assessing and enforcing anti-discrimination policies, and implementing interventions to reduce wait times such as the collaborative care model. At the system level, recommendations include creating a new accessibility standard so safety-net agencies can reduce such burdens on prospective clients.

#### **Overview of Three Papers**

#### Paper 1

The primary goal of Paper 1 is to describe the availability and accessibility of MH services for children and adolescents at safety-net health agencies in Cook County, Illinois, a year after the COVID-19 pandemic began in the United States. The secondary goal of the survey was to establish the sample of safety-net health agencies for Paper 2, the mystery shopper study. To complete these goals, a comprehensive sample of safety-net health agencies was developed using the SAMHSA Treatment Locator and the Uniform Data System and validated against multiple sources to ensure completeness and accuracy. In March and April of 2021, a research assistant and myself called 117 CMHCs and 117 FQHCs and administered a 5-minute survey.

Analyses descriptively state the availability and accessibility of outpatient MH services during what had, at that point, been a year of pandemic impact. Results are stratified for FQHCs and CMHCs, given that each organizational type experiences different incentives, mandates, and funding streams that may impact service availability and accessibility. I find that approximately 12% of agencies in the initial sample were closed. Roughly 20% of agencies (28.2% of FQHCs and 7.7% of CMHCs) reported not offering outpatient MH services. CMHCs had three times

more MH providers on staff than FQHCs (mean of nine vs. three providers). Most agencies reported offering only virtual services (46.2%) or both in-person and virtual services (44.0%), with few differences in the delivery of services noted between organizational types. The median wait time for virtual services was 60 days at CMHCs and 15 days at FQHCs and wait times at CMHCs were three times longer than estimates conducted prior to the pandemic.

#### Paper 2

Once the sample of eligible safety-net health agencies was established in Paper 1, Paper 2 used a mystery shopper methodology to understand what access to MH services for adolescents looks like from a family's perspective. The specific research questions are: (1) Is insurance type (Medicaid vs. private insurance) associated with the likelihood of scheduling an appointment and wait times? (2) Is organizational type (FQHC vs. CMHC) associated with the likelihood of scheduling an appointment and wait times for individuals with different insurance types? (3) Is the race of the pseudo-mother (based on the tone of voice of the caller and racially aligned pseudonym provided) associated with the likelihood of scheduling an appointment and wait times? (4) What percentage of agencies offer trauma-informed treatment for adolescents? What types of trauma treatments do they offer, and how often are they offering evidence-based treatments?

To answer these questions, three pseudo-mothers (White, Latina, and Black voice actresses) called eligible CMHCs and FQHCs (N = 229) in Cook County, Illinois, to schedule an MH appointment for their adolescent child who had recently witnessed a traumatic event. The women called each agency once in the spring of 2021 and again that summer—telling the agency in one call that they were covered by Medicaid and in another that they had private insurance. Barriers to MH access, wait time, and the availability of trauma-informed treatment was then

identified. A generalized linear model was used to assess the contributing factors that impacted the scheduling of an appointment.

*Conceptual Framework*. For Paper 2, I drew on three conceptual frameworks relevant for a focus on healthcare access: 1) the Behavioral Model of Health Services, developed by Andersen (1995), 2) the Gateway Provider Model, developed by Stiffman, Pescosolido, and Cabassa (2004), and 3) the Patient-centered Access to Care Framework, developed by Levesque, Harris, and Russell (2013). Following the Patient-centered Access to Care Framework, this study defines access as "the possibility to identify healthcare needs, to seek healthcare services, to reach the healthcare resources, to obtain or use health care services, and to actually be offered services appropriate to the needs for care" (Levesque et al., 2013, p. 7).





Andersen's preeminent theory on healthcare access, the Behavioral Model of Health Services Use, identifies three factors that are key predictors of access to healthcare for adolescents: 1) *enabling factors*, such as the availability or affordability of services, with insurance being one of the key variables studied, 2) *need* for services – reported symptoms, diagnosis, and impairment, and 3) *predisposing factors* such as demographics and other risk and protective factors (Andersen, 1995). The Gateway Provider Model extends Andersen's influential model by theorizing the role of organizational characteristics (e.g., type, size, revenue, ownership) on the development and implementation of organizational policies and practices (e.g., scheduling and waitlist procedures) that impact access. Figure 1 above shows how constructs in the guiding frameworks map onto the constructs of Paper 2. My conceptual framework aims to demonstrate the relationship between adolescent/family level characteristics, organizational/health system characteristics, and access outcomes, such as the availability, affordability, and acceptability of services. It has a specific focus on *organizations* as the primary mechanism families use to access MH services.

*Outcomes.* This study found that only 17% of the calls resulted in an MH appointment. The primary reasons for denial of an appointment given by schedulers at agencies involved capacity or waitlist (n = 87) and an administrative requirement to switch their primary care provider into the organization's network (n = 71). The average wait time, regardless of insurance type, was 12 days, and CMHCs had shorter wait times than FQHCs (p = .019). This suggests that safety-net MH agencies may be struggling to keep up with the increasing demand for services. Of the agencies called, 38% reported offering trauma-informed treatment, and fewer than half of those could name a specific type of trauma treatment that was offered. Insurance and organizational type did not predict MH access. The Black and Latina pseudo-mothers were 18% more likely to be denied an appointment than the White caller (p = .019). Results suggest that discrimination may be occurring at the point of scheduling and that agencies should develop and

regularly assess anti-discrimination policies to ensure appointments are given equitably.

Paper 3

While Papers 1 and 2 demonstrate that FQHCs were implementing onerous administrative requirements on prospective clients prior to scheduling an appointment, Paper 3 seeks to determine the type and role of these administrative burdens—understood as the "learning, psychological, and compliance costs that citizens experience in their interactions with the government" (Herd & Moynihan, 2019, p. 22). This mixed-methods study uses qualitative data from 12 semi-structured interviews with hospital and community-based social workers and quantitative data from a survey and a mystery shopper study conducted with FQHCs in a large metropolitan county in the United States during the COVID-19 pandemic. This study addresses two research questions: *What kinds* of administrative burdens exist in accessing MH care? And *how* do they act as barriers to accessing MH services within safety-net agencies?

I argue that rather than directly refusing to schedule an appointment (or provide access to care), FQHCs increase administrative burdens and compliance costs for families, in effect increasing the barriers to scheduling an appointment. These burdens include a requirement to designate their primary care physician into the FQHCs network through their insurance prior to scheduling, difficulty navigating phone trees, voicemails that are never returned, and rude or discriminatory actions on the part of schedulers. Although FQHCs have been touted as a key mechanism to improve access to care for Medicaid populations, I show that administrative burdens implemented by them may act as barriers to accessing care and then make recommendations to reduce administrative burdens at both the organizational and system-level.

**Paper 1:** Availability and Accessibility of Mental Health Services for Youth: A Descriptive Survey with Safety-Net Health Agencies

#### Abstract

**Purpose.** To describe the availability and accessibility of outpatient mental health (MH) services for children and adolescents at community-based outpatient health agencies in a large metropolitan county during the year after the start of the COVID-19 pandemic in the United States.

**Methods.** A comprehensive sample of safety-net health agencies was developed using the SAMHSA Treatment Locator and the Uniform Data System and validated against multiple sources to ensure completeness and accuracy. Approximately one year after the COVID-19 pandemic began in the U.S., 117 community mental health centers (CMHCs) and 117 Federally Qualified Health Centers (FQHCs) were called and administered a 5-minute survey.

**Results.** Approximately 12% of agencies listed in the SAMHSA Treatment Locator and the UDS were closed. Twenty percent of agencies (28.2% of FQHCs and 7.7% of CMHCs) reported not offering outpatient MH services. Community mental health centers had three times more MH providers on staff than FQHCs (mean of nine vs. three providers). Most agencies reported offering only virtual services (46.2%) or both in-person and virtual services (44.0%), with few differences in the delivery of services noted between organizational types. Despite having more staff, the median reported wait time for virtual services was 60 days at CMHCs vs. 15 days at FQHCs and reported wait times at CMHCs were three times longer than estimates conducted prior to the pandemic.

**Conclusions.** These findings indicate that gold-standard online directories such as the SAMHSA Treatment Locator are often inaccurate or out-of-date. Despite having more staff, reported wait times were longer at CMHCs than FQHCs. Data from this study provide a benchmark for policymakers and safety-net health agencies that aim to increase access to MH care coming out of the pandemic. To reduce wait times, CMHCs could consider implementing collaborative care models; FQHCs may consider hiring more full-time equivalent MH providers to increase their capacity.

**Keywords.** Mental Health Care Availability, Mental Health Care Access, Waiting Lists, Community Mental Health Centers, Federally Qualified Health Centers

#### Introduction

Childhood and adolescence are times of heightened stress, with the majority of lifetime mental health (MH) disorders developing before adulthood (Kessler et al., 2005). When MH disorders early in life are left untreated and extend into adulthood, results include poorer academic outcomes (Woodward & Fergusson, 2001), higher rates of avoidable hospitalization and emergency department use (Bardach et al., 2014), and substance use (Winstanley et al., 2012). Untreated MH disorders are also major risk factors for suicide, the second leading cause of death for 15- to 24-year-olds (U.S. Department of Health and Human Services, 2017). Fortunately, early intervention has been shown to improve these outcomes (Wolk et al., 2015). Multiple evidence-based treatments have been developed (Weisz et al., 2006), yet, only 30%-50% of youth access necessary treatment (Merikangas et al., 2011). The gaps between the need for and access to services disproportionately impacts racial and ethnic minority and low-income, Medicaid-enrolled youth, groups found to have higher levels of unmet MH needs than White, higher-income youth (Alegria et al., 2010; Cunningham & Freiman, 1996; Satcher, 2001; Yeh et al., 2003).

A range of barriers to accessing MH care exist, including cost, lack of insurance coverage and acceptance, and long wait times (Carrillo et al., 2011; Schraeder & Reid, 2015; Substance Abuse and Mental Health Services Administration, 2021). Early evidence suggests that the risk factors related to the COVID-19 pandemic and lockdown (e.g., isolation, grief) may have increased the development and exacerbation of MH symptoms (Golberstein et al., 2020; Panchal et al., 2020; Yao et al., 2020). While the pandemic and the sudden shift to virtual services may have improved access in some ways, it also brought a reduction in school-based services and privacy and technology concerns associated with telehealth (Golberstein et al., 2020; Svistova et

al., 2021). Nonetheless, how exactly the onset of the COVID-19 pandemic, and the resulting shift to virtual services, impacted the actual availability and accessibility of outpatient MH, particularly youth services, is not clear (Purtle et al., 2022).

This descriptive study aims to assess the availability and accessibility of outpatient MH services in FQHCs and CMHCs for youth during the year after the COVID-19 pandemic began in the United States. Drawing on phone survey data from March and April of 2021, it posed the following research questions:

- How many agencies listed in prominent online directories (e.g., SAMHSA Treatment Locator) are closed? How many offer MH services? How many offer MH services to children and adolescents?
- 2) What does the availability (e.g., number of providers) and accessibility (e.g., wait times) of MH services look like in community mental health centers s and Federally Qualified Health Centers?

#### Safety-net Health Agencies

Youth are most likely to receive MH services at schools and outpatient agencies (Duong et al., 2020). For children and adolescents with MH disorders who are enrolled in Medicaid, community mental health centers (CMHCs) and Federally Qualified Health Centers (FQHCs) are two different critical access points of care (Panchal et al., 2020). Providers at these agencies offer a range of evidence-based psychosocial treatments for adolescents. Moreover, these sites act as the "de-facto safety net system for youth with MH disorders" (Cummings et al., 2016, p. 718) because the majority accept Medicaid, contrary to MH providers in private practice (Bishop et al., 2014; Rhodes et al., 2009).

CMHCs began in 1963 when President John F. Kennedy's administration passed the

Community Mental Health Act (CMHA), which aimed to reduce the population in the nation's psychiatric institutions by half. Beyond deinstitutionalization, the CMHA aimed to create a system of CMHCs that would "reduce the price of community-based MH services, thereby encouraging access to care" (Frank & Glied, 2006, p. 59). Initial federal funding incentivized states and municipalities to create a robust system of CMHCs throughout the country, yet these federal funds were not reallocated to sustain the CMHC system. Today, however, CMHCs rely primarily on Medicaid and Medicare funds, supplemented by state MH agencies, private health insurance companies, and foundations (Frank & Glied, 2006). This study hopes to help determine whether CMHCs have in fact achieved the goal of "reducing the price of community-based MH services" and "encouraging access to care"—especially for special populations (e.g., children and adolescents).

There are four primary reasons why FQHCs have been touted as a key to improving access to MH services. They are placed in medically underserved areas; mandated to accept Medicaid and prospective clients without insurance; required to offer "enabling services," such as interpreters and a sliding fee scale; and can offer "integrated" physical and MH services (Substance Abuse and Mental Health Services Administration, 2013). Whereas CMHCs funding is more fragmented, coming from a mix of public and private insurance, grants, and donations (Frank & Glied, 2006), FQHCs receive almost half of their revenue from Medicaid (MACPAC, 2017) while using a prospective payment system that supports the integration of MH care in primary care settings because health centers can include the costs of licensed behavioral health practitioners in the calculation of their prospective rates (MACPAC, 2017). This integration of Medicaid funding for physical and behavioral services in the FQHC context contrasts with Medicaid fee-for-service payment, where primary care and behavioral health providers are

reimbursed separately (Nardone et al., 2014). The ability to bundle payments and receive an enhanced reimbursement rate from Medicaid makes FQHCs an ideal location to integrate MH services for the most marginalized. Despite their promise, however, evidence suggests that FQHCs are limited by a paucity of staff trained to serve youth with severe MH disorders (Bonilla et al., 2021; Cummings et al., 2013, 2020).

As for CMHCs, while they offer a comprehensive array of services for youth with severe MH disorders, including specialized and evidence-based services, they are not mandated to serve youth enrolled in Medicaid or offer enabling services such as a sliding fee scale (Substance Abuse and Mental Health Services Administration, 2013). Given that nearly half of youth in the United States are insured by Medicaid (42%; Cohen et al., 2018), it is imperative to analyze the availability and accessibility of MH services at these safety-net health agencies, which serve as a cornerstone for low-income adolescents and their families. As each organizational type (FQHC vs. CMHC) experiences different funding streams, mandates, and incentives (e.g., FQHCs can receive enhanced reimbursement rates for accepting Medicaid clients; Centers for Disease Control and Prevention & Office for State, Tribal, Local and Territorial Support, 2014), it's essential to understand how the availability and accessibility of outpatient MH services for youth varies by organizational type.

#### Patient-Centered Access to Care Framework

To better understand patterns of availability and accessibility in safety-net health agencies, I deployed and adapted the patient-centered access to care framework (Levesque et al., 2013). I chose this framework because it provides a synthesis of published literature on the conceptualization of access. I thereby assess availability in the following way: 1) whether the agency offers MH services and is accepting new clients, 2) the number of providers who can

offer services, and 3) the delivery format services are offered in. Accessibility is assessed regarding: 1) timeliness of service delivery (wait time), 2) types of insurance accepted, 3) cost of services, 4) other organizational factors, such as the requiring of referrals before receipt of treatment, and 5) languages services are offered in and the availability of interpreter services. The variables being studied have been adapted from the original framework to ensure they fit the context of service providers in safety-net agencies.

Overall, little is known about the availability and accessibility of outpatient MH services within safety-net health agencies and how it varies by organizational type, especially in the context of a shift to virtual services due to the pandemic. This descriptive study aims to assess the availability and accessibility of outpatient MH services for youth through a phone survey of FQHCs and CMHCs in the second largest metropolitan county in the U.S. approximately a year after the COVID-19 pandemic began.

#### Methods

#### Stage 1: Initial Sample Development from the SAMHSA Treatment Locator

Figure 2 below shows development of the sample. Safety-net health agencies in Cook County, Illinois, were identified using the SAMHSA Treatment Locator in November of 2020, a publicly available search tool where agencies can be filtered according to need (e.g., geographic area). The SAMHSA Treatment Locator is populated annually by the National Mental Health Services Survey (N-MHSS). The N-MHSS collects information from all known facilities in the United States that provide services for MH disorders. In Illinois, the response rate for the 2019 N-MHSS was 92% (Substance Abuse and Mental Health Services Administration, 2018a). I determined the initial sample by selecting 1) "Cook County, Illinois" for location, 2) "MH" for service and type of care, and 3) "Health Care Centers" so that FQHCs would be included. This search resulted in a sample of 357 agencies. Agencies were considered eligible to be distributed the survey if they were listed as offering outpatient MH services to children and adolescents (< 18 years old). Agencies were stratified into two categories: FQHCs (n = 249) and CMHCs (n = 108).

#### Figure 2. Visual Flow Chart of Sample Development

STAGE 1: Initial sample from the SAMHSA Treatment Locator

#### N = 357 Community-based Outpatient Health Agencies 249 Federally Qualified Health Centers 108 Community Mental Health Centers

STAGE 2: Validation of initial sample against additional sources (i.e., UDS, CDPH, and IDHS)

#### Federally Qualified Health Centers: N = 249

28 (11.2%) they did not offer outpatient mental health services (e.g., vision only)

7 (2.8%) were reported as closed on the UDS

2 FQHCs were added from the UDS

Total: 216 Federally Qualified Health Centers

### **Community mental health centers: N = 108**

22 (20.4%) were removed as they only offered outpatient mental health services to adults

23 (21.3%) were removed as they only offered residential treatment

92 CMHCs were added from the CDPH and the IDHS

Total: 155 Community Mental Health Centers

**STAGE 3:** Survey Administration - Excluded Agencies

## Federally Qualified Health Centers: N = 216

26 (12.0%) were closed or could not be located

61 (28.2%) did not offer outpatient mental health services

12 (5.6%) only offered outpatient mental health services to adults Final Sample: 117 Federally Qualified Health Centers

#### **Community mental health centers:** N = 155

11 (7.1%) were closed or could not be located

12 (7.7%) did not offer outpatient mental health services

15 (9.7%) only offered outpatient mental health services to adults

Final Sample: 117 Community Mental Health Centers

#### Stage 2: Validation of Initial Sample Against Additional Sources

To ensure completeness and accuracy of the initial sample of safety-net health agencies, I validated each list of agencies against other directories. The initial sample of FQHCs was validated against the Uniform Data System (UDS; Health Resources and Services Administration, n.d.) an online portal operated by the Health Resources and Services Administration that lists up-to-date information on FQHCs. The list of CMHCs was validated against: 1) the Chicago Department of Public Health's online directory of MH providers (CDPH; Chicago Department of Public Health, n.d.) and 2) the Illinois Department of Human Services list of outpatient MH agencies (Illinois Department of Human Services, 2021).

I removed 28 FQHCs (11.2%) from the initial sample as the UDS noted that they do not offer outpatient MH services (e.g., administrative site only, vision services only) and 7 FQHCs (2.8%) because the UDS indicated they were closed. I then added 2 FQHCs from the UDS to make a total of 216 FQHCs. I removed 22 CMHCs (20.4%) since they were listed as only offering MH services to adults and 23 CMHCs (21.3%) because they only offered inpatient or residential services. I added 92 CMHCs that had not been listed in the SAMHSA Treatment Locator but were listed in the CDPH or IDHS lists. This made a total of 155 CMHCs. After validating the initial sample against additional sources, the analytic sample consisted of 371 agencies (n = 216 FQHCs, n = 155 CMHCs).

#### Stage 3: Survey Administration and Screening for Eligible Agencies

The research team called each agency in the final analytic sample between March–April 2021, approximately one year after the United States was impacted by the pandemic. They asked to speak to the MH director or intake coordinator to administer a voluntary 5-minute survey on the availability and accessibility of services their agency offered (see Appendix 1.1 for the

survey). At least three call attempts to each agency were made, separated by at least 24 hours in time. After three call attempts, seven FQHCs (6.0%) and six CMHCs (5.1%) were unable to be reached but were in operation. For these agencies, the team completed their survey using publicly available information about the agency online. Upon attempting to contact them, an additional 26 FQHCs (12.0%) and 11 CMHCs (7.1%) were closed or could not be located online. In total, 44 agencies (12.4%) in the initial sample were closed. Regarding response rates, no agency declined participation.

Two screener questions were asked to ensure agencies were eligible to be administered the full survey: 1) Does your agency offer outpatient MH services? and 2) Does your agency offer outpatient MH services to children and adolescents? Upon administering the screener questions, 61 (28.2%) FQHCs and 12 (7.7%) CMHCs reported over the phone that they did not offer outpatient MH services. See Table 1 for the primary service offered by the agency when MH services were not available, stratified by organizational type. Further, 12 (5.6%) FQHCs and 15 (9.7%) CMHCs reported over the phone that they only offered outpatient MH services to adults. These agencies were excluded from the study sample as they did not fit the eligibility criteria. Only agencies that reported offering outpatient MH services to children and adolescents were eligible to be administered the full survey.

The University of Chicago Crown Family School of Social Work, Policy, and Practice and Chapin Hall Institutional Review Board determined that this research is exempt, given minimal risk level to participants. Analyses descriptively state the availability and accessibility of outpatient MH services during the COVID-19 pandemic. Results were stratified for FQHCs and CMHCs, given that each organizational type experiences different incentives, mandates, and

funding streams that may impact service availability and accessibility. The data were analyzed using SPSS version 28.0. (IBM Corp., 2021).

# Results

See Table 1 below for descriptive statistics of agency variables, stratified by organizational type.

	Safety-Net Health Agency		
	<b>FQHCs</b> ( <b>n</b> = 117)	<b>CMHCs</b> ( <b>n</b> = 117)	Total Sample (N = 234)
Availability of MH Services	N (%) or Mean (SD)	N (%) or Mean (SD)	N (%) or Mean (SD)
Currently accepting new child and adolescent clients	113 (96.6%)	97 (82.9%)	210 (89.7%)
Offers medication management / psychiatry services	51 (43.6%)	48 (41.0%)	99 (42.3%)
Availability – Number of Providers <sup>a</sup>			
Number of MH providers working at agency	3.27 (5.92)	8.66 (9.28)	5.90 (8.19)
Number of MH providers who specialize in providing services to children and adolescents at agency	2.28 (2.47)	7.44 (8.97)	4.65 (6.83)
Availability – Delivery Format of Service <sup>b</sup>			
In-person only	4 (3.4%)	3 (2.6%)	7 (3.0%)
Virtual only	50 (42.7%)	58 (49.6%)	108 (46.2%)
Both in-person and virtual offered	55 (47.0%)	48 (41.0%)	103 (44.0%)
Accessibility – Timeliness of Services <sup>c</sup>			
Reported wait time for in-person (M, Median, (SD))	22.78, 21.00, (21.83)	72.24, 60.00, (70.00)	45.05, 28.00, (55.01)
Reported wait time for virtual/telehealth (M, Median, (SD))	24.89, 15.00, (26.41)	73.43, 60.00, (82.24)	50.27, 28.00, (66.48)
Reported wait time for medication management / psychiatry services (M, Median, (SD))	37.26, 21.00, (43.25)	46.23, 30.00, (42.93)	41.47, 28.00, (42.99)

Table 1. Continued			
Accessibility – Insurance			
At least one Medicaid MCO accepted	117 (100%)	108 (92.3%)	225 (96.2%)
Number of Medicaid MCOs accepted (out of 5)	4.74 (.44)	4.25 (1.47)	4.50 (1.11)
Accepts at least one private insurance plan	117 (100%)	77 (65.8%)	194 (82.9%)
Accepts individuals without insurance	111 (94.9%)	88 (75.2%)	199 (85.0%)
Accessibility - Cost			
Agency offers free services	5 (4.3%)	32 (27.4%)	37 (15.8%)
Agency offers a sliding scale	115 (98.3%)	69 (59.0%)	184 (78.6%)
Lowest rate (per session) on agencies sliding scale	\$20.84 (\$9.81)	\$34.78 (\$46.95)	\$25.52 (\$29.11)
Accessibility - Organizational			
Agency requires referral prior to scheduling appointment	76 (65.0%)	9 (7.7%)	85 (36.3%)
Agency requires internal primary care physician prior to scheduling appointment	64 (54.7%)	5 (4.3%)	69 (29.5%)
Agency has geographic restrictions for clients they will serve	1 (.9%)	15 (12.8%)	16 (6.8%)
Agency offers at least one form of transportation assistance (i.e., bus pass, ride share, or private transportation through agency)	40 (34.2%)	26 (22.2%)	66 (28.2%)
Accessibility - Language			
Agency has MH providers who can provide services in Spanish	51 (43.6%)	75 (64.1%)	126 (53.8%)
## **Table 1. Continued**

Number of licensed MH providers who can provide services in Spanish at the agency	1.45 (.60)	3.52 (4.42)	2.71 (3.61)			
Agency offers services in a language other than English or Spanish	3 (2.6%)	20 (17.1%)	23 (9.8%)			
Agency offers language interpretation service	114 (97.4%)	12 (10.3%)	126 (53.8%)			
<sup>a</sup> When agencies gave a range in the number of clinicians (e.g., between 5 to 10) I took the median between the estimates (e.g., 7.5)						

<sup>b</sup> Does not add up to 100% because of missing response

<sup>c</sup> When agencies gave a range of wait times (e.g., between 2 to 4 weeks) I took the median wait time between the estimates (e.g., three weeks); Months were calculated as 30 days

Notes: Abbreviations: FQHC – Federally Qualified Health Center; CMHC – community mental health center; SD - standard deviation

Availability of MH Services. After excluding agencies due to ineligibility, the full survey was administered to 117 FQHCs and 117 CMHCs (N = 234). Twenty-six percent (n = 30) of CMHCs were affiliated with hospitals while 74% (n = 87) were community-based. Less than half of the agencies (42.3%) who offered therapy services also offered psychiatry or medication management services. Eighteen CMHCs required that clients receive therapy at their agency before receiving a referral for psychiatry services—no FQHCs reported a similar requirement. Most child-serving agencies were accepting new clients.

Availability – Number of Providers. Overall, safety-net health agencies had an average of six MH providers, five of which specialized in providing services to children and adolescents. CMHCs had more MH providers on staff than FQHCs (mean of nine vs. three providers). This disparity was also seen in providers who specialized in serving children and adolescents (mean of seven vs. two providers).

Availability – Delivery Format of Services. A year after the COVID-19 pandemic began, only three percent of agencies overall were offering only in-person services. Most agencies reported offering only virtual services (46.2%) or both in-person and virtual services (44.0%). Many agencies who offered both virtual and in-person services said that in-person services were limited and had to be approved by management (e.g., clients who did not have access to broadband internet). There were no significant differences between FQHCs and CMHCs in the delivery format of services they offered.

*Accessibility – Timeliness of Services*. When agencies reported that they offered both inperson and virtual services, the research team asked for wait time estimates for both. Agencies rarely reported a significant difference in wait times between in-person and virtual services, with an overall median wait time of 28 days for virtual/telehealth services. Significant differences in

reported wait time between organizational types were noted. The median reported wait time for virtual services was 60 days at CMHCs compared to 15 days at FQHCs. Within CMHCs, agencies affiliated with hospitals reported longer wait times for virtual services than agencies not affiliated with hospitals (median of 75 days vs. 45 days). Eight CMHCs reported that their waitlist for new therapy clients was closed, with no estimate of when it would reopen, and twelve reported they were unsure how long their waitlist was. For medication management/psychiatry services, reported wait times were similar between organizational types, with a median of 21 days at FQHCs and 30 days at CMHCs. Eight FQHCs and four CMHCs reported their waitlist for new psychiatry clients was closed.

*Accessibility – Insurance.* Given that we purposively sampled safety-net health agencies, it is no surprise that 93.2% of CMHCs and 100.0% of FQHCs accepted at least one Medicaid managed care plan. FQHCs accepted more Medicaid managed care plans than CMHCs did (mean of 4.7 vs. 4.2 out of 5 plans). Only two-thirds (65.8%) of CMHCs accepted at least one private insurance plan compared to 100% of FQHCs. CMHCs were less likely to accept uninsured clients (75.2%) than FQHCs (94.9%).

*Accessibility* – *Cost.* Approximately 27.4% of CMHCs offered free MH services, versus only 4.3% of FQHCs. On the other hand, most FQHCs (98.3%) offered a sliding fee scale, while only 59.0% of CMHCs did. On average, the lowest rate on FQHCs sliding scales was more affordable than CMHCs (\$21 per session vs. \$35). Additionally, many CMHCs put restrictions on their sliding scale and free services. For example, some agencies stated their sliding scale could only be offered to individuals without insurance or if they lived in a specific catchment area. Further, most CMHCs noted their free services were only available for specific populations (such as domestic assault survivors), given restrictions implemented by grant funding.

*Accessibility – Organizational Factors.* Significant differences between organizational types were noted on other accessibility factors. Approximately two-thirds (65.0%) of FQHCs required prospective clients to have a referral before scheduling a MH appointment; only 7.7% of CMHCs had the same requirement. Further, more than half (54.7%) of FQHCs required prospective clients to switch their primary care provider into their health agency network before they would schedule a MH appointment. Only 4.5% of CMHCs (all of which were hospital-based) had the same requirement. Fifteen CMHCs required clients to live in a specific catchment area or geographic region to receive services; only one FQHC had a similar requirement. Approximately one-third (34.2%) of FQHCs reported the ability to assist clients with at least one form of transportation to their appointments (i.e., bus pass, rideshare, or private transportation through the agency) compared to 22.2% of CMHCs.

*Accessibility* – *Language*. Overall, around half of the agencies (53.8%) had at least one Spanish-speaking MH provider, with an average of three Spanish-speaking providers on staff. Approximately 9.8% of agencies offered MH services in a language other than English or Spanish, and around half could offer language interpreter services (53.8%). Significant differences between organizational types were noted for language-based accessibility factors. Around two-thirds of CMHCs (64.1%) had at least one MH provider on staff who could provide services in Spanish, whereas less than half (43.6%) of FQHCs had a Spanish-speaking MH provider. On average, CMHCs had three MH providers who could offer MH services in Spanish, whereas FQHCs had just one. Further, 17.1% of CMHCs (n = 20) had MH provider(s) who could speak a language other than English and Spanish, including Russian (n = 6), Polish (n = 5), Urdu (n = 4), Hindi (n = 3), Arabic (n = 2), German, Chinese, Cantonese, and Korean (n = 1 each). Only three FQHCs were able to offer MH services in other languages, including Arabic (n = 2), Hindi, and Urdu (n = 1 each). Instead, most FQHCs (97.4%) offered language interpretation services to accommodate individuals who speak other languages, which few CMHCs did (10.3%).

## Discussion

Due to various barriers (e.g., wait times, insurance status, family income), youth who need MH services often do not receive them. Given school disruptions and increasing demand for services, the COVID-19 pandemic likely exacerbated this disparity. This study's findings provide insight into the availability and accessibility of outpatient MH services for youth in safety-net health agencies one year after the COVID-19 pandemic began.

In the current study, approximately 12% of safety-net health agencies listed in the SAMHSA Treatment Locator were closed or could not be located online. Interestingly, in validating the initial sample against additional sources, another 92 CMHCs not listed on the SAMHSA Treatment Locator were identified. Further, about 20% of the final sample (28.2% of FQHCs and 7.1% of CMHCs) reported not offering outpatient MH services, despite multiple online directories listing them as being offered. These findings combined suggest that online directories of MH agencies, when used, should be validated against multiple sources.

Around 10% of agencies that offered outpatient MH services only served adults. Aligned with their mission to specialize in MH services, CMHCs had significantly more MH providers on staff than FQHCs (mean of 9 vs. 3 providers). CMHCs also had more MH providers who could provide services in Spanish or another language other than English than FQHCs. To compensate, FQHCs were more likely to offer a service where providers call a language interpretation line, increasing their ability to serve individuals who speak any language.

Despite CMHCs having more specialty MH providers on staff (indicating higher capacity), their reported wait times were significantly longer FQHCs (median of 60 days vs. 15 days). This suggests that demand for MH services may be higher at CMHCs than FQHCs. Parents might be more likely to intuitively seek MH services for their children at specialty agencies such as CMHCs rather than FQHCs, as FQHCs tend to be better known in the community for the medical services they provide. Increasing community knowledge that FQHCs offer MH services may increase demand. That said, more than half FQHCs required a referral and/or an internal primary care provider before they would schedule a MH appointment. While these are well-intentioned tasks meant to better integrate physical and MH care, they could pose an additional barrier for families seeking treatment. These administrative tasks may prevent families from being added to the waitlist, possibly keeping waitlists shorter at FQHCs.

Another potential reason for this extreme difference in reported wait times between organizational types is that CMHCs were more often hospital-based than FQHCs. Previous research has found that hospital-based clinics had longer wait times than community-based clinics (Olin et al., 2016). Finally, this disparity in reported wait times could be due to different treatment modalities offered by each organizational type. For example, FQHCs provide routine and preventative MH treatment that is often short-term in nature (Jacobs & Steiner, 2016). By providing shorter-term therapy, FQHCs may be able to see more clients than CMHCs, in turn shortening wait times. They may also be less equipped to serve youth with severe MH disorders, referring out clients who present with these symptoms (Cummings et al., 2020). Combined, these factors may help keep provider caseloads low at FQHCs and increase their ability to move through waitlists faster.

Results indicate that the cost of outpatient MH services varies by organizational type. Aligned with the mandates they encounter from their funder, the Health Resources and Services Administration, FQHCs offered sliding fee scales, interpreter services, and transportation assistance more often than CMHCs. They were also more likely to accept Medicaid, private insurance, and individuals without insurance than CMHCs. These results are encouraging as they all allow FQHCs meet their slated mission of making MH services more accessible for marginalized populations.

In contrast, CMHCs are under no such mandates from the federal government to accept any particular insurance types or to offer enabling services. Therefore, they appear to be less likely to offer enabling services such as sliding fee scales and less likely to accept certain insurance types or individuals without insurance. At the same time, CMHC employees shared that a portion of their work is grant-funded, which allowed for additional offerings (e.g., free services) but often came with specific funding restrictions. More research should be done on the relationship between funding streams (and the mandates and incentives that go with them) and how they impact the accessibility of MH services.

Results from this survey suggest that the pandemic may be having an impact on wait times for outpatient MH services. A mystery shopper study of CMHCs in New York State prior to the pandemic found the median wait time for a therapy appointment was 21 days (range 1-181 days), whereas the median wait time in CMHCs during the pandemic was three times longer (60 days, range 0-540). A survey conducted in 2016 (most up-to-date data) by the Chicago Department of Public Health found that the average wait time for individual psychotherapy at community-based providers was 57 days (range 0-365 days; Chicago Department of Public Health, 2016), compared to an average of 73 days at CMHCs in this study. While a comparison

between these wait times should be interpreted lightly as different methods were used to measure each, the wait time estimates seen in this study are a cause for alarm.

Results signal intervention points to increase access for each organizational type. At CMHCs, wait times were very long. One intervention shown to reduce wait times in FQHCs is the collaborative care model, an evidence-based approach that includes case management, care coordination, and measurement-based care (Kinnan et al., 2019). Future research should assess the feasibility and acceptability of implementing collaborative care models in CMHCs, particularly hospital-based CMHCs, which tend to have the longest waiting times. While wait times at FQHCs were shorter than CMHCs, they had fewer MH providers overall, reducing their promise to increase MH access to the most marginalized communities. Increasing the capacity of these agencies by adding more full-time equivalent MH providers on staff has been shown to increase access to such treatment (Bonilla et al., 2021). Policymakers should also consider expanding loan repayment programs, easing the administrative burden of participating in the Medicaid program, and increasing Medicaid reimbursement rates to help agencies hire and retain staff, increasing their capacity to treat prospective clients in a timely manner (Adams et al., 2019; Long, 2013; Olfson et al., 2014).

#### Limitations

Several limitations should be noted. First, the survey was self-report (i.e., not subject to independent verification) and could have been subject to social desirability and recall bias. In future studies, wait time should be assessed more rigorously through mystery shopper methodologies to provide more accurate, real-time estimates (Olin et al., 2016). Second, we cannot determine just how much the pandemic has impacted the availability and accessibility of services as data is cross-sectional and only collected at one point in time. We did not ask what

the availability and accessibility of services looked like prior to the pandemic. We only asked about a point in time estimates of availability and accessibility. Finally, while Cook County is the second most populous county in the U.S. (Cook County Government, n.d.), reducing this concern, this study is limited to one county and may not generalize to regions with different behavioral health financing or policies.

#### Conclusion

Despite these limitations, this study represents the first of its kind to assess the availability and accessibility of outpatient MH services for youth during the COVID-19 pandemic. The COVID-19 pandemic has likely increased the development and exacerbation of MH disorders in children and adolescents and shifted the availability and accessibility of services within safety-net health agencies. In this study, wait times at CMHCs were three times longer than estimates conducted prior to the pandemic. The availability and accessibility of outpatient MH services varied by organizational type, with longer wait times at CMHCs and fewer MH providers at FQHCs. The data from this study provide a meaningful benchmark for policymakers and safety-net health agencies that aim to increase access to MH care coming out of the pandemic. Suggestions to increase access at each organizational type, include hiring more MH providers at FQHCs and implementing collaborative care models at CMHCs to reduce wait times.

# Appendix 1.1 Survey Questions

# **INTRO** – Confirm correct agency

"Hi, is this [FQHC / CMHC AGENCY NAME] at..."

- Address 1
- City, State, Zip

# AGENCY SURVEY SECTION

"My name is [NAME] and I'm calling from the University of Chicago to verify lists of mental health agencies in Cook County, Illinois. May I speak to the director of mental health programming or the intake coordinator for mental health services? We are conducting a voluntary survey on the availability and accessibility of outpatient mental health services one year after the pandemic started. Would you have 5-minutes to participate?" (Yes/No)

IF NO: Thank you for your time, have a nice day.

IF YES:

- 1) Does your agency offer outpatient mental health services (e.g., individual therapy, group therapy)? (Yes/No)
  - a) IF NO OUTPATIENT MENTAL HEALTH SERVICES ARE OFFERED: Can provide me an overview of the primary service(s) your agency does offer?
- 2) Does your agency offer outpatient mental health services to children and adolescents? (Yes/No, we only serve adults)
- 3) Are you currently accepting new child and adolescent clients for outpatient mental health services? (Yes/No)
- 4) Are services being offered in-person, virtually/telehealth, or both? (In-person/virtually/both)
  - a) IF SERVICES ARE BEING OFFERED IN PERSON: Approximately how long is the wait for in person outpatient mental health services for children and adolescents [IN DAYS]?
  - b) IF SERVICES ARE BEING OFFERED VIRTUALLY / VIA TELEHEALTH: Approximately how long is the wait for telehealth outpatient mental health services for children and adolescents [IN DAYS]?
- 5) Do you accept Medicaid? (Yes/No)
  - a) If so, which Medicaid Managed Care plans are accepted at your location? For example, do you take Medicaid through... [Yes/No/Don't Know]
    - (1) CountyCare
    - (2) Blue Cross Community Health Plans
    - (3) IlliniCare Health
    - (4) Meridian Health
    - (5) Molina Healthcare
- 6) Do you accept private insurance? (Yes/No/Don't know)
  - a) If so, which Commercial Insurance Plans are accepted at your location?

- i) Blue Cross Blue Shield
- ii) United Health Care Group
- iii) Other:\_\_\_\_\_
- 7) Does your agency accept individuals who are uninsured? (Yes/No/Don't know)
- 8) Is a referral required (for example, from a primary care doctor) to receive mental health services at your clinic? (Yes/No/Don't know)
- 9) Do prospective clients need to have a primary care doctor within your agency in order to receive mental health services at your clinic? (Yes/No/Don't know)
- 10) Are there any geographic restrictions for the clients your agency will serve? (Yes/No/Don't know)
  - a) [IF SO]: What are the geographic restrictions for the clients you serve?
- 11) How many licensed mental health providers (e.g., social workers, marriage and family therapists, psychiatrists, counselors, etc.) work at your agency?
  - a) And of those mental health providers, about how many provide mental health services to children and adolescents?
- 12) Does your agency have mental health providers who are willing and able to provide services in Spanish? (Yes/No/Don't know)
  - a) [IF AGENCY HAS PROVIDERS WHO SPEAK SPANISH]: How many mental health providers within your agency are willing and able to provide services in Spanish?
- 13) Is your agency able to mental health offer services in any languages other than English and Spanish? (Yes/No/Don't know)
  - a) If so, what languages can these providers offer mental health services in?
- 14) Does your agency offer a sliding scale? (Yes/No/Don't know)
  - a) [IF YES, AGENCY OFFERS A SLIDING SCALE]: What is the lowest rate on the sliding scale?
- 15) Are free services ever offered as an option? (Yes/No/Don't know)
- 16) Does your clinic offer medication management / psychiatry services? (Yes/No/Don't know)
  - a) [IF PSYCHIATRY SERVICES ARE OFFERED]: Approximately how long is the wait to see a psychiatrist for medication management services (IN DAYS)?
- 17) Do you offer any type of transportation assistance such as.... (check all that apply):
  - i) Uber / Lyft
  - ii) CTA / Bus Pass
  - iii) Other (e.g., agency private transportation)
  - iv) None of the above

**Paper 2:** Assessing Real-World Access to Trauma-informed Outpatient Mental Health Services for Youth: A Mystery Shopper Study

# Abstract

**Objective** To examine how access to trauma-informed mental health (MH) services delivered in safety-net health agencies varies by insurance type, the race of the caller, and organizational type.

**Method** Using a mystery shopper methodology, three pseudo-mothers (White, Latina, and Black voice actresses) called eligible community mental health centers (CMHCs) and Federally Qualified Health Centers (FQHCs) (N = 229) in Cook County, Illinois, requesting to schedule a MH appointment for their adolescent child who recently witnessed a traumatic event. The women called each agency twice in the spring and summer of 2021 with alternating Medicaid and private insurance coverage. The ability to schedule an appointment, barriers to MH access, wait time, and the availability of trauma-informed treatment were identified. A generalized linear model was used to assess the impact of contributing factors on scheduling an appointment.

**Results** Only 17% (n = 78) of pseudo-mothers could schedule an appointment across both waves of data collection. The primary reasons for denial of an appointment given by schedulers at agencies involved capacity or waitlist (n = 87) and an administrative requirement to switch their primary care provider into the organization's network (n = 71). The average wait time regardless of insurance type was 12 days, and CMHCs had shorter wait times than FQHCs (p = .019). Thirty-eight percent of agencies reported offering trauma-informed treatment. Insurance and organizational type did not predict MH access. The Black and Latina pseudo mothers were 18% more likely to be denied an appointment than the White caller (p = .019).

**Conclusion** Less than one in five pseudo-mothers could schedule a MH appointment for their adolescent child, indicating safety-net agencies may not be meeting the increasing demand for services. Results suggest that racial discrimination may be occurring at the point of scheduling. Agencies should develop and regularly assess anti-discrimination policies to ensure equitable access to care. Future research will develop and test organizational-level strategies to reduce administrative requirements, enforce anti-discrimination policies, and increase the availability of trauma treatments.

### Introduction

In the Fall of 2021, the American Academy of Pediatrics, American Academy of Child and Adolescent Psychiatrists, and the Children's Hospital Association declared a national emergency in children and adolescent mental health (MH). They noted "soaring rates of MH challenges among children, adolescents, and their families over the course of the COVID-19 pandemic, exacerbating the situation that existed prior to the pandemic" (The American Academy of Pediatrics et al., 2021). More recently, the United States Surgeon General issued an advisory highlighting the urgent need to address the nation's youth MH crisis (Office of the Surgeon General, 2022). One in five youth in the US have a MH disorder, yet less than half of them ever receive treatment (Center for Disease Control and Prevention, 2013; Merikangas et al., 2011; Whitney & Peterson, 2019). This gap between the need for services and engagement in services has been attributed to a variety of barriers, including difficulty navigating the system, a shortage of specialized providers, lack of insurance acceptance, and long wait times (Carrillo et al., 2011; Schraeder & Reid, 2015; Substance Abuse and Mental Health Services Administration, 2021). Further, previous research indicates discrimination may occur at the point of scheduling, creating additional barriers for families of color (Kugelmass, 2016; Shin et al., 2016). Using an innovative mystery shopper methodology, this study aims to understand how access to traumainformed MH services delivered in safety-net health agencies varies by client insurance type, the race of the caller, and the type of organization providing the services. This study builds off previous work that established the mystery shopper methodology as feasible for this subject matter, improving upon previous methodology by resolving limitations such as placing only one call to each agency (Olin et al., 2016).

Understanding the impact of insurance on access to care is important given that the

majority of MH services in the United States are financed by public or private insurance (Garfield & Kaiser Commission on Medicaid and the Uninsured, 2011). Evidence of an association between insurance type (private vs. public) and adolescents' access to and utilization of MH services is mixed. Having private insurance may improve access to services in high demand, such as child and adolescent psychiatrists, due to major shortages in providers and disparities in reimbursement rates (Bisgaier & Rhodes, 2011; Steinman et al., 2012). On the other hand, enrollment in Medicaid may provide greater access to non-psychiatric MH services (e.g., individual or group therapy), (Busch & Barry, 2009; Graaf & Snowden, 2020; Nageswaran et al., 2011; Walker et al., 2015; Yu et al., 2008) as Medicaid offers more comprehensive coverage of a wide array of MH services for youth than many private insurance plans (MentalHealth.gov, 2020). However, this varies by age group – Ali and colleagues found that, "adolescents covered under Medicaid were less likely to receive both types of treatment [psychotropic medicine and psychotherapy] compared with those with private insurance, and they also had a lower rate of receiving psychotherapy only" (2019, p. 3). Further, health system factors, such as low Medicaid reimbursement rates for outpatient services and high administrative burdens, are barriers to providers accepting Medicaid clients (Frank et al., 2003; Long, 2013).

Beyond insurance, a burgeoning line of research indicates that discrimination based on race or ethnicity may also act as a barrier for families of color trying to access MH care. Audit field experiments, also known as "mystery shopper" studies, are considered the gold standard for measuring discrimination (Al-Ubaydli & List, 2016; Bertrand & Duflo, 2016; Neumark, 2018). Two mystery shopper studies conducted over email, one in New York City (Kugelmass, 2016) and another in a "mid-Atlantic state" (Shin et al., 2016), found that callers with stereotypically

White-sounding names were more likely to receive a call back from a MH provider than a caller with a non-White sounding name. Understanding whether racial discrimination occurs in the scheduling process could help explain the significant racial disparities seen in MH access outcomes (Alegria et al., 2010).

In this paper I build on the work of two previous mystery shopper studies. The first was conducted within specialty outpatient MH agencies in New York State, finding disparities in access (defined by availability and timeliness) to outpatient MH services for adolescents. While that study established the feasibility of this method for outpatient MH settings (Olin et al., 2016), it contained limitations that my study improves on. In the New York study, each MH agency was called only once and did not vary on insurance type, so that its authors were unable to distinguish whether differences in appointment scheduling success and wait times were due to contextual factors such as insurance type, the persistence of caller, and tone of voice (Bisgaier & Rhodes, 2011; Olin et al., 2016). Further, the presented scenario was of an adolescent girl; scheduler responses might have varied had the sex of the youth been different (Olin et al., 2016). A major contribution of this study is its ability to experimentally disentangle the differences in access based on insurance type and sex of the child.

The second mystery shopper study my study builds upon was conducted by Health Services Advisory group as a part of an external quality review for the Illinois Department of Healthcare and Family Services Division of Medical Programs (2020). This mystery shopper was conducted in 2019 prior to the pandemic within primary care and OB/GYN providers offices throughout Illinois. It found low levels of appointment availability, ranging from 16.2% to 60% across various type of Medicaid MCO noted by callers (Illinois Department of Healthcare and Family Services, 2020, p. 91). My study builds upon this study by measuring access in a new

context, that is, outpatient MH services within safety-net agencies, and extends it by asking whether access varies based on public or private insurance status reported by the caller.

I seek therefore to assess appointment availability, wait times for therapy appointments, and the availability of trauma-informed care for adolescents. Using the mystery shopper methodology, I ask the following research questions:

- Is insurance type (Medicaid vs. private insurance) associated with the likelihood of scheduling an appointment and wait times?
- 2) Is organizational type (FQHC vs. CMHC) associated with the likelihood of scheduling an appointment and wait times for individuals with different insurance types?
- 3) Is the race of the pseudo-mother (based on the tone of voice of the caller and racially aligned pseudonym provided) associated with the likelihood of scheduling an appointment and wait times?
- 4) What percentage of agencies offer trauma-specific treatment for adolescents? What types of trauma treatments do they offer, and how often are they offering evidence-based treatments?

#### Safety-net Health Agencies

Youth tend to access MH services through schools, primary care, and community-based outpatient agencies (Duong et al., 2020; Human Services Research Institute, 2015), such as community mental health centers (CMHCs) and Federally Qualified Health Centers (FQHCs). Providers at these agencies offer a range of evidence-based psychosocial treatments designed for adolescents and are critical access points or "safety nets" for low-income youth (Cummings et al., 2016, p. 718; Panchal et al., 2020), as the majority accept Medicaid, contrary to MH

providers in private practice (Bishop et al., 2014; Rhodes et al., 2009). In fact, FQHCs provide the highest percentage of MH services to Medicaid recipients in Cook County, Illinois, according to a report done by the Chicago Department of Public Health (2016). Given that nearly half of youth in the United States are insured by Medicaid (Cohen et al., 2018), it is imperative to analyze the availability and accessibility of MH services at these safety-net health agencies. FQHCs and CMHCs experience different funding streams, mandates, and incentives, so it is essential to understand whether the availability and accessibility of outpatient MH services for youth vary by organizational type.

#### Trauma-informed Care

The COVID-19 pandemic has increased potential exposure to trauma for youth through media coverage of traumatic events, increased exposure to maltreatment and family violence, or the loss of a family member or loved one to COVID-19 (Collin-Vézina et al., 2020; Hillis et al., 2021). Understanding whether youth who have experienced traumatic events have access to evidence-based, trauma-informed services is a serious public health concern, given that the majority of youth are exposed to at least one and often multiple traumatic experiences by age 17 (Finkelhor et al., 2009). A secondary aim of this study is to understand 1) whether front-line staff such as schedulers and receptionists respond in a trauma-informed way to callers and 2) the availability of trauma-specific treatment (e.g., trauma-focused cognitive behavioral therapy) in safety-net agencies, how knowledgeable schedulers are about this form of treatment, and what specific types of trauma treatments are offered. When attempting to schedule an appointment, the pseudo-mother will request "trauma treatment," noting that their child's school social worker recommended it.

Prior to the actual provision of trauma-specific treatment, trauma-informed care should

begin with the agency scheduler. The manner and tone in which a scheduler responds to a family's outreach for care could determine whether the family chooses to engage in services. Given the stigma surrounding the need for MH services, making the first call to schedule a MH appointment takes courage. When a scheduler is rude, curtly says the waitlist is closed without offering referrals, or fails to thoroughly answer questions about treatment, it may dissuade an individual or family from seeking care. Further, while screening for trauma is a priority in the use of trauma-informed care, it also acknowledges that a family should not have to disclose the details of their traumatic event to everyone at the agency unless it is clinically necessary (Substance Abuse and Mental Health Services Administration, 2014).

## Methods

#### Study Design

To examine access to outpatient MH services for adolescents from a family's perspective, I performed a mystery shopper study of publicly listed FQHCs and CMHCs. Mystery shopper studies, also known as audit studies or simulated client studies in the literature, are methodologically robust, innovative, and practical as they mimic real-world experiences of families seeking care. These studies use a deceptive design in which the same trained voice actress calls the same health agency twice to schedule a real appointment using a script that varies on only a predictor variable—in this case, insurance type (Medicaid vs. private insurance). All appointments were cancelled at the end of the call to not take up agency resources. The order of the calls (i.e., whether private insurance or Medicaid is reported on the first or second call) was randomly assigned. This allowed me to experimentally control for all other variables and isolate insurance type as the sole predictor variable. Any variations in the ability to schedule an appointment, the primary outcome variable, that could be attributed to the parent (e.g., persistence) are eliminated or minimized. Mystery shopper studies have the unique ability to reduce social desirability, non-representative samples, and recall biases that are common in traditional surveys administered to clients, providers, or health plans (Rhodes, 2011). This method is appropriate for this study because it also allows critical insight onto what accessing MH services looks like from a family's perspective. Given that individuals who seek services vary in their need for treatment, the persistence with which they seek them, and their ability to navigate complex health systems, it is vital to understand what access looks like from a family's perspective (Andersen, 1995; Olin et al., 2016).

### Study Population and Sample Selection

To define the sample frame of FQHCs and CMHCs in Cook County, Illinois, in November of 2020, I used the Substance Abuse and Mental Health Services Administration (SAMHSA) Treatment Locator, a publicly available search tool where agencies can be filtered according to need (e.g., geographic area). The SAMHSA Treatment Locator is populated annually by the National Mental Health Services Survey (N-MHSS). The N-MHSS collects information from all known facilities in the U.S. that provide services to people with MH disorders. In Illinois, the response rate for the 2019 N-MHSS was 92% (Substance Abuse and Mental Health Services Administration, 2018a).

To ensure completeness and accuracy of the initial sample, the list of CMHCs and FQHCs was validated against other directories. The initial sample of FQHCs was validated against the Uniform Data System (Health Resources and Services Administration, n.d.), an online portal operated by the Health Resources and Services Administration that lists up-to-date information on FQHCs. The list of CMHCs was validated against: 1) the Chicago Department of Public Health's online directory of MH providers (Chicago Department of Public Health, n.d.)

and 2) the Illinois Department of Human Services list of outpatient MH agencies (Illinois Department of Human Services, 2021) Agencies that were listed as not offering outpatient MH services to adolescents or being closed were removed from the sample.

As described above (Adams, Paper 1), all agencies in the sample were called from March to April of 2021 and administered a five-minute survey to ensure eligibility. Agencies were considered eligible if they: 1) offered outpatient psychosocial therapy to adolescents ( $\geq$ 14 years of age), 2) accepted at least one Medicaid Managed Care Plan, and 3) were in Cook County, Illinois. After removing ineligible agencies, the final sampling frame consisted of 229 agencies, or 119 FQHCs and 110 CMHCs.

The University of Chicago Crown Family School of Social Work, Policy, and Practice and Chapin Hall Institutional Review Board approved the study with a waiver of informed consent. The deceptive design was considered necessary to accomplish the primary objective of the study: to identify whether disparities in access to outpatient MH services existed according to the insurance type of the family by measuring the real-life behavior of FQHCs and CMHCs contacted for outpatient appointments. Debriefing letters were sent to all agencies in the sampling frame after the study, informing agencies that the purpose of the study was to monitor the system rather than individual agencies and that the identities of individual agencies would never be disclosed.

#### Data Collection

I hired self-identified White, Latina, and Black voice actresses to pose as mothers with either Medicaid coverage or private health coverage. They participated in a four-hour training with the principal investigator prior to the study initiation, at which time they selected pseudonyms that were aligned with their racial and ethnic backgrounds for all calls (See

Appendix 2.1). Voice actresses (herein known as 'callers') piloted the scripts with a total of nine agencies (three each) that were not in the sample (e.g., because they did not accept Medicaid). Scripts were iteratively adjusted after completing pilot calls to ensure questions and responses were as close to real-life as possible. Team meetings with the principal investigator were held weekly over Zoom to discuss questions and progress and to debrief how the calls were going. These weekly meetings also allowed callers to process their experiences interacting with the agencies. After data collection was complete, each caller wrote a two-page reflection/memo of their thoughts, emotions, and experience playing the part of a mother seeking MH services for their child.

Calls were made in two waves of data collection during the COVID-19 pandemic. Wave one occurred in the spring of 2021 (mid-May to mid-June of 2021). Wave two occurred in the summer of that year (mid-June to mid-July of 2021). In Wave one, the caller reported they were seeking services for their daughter, whereas in wave two, the caller sought services for their son. Callers used a standardized script that simulated a mother seeking therapy for her adolescent child who had recently witnessed a traumatic event in their neighborhood and was experiencing symptoms of post-traumatic stress disorder (PTSD). Post-traumatic stress disorder was chosen as it warrants an urgent outpatient appointment with a MH specialist, and evidence-based psychosocial interventions are recommended by practice parameters to treat adolescent PTSD (e.g., TF-CBT; Cohen, 2010; Cohen et al., 2016).

Two different scripts simulated prospective clients with identical clinical histories, varying *only* on 1) insurance type: Medicaid and private insurance (see Appendix 2.2 & 2.3 for scripts) and 2) racially aligned pseudonyms selected by voice actress. The order of calls was randomized and separated by four weeks.

Callers made up to five separate call attempts at each agency to schedule an appointment when there was some initial contact with the clinic (e.g., the caller spoke to a receptionist but was waiting to hear back from the scheduler). If the caller could not talk with anyone at the agency (e.g., went straight to a machine), only three separate call attempts were made. On average, it took 1.8 calls (SD: 1.2 calls) to reach the scheduler. A series of standardized variations to the script were developed to address potential questions that the caller would not be able to answer (e.g., insurance identification number; Appendix 2.4).

Each agency in the sample was contacted twice by the same caller using the Medicaid or privately insured script. There were minor variations in the client's names, addresses, and date of birth between the two scripts to ensure callers were not recognized (see Appendix 2.1). Calls were made during normal business hours (9 a.m. to 12:00p.m. and 1:00p.m. to 5p.m.). Callers used an app to conceal their personal phone number, calling from a computer-generated number with a Cook County, Illinois area code. When prompted, callers left voicemails, requesting the agency call them back to schedule a therapy appointment for their child, and returned calls from agencies who called back. Real appointments were made and canceled at the end of the call, enabling the comparative analysis of appointment rates and exact wait times using paired calls made by the same caller to each MH agency. All calls were kept as short as possible to respect agency resources.

#### Insurance Types to be Tested

In Illinois, Blue Cross Blue Shield (BCBS) is the largest private insurance agency. In 2018 it had 71% of the market share (Kaiser Family Foundation, 2019). Therefore, BCBS acted as the default private insurance plan when requested by schedulers. In Cook County, Illinois, 100% of Medicaid beneficiaries are enrolled in a Medicaid Managed Care Organization (MCO;

Cook County Health and Hospital Systems, 2015), and approximately one-third of those are enrolled in CountyCare, the MCO owned and operated by Cook County Health and Hospitals System. When asked, CountyCare was reported as the Medicaid MCO in this study.

#### Trauma-informed Care

To assess the availability of trauma-informed care, the fictional youth described by the caller was said to be presenting with trauma symptoms (e.g., nightmares) after witnessing an act of violence in their neighborhood. When attempting to schedule an appointment, callers requested "trauma treatment," noting that their child's school social worker recommended it. If schedulers affirmed that the agency offers trauma treatment, the caller asked what types of trauma treatments are offered and record the response. Beyond assessing the availability of trauma-informed services, callers also captured whether schedulers screened for trauma and the general demeanor and tone of the schedulers.

### Study Variables

The primary outcomes were the ability to schedule an appointment and wait time for an initial appointment (measured in days). Secondary outcomes included the availability of traumainformed treatment. The primary independent variables of interest were insurance type (Medicaid or private insurance) and the caller's race (White, Latina, and Black). Callers asked for the earliest available date for an appointment and documented whether the appointment would be telehealth or in person. If an appointment was offered, the caller documented the number of days until the appointment from the date of the call. When an exact date for any of the outcomes could not be given, but a range was provided (e.g., "two to three weeks"), then an estimated date in the middle of the range was recorded. All appointments were cancelled at the end of the call to not take up agency resources.

If an appointment was not offered, the caller recorded why the appointment was denied. Offers to be put on a waitlist were defined as "no appointment offered" to avoid taking up agency resources and due to the uncertainty of whether the client would receive a call back to receive timely access to therapy. When an agency required additional steps to be taken before they would schedule an MH appointment, such as obtaining a referral or switching their primary care provider (PCP) into the agency's health network, callers recorded these as "no appointment offered" as these may act as additional barriers to accessing care. It is unclear how many families would follow through with accomplishing these administrative tasks.

### Analytical Plan

Descriptive results were calculated for appointment availability and wait time when appointments were offered, stratified by the insurance and race of the caller. A generalized linear model (GLM) was run to understand how contributing factors (i.e., insurance type, season the call was made in, organizational type, and race of the caller) impacted access outcomes (appointment availability and wait times).

#### Results

Figure 3 below illustrates the sampling process and cohort flow diagram. From the initial sampling frame of 229 safety-net health agencies in Cook County, Illinois, seven agencies (3.0%) were excluded after it was discovered in wave one that these agencies no longer offered outpatient MH services to youth. After three call attempts in each wave, callers could not speak to anyone at 32 agencies (13.9%) in the sampling frame. Of the remaining agencies (n = 190), callers were able to reach 110 agencies (48.0%) in both waves and 80 agencies in only one of the waves (35.1%).

# Figure 3. Cohort Flow Diagram.



\* Notes: Each agency was called under two scenarios—a family covered by Medicaid and a family covered by private insurance —represented by "contacts," such that there are two contacts for each agency. We were able to contact 110 of the 229 in-sample agencies twice, once by the Medicaid-insured caller and once by the privately insured caller. For 80 agencies, we were only able to reach them in one out of the two waves (50 Medicaid, 30 private insurance).

Callers were less likely to have two contacts (or calls, one for each script) with a response from an agency if the caller was Black or Latina or if the script used was private insurance (Table 2). Overall, contacts with a response were similar between organizational types (Table 2).

Agency Characteristic	Agencies, by Number of Contacts with a Completed Response						
	Out of	No	One	Two	Total		
	Sample	Contacts	Contact	Contacts			
	n (%)	n (%)	n (%)	n (%)			
Organizational Type							
Federally Qualified	4 (3.4)	16 (13.4)	40 (33.6)	59 (49.6)	119 (52.0)		
Health Center							
Community Mental	3 (2.7)	16 (14.5)	40 (36.4)	51 (46.4)	110 (48.0)		
Health Center							
Client Characteristics							
Insurance type	Insurance type						
Medicaid	3 (2.5)	17 (14.2)	50 (41.7)	50 (41.7)	120 (52.4)		
Private	4 (3.7)	15 (13.8)	30 (27.5)	60 (55.0)	109 (47.6)		
Race of caller							
White	5 (6.6)	1 (1.3)	9 (11.8)	61 (80.3)	76 (33.2)		
Black	0 (0.0)	13 (16.9)	39 (50.6)	25 (32.5)	77 (33.6)		
Latina	2 (2.6)	18 (23.7)	32 (42.1)	24 (31.6)	76 (33.2)		
Total	7 (3.1)	32 (14.0)	80 (34.9)	110 (48.0)	229		

**Table 2.** Contacts with Response, by Agency and Client Characteristics (N = 229 Agencies)

### Appointment Availability and Wait Time

Across two waves of data collection, a total of 451 contacts were completed. Regardless of the insurance type or race of the caller, an appointment was offered in less than one out of five contacts made (n = 78 or 17.3%). In around half of the contacts (n = 222 or 49.2%), appointments were denied. In a third of contacts (n = 144 or 31.9%), the caller was unable to speak to the scheduler after three to five attempts were made, and in seven contacts (1.6%), agencies were found to be out of the sample (Table 3).

Status	n (%)
Appt offered	78 (17.3%)
Appt denied	222 (49.2%)
Unable to speak to scheduler after 3-5 attempts	144 (31.9%)
Out of sample (removed after Wave 1)	7 (1.6%)

**Table 3.** Call Status (N = 451 Total Calls Across Two Waves)

After removing contacts where the caller was unable to reach a scheduler and out of sample agencies, I assessed whether an appointment was offered by insurance type. An appointment was offered in 44 of 160 contacts (27.5%) by the Medicaid caller and 34 of 140 (24.3%) by the caller with private insurance caller (Table 4).

Insurance Type						
Characteristic	Medicaid N (%)	Private insurance N (%)	Full eligible sample N (%)	P value		
All calls	160 (53.3)	140 (46.6)	300 (100)			
Organizational Type						
Federally Qualified Health Center	81 (50.6)	77 (55.0)	158 (52.7)	.449		
Community Mental Health Center	79 (49.4)	63 (45.0)	142 (47.3)			
Season						
Spring	83 (51.9)	80 (57.1)	163 (54.3)	.361		
Summer	77 (48.1)	60 (42.9)	137 (45.7)			
Race of caller						
White	66 (41.3)	66 (47.1)	132 (44.0)	.253		
Black	54 (33.7)	35 (25.0)	89 (29.7)			
Latina	40 (25.0)	39 (27.9)	79 (26.3)			
		Outcomes				
Appt Status						
Appt denied	116 (72.5)	106 (75.7)	222 (74.0)	.527		
Appt given	44 (27.5)	34 (24.3)	78 (26.0)			
Wait time in days						
Mean (SD)	13.6 (12.2)	9.5 (8.2)	11.8 (10.8)	.092		

**Table 4.** Characteristics of Completed Calls to Agencies (N = 300)

Among the 110 agencies reached by both the Medicaid and privately insured callers, 9.1% offered appointments to both callers, 59.1% to neither caller, 15.5% to the Medicaid but not the privately insured caller, and 16.4% to the privately insured but not the Medicaid caller (Table 5).

		Appointment   caller	Appointment by Privately Insured caller			
Appointment		No	Yes	Total		
by Medicaid	No	65 (59.1%)	18 (16.4%)	83 (75.4%)		
Caller	Yes	17 (15.5%)	10 (9.1%)	27 (24.5%)		
	Total	82 (74.5%)	28 (25.4%)	110		

**Table 5.** Completed Appointments by Insurance Status for Paired Calls Only (N = 110)

Wait times were only calculated for the subset of calls where callers were able to make an appointment (n = 78). The average wait time regardless of insurance type was 11.8 days (SD: 10.8 days; Table 4). On average, adolescents enrolled in Medicaid waited 13.6 days for an appointment, whereas privately insured adolescents waited 9.5 days (mean difference: 4.1 days; 95% CI: -.69 to 9.02; P = .092; Table 4). There was a statistically significant difference in wait times between organizational types, with an average wait time of 14.2 days in FQHCs and 8.4 days in CMHCs (mean difference: 5.8 days; 95% CI: .98 to 10.60; P = .019). On average, the White caller waited 11.0 days for an appointment, whereas the Black and Latina callers waited 12.7 days (mean difference: 1.7 days; 95% CI; -6.64 to 3.18; P = .486).

Appointments were denied most frequently because the agency required the family to switch their PCP into their network (32.0%), the family had to be put on a waitlist (22.1%), or the agency's waitlist was closed to new clients (17.1%; See Table 6 below). There was a significant association between reasons for appointment denials and organizational type ( $X^2(1) = 114.19, p < .001$ ). FQHCs overwhelmingly instituted the requirement that families must switch

their PCP into their network (31.1%) and rarely put families on waiting lists (2.7%). In contrast, CMHCs were more likely to put families on waitlists (19.4%) or report their waitlist as closed (14.0%). Further, there was a significant association between reasons for appointment denials and insurance type of the caller ( $X^2(1) = 14.50$ , p < .05), with Medicaid callers more likely to be required to switch their PCP (19.8%) than privately insured callers (12.2%). Finally, there was a significant association between reasons for appointment denials  $(X^2(1) = 73.67, p < .001)$ .

	Denials by Organizational Denials by Insurance Type		Denials by Race of Caller			Overall		
	Ту	ре						
	CMHC	FQHC	Medicaid	Private	White	Black	Latina	<b>All Denials</b>
Primary	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
Reason								
Internal	2 (1.0%)	69 (31.0%)	44 (19.8%)	27 (12.2%)	28 (12.6%)	30 (13.5%)	13 (5.9%)	71 (32.0%)
primary care								
physician								
needed								
Put on	43 (19.4%)	6 (2.7%)	28 (12.6%)	21 (9.5%)	27 (12.2%)	6 (2.7%)	16 (7.2%)	49 (22.1%)
waiting list								
Waiting list	31 (14.0%)	7 (3.2%)	18 (8.1%)	20 (9.0%)	16 (7.2%)	4 (1.8%)	18 (8.1%)	38 (17.1%)
closed								
Insurance	13 (5.9%)	14 (6.3%)	14 (6.3%)	13 (5.9%)	0 (0.0%)	23 (10.4%)	4 (1.8%)	27 (12.2%)
plan number								
needed								
Insurance	11 (5.0%)	4 (1.8%)	2 (0.9%)	13 (5.9%)	9 (4.1%)	1 (0.5%)	5 (2.3%)	15 (6.8%)
type not								
accepted								
Need	4 (1.8%)	10 (4.5%)	5 (2.3%)	9 (4.1%)	9 (4.1%)	1 (0.5%)	4 (1.8%)	14 (6.3%)
referral								
Other (e.g.,	6 (2.7%)	2 (1.0%)	5 (2.3%)	3 (1.4%)	1 (0.5%)	4 (1.8%)	3 (1.4%)	8 (3.6%)
SSN								
needed)								
Total	110 (49.5%)	112 (50.5%)	116 (52.3%)	106 (41.7%)	<b>90</b> ( <b>40.5</b> %)	<b>69 (31.1%)</b>	<b>63 (28.4%)</b>	222 (100%)

**Table 6.** Reasons for Appointment Denials by Organizational Type (N = 222)

Table 7 below shows results from the GLM. Insurance and organization type were not predictive of the ability to schedule an appointment. Calls made in the summer were 19% more likely to have an appointment be denied than calls made in the spring (IRR: 1.189; p = .010; 95% CI: 1.042 to 1.358). The Black and Latina callers were 18% more likely to be denied an appointment than the caller who identified as White (IRR: 1.183; p = .019; 95% CI: 1.028 to 1.362).

Outcome	IRR	Standard Error	P value	95% conf	idence interval
Insurance type (reference group: Private insurance)	.934	.063	.311	.819	1.066
Seasonality (reference group: Wave 1)	1.189	.080	.010	1.042	1.358
Org Type – (reference group: CMHC)	1.105	.074	.136	.969	1.259
Race (reference group: non-White)	1.183	.085	.019	1.028	1.362

**Table 7.** Generalized Linear Model, All Completed Calls (N = 300)

#### Availability of Trauma-informed Care

Regardless of whether an appointment was given, the caller asked the scheduler whether trauma-informed treatment was available: "My daughter/son's school social worker recommended that she see someone who does trauma therapy. Do you know if anyone at your clinic does trauma therapy with teenagers?" If the scheduler said yes, the caller asked a followup question to ascertain whether evidence-based trauma-informed treatments were offered: "Could you tell me more about what types of trauma therapy you offer to teens?" Initially, the script asked the scheduler whether they provided a specific evidence-based treatment for trauma, TF-CBT. However, in the pilot calls, zero agencies knew what this treatment was, so I decided to broaden the question from TF-CBT to "trauma treatment" to increase response rates.

In 38.3% of the calls (n = 115), schedulers reported that their agency offers trauma treatment and the same proportion reported that they were unsure if their agency offered trauma treatment. Approximately 10.3% of schedulers reported that their agency did not offer trauma treatment. When schedulers noted that they were not sure, callers asked for someone else at the agency to call us back with the information stating that "It's important to me that my son/daughter gets trauma-informed care. Can you have someone call me back and tell me more about the trauma treatments your agency offers?" Out of 115 requests for a callback, only five agencies ever called back to provide more information on the trauma-informed services offered. Most schedulers noted that the caller could ask their therapist on the day of their intake appointment, said they were too busy to have anyone call back, or told the family they would call them back with the information but never did. Some schedulers told callers they would not provide information on whether the agency provided trauma-informed care because they did not have an appointment. In 13.0% of calls, callers were unable to ask the scheduler whether they offered trauma treatment (this often occurred when callers were hung up on after being denied an appointment).

Among the schedulers who reported their agency offered trauma treatment, 39.1% (n = 45) of those (or 15% of the sample) could name a specific trauma treatment that the agency offered. Most commonly, schedulers reported that cognitive behavioral therapy was available (n = 24), followed by TF-CBT (n = 6), eye movement desensitization and reprocessing (EMDR; n = 5), dialectical behavior therapy (n = 4), and play therapy (n = 2). Notably, only TF-CBT and EMDR are considered evidence-based treatments for PTSD in adolescents (Lewey et al., 2018). **Discussion** 

Although the United States is facing a youth-MH crisis, less than one out of five callers

in my study were able to schedule an appointment. Various barriers prevent families from accessing MH services, including a lack of capacity to take on new clients, waitlists, and administrative hurdles such as switching primary care providers. Using an innovative mystery shopper study of safety-net health agencies in Cook County, Illinois, this study measured whether the insurance type of the caller (Medicaid vs. private insurance) and race of the caller (White, Latina, or Black) would predict access to MH care (ability to schedule an appointment and wait times). While results did not show that insurance type predicted access to care, overall levels of scheduled appointments were very low, with less than one in five calls resulting in an appointment. There were five major findings.

First, regardless of insurance type, callers were only able to schedule an appointment in less than one out of five calls. This is a concerning number that indicates the MH system, especially safety-net agencies which serve Medicaid populations, may not have the capacity to meet the increasing demand for services. When callers *could* schedule an appointment, overall wait times regardless of insurance type were relatively low, with an average wait of twelve days. As previous research has found disparities in access between individuals enrolled in Medicaid and private health insurance (Bisgaier & Rhodes, 2011; Steinman et al., 2012), the finding in this study that the insurance type of the caller did not predict access to MH care in safety-net agencies is an improvement. However, it is still extremely concerning that less than one in five adolescents could schedule an appointment, indicating the larger takeaway from this finding is that access is *equally bad* for both privately and publicly insured clients.

Second, whether an agency was an FQHC or a CMHC did not predict access to MH services, indicating these agencies are likely not prioritizing one insurance type over the other. However, wait times were significantly different between organizational types, with CMHCs

offering appointments five days sooner than FQHCs. Further, reasons for appointment denials varied by organizational type, with FQHCs effectively denying appointments due to an administrative requirement to switch the PCP into their network. In contrast, CMHCs primarily denied appointments due to waitlist or capacity reasons.

Third, the caller's race significantly predicted the ability to schedule an appointment, with the Black and Latina caller being 18% less likely to schedule an appointment than the White caller. These results add to the literature indicating that discrimination may be occurring at the point of scheduling, with schedulers having a bias toward scheduling a White-sounding name and tone of voice. Given that discrimination in scheduling may play a role in the long-standing racial disparities in MH access and outcomes (Cummings & Druss, 2011; McGuire & Miranda, 2008), more work must be done to investigate and intervene in discrimination that occurs in the MH field.

Fourth, results indicate the time of year a family is requesting services matters—families were 19% more likely to be denied an appointment in the summertime vs. the spring. While this finding could also be explained by the sex of the child that was reported on the scripts (spring: female, summer: male), prior literature and theory supports the hypothesis that seasonality is the causal variable of interest. For example, a mystery shopper conducted in New York State found that "the ability to schedule an intake for a psychiatry appointment was 4.1 times higher in the spring than summer" (Olin et al., 2016, p. 397). Olin and colleagues posit that agencies stop scheduling appointments in the summer as waitlists from the spring begin to exceed capacity (2016). Safety-net agencies, in particular, are often dependent on student therapists who complete practicums with them during the academic year (Palitsky et al., 2022). When summer comes around, these agencies lose their interns and with them some capacity to see new clients.

Seasonality effects may also be due to the academic school year for adolescents, with families more likely to request MH services later in the year once they know and trust the school staff, leading to increased referrals in the spring.

Fifth, and finally, this study uncovered issues regarding the *availability* of traumaspecific services (measured as a secondary outcome). I found that approximately 38% of agencies reported offering trauma treatment; however, only 40% of those agencies could name a specific type of trauma treatment that was offered. Of the treatments that were named, only eleven agencies (less than one percent of the sample) reported offering evidence-based treatments for trauma (i.e., TF-CBT and EMDR). When a scheduler was not sure if their agency offered trauma treatment, the caller requested that someone in the agency call them back to let them know of trauma treatment availability, given the importance of finding treatment that matches a parent's preference and child's needs (Bannon & McKay, 2005). Out of 115 requests for a callback, only five agencies ever called the pseudo-mother back to provide more information on the trauma treatment(s) offered by the agency. These findings indicate that schedulers have a gap in knowledge of the agency's existing services and that agencies lack the resources to return calls, both considerable issues for parents who are seeking to be informed consumers of MH services for their children (Sanders & Kirby, 2012).

Further, trauma-informed care should begin at the first interaction with the agency. However, callers frequently reported that schedulers were rude or lacked empathy, occasionally hanging up on them in the middle of a question. Trauma-informed care also acknowledges that a family shouldn't have to disclose their trauma to everyone at the agency unless it is clinically necessary (Substance Abuse and Mental Health Services Administration, 2014). However, callers reported that many schedulers asked for in-depth details about the trauma the adolescent

experienced, which could have the effect of re-traumatizing the family or dissuading them from seeking treatment. This study suggests a need for trauma-informed MH systems, encompassing both trauma-informed workforce and trauma-specific treatments. A trauma-informed workforce involves all professionals within the MH organization and will look different for schedulers than therapists. Regardless of their role, a trauma-informed workforce will offer sensitivity and understanding of the impact of trauma from the first interaction with the family to the final session of treatment (Fraser et al., 2014). Further, a trauma-informed MH system will prioritize the availability of trauma-specific treatments such as TF-CBT or EMDR, recognizing the complex and unique nature of trauma in the treatment of MH disorders (Beidas et al., 2016). *Policy Implications* 

These findings suggest three implications for policy and practice. First, I found that FQHCs denied appointments primarily due to an administrative requirement to switch one's PCP into their health network. While this administrative requirement is well-intentioned and designed to integrate physical and MH for clients, it may have the unintended consequence of denying access to families who have limited knowledge of how to navigate complex health systems to switch their PCP. Second, results show that the Latina and Black callers were 18% less likely to schedule an appointment than the White caller, indicating that, whether conscious or unconscious, discrimination (based on the tone of voice of the caller and racially aligned pseudonym provided) may be occurring at the point of scheduling. It is vital that MH agencies have an anti-discrimination policy in place and regularly audit whether employees are offering equitable services to everyone who comes through the door.

Third, fewer than forty percent of the agencies reported offering some form of trauma treatment, and only 15% of the sample could report a specific type of trauma treatment that was
offered. Further, callers reported being hung up on, being spoken to rudely, and being asked excessive details about the traumatic event by schedulers, indicating a lack of trauma-informed care at the first point of contact with the MH system. If schedulers are not aware of the services being offered and lack empathy with prospective clients, clients may disengage from seeking services or seek services from an agency with more knowledgeable and friendly front-line staff. More emphasis should be placed on the knowledge and training of front-line schedulers and staff to build a trauma-informed MH system.

#### Strengths & Limitations

Several aspects of this study's design allow for novel contributions to the literature. First, we called each agency twice using identical scripts that varied only on insurance type and sex of the child. This study provides the first experimental test of access to outpatient MH services for adolescents based on insurance type within safety-net health agencies. Second, most audit studies measuring discrimination in the MH field request appointments by emailing (Button et al., 2020) or leaving a voicemail with a provider without actually speaking to them (Kugelmass, 2016; Shin et al., 2016). A strength of my study is hiring women of different races and ethnicities and asking them to actually call (compared to emailing) to schedule and then cancel an appointment, providing a more authentic life approximation of a scheduling scenario. Another strength is the caller's ability to leave and return voicemails, an aspect missing from many mystery shopper studies previously conducted.

The limitations of this study suggest areas for future research. This study can not make conclusive statements on the impact of race on access to MH care because different races were represented by only one caller. Future studies should hire multiple callers of each race and ethnicity, as callers will naturally have different abilities at navigating calls. Second, this study

included only one Medicaid MCO and one private health insurance plan. A mystery shopper study conducted in Illinois found that access to care varied significantly (from 16.2% to 60%) based on the MCO that was reported to the PCP, indicating that the prospective client's Medicaid managed care plan may have an impact on access to care (Illinois Department of Healthcare and Family Services, 2020). Future research should consider testing multiple MCOs and private insurance plans against each other to understand how health plans lead to variations in access.

Further, my study did not include callers who were English Language Learners, who may face additional barriers to access. I am unable to fully disentangle the effect of seasonality and sex of the child on the ability to access MH care, given that they overlapped in my study. Future research should test both variables separately to understand the impact of each independently on access to care. Importantly, access alone does not equate to positive treatment outcomes and my study can not make determinations on the effectiveness of services offered in each of these organizational settings. Finally, demand for MH services increased during the COVID-19 pandemic when this study was conducted (Byrne et al., 2021). It is difficult to disentangle the impact of the pandemic on adverse-care patterns noted in this study, such as the impact of seasonality on access. Future research will be needed to determine how generalizable these findings are outside of the pandemic.

#### Conclusion

This study found that regardless of insurance type, pseudo-mothers were able to schedule a MH appointment for their adolescent child in fewer than one out of five calls (17%) made. This is a concerningly low rate indicating that safety-net MH agencies may be struggling to keep up with the increasing demand for services. Further, results suggest that racial discrimination (based on tone of voice of the caller and racially aligned pseudonym provided) may be occurring at the

point of scheduling – agencies should develop and regularly assess anti-discrimination policies to ensure appointments are given equitably. Less than half of the agencies in the study reported offering trauma treatment, and only 15% could name a specific type of trauma treatment that was offered. Coming out of the pandemic, our nation is facing a youth MH crisis. Substantial resources must be allocated to safety-net health agencies to ensure they are able to meet the needs of the marginalized populations they serve. **Appendix 2.1.** Self-Identified Pseudonyms Aligned with Caller's Own Racial and Ethnic Background

	Wave One	Wave Two
White caller	Claire Mayfield	Beth Schwab
Latina caller	Catalina Hernández	Ximena Rodriguez
Black caller	Marwa Metwally	Nagat Hamza

# Appendix 2.2. Medicaid Script

# **Mystery Shopper Script**

Medicaid / CountyCare Insurance Arm

**Opening:** Hi, I'm calling to schedule an appointment for my 14-year-old [daughter/son]. She/He needs to see a therapist.

• [CHILD SEX WILL BE RANDOMIZED BETWEEN CALLS]

# Likely will be asked for identifying information. At the next opportunity, ask:

- Insurance: "I have Medicaid through CountyCare; do you take that?" [**RECORD:** Accept Medicaid? Yes / no]
  - *If no, Medicaid / County Care is not accepted:* Can I pay for the appointment myself? [**RECORD:** Yes / No self-pay]
    - *If yes self-pay:* How much is the first intake appointment? How much are appointments with their therapist? [**RECORD:** Costs]
    - *If yes self-pay:* I am worried about that cost... Does your agency offer any ways to help with the cost if you don't have a lot of money? Like a sliding fee scale? [**RECORD:** Yes / No, and any other details they provide]
- If they ask, "What is your insurance number?": "Sorry, I don't have it on me. I can bring it in on the day of our appointment."

## If more questions are asked, answer then divert as quickly as possible:

• Divert Qs: "Actually, before starting the paperwork, do you know when the soonest appointment is?"

## If an appointment is offered:

- Specify Type of Appointment: "Okay, is this for an intake appointment or for when she/he will see their therapist?"
  - If it's for an intake appointment (it usually will be): "Do you know how long it usually takes to see the therapist after the intake appointment? We're really worried about her is all" [RECORD: Type of appointment, Days until seen by the therapist after intake]
- Specify whether the appointment will be in person or virtual: "Do you want us to come to the clinic, or will the appointment be over the internet?" [**RECORD:** In-person or Telehealth]
  - *Note:* If they give you the option of in-person or virtual, just tell them you want whichever will get you an appointment faster.
  - If the appointment will be in person: Confirm the agency address

- Specify Date. *If given a range, push for a specific day*: "Oh, do you know which day it would be? Because I was actually planning to be out of town around then." [**RECORD**: Date of call and date appointment scheduled]
- Book the appointment but ALWAYS CANCEL before you get off the call. "Oh shoot, you know what? I just looked at my schedule and see that I have an all-day training that day... please don't hold that appointment for me; I'll call you back to reschedule."

# Ask about Trauma Therapy:

- "Oh, also, my daughter/son's school social worker recommended that she see someone who does trauma therapy. Do you know if anyone at your clinic does trauma therapy with teenagers?" [**RECORD:** Yes/No]
  - *If yes:* "Oh, that's great to hear. Could you tell me more about what types of trauma therapy you offer to teens?" [**RECORD:** Type their response]
    - If the scheduler is unsure what you mean: "The school social worker told us to ask for something called trauma-focused cognitive behavioral therapy. Does that sound like something you offer?'
  - If no: "What types of treatment do you offer?"
  - *If they 're not sure:* It's really important to me that my son/daughter gets traumainformed care... Is there someone I can speak to in the behavioral health dept who might know more about your trauma treatments?

# IF TOLD THAT YOU CAN'T GET AN APPOINTMENT / THE WAIT LIST IS CLOSED, ASK:

- If told they can't give you an appointment, but they can put you on the waitlist and call you back when appointments open up: "How long is the wait list right now?" / "Oh, that is too long for us. No need to put us on the wait list" [**RECORD:** No appointment offered reason: put on a waitlist; also record Wait list estimate] THEN ask for referrals
- *If told the wait list is closed:* "Do you know when it will open up? Even your best guess?"
- ASK FOR REFERRAL ELSEWHERE: "Can you refer me somewhere else?" [RECORD: Yes / No, and where they refer you if applicable]

# BE SURE TO CANCEL THE APPOINTMENT BEFORE YOU GET OFF THE PHONE! DON'T LET THEM HOLD A SLOT FOR YOU!

Appendix 2.3. Private Insurance Script

# **Mystery Shopper Script**

Private Insurance / Blue Cross Blue Shield Insurance Arm

**Opening:** Hi, I'm calling to schedule an appointment for my 14-year-old [daughter/son]. She/He needs to see a therapist.

• [CHILD SEX WILL BE RANDOMIZED BETWEEN CALLS]

# Likely will be asked for identifying information. At the next opportunity, ask:

- Insurance: "I have Blue Cross Blue Shield; do you take that?" [**RECORD:** Accept Private? Yes / no]
  - *If yes, BCBS Accepted:* How much is the co-pay per session with my insurance? **[RECORD:** Co-pay cost per session]
  - If yes, BCBS Accepted: I know we have a high deductible plan and will be paying out of pocket until we reach our deductible... can you tell me how much is the first intake appointment? How much are appointments with their therapist?
    [RECORD: Costs per session]
  - *If yes, BCBS Accepted*: I am worried about that cost... Does your agency offer any ways to help with the cost if you don't have a lot of money? Like a sliding fee scale? [**RECORD:** Sliding Scale Yes / No, and any other details they provide]
- *If no, private insurance is not accepted:* Can I pay for the appointment myself? [**RECORD:** Self-pay Yes / No]
  - *If yes, self-pay:* How much is the first intake appointment? How much are appointments with their therapist? [**RECORD:** Costs per session]
  - If yes, self-pay: I am worried about that cost... Does your agency offer any ways to help with the cost if you don't have a lot of money? Like a sliding fee scale?
    [RECORD: Yes / No, and any other details they provide]
- If they ask, "What is your insurance number?": "Sorry, I don't have it on me. I can bring it in on the day of our appointment. Can you let me know when the next available appointment is in the meantime? I'm trying to shop around to find the fastest appointment as I'm really worried about my son/daughter."
- If they want to look up your insurance number: "We just signed up last week so we could get mental health services for my daughter/son. We're probably not in the system yet. Can you let me know when the next available appointment is?

# If more questions are asked, answer then divert as quickly as possible:

• Divert Qs: "Actually, before starting the paperwork, do you know when the soonest appointment is? I'm shopping around to find the fastest appointment as I'm really worried about my daughter/son"

# If an appointment is offered:

- Specify Type of Appointment: "Okay, is this for an intake appointment or for when she/he will see their therapist?" [**RECORD:** Type of appointment] (*Note: will usually be intake first*)
- Specify whether the appointment will be in person or virtual: "Do you want us to come to the clinic or will the appointment be over the internet?" [**RECORD:** In-person or Telehealth]
  - *Note:* If they give you the option of in-person or virtual, just tell them you want whichever will get you an appointment faster. If they tell you both options are just as fast, you can use the 'both' option in the drop-down
  - If the appointment will be in person: Confirm the agency address
- Specify Date. *If given a range, push for a specific day:* "Oh, do you know which day it would be? Because I was actually planning to be out of town around then." [**RECORD:** Date of call and date appointment scheduled]
- Book the appointment but ALWAYS CANCEL before you get off the call. "Oh shoot, you know what? I just looked at my schedule and see that I have an all day training that day... please don't hold that appointment for me; I'll call you back to reschedule."

# Ask about Trauma Therapy:

- "Oh, also, my daughter/son's school social worker recommended that she see someone who does trauma therapy. Do you know if anyone at your clinic does trauma therapy with teenagers?" [**RECORD:** Yes/No]
  - *If yes:* "Oh, that's great to hear. Could you tell me more about what types of trauma therapy you offer to teens?" [**RECORD:** Type their response]
    - If the scheduler is unsure what you mean: "The school social worker told us to ask for something called trauma-focused cognitive behavioral therapy. Does that sound like something you offer?'
  - If no: "What types of treatment do you offer?" [RECORD: Type their response]
  - *If they're not sure:* It's really important to me that my son/daughter gets traumainformed care... Is there someone I can speak to in the behavioral health dept who might know more about your trauma treatments? [**RECORD:** asked to speak to someone yes/no, and whether they gave you more information]

# IF TOLD THAT YOU CAN'T GET AN APPOINTMENT / THE WAITLIST IS CLOSED, ASK:

• If told they can't give you an appointment, but they can put you on the waitlist and call you back when appointments open up: "How long is the wait list right now?" / "Oh, that is too long for us. No need to put us on the wait list" [**RECORD:** No appointment offered reason: put on a waitlist; also record Wait list estimate] THEN ask for referrals

- *If told the wait list is closed:* "Do you know when it will open up? Even your best guess?"
- "Are you not offering appointments due to COVID, or is it due to something else?" [**RECORD:** Reason they stated you could not have an appointment]
- ASK FOR REFERRAL ELSEWHERE: "Can you refer me somewhere else?" [RECORD: Yes / No, and where they refer you if applicable]

# BE SURE TO CANCEL THE APPOINTMENT BEFORE YOU GET OFF THE PHONE! DON'T LET THEM HOLD A SLOT FOR YOU!

Appendix 2.4. Examples of Standardized "Work-Arounds" for Mystery Shopper Scripts

How did you hear about us?

• I found you online through a Google search.

Do you have a referral?

•

• No, but I can bring one in on the day of the appt

If told that you need a referral in order to get an appointment:

• OK, no problem, I can bring it in at the time of the appointment. Can you just let me know the next available appointment you have? I am shopping around and trying to find the fastest appointment as I'm really worried about my son/daughter

If told that the office must actually receive the referral before making the appointment:

- I'll ask the doctor's office to fax it to you, but can you just tell me what day and time you can give me an appointment? I'm trying to work out my schedule.
  - *If they still won't tell you the day and time, document it as* "no appointment offered, referral required."

Who is your employer - where is your insurance coming from?

- [FOR PRIVATE INSURANCE] My insurance is through my husband.
  - Profile 1: It's through my husband's work. [IF NECESSARY] He works for United Airways
  - Profile 2: It's through my husband's work. [IF NECESSARY] He works for Staples

If asked for an address for your husband's place of work:

- Profile 1: He's working remotely right now
- Profile 2: I don't actually know the address. But I can find it and bring it in.

If told that the distance between your address and the agency doesn't make sense:

- Profile 1: His/Her aunt watches him/her during the day, and it's close to her house.
- Profile 2: A friend told me to go to your agency because they were really happy with the care

I need to talk to your child's primary care doctor first before I can schedule the appointment:

• I don't know his number by heart. I'll look it up and call you back.

If told you need to switch primary care doctors in order to receive services:

• We are really happy with his/her primary care doctor. We would prefer not to switch. Is it necessary to switch doctors in order to receive an appointment?

• If they continue to say yes, you have to switch PCP: "We're open to switching his/her PCP because we would really like to receive services at this agency, and I believe his PCP is close to retirement anyway. Can you tell me the process to switch our PCP?"

If told they need to look up your insurance number:

• We just switched to this insurance last week; our old insurance didn't cover mental health services so we switched to [MEDICAID / BCBS]. We haven't gotten our card yet and won't be in the system. Can you just let me know the next available appointment you have? I am shopping around and trying to find the fastest appointment as I'm really worried about my son/daughter

If told they need your child's social security number:

• I don't have it memorized. I'll find it in my papers and call you back later. In the meantime, can we proceed with scheduling? I'm trying to get my schedule figured out.

**Paper 3:** Administrative Burdens as "Hidden" Barriers to Accessing Mental Health Services in Federally Qualified Health Centers: A Mixed-Methods Assessment

#### Abstract

Increasingly, adolescents are struggling with poor mental health (MH) outcomes, making it essential to understand how to improve access to high-quality MH services. This study examines how administrative burdens-the challenges citizens face when interacting with a government agency-can act as barriers to accessing MH services, especially for the most marginalized individuals. This mixed-methods study uses qualitative data from semi-structured interviews with hospital- and community-based social workers and quantitative data from a survey and a mystery shopper study conducted with Federally Qualified Health Centers (FQHCs) in a large metropolitan county in the United States during the COVID-19 pandemic. This study addresses two research questions: What kinds of administrative burdens exist in accessing MH care, and how do they act as barriers to accessing MH services within safety-net agencies? Findings reveal that FQHCs implement a variety of administrative burdens on prospective clients, such as a requirement to designate their primary care physician into the FQHCs network through their insurance prior to scheduling, difficulty navigating phone trees, and voicemails that are never responded to, and rude or discriminatory interactions with schedulers. Although FQHCs have been touted as a key mechanism to improve access to care for Medicaid populations, this study finds that administrative burdens implemented by them may act as "hidden" barriers to accessing MH care. Recommendations to reduce administrative burdens at both the organizational and system level are discussed.

#### Introduction

Approximately one in five adolescents in the United States has a mental health (MH) disorder, yet less than half ever receive treatment. The gap between the need for care and engagement in care is greater for low-income families who rely on Medicaid for their health insurance. Although significant policy advances in the past decade have aimed to increase insurance enrollment and reduce the costs of care, surveys consistently report the top three barriers to accessing MH treatment are: 1) high costs of services, 2) lack of insurance coverage and acceptance, and 3) difficulty navigating the MH system (Carrillo et al., 2011; Collaborative for Community Wellness, 2018; Heun-Johnson et al., 2019; Kaiser Family Foundation, 2017; Substance Abuse and Mental Health Services Administration, 2021). Often praised as a way to reduce these barriers, Federally Qualified Health Centers (FQHCs) are safety-net health agencies that focus on providing comprehensive and affordable primary and preventive health care to individuals with low incomes who are publicly insured or uninsured (MACPAC, 2017). In fact, they are mandated to accept anyone who walks through their door, regardless of their ability to pay or their insurance status and are supposed to make it easier to navigate the MH system by integrating these services into primary care, creating a "one-stop-shop" for a family's health needs.

However, the design of FQHCs cannot overcome a lack of resources required to help everyone who needs services. This may cause them to "ration" care, finding more subtle ways to turn away prospective clients. For example, Adams (Paper 2) found that in a subset of FQHCs, before prospective clients could schedule an appointment, they faced onerous administrative requirements, such as providing a referral or switching their primary care provider (PCP). These requirements may serve legitimate purposes to FQHCs, but they have unintended consequences

for clients already struggling with serious MH concerns, given the time, knowledge, and resources they take to navigate and accomplish.

Despite their legitimate purposes, these requirements may be onerous to individuals attempting to comply with them, a phenomenon otherwise known in the public administration literature as "administrative burdens" (Herd & Moynihan, 2019). Such administrative burdens placed on the client are found in many means-tested social welfare programs, such as Medicaid (Herd et al., 2013), Supplemental Nutrition Assistance Program (SNAP; Herd, 2015), Temporary Assistance for Needy Families (TANF; Fox et al., 2022), and the Earned Income Tax Credit (EITC; Bhargava & Manoli, 2012). Despite their prevalence in other social welfare programs, administrative burdens have not been systematically studied in safety-net agencies such as FQHCs, and little is known about *how* they may act as barriers to accessing MH care within these safety-net providers.

Thus, building on the administrative burden literature, this paper investigates how and why, despite their legitimate intentions, FQHC policies and practices may act as barriers to accessing MH services. Drawing on 12 in-depth, semi-structured interviews with hospital- and community-based social workers, survey data from 117 FQHCs, and a mystery shopper study, I address the following research questions: 1) *What kinds* of administrative burdens exist in accessing MH care and 2) *How* do these administrative burdens act as barriers to accessing MH services within safety-net agencies.

I argue that rather than directly refusing to schedule an appointment (or provide access to care), FQHCs increase administrative burdens for families and thereby increase barriers to accessing care. By creating onerous administrative burdens, FQHCs are creating new, hidden barriers to accessing care, especially for the most marginalized, for whom it is their mission to

serve. Policy implications for reducing administrative burdens at the organizational and systemlevel are therefore discussed.

#### Administrative Burdens in Health Care

Administrative burdens can take the shape of any policy that an individual perceives as excessively onerous while attempting to access a public benefit or program (Herd & Moynihan, 2016). Administrative burdens occur in various settings, from healthcare to voting to social welfare programs. Requiring a family to verify their income through the submission of W-2s to qualify for a program or produce an ID to vote are examples of administrative burdens. Five characteristics define administrative burdens: 1) they are consequential for individual's lives and can sway outcomes, 2) they are the product of deliberate choices by policymakers and organizations and are not simply unintended consequences, 3) they are distributive, in that they have the largest impact on the most vulnerable groups, 4) how administrative burdens are implemented will impact how people experience them, and 5) they often serve legitimate purposes and are not inherently bad (Herd & Moynihan, 2019).

The literature on administrative burdens distinguishes between the actions of the state and an individual's experience of that action. The same administrative burden may impact individuals differently based on their resources, social networks, knowledge, and MH or functioning. Herd and Moynihan posit that administrative burdens come with three distinct costs: learning, compliance, and psychological. Learning costs are "the time and effort expended to learn about the program, ascertain eligibility status and the conditions that must be satisfied, and how to gain access" (2019, p. 23). Compliance costs involve providing documentation to demonstrate eligibility or gain access, financial burdens related to accessing services (e.g., travel costs), and responding to discretionary demands made by administrators. Finally, psychological

costs involve the stigma from participating in an unpopular program, loss of autonomy from intrusive administrative supervision, frustration from coping with learning or compliance costs, and stress from negotiating compliance costs.

When resources are stretched thin, FQHCs use administrative burdens as a way of shifting agency tasks onto the shoulders of prospective clients, thereby reducing agency costs. To this end, agency staff (i.e., street-level bureaucrats) are given discretionary authority to determine the distribution of agency resources and the capacity to ration time and energy as needed (Brodkin, 2011; Lipsky, 2010). In this study, the FQHC schedulers who implement organizational policies act as mediators between agency and client and operate with the ability to impose or lighten administrative burdens, often in ways that reinforce inequality.

These burdens impact individuals in different ways, with marginalized groups fairing the worst (Chudnovsky & Peeters, 2020; Heinrich & Brill, 2015). While all individuals are likely to encounter administrative burdens at one point in their lives, some people are better equipped to cope with them because they have higher levels of human capital. Human capital is defined as "the stock of innate abilities and characteristics that people possess and the knowledge and skills they acquire over time" and can include "knowledge, personality traits, health, education, and cognitive functioning" (Christensen et al., 2020, p. 127). Individuals experiencing poor MH are more likely to rely on means-tested programs (such as Medicaid) and face unique difficulties navigating the processes required to use such programs. As the severity of MH disorder increases, an individual's ability to function in the world typically decreases. This likely includes a decrease in the ability to navigate and complete complex administrative requirements (Christensen et al., 2020). Living in poverty also reduces an individual's ability to cope with compliance, learning, and psychological costs associated with accessing benefits. The resource

scarcity involved with living in poverty leaves people feeling cognitively drained and can create a short-term mindset that makes it challenging to overcome compliance burdens (Chudnovsky & Peeters, 2020). This creates a catch-22 scenario where the individuals with the highest need for MH services at safety-net health agencies may be the least likely to access them, given difficulties in completing administrative burdens implemented by agencies.

### Barriers to Accessing Mental Health Services

There is a rich literature documenting the various barriers families experience when attempting to access MH services. The Substance Abuse and Mental Health Services Administration (SAMHSA) surveys Americans about these barriers every year. In 2020, the top reasons for not receiving MH treatment among individuals who perceived a need for treatment but did not receive it were 1) could not afford the cost, 2) did not know where to go for services, and 3) thought they could handle the problem themselves without treatment (Substance Abuse and Mental Health Services Administration, 2021). Yet, the SAMHSA survey contains no options related to the difficulty of completing requirements or administrative burdens as potential reasons for not receiving care, leaving a gap in knowledge regarding how prevalent and prohibitive these burdens are.

While there are various ways to categorize barriers, the World Health Organization and the National Comorbidity Survey, a representative survey of the U.S. population, both classify them under two broad categories: structural or attitudinal (Andrade et al., 2014; Mojtabai et al., 2011). Structural barriers are "defined by the health care system's availability" and include but are not limited to "availability and proximity of facilities, transportation, child care, and the structural characteristics of care" and wait times (Carrillo et al., 2011, p. 566). Attitudinal barriers tend to focus on cognitive beliefs and knowledge, with stigma, a view that one can

handle their problems on their own, and concerns that others will judge them for accessing treatment as key examples. Occasionally, structural barriers will be subdivided into financial barriers, homing in on the issues of cost and insurance coverage.

What neither of these categories covers in any detail is the issue of administrative burdens as a significant barrier to accessing MH services. They may fall under the category of structural barriers within "difficulty navigating the MH system," yet this phrase is still vague and does not allow us to distinguish *what* exactly makes the system difficult to navigate. Standardized surveys that assess barriers to accessing MH care have no questions about how the burden of completing onerous paperwork/policies may deter a prospective client from seeking care (Hooley et al., in prep). This is a major limitation in the current strategy for understanding and addressing barriers; to improve access to MH care, we must interrogate the existence and impact of administrative burdens.

I argue that administrative burdens are distinct from structural and attitudinal barriers to accessing MH services. The key distinction between barriers and administrative burdens is the level of mutability and intentionality between them. Using the administrative burden framework, we can understand the *how* and *why* behind requirements that serve as obstacles for clients, and we get a more realistic sense of the challenges of intervening in them. Unlike administrative burdens, structural barriers are rarely the result of deliberate policy choices but rather the result of underinvestment or disinvestment in the public MH system. For example, wait times are at least partially due to shortages in specialized providers and system capacity issues. In general, MH agencies don't *choose* to create long wait times; instead, they lack the resources necessary to hire more staff and must grapple with a nationwide shortage of MH providers (Kaiser Family Foundation, 2021b; Office of Inspector General, 2019). Transportation is another example of a

structural barrier to accessing MH care, but not an administrative burden, given that a lack of transportation options to MH agencies was likely not a deliberate policy decision. On the other hand, administrative burdens are deliberate and often well-intentioned policies implemented by an organization that have unintended consequences on an individual's ability to access or engage with care. By differentiating administrative burdens from structural barriers to accessing care, we can more easily identify intervention points.

#### The Case: Federally Qualified Health Centers as Safety-Net Mental Health Providers

Championed by President Lyndon B. Johnson in 1965 under the Office of Economic Opportunity, FQHCs began as community health centers. They quickly expanded from two clinics in the mid-60s, transitioned to the FQHC program in 1989 under new legislation (Lefkowitz, 2005), and expanded their reach in underserved communities through Medicaid and Medicare dollars. Today they are the nation's largest safety-net health provider.

Located in medically underserved areas, FQHCs are a critical component of the health care safety-net, serving client populations that are predominantly low-income, uninsured, underinsured, or who rely heavily on Medicaid. Further, FQHCs are required to offer "enabling services" to address access-related barriers, such as transportation, translation and interpretation, and insurance enrollment (Substance Abuse and Mental Health Services Administration, 2013). A 2010 assessment of behavioral health services in FQHCs found that approximately 70% of FQHCs offer on-site MH services (National Association of Community Health Centers, 2011). Significant funding has been funneled to FQHCs over the past decade, so this percentage has likely increased. FQHCs provide MH services by employing or contracting licensed psychologists or social workers to treat clients with mild to moderate MH disorders (Nardone et al., 2014). By "co-locating" physical and MH services, FQHCs hope to reduce childcare and

transportation costs associated with making trips to multiple locations to receive health services and better coordinate care between providers.

In Cook County, Illinois, the second-most populous county in America and the location for this research, FQHCs provide the largest percentage of MH services to Medicaid populations (Chicago Department of Public Health, 2016). Medicaid is the largest source of revenue for FQHCs, accounting for about 44 percent nationally in FY 2015 (Kaiser Family Foundation, 2021a). In the calendar year 2016, nearly half of FQHC patients had Medicaid as their primary source of insurance, approximately 37% were uninsured, and 13% had private insurance (Health Resources and Services Administration, 2020).

Because of their location in underserved areas, their open-door policy, and their ability to offer both MH and physical health services, researchers and policymakers alike have suggested that FQHCs are a primary portal for improving access to MH services for low-income individuals (Cummings et al., 2020). Yet, little systematic evidence exists on the real-world accessibility of these agencies and the degree to which administrative burdens, typical in these kinds of safety-net settings, are prevalent.

#### Methods

#### Qualitative Interviews

Sampling and Participants. To assess what kinds of burdens are typical for families accessing MH services through FQHCs, I conducted in-depth qualitative interviews with social workers whose jobs required frequent referrals and scheduling. Participants were eligible to participate in the study if they: 1) worked in a hospital or community-based health agency in Chicago and 2) their job function involved direct assistance to clients navigating the MH system. Twelve social workers participated after being recruited using snowball sampling. At the end of

each interview with a participant, I asked if they knew other social workers in hospitals or community-based health agencies whose primary role involved navigating the MH system. If so, I asked the participant if they would be willing to ask the social worker if they were interested in participating in an interview. If the social worker said yes, the participant connected us via email, and I sent them more information on the study.

*Data Collection.* This study received approval from the Crown Family School of Social Work, Policy, and Practice at the University of Chicago's Institutional Review Board. All participants gave verbal consent. A single interview session lasting between 45 and 60 minutes was conducted with participating social workers. Participants selected a charity to receive a \$20 donation for their participation. All interviews were conducted virtually over Zoom and were digitally recorded for accuracy. Data were collected from November 2020 through March 2021. The interview protocol consisted of semi-structured questions centered on participants' experiences navigating the MH system with their clients. Probes and follow-up questions were used in response to develop themes as the interview process progressed. Two qualitative research experts reviewed the interview protocol, and I edited it based on their feedback. Participants were asked what types of barriers their clients face when scheduling and attending appointments, and how they thought organizational type (e.g., FQHC status) impacts appointment access and wait times, among other questions (see Appendix 3.1).

*Data Analysis.* Notes were kept regarding participant responses, capturing impressions from body language as well as providing a backup to the digitally recorded data. Verbatim transcripts of all interviews were produced. Interviews were transcribed and later coded using Dedoose, a software program designed to support computer-assisted qualitative methods. A

pseudonym was assigned to every participant, and health agency names were redacted and replaced with their organizational type (e.g., hospital) to maintain anonymity and confidentiality. Transcripts were both inductively and deductively coded. First, using an iterative process, I read all transcripts and inductively began to look for major themes. Once the research questions and theoretical lens (administrative burden) were established, I switched to deductive coding methods, searching the transcripts specifically for quotes that would fit my theory-based categories.

*Demographics*. I interviewed twelve social workers employed in two settings: 1) within four hospital systems, I interviewed seven participants, and 2) within three community-based organizations, I interviewed five participants. The mean age of participants was 35 (range: 25 to 56). Eight participants identified as female, and four identified as male. Eight individuals identified as White, three identified as Latino/a, and two identified as Asian American (one individual listed multiple races). Three participants reported Hispanic ethnicity, and nine participants reported they were non-Hispanic. Eight participants were licensed, and four were working on hours towards their licensure.

#### Survey

A comprehensive sample of FQHCs and community mental health centers (CMHCs) were developed using the SAMHSA Treatment Locator and Uniform Data System and validated against multiple sources to ensure completeness and accuracy (see Paper 1 for more details). Approximately one year after the COVID-19 pandemic began in the U.S., 117 FQHCs and 117 CMHCs in Cook County, Illinois, were called and administered a 5-minute survey. This survey aimed to describe the availability and accessibility of outpatient MH services for children and adolescents at FQHCs and CMHCs, both types of community-based safety-net providers.

Sample questions include, "Is a referral required (for example, from a primary care doctor) to receive MH services at your clinic?" and "Do prospective clients need to have a primary care doctor within your agency to receive MH services at your clinic?" See Appendix 1.1 for the full survey and Adams (Paper 1) for more details on methods.

#### Mystery Shopper

This analysis draws on a mystery shopper study that examined how access to traumainformed MH services delivered in safety-net health agencies varied by insurance type, the race of the caller, and organizational type (see Paper 2 for more details). Three pseudo-mothers (White, Latina, and Black voice actresses) called eligible CMHCs and FQHCs (N = 229) in Cook County, Illinois, requesting to schedule a MH appointment for their adolescent child who recently witnessed a traumatic event. The women called each agency twice in the spring and summer of 2021 with alternating Medicaid and private insurance coverage. See Adams (in prep, paper 2) for more details on the methods. After each call, the voice actresses recorded the reasons the schedulers provided for denying appointments, discussed in-depth for this analysis.

Beyond quantitatively documenting the availability of appointments and reasons for appointment denials, voice actresses also qualitatively recorded their experiences interacting with schedulers by responding to the question, "Please provide any comments you may have on your experience on the phone with the organization (e.g., cordiality, if you were hung up on, level of knowledge, whether scheduler seemed distracted / busy, etc.)." Analysis in this study draws on that post-call memoing.

#### Results

The findings below help us better understand *what types* of administrative burdens exist and *how* these administrative burdens can act as barriers to accessing MH care. Findings are

organized by the administrative burdens found in this study, the details of how it acts as a barrier, and the learning, compliance, and/or psychological costs involved. See Table 8 below for an overview of the major administrative burdens found in FQHCs, the type of burden created by them, and how the requirement acts as an administrative burden.

Administrative Burden Examples	Type of Burden Created	<i>How</i> does the requirement act as an administrative burden?
A client must designate PCP with the agency through their insurance before an appointment can be scheduled	Compliance costs Learning costs	Compliance - Responding to discretionary demands made by administrators Compliance - Provision of documentation to access services Learning - Time and effort expended to learn how to complete the requirement
A client must provide the agency with a referral from their current PCP before an appointment can be scheduled	Compliance costs Learning costs	Compliance - Responding to discretionary demands made by administrators Compliance - Provision of documentation to access services Learning - Time and effort expended to learn how to complete the requirement
Negative interactions, such as being hung up on, being discriminated against, or being invalidated by administrators	Psychological costs	Psychological costs - Violates basic psychological needs for autonomy and respectful treatment, exacerbates burdens
Difficulty navigating phone trees, long hold times to speak to an agent, voicemails never returned	Learning costs Psychological costs	Learning costs - Time and effort expended to learn how to navigate call trees Psychological – the act of waiting conveys that individuals time is of little value

Table 8. Examples of Administrative Burdens Implemented by Safety-net Health Agencies

# Administrative Burden #1) A client must designate their PCP with the FQHC through their insurance before an appointment can be scheduled

Mr. Jones (pseudonym) is a social worker at one of the largest public hospitals in the United States. He works for a program that helps youth who have experienced physical violence in their community recover both physically and emotionally. Most of Mr. Jones' clients are insured by Medicaid or uninsured, relying on safety-net hospitals and community-based services for their health needs. Mr. Jones' job is to help his clients get connected to community-based social services to assist in their recovery once they are discharged from the hospital. In particular, he is tasked with referring his clients to MH services at community-based providers who will accept his client's Medicaid insurance or uninsured status. Given their open-door policy, FQHCs should be the ideal location for Mr. Jones to refer his clients to.

However, Mr. Jones notes that he rarely, if ever, refers clients to FQHCs, given an administrative requirement imposed by them that he perceives as burdensome. He reports that "for all of them [FQHCs], they've always been like, your client needs to see a primary care provider (PCP) at our center before they're referred to a behavioral health provider. And maybe this is just me feeling like I don't want to go through multiple barriers, but it's just discouraging to me." Mr. Jones proceeds to discuss *why* this requirement is so onerous on him and his clients. "If they have a managed care plan, you have to call the provider, you have to get their NPI (National Provider Identifier) number. Then you have to go to the insurance and be like, we want to switch the PCP to this FQHC. And then you go back to the FQHC, get an appointment with a PCP, and only then will they [the PCP] refer them to behavioral health. And so that's been why I don't go through those because I don't want to have to figure out their PCP."

The requirement that prospective clients designate their PCP into the FQHCs network through their insurance before they can schedule an appointment clearly illustrates an administrative burden. FQHCs may institute this requirement to for a legitimate reason: to better coordinate care and integrate physical and MH services. These goals have long been sought after by health care providers (Patel et al., 2013). Despite this requirement fulfilling the legitimate interests of FQHCs, Mr. Jones notes that his experience of it is onerous because of the difficulty involved in completing the multiple steps required to meet the administrative requirements. He notes that this requirement delays access to care and causes some potential clients to seek care elsewhere.

This burden is common; more than half (54.7%) of FQHCs reported that they required prospective clients to designate their PCP into their health agency network through their insurance before the agency would schedule an appointment. This finding was seen in the survey administered to 117 FQHCs in Cook County, Illinois, one year after the COVID-19 pandemic began.

Out of 158 calls to FQHCs to schedule a MH appointment in the mystery shopper study, 43.6% of pseudo-mothers were effectively denied an appointment, being told they must first designate their PCP with the FQHC through their insurance before the agency would schedule an appointment. FQHCs instituted this requirement for callers with both public (n = 43) and private insurance (n = 26). Almost no CMHCs (n = 2) called during the mystery shopper study imposed the same administrative burden, indicating there is something in particular about the FQHC organizational model that is causing them to implement this requirement. When the pseudo-mothers asked for details on *how* to designate their PCP with the FQHC through their insurance company, schedulers were rarely able to give them any instructions.

Mr. Jones found that the requirement dissuades potential clients, and both hospital- and community-based social workers I interviewed said that they too avoided referring clients to these safety-net agencies for that reason. It should be noted that hospital-based social workers were more likely to see this requirement as a barrier than community-based social workers, given that most of the clients they work with already have a PCP through their hospital network.

Participant 5 (Hospital-based): The FQHCs are, are great, but typically you have to be in primary care there to get the other services. But, um, if someone's coming here [Hospital name redacted], they're likely in care with us to some degree. Um, I would say that's the main barrier, you know, if they have to switch their PCP... which they won't do... they're not able to see someone as far as I understand who's not also in care there. They, um, you can't just access mental health services without a PCP and same as like in [FQHC name redacted] or a [FQHC name redacted] or any of those places. ... Uh, so FQHCs are a little bit limiting for us...

However, a few participants did note that they understood the rationale for requiring an internal PCP, for example, coordinating care, "Personally, I like when they [her clients] go to an FQHC. I think you get more services. I think you get a better support experience. I think there's more handholding. I think the FQHCs are a good transition for a lot of our kids that are used to quite frankly, probably too much, too much handholding from us." Another social worker discussed how FQHCs make it easier for clients to access medications:

**Participant 3** (**Community-based**): *I know certain individuals have told me that theythey do also, on the other hand, like having their PCP and their therapist in the same place, um, or psychiatrist even, in case they need to get medication there... then it's just* 

easier for them because they'll go and pick up their antibiotics and then also pick up, you know, any *m*- any other medication that they need as well.

When social workers were asked *why* their clients might not want to switch their PCP into the FQHCs network, many of them reported that the difficulty of the process of switching acts as a barrier:

**Participant 7** (**Community-based**): And another issue, I do notice that, uh, with community, some of the- these community health clinics, they, um, they want, they have a process, right? So they want clients to go through a PCP, so to establish care with a PCP at their agency, and then they would be referred to a therapist. They would always want our clients to go first through the PCP, and- and if I had clients that had already established care with someone else, they didn't wanna make that transition to another clinic just to be able to see a therapist. The ones [FQHCs] that had this process of going through a PCP first in order to see a therapist, that was difficult. I don't think a lot of my clients would really be okay with going through that whole process.

A primary reason shared by social workers for why their clients might not want to designate their PCP with an FQHC was already having a trusted PCP in another health network and the desire to maintain that relationship with the trusted PCP. Families may have a close relationship with a PCP in another health network but also need to access MH services closer to their home, as therapy generally occurs once weekly. Given that FQHCs are community-based and located in under-resourced neighborhoods, scheduling weekly therapy at a nearby FQHC and retaining their PCP at their primary healthcare location seemed to be the reported preference of many social workers' clients. One community-based social worker talks about the importance of trust with a PCP: Participant 9 (Community-based): So some of the FQHCs my- my clients have been told that they cannot receive services there if they don't have a PCP from there. So let's say they feel, you know, very comfortable going to a certain doctor, but if that doctor does not work in that FQHC, there's almost like a push and an insistence that they switch to the FQHCs program. Um, I think their rationale is just for communication, but itsome- I know certain individuals who were like, "No, I've been- I don't ... No, I like my doctor. It took me a very long time (laughs) to find a doctor that I trust and to be told that I have to switch, that's just not, you know, that's not happening." So that's one of the barriers.

Social workers also discussed how this administrative burden implemented by FQHCs differentially impact their most marginalized clients:

Participant 10 (Hospital-based): And a lot of our patients with serious mental illness don't feel comfortable navigating the, like these systems, like being on hold for a while, like being able to just talk to your representative and like, know exactly what they need. A lot of them, like don't really understand what a PCP is. And so I ended up just being like, okay, let's call together. Often the insurer is like, "why do you, why are you changing your PCP? Like we want you at this particular PCP?" It's just like, it's a lot of rigmarole that yeah. And it would be one thing.... this is going to sound how it's going to sound. But it would be one thing if it were me, like I have a job, like I am literate in the health system, I do this for a living. I'm happy to go to a PCP every year, like whatever. Um, but I mean, I'm also healthy. I am maybe borderline per paternalistic, which I definitely need to reign in, but it also is like, I'm just protective of our patients with severe mental health disorders, and I don't want to send them to someplace who isn't going to take their issues seriously and to do it well.

This burden acts as a learning and compliance cost on prospective clients, given that FQHCs are asking prospective clients to 1) respond to discretionary demands made by administrators, 2) provide documentation to access services, and 3) invest time and effort in learning how to complete these requirements. Depending on the stress involved in accomplishing this requirement, this burden may exert psychological costs as well.

Administrative Burden #2) A client must provide the agency with a referral from their current PCP before an appointment can be scheduled

Another administrative burden is simply that approximately two-thirds (65.0%) of FQHCs reported that they required prospective clients to have a referral (from a PCP or other healthcare provider) before scheduling an appointment. This causes difficulties and services as a barrier for a few reasons. First, if a family doesn't have a usual source of care to request a referral from, it would be nearly impossible to complete this requirement. Second, even if a family does have a usual source of care, it takes time away from both the family and the provider to request a referral for a service the family likely already knows they need. Third, families may not know how to navigate the process of retaining a referral, causing them to have to learn new information and navigate complex health systems.

Interestingly, while two-thirds of FQHCs reported requiring a referral prior to scheduling in the survey discussed above, only ten FQHCs who were called for the mystery shopper required a referral prior to scheduling. FQHCs who told us in the survey (which was administered two months prior to the mystery shopper study) that they required a referral prior to scheduling instead often told families they needed to switch their PCP into their network before

they could schedule, ostensibly switching the policy that had been previously shared to become a client. This highlights how these administrative burdens are conveyed inconsistently and provides an example of how street-level bureaucrats have discretion in which organizational policies they choose to enforce, who they choose to enforce them with, and how they choose to implement them.

While this administrative burden was noted in both the survey and the mystery shopper, social workers rarely discussed it in the qualitative interviews. This may imply that it is not a burden for social workers in hospital and community-based settings, likely because they themselves could make referrals for clients to these agencies. In contrast, it would still act as an administrative burden for families who did not have access to these social workers to provide referrals for them.

Requiring a family to provide a referral to receive MH care could act as both compliance and learning burdens, as FQHCs are asking prospective clients to 1) respond to discretionary demands made by administrators, 2) provide documentation to access services, and 3) expend time and effort involved in learning how to complete these requirements.

Administrative burden #3): Negative interactions, such as being hung up on, being discriminated against, or being invalidated by administrators

Another administrative burden I found was the presence of negative interactions with agency staff over the phone, such as being hung up on, being invalidated or talked down to, or experiencing discrimination. Out of 300 calls where voice actresses were able to speak to a scheduler during the mystery shopper study, they reported being hung up on 27 times, or in almost 10% of calls. One voice actress noted, "The receptionist stated, "we are not accepting

clients, and we do not know when we will accept new clients" and immediately hung up the line, not leaving any time for me to ask follow-up questions."

Beyond hanging up on prospective clients, voice actresses reported a range of negative interactions with the schedulers that acted as psychological costs of attempting to schedule a MH appointment during the mystery shopper study. Here the voice actresses discuss their experiences with rude schedulers, "The woman seemed exhausted by having this conversation and generally annoyed with me asking questions, just a lot of long sighs and sharp responses from her." Another voice actress discusses her experience with a short-tempered and unknowledgeable scheduler:

**Voice Actress:** The agent was very rude. When I told him I was not able to hear, he kept replying, "I have been telling you hello for over a minute now and you don't answer" which was not true because I had just started the call. He right away said that they are not accepting new clients. I was trying to ask him questions regarding insurance and treatment options, and he kept saying he was not sure and to visit their website.

Voice actresses frequently reported experiencing schedulers who were unknowledgeable, unable to answer basic questions such as whether their insurance type was accepted or when the next available appointment was, "This scheduler had no information on pricing or what types of therapy were offered, and she was not interested in finding any answers, it was a

### FRUSTRATING experience,"

On rare occasions, schedulers acted invalidating and condescending towards voice actresses. In the illuminating quote below, the voice actress shares how the scheduler made her feel like she did not understand her pseudo-son's MH symptoms and talked down to her as she was "not a doctor."

**Voice Actress:** This scheduler was frustrating and infuriating and would not let me make an appointment, stating my son did NOT need a referral. So I asked why I couldn't sign him up for therapy if I didn't need a referral and she stated that he was not exhibiting mental health symptoms because he was NOT HARMING HIMSELF. When I stated that he was being quiet and having nightmares, were these mental health symptoms? she said, "no they are not. Are you a doctor?"

Another voice actress notes how the scheduler made her feel discouraged from accessing care after a using complex medical terminology, directing her to call her insurance, and seemingly attempting to disinterest her in their treatment model:

**Voice Actress:** The agent was speaking in a very condescending tone by saying, "I just want it to be clear," and using medical terminology (like Diagnostic Statistical Manual or DSM) without explaining it. They seemed like they did not want to help me get scheduled instead, they wanted me to call CountyCare, my insurance number. They also mentioned that "they are not the regular therapy place." They follow the medical model which the therapy sessions are shorter, from 3-10 weeks and 20 to 30 minutes. The whole conversation seemed very discouraging.

Voice actresses also experienced instances of potential discrimination based on their tone of voice and the sex of the child for whom they sought to schedule an appointment. In the first quote below, the Latina caller discusses her experience with one agency where she had trouble navigating phone trees and potential discrimination based on the tone of her voice:

**Voice Actress:** *I* had to call this organization multiple times and leave voicemails, but no one called back. I then called again and was provided two additional numbers to contact for behavioral health. One of the numbers sent me to voicemail, and the other one

answered my call. The receptionist needed my ID number from Medicaid to then be transferred to scheduling. After asking multiple times about a wait time estimate for a child appointment, she shared that because my English was "pretty good," and they assumed my child's English would also be "pretty good," my wait time would be three weeks to be put on the waitlist. I then proceeded to ask, "what do you mean that my English is pretty good?" and they mentioned that for Spanish speakers, the wait time is more than a month long. Keep in mind that I never asked for services in Spanish. In the next quote, the scheduler speaks to the Latina voice actress and assumes her son is "hanging out with the wrong people" before hanging up on her.

Voice Actress: The receptionist was very rude and very rushed. She asked me if I was asking for services because my child has ADHD, depression, or anxiety. I replied saying, I was not sure what those were, so I was not sure. Then she said hold on. Then she got back to me asking if I was there "because my son was hanging out with the wrong people?" I replied that I never mentioned that he was hanging out with the wrong people. Then as I was asking questions about trauma therapy, she said, "I have another person on the line, I have to go. The therapist will get back to you to schedule an appointment," and proceeded to hang up.

These quotes highlight the psychological costs of accessing MH services at a FQHC. Parents attempting to access MH services for their children are likely already overburdened and stressed. When schedulers are rude, invalidating, condescending, unknowledgeable, and even discriminatory, it violates one's autonomy and creates a powerful incentive to not engage with services. It is important to note that for every negative interaction that voice actresses reported with a scheduler at one agency, a scheduler at a different agency went out of their way to either help schedule them for services or refer them somewhere else. The subset of quotes above are only *examples* of how families experience administrative burdens.

Administrative burden #4): Difficulty navigating phone trees, long hold times or inability to speak to an agent, voicemails never returned

Finally, the last major administrative burden identified was the difficulty involved in navigating complex organizational phone trees (e.g., "Press 9 for the intake coordinator"), long hold times to speak to an agency, inability to speak to anyone at the agency, and many voicemails that never get a response. Despite having called each agency in the sample during the initial survey to validate the sample, voice actresses were unable to speak to the scheduler in a third of calls during the mystery shopper study (n = 144 or 31.9%). This indicates the extreme persistence required to reach a safety-net agency or get a voicemail returned.

In post-call memos, voice actresses from the mystery shopper study point to these issues as well: "Severely long cue positions and wait times and my intake info never received a return call after ten days of submitting it," "I never spoke with anyone that could help and I was transferred to voicemail multiple times and then around to numerous departments, as the receptionists seemed lost or confused."

In the qualitative interviews, social workers also spoke about how the difficulty of navigating phone systems acts as an administrative burden. When asked about the struggles that adolescents in their families faced when scheduling appointments, one hospital-based social worker responded, "Well, I think calling places and leaving voicemails and never get a callback. Or calling places and being on hold for hours. Those are difficulties that are very real." The same social worker coaches the families she works with, "We often say, "Please don't just call one agency," right. Here is a list of five or six or seven, I mean even ten community MH places or,

you know, universities or hospitals, please call everyone just get on the list. And see who calls you back the quickest."

The burden of navigating call trees, sitting through extended hold times, and never having voice mails returned conveys both learning and psychological costs to prospective clients. Families must expend learning costs by spending time and effort learning how to navigate call trees. Psychological costs are expended when voicemails are never returned. Waiting on hold to speak to a scheduler conveys that an individual's time is of little value. Further, seeking MH services is an especially vulnerable process; when providers don't return voicemails, it conveys a lack of care for the family. One hospital-based social worker speaks to this in responding to a question regarding how she would fix the MH system if she had unlimited resources:

**Participant 1, (Hospital-based):** I mean, I think it would be amazing... If, when a parent or adolescent call and mental health agency... That someone picks up the phone and returns a call within 24 hours. Yeah, because often times families call, and they don't get an answer. And we know how difficult and how much courage it takes for adolescents to seek mental health services and be constantly faced with barriers or rejection, or you got to wait or, you know, or I'm not calling you back like those things don't help. So I think immediately return a phone call. I think waiting and constantly being told, "No, you can't be seen," and never getting phone calls returned, you know, those are such barriers that really turn people off mental health care.

#### Miscellaneous Administrative Burdens

Additional administrative burdens were noted in this study that deserves further attention to understand how widespread they are. For instance, one social worker noted how FQHC attendance policies acted as a barrier to her most economically marginalized clients,
**Participant 1 (Hospital-based):** Some of these places [FQHCs] have a very strict attendance policy. So, I know that one family told me that [FQHC name] told them if they miss one appointment or if they don't attend X amount of times, they're immediately cut off from services - their case is closed. But currently, this person's internet is not very stable. She was unable to log in, so she was considered to have missed the appointment and therefore was terminated from care. So I think even with attendance thinking through internet issues, right.

Another social worker discussed how some FQHCs require clients to get a physical from a PCP within the agency before they can be referred to MH services. They share how this process can duplicate work already done by the hospital and create compliance costs for clients, dissuading him from referring his clients to FQHCs,

**Participant 10 (Hospital-based):** We're already a health provider, and I know that our patients are ready. They usually have acute health needs. And it is laughable to me to be like, well, you know, you really should really think about getting a physical and seeing our primary care doctor before you can be referred to a behavioral health provider. And they (his clients) are like, "I've already seen six doctors. Like, I don't want to do that."

Finally, during the survey conducted with 117 FQHCs, we also asked about the availability of psychiatry/medication management services. In response to this question, a subset of schedulers told us that to receive psychiatry or medication management services, the client must also be seeking therapy services at the FQHC. This could act as a compliance cost by forcing a family to comply with a policy that may not be necessary for high-quality MH care. For instance, some MH disorders, such as schizophrenia, can respond well to only medications. Further, given social stigmas surrounding MH care, families may not want to engage in therapy

but be open to medication. By restricting access to psychiatry appointments to only individuals who enroll in therapy, FQHCs may be adding additional compliance costs or swaying families not to engage with any MH treatment. I did not systematically track how many agencies had this requirement, given that it was only discovered that it existed during the administration of the survey. Therefore, future studies should systematically assess how common this requirement is and how it may or may not act as an administrative burden on families.

### Discussion

A major finding of this study is that families seeking MH care from safety-net providers encounter multiple administrative burdens. Specifically, a subset of FQHCs required prospective clients to obtain a referral or switch their PCP into their network through their insurance prior to scheduling an appointment. Some FQHCs had confusing call trees, long hold times to speak to a scheduler, infrequently returned voicemails, and representatives were occasionally rude, invalidating, and in the worst cases, discriminatory. These burdens generate extensive learning, compliance, and psychological costs for clients, such as the time and effort required to learn how to complete the requirements, the provision of documentation (e.g., referrals) to access services, and a violation of basic psychological needs for autonomy and respectful treatment.

I argue that these learning, compliance, and psychological costs keep individuals from accessing MH services at safety-net agencies, such that the most marginalized individuals—in this case, those with serious mental illness—are those most likely to disengage from the process of accessing MH care. Administrative burdens found within this study operate as barriers to accessing MH services; yet they are not measured or operationalized in the literature on access to MH services. Because of this omission in the literature, I refer to them as "hidden barriers."

By putting the administrative burden literature in conversation with the barriers to accessing MH care literature, we can bolster our understanding of how to improve access to MH care. Distinct from structural or attitudinal barriers typically discussed by the MH services field, administrative burdens may be well-intended, are distributive, and are the product of deliberate organizational or policy decisions. Framing these barriers as administrative burdens gives us a clearer picture of the proper place to intervene and allows us to measure these burdens in surveys to assess barriers going forward more accurately. By connecting the literature on MH services to public administration and organizational theory, we can better understand *how* and *why* barriers operate in organizations.

The mystery shopper study found that 43% of pseudo-mothers were effectively denied an appointment due to an administrative requirement that families switch their PCP to the FQHC network through their insurance prior to scheduling. A similar finding was reported in a mystery shopper of PCPs in Illinois conducted in 2019 as a part of an external quality review (Illinois Department of Healthcare and Family Services, 2020). The report noted that requiring families to designate their PCP with the FQHC through insurance before scheduling an appointment acted as a "barrier to all Medicaid enrollees trying to schedule appointments" (Illinois Department of Healthcare and Family Services, 2020, p. 60).

Previous research indicates that wait times for outpatient MH appointments at FQHCs are less than half of CMHCs (Adams, Paper 1). Street-level bureaucrats within FQHCs implemented compliance burdens around referrals and PCP requirements on almost 50% of callers, yet, almost no CMHCs implemented similar compliance burdens. This may provide initial evidence that: 1) FQHCs use administrative burdens to achieve an organizational imperative to reserve resources and ration care, and 2) these administrative burdens are acting as barriers to accessing MH

services at FQHCs by turning away prospective clients from even getting on the waitlist. Perhaps these administrative burdens implemented by FQHCs (and in turn, the number of people it turns away from care) are a part of how FQHCs keep wait times low. Future studies should systematically assess this hypothesis.

Surveys consistently report that "difficulty navigating the MH system" is a major barrier to accessing care. The learning costs imposed by the administrative burdens identified in this study are directly related to difficulties families report in navigating the MH system. For instance, tracking down and calling multiple agencies, working through complex phone trees, and taking the time and effort to learn how to submit paperwork and comply with demands made by street-level bureaucrats lead to this difficulty in navigating the system. Unfortunately, the individuals who should be benefitting most from MH services at safety-net agencies such as FQHCs may be the least likely to access them, given the human capital necessary to overcome these learning costs.

This study found that families experience significant compliance costs when attempting to access MH services at FQHCs. By requiring families to submit referrals or switch their PCP, FQHCs increase the amount of documentation required to access care and require families to respond to the discretionary demands of schedulers or street-level bureaucrats. These findings are echoed in another mystery shopper study conducted in New York State, which found that more than 50% of MH agencies required more than two steps (e.g., paperwork and a referral) prior to the family's first MH appointment (Gallo et al., 2017). Of the three components of administrative burden, compliance costs have been studied the most extensively. Among a range of social welfare programs, studies have found that an increase in documentation requirements or conditions for participation generally leads to a reduction in program participation (Herd &

Moynihan, 2019). Conversely, efforts to reduce compliance costs for participants increase program participation (Herd et al., 2013). This indicates that the compliance costs implemented by FQHCs may be decreasing engagement with MH services.

Notably, the administrative burdens identified in this paper indeed inflict psychological costs on families seeking services. An individual's first point of contact with the MH system is a critical juncture for developing trust in the MH system. Accessing MH services is an especially vulnerable moment for families, given the stigma surrounding accessing care. Being disrespected by schedulers or told to comply with confusing and complex administrative burdens may reduce the likelihood an individual or family engages in MH care at that agency. Suppose these experiences occur at multiple agencies, as happened to the voice actresses in the mystery shopper study. In that case, one might lose trust in the MH system entirely and begin to perceive MH treatment as ineffective. As Christensen et al. write, "It is possible that as citizens experience psychological costs in relation to interactions with the state, worsened MH may create a negative feedback effect between experiences of burden and executive functioning, further eroding people's ability to cope with burdensome state actions" (2020, p. 131). Future research should explore how reducing administrative burdens, whether learning costs, compliance costs, or psychological costs, may improve engagement in MH treatment.

Given that administrative burdens result from deliberate organizational decisions, organizations can also take steps to reduce these burdens while still finding alternative methods to achieve their original goals. First, FQHCs could simply reduce or eliminate administrative burdens on families trying to access MH services. They could eliminate compliance costs for families by not requiring a referral from prospective clients and not requiring families to switch their PCP. In the mystery shopper study, very few schedulers were able to walk callers through

the process of completing administrative tasks (such as how to switch their PCP), which adds significant learning costs for families. If FQHCs would like to retain this requirement, they could reduce learning costs by providing clear instructions to families on how to complete the administrative tasks necessary to become a client. Schedulers could also follow up with families to see if they had questions or needed assistance and FQHCs could ask families to switch their PCP only after they have scheduled and attended their first appointment so that the family can decide if the agency feels like a good fit for their needs and switching their PCP truly makes sense.

Administrative burdens are also mutable through proper regulations, incentives, and penalties at the system level. Beyond traditional access standards such as provider network standards, distance standards, and timeliness standards, Medicaid notes additional accessibility standards such as language, cultural competence, and physical accessibility of health agencies (i.e., ADA compliance). For example, the Center for Medicare and Medicaid Services (CMS) requires states to develop standards that consider care to non-English speaking individuals through the provision of interpreters. FQHCs, in particular, are mandated to offer interpretation services for non-English speaking individuals, and results from Adams (in prep, Paper 1) show that almost all FQHCs (97%) comply with this mandate.

I argue that, similar to the language standard and interpretation requirement, CMS should add a new accessibility standard around appointment scheduling requirements. States should require health plans to conduct a review of the provider offices' appointment scheduling requirements to ensure that administrative burdens are not unduly burdening a family's ability to schedule a MH appointment. Following the secret shopper conducted in Illinois in 2019, Health Services Advisory Group, the external quality reviewer, made a similar recommendation to the

Illinois Department of Healthcare and Family Services (Illinois Department of Healthcare and Family Services, 2020). States should also consider developing standards regarding the administrative requirements that are necessary or onerous to schedule an appointment to ensure that these requirements to become a client are not imposing burdens on families and impacting their ability to schedule an appointment. Right now, to my knowledge, the administrative requirements to become a client at any FQHC are not standardized, nor are they regulated. By standardizing these requirements and asking FQHCs to report on them frequently, we may reduce administrative burdens on families who simply wish to access MH services.

There are limitations to this study. A convenience sample was used for qualitative interviews, which may produce bias and limit generalizability. Future research should address additional perspectives on administrative burdens in MH access, such as FQHC leaders, administrators, and schedulers. As I was unable to speak to these individuals, I am unable to determine the exact reason that various administrative burdens are implemented. Finally, I am unable to determine how families perceive the administrative burdens discussed in this paper and can not make conclusions regarding how administrative burdens impact engagement with care.

#### Conclusion

The FQHC model has the potential to improve access to care, especially for the most marginalized in our society. Yet, a significant portion of these safety-net agencies are implementing administrative burdens on prospective clients that act as barriers to access and may dissuade individuals from engaging in care. Administrative burdens are distinct from structural or attitudinal barriers to accessing care in that administrative burdens are the result of deliberate organizational or policy choices and may serve legitimate purposes. In contrast, barriers (e.g., lack of transportation) are generally not deliberately constructed and do not serve a legitimate

purpose. This study highlights what types of administrative burdens exist and how frequently FQHCs implement them. It also highlights how administrative burdens can act as a specific type of barrier to accessing care that differentially impacts marginalized populations. I highlight policy and practice implications to reduce administrative barriers on clients, such as eliminating administrative burdens on families prior to scheduling and creating a new accessibility standard around organizational requirements to access care.

## Appendix 3.1. Interviews with Navigators, Qualitative Interview Guide

These questions are intended to help me learn more about the accessibility of outpatient mental health services for adolescents. I'm interested in chatting with you as you have a track record of helping families secure appointments at outpatient mental health agencies and assisting them with navigating the barriers they face in accessing care. In this interview, I'm interested in learning about how different organizational, client, and health system factors impact access to mental health services. Finally, I'd like to learn more about how COVID-19 has made it easier or harder for clients to access appointments, how it has impacted how you assist clients, and how you have adapted. As a reminder, your responses will stay confidential – I will not share your name, your agency's name, or your location with anyone outside the research team. Before we begin, do you have any questions? Okay, let's begin.

## **Personal Background**

- 1) How long have you worked for [org name]?
- 2) What is your current job title?
- 3) With regards to assisting clients in navigating the mental health system, what are your roles and responsibilities? This could include anything from connecting them to resources to reduce barriers such as transportation or assisting them with making the call to mental health agencies to schedule services.

### **Scheduling Process**

- 4) Ok, now let's turn to the nuts and bolts of scheduling. To get a better understanding of how you assist clients with navigating the scheduling process, I'd like to hear about an actual encounter you've had with coaching/assisting an adolescent or a family in how to schedule an appointment at an outpatient mental health agency. Please do not use any names when discussing this scenario.
  - a) **Follow-up:** What strategies do you teach families to get through various organizational call trees?
  - b) **Follow-up:** Are there any strategies you have developed to help families get appointments faster?
  - c) **Follow-up:** When a family you are working with calls for an appointment, but there are no slots available in the time frame they request, how would you navigate them through this?
- 5) I'd like to better understand what **you** think causes wait times at outpatient mental health agencies. When a client is given a wait time longer than they perceive as acceptable, what do you see as the factors that cause this?
  - a) **Probe:** Not enough clinicians to serve clients; bottlenecks e.g., scheduling clients and they don't show up
- 6) In your opinion what are the most important factors that can lead to long wait times or difficult scheduling? That is, what are the factors if any, that can influence how many days, weeks, or months someone must wait for an appointment?
  - a) **Probe:** Time of year/season? Insurance type? Age of client? Diagnosis of a client? The severity of a client's symptoms? [Be sure to probe about all factors]

- 7) What resources do you use to find agencies to refer clients to?
  - a) Probe: SAMHSA Treatment Locator
- 8) Now I'd like to hear your thoughts on wait times. Currently, there are no national standards or regulations set for acceptable wait times for mental health services. In your own words, what do **you** think should be the standard for an **acceptable** wait time for an adolescent's initial outpatient mental health appointment/intake? What is the boundary for when a wait time is too long?
- 9) If you had unlimited resources and could do one thing to improve how outpatient mental health agencies schedule clients or implement their waitlist process, what would it be?

# **Client-level**

Next, I'd like to talk about barriers your clients face when scheduling and accessing appointments.

- 10) Could you tell me more about the struggles that adolescents and their families face when scheduling appointments? What about attending scheduled appointments?
  - a) **Probe:** Transportation, childcare, co-pays, insurance status
  - b) Follow-up: [Use responses from the previous question]: You mentioned that [<u>transportation]</u> is an issue for your clients. How have you seen outpatient mental health agencies attempting to relieve this barrier for clients? What do you believe are the solutions, big or small, to resolving this barrier to accessing mental health care?
- 11) In your experience, how do different outpatient mental health agencies attempt to assist families to reduce out-of-pocket payments when they report economic hardship, if at all? What strategies do mental health agencies use to adjust client fees? And how have you helped clients pursue these?
  - a) **Probe:** Sliding scale, fee waivers
- 12) Could you talk more about the specific challenges that adolescents with serious mental health conditions (vs. more mild or moderate conditions) face when navigating the mental health system?
  - a) **Follow-up:** Are there certain organizations/agencies which are better suited to serve adolescents with serious mental health conditions (vs. mild or moderate conditions)?

## **Organizational-level**

Now I would like to learn more specifically about your experiences working with different community-based organizational types, that is, community mental health centers and federally qualified health centers, and how each may uniquely facilitate or hinder access to mental health services for different client types.

13) In general, what type(s) of organizations do you generally refer your clients to? Why?

- a) **Probe:** Location of agency, agency treatment model, presence of enabling services, connections/network with individuals who work at certain agencies, past experience with the agency
- 14) What have you heard about how mental health care delivery & treatment models differ between community mental health centers and federally qualified health centers?
  - a) **Probe:** On average, how many minutes are sessions at each organizational type? About how many sessions do clients receive before termination or referral, on average? What type of treatment modalities are able to offer, in your experience (e.g., long-term vs. short)?

# Health-system level

Next, I'd like to hear more about how health system factors, such as insurance type and managed care organizations, impact access to mental health services for the families that you work with.

- 15) Could you compare for me the experiences that you have had when assisting clients who have Medicaid vs. clients who have private insurance? For example, how do the barriers that clients with these two insurance types vary?
- 16) I'd like to talk more specifically about your experience working with adolescents & their families who are insured by Medicaid Managed Care Organizations (MCO). First, could you tell me about your experience working with families insured by the preferred Medicaid MCO in Cook County CountyCare?
  - a) **Follow-up:** Are clients insured CountyCare more or less likely to get appointments than clients who are insured by private insurance?
- 17) Next, I'd like to learn more about your specific experiences working with CountyCare as an MCO **compared to** other Medicaid MCOs. What are the major differences you have noticed in working with clients who are insured through these various Medicaid MCOs?
  - a) **Follow-up:** In your experience, does the rate of access or wait times vary based on the Medicaid MCO the family is enrolled in? That is, are clients insured CountyCare more or less likely to get appointments than clients who are insured by a different Medicaid MCO?
  - b) **Follow-up:** Do you prefer to work with families who are enrolled in one MCO over another? If so, why?
- 18) How do insurance company restrictions such as prior authorization act as barriers to families accessing mental health services? What about session limits imposed by insurance companies?
  - a) **Follow-up:** Walk me through the process of assisting families with navigating these various health system barriers

## **COVID-19 and Telehealth**

Just a few more questions on how the pandemic has impacted your work, access to mental health services, and your thoughts on telehealth.

- 19) How has COVID impacted access to outpatient mental health services?
  - a) **Follow-up:** Have telehealth services reduced barriers for any of the adolescents & families you work with? If so, which types of families have it reduced barriers for, and what barriers has it removed?
- 20) In your experience, what have been some of the benefits of moving to a virtual model? Some of the challenges?

Thank you so much for your time and thoughtful responses. Is there anything else you would like to tell me about access to mental health services, scheduling strategies, or telehealth that we didn't cover?

[END]

#### **Dissertation Conclusion**

Despite recent policy changes to increase insurance coverage and expand safety-net providers in underserved communities (Myong et al., 2020; U.S. Department of Health and Human Services, 2021), the gap between the number of adolescents who need MH services and those who receive them continues to grow (Office of the Surgeon General, 2022). This gap is even greater for racial- and ethnic-minority and low-income youth, where additional barriers such as discrimination and a lack of providers who accept their insurance coverage are at work (Alegria et al., 2010; Bisgaier & Rhodes, 2011; Kugelmass, 2016). The findings of this study document the challenges that families face when they attempt to navigate the tangled web of the mental health (MH) system and find care for their child. Notably, Paper 2 found that pseudomothers were able to schedule a MH appointment for their adolescent child in less than one out of five calls (17%), indicating that safety-net agencies have very little appointment availability, regardless of one's insurance type. Further, racial discrimination based on tone of voice of the caller and racially aligned pseudonyms may be at play, as the Black and Latina pseudo-mothers were 18% more likely to be denied an appointment than the White pseudo-mother. As opposed to well-understood barriers such as lack of insurance acceptance, this study uncovers a variety of "hidden" barriers, such as inaccurate or outdated online directories of providers, discrimination, administrative burdens or onerous requirements, and difficulty reaching providers through phone or voicemail.

Regarding the theoretical model posed for Paper 2 in the introduction of this dissertation, my study poses mixed findings. Paper 2 finds that family characteristics (e.g., race/ethnicity) lead to variation in the scheduler's implementation of organizational policies and practices. This in turn, leads to the access outcomes defined by Levesque and colleagues (2013). For example,

Paper 2 found that the Black and Latina callers were 18% more likely to be denied an appointment than White families. By contrast, Paper 2 found that the insurance type of the family did not predict the ability to schedule an appointment. This finding may indicate that safety-net health agencies such as CMHCs and FQHCs are working to fulfill their mission to increase access to MH services for marginalized individuals.

As outlined in Paper 3, each of these barriers adds learning, compliance, and psychological costs on families who are attempting to access MH care at every step of the helpseeking process. My dissertation outlines the various barriers that families must navigate once they have decided to seek treatment for their child. As highlighted below, each of the papers in my dissertation highlights one or more steps of the help-seeking process from a family perspective and social worker's perspective.

#### Step 1: Finding a MH Provider to Call

While some families may get connected to MH providers through their primary care physician or a school-based provider, many families seek out MH services near them online. Further, primary care and school-based providers also use online directories to help connect families to care. In Paper 1, I found that online directories of MH providers, such as the SAMHSA Treatment Locator, are out-of-date or provide inaccurate information. Specifically, I found that 12% of agencies were closed, and 20% did not offer MH services. This finding echoes the literature on "ghost networks," where insurance plan directories contain inaccurate information, leading to disruptions in access to care (Burman, 2021). However, while insurance companies have little incentive to keep their directories up to date given the time and money it takes to do so, online directories such as the SAMHSA Treatment Locator's sole purpose is to connect families to care. Further, SAMHSA administers its survey annually to MH agencies in an attempt to stay up to date. Likely, it's difficult for SAMHSA to provide accurate, up-to-date information not because the MH system is constantly in flux with providers opening and closing their doors daily. This leads us to the question: if insurance plan directories and online directories are inaccurate, where can families turn for up-to-date information on who is providing high-quality MH services near them?

### Step 2: Calling Mental Health Providers

Once a family has located an MH provider that they think will meet their needs, the next step is to call them to learn more about their services and schedule an appointment. In Papers 2 and 3, I found that families experience issues reaching providers, facing long call hold times, confusing call trees, and too many unreturned voicemails. In Paper 2, I show that callers were unable to speak to a human at a MH agency in one-third of the calls, indicating that the difficulty involved in reaching providers is substantial. Anecdotally, one provider told a research assistant for the mystery shopper study that their health network was receiving over 1800 calls a day, of which they were only able to answer less than half.

When families were able to speak to a scheduler, they occasionally had negative experiences on the call, such as being invalidated, talked down to, or even discriminated against. Paper 3 illuminates this with quotes from voice actresses who posed as mothers calling safety-net agencies attempting to schedule a MH appointment. Although she never asked for services in Spanish, the Latina voice actress noted that a scheduler told her that her English was, "pretty good" which would allow her daughter to get therapy services faster, as the wait time for Spanish speaking families was longer. This quote along with the quantitative findings from Paper 2 indicate that discrimination based on tone of voice and name of caller may be occurring. This means that racial and ethnic minority families face even more barriers to accessing MH care then White families. In another distressing quote, a voice actress discusses how a scheduler invalidates her sons need for services as he was "not harming himself" and she was "not a doctor." While these quotes may be outliers among the hundreds of calls placed by voice actresses during the mystery shopper, the psychological costs inflicted on families who may interact with these schedulers might be enough to fully deter them from continuing their pursuit to engage in MH services.

In approximately 10% of the calls conducted in Paper 2 where we were able to speak to a scheduler, the caller was hung up on by the scheduler, sometimes midsentence. Callers also experienced unknowledgeable schedulers who could not answer their questions regarding the type of treatments offered by the agency or the potential cost of services. For example, Paper 2 found that only half of the schedulers knew whether their agency offered trauma treatment, and only 39% of those could name a specific trauma treatment that the agency offered. These findings have implications for whether families persist in their process of seeking MH services, given the substantial psychological costs associated with fielding these burdens.

#### Step 3: Overcoming Administrative Requirements/Burdens

Assuming a family reaches a scheduler, they may first have to overcome administrative burdens implemented by the agency. In Paper 3, I discuss the types of administrative burdens implemented by federally qualified health centers (FQHCs) and how they act as barriers to families accessing MH care. As shown in Paper 2, almost half (44%) of FQHCs require families to designate their PCP with the FQHC through their insurance before the agency would schedule an appointment. When the callers asked for details on *how* to designate their PCP with the FQHC through their insurance company, schedulers were rarely able to give them any instructions. In Paper 3, social workers discussed how this requirement acts as a barrier for families they work with who trust their current PCP and don't want to switch. They also report this as a compliance cost for their clients who have difficulty managing complex health systems given their MH disorder. Navigating the learning and compliance costs associated with achieving these administrative requirements is difficult and takes time and human capital that many low-income families caring for a child with a MH disorder lack. More attention should be paid at both the organizational and the system level as to how these administrative requirements, while wellintentioned, may be acting as hidden barriers to accessing care.

#### Step 4: Scheduling an Appointment

Once a family has researched a provider, called them, and accomplished any administrative requirements implemented by the agency, they must then schedule an appointment. Yet, in Paper 2, I found that callers posing as mothers attempting to schedule a MH appointment for their adolescent child who had recently witnessed a traumatic event were only able to schedule an appointment 17% of the time. This finding suggests that safety-net MH agencies may be struggling to keep up with the increasing demand for services. Further, the Black and Latina pseudo-mothers were 18% more likely to be denied an appointment than the White caller. These results suggest that discrimination may be occurring at the point of scheduling and that agencies should develop and regularly assess anti-discrimination policies to ensure appointments, a scarce resource, are given equitably.

Even if a family is able to schedule an appointment, they face additional barriers that this study does not address, such as high costs of care, lack of transportation options, and a lack of high-quality internet or childcare (Carrillo et al., 2011; Ralston et al., 2019). If a family is denied an appointment, as so many were in my study, they must start the process over and begin with Step 1. We should further investigate how navigating the complex web that is the MH system

might cause some families to disengage from seeking services, exacerbating the gap between the need for and receipt of services that researchers and policymakers have been working to reduce for decades.

A family's first point of contact with the MH system is a critical juncture for whether they will decide to put their trust in and work through the system to engage in care. The combination of inaccurate online directories, rude/dismissive schedulers, racial discrimination, lack of appointments, and administrative burdens make the MH system feel "impenetrable" to the average individual, let alone a person recovering from trauma, experiencing an acute crisis, or living with a serious mental illness. When potential clients live in poverty and have a scarcity of resources, time, and human capital, combined with decreased functioning related to MH symptoms, navigating the complex web of the MH system no doubt feels impossible (Chudnovsky & Peeters, 2020). Parents are thus put in the insufferable position of being extremely persistent in their pursuit of MH services for their child, likely calling multiple agencies to experience denials, wait lists, and in the worst-case scenario, even discrimination or invalidation. A larger question posed by this study is how to untangle the fragmented web that is the MH system to make the system more accessible for all families, regardless of their racial or ethnic background or socioeconomic status.

#### Implications for Social Work Research, Policy, and Practice

This study is the first of its kind to empirically assess access to outpatient MH services for low-income adolescents who are experiencing trauma symptoms. Given the worsening gap that exists between youth who need MH services and those who receive them, this data is critical to inform policy and advocacy efforts as well as the development and testing of interventions to improve access. The profession of social work is the ideal avenue to pursue these efforts. The social work code of ethics notes that,

Social workers pursue social change, particularly with and on behalf of vulnerable and oppressed individuals and groups of people. Social workers' change efforts are focused on issues of poverty, unemployment, discrimination, and other forms of social injustice. Social workers strive to ensure access to needed information, services, and resources; equality of opportunity; and meaningful participation in decision making for all people (National Association of Social Workers, n.d.).

Paper 2 found that pseudo-mothers were only able to schedule a MH appointment for their adolescent child in less than one in five calls to safety-net health agencies. Further, the Black and Latina pseudo-mothers were 18% more likely to be denied an appointment than the White caller, indicating discrimination may be occurring at the point of scheduling. The lack of access to services and discrimination noted in my study are in direct opposition to the social work code of ethics. Given that social workers train and work in the safety-net health agencies in this study (Lynch et al., 2016), efforts to create change could begin internally, with social workers advocating for stricter enforcement of anti-discrimination policies within organizations. At a policy level, professional organizations such as the National Association of Social Workers could advocate for measures to improve the shortage of MH providers such as expanding loan repayment programs for MH professionals to practice in underserved areas and raising Medicaid reimbursement for treating MH disorders (Olfson, 2016).

A strength of this dissertation is the use of mixed methods to expand our understanding of how to improve access to MH services within safety-net health agencies (Creswell & Plano Clark, 2017). Interestingly, I found discordant results between two of the research methods

employed by this study. When callers were able to schedule an appointment during the mystery shopper study, the average wait time was shorter in CMHCs than FQHCs by six days (8 days vs. 14 days). These wait time estimates are on par with or lower than similar estimates (Chicago Department of Public Health, 2016; Olin et al., 2016). However, when schedulers were asked for wait time estimates during the survey administered in Paper 1, estimates were significantly longer in CMHCs than what we found in the mystery shopper study - the median wait time for virtual services was 60 days at CMHCs vs. 15 days at FQHCs (median was used given significant outliers reported by schedulers in the survey, whereas these outliers were not noted in Paper 2). This could relate to the nature of wait lists at CMHCs. Many of the CMHCs who reported the longest wait times (one year to a year and a half) reported to the callers in the mystery shopper study that their waitlist was closed, and therefore, the caller reported that the appointment was denied. However, on the survey, schedulers reported how long their waitlist was and not necessarily whether the waitlist was closed to new clients or not.

Another disparity between the two methods is the requirement that a family provide a referral prior to scheduling a MH appointment at FQHCs. In the survey, 65% of FQHCs reported that they implemented this requirement for prospective clients, whereas in the mystery shopper, only 5% of appointments were denied for this reason. FQHCs who reported requiring a referral generally also reported requiring prospective clients to designate their PCP with their agency before scheduling; it may be the case that FQHCs prioritize implementing the latter policy over the referral policy when speaking to an actual client as opposed to a survey response. These two discordant findings provide evidence that using different methodologies can produce different results on the same topic area.

Future research should identify effective models that improve access to high-quality MH

services for youth. The collaborative-care model has been shown to be effective at improving wait times in FQHCs (Kinnan et al., 2019), yet it has not been tested in CMHCs where wait times are more than double (Adams, Paper 1). Could collaborative care models be implemented in CMHCs that see clients with higher levels of acuity for longer periods of time? What other models might be effective at improving the availability of MH appointments for youth in community-based settings, and what are the major barriers to implementing them?

Second, researchers should aim to test the implementation of effective organizationallevel interventions to improve access to MH care. Importantly, this work should be done in collaboration with community-based organizations to conduct research that is not only more valid, but also more relevant to the needs of stakeholders in the settings for which it is ultimately designed for (Adams, 2019). Results from this study indicate that interventions should work to improve scheduling efficiency, implement and evaluate anti-discrimination policies, and reduce administrative burdens to make it easier for families to get high-quality care when they need it.

Third, data from this dissertation and supplementary data should determine where geographical gaps in access to outpatient MH services exist in Cook County, Illinois. While individual agency names will never be disclosed, neighborhood-level analyses could identify areas with "mental health service deserts" (Walker et al., 2016) where availability and accessibility of services are not existent or sparse. This data could then be used to develop geographically based policy recommendations in partnership with local agencies and community-based organizations, such as the Chicago Department of Public Health and the Collaborative for Community Wellness.

Finally, future research should be done on how administrative burdens or "hidden barriers" hinder families in their process of seeking care. Qualitative interviews with families

who have encountered these administrative burdens while seeking MH services would be especially enlightening to understand this issue from a family's perspective. Further, strategies should be developed and tested to eliminate or reduce administrative burdens within safety-net health agency settings. For example, FQHCs could remove the requirement that prospective clients must designate their PCP with the agency through their insurance prior to scheduling, and then test whether that increases the number of families who schedule MH services within their agency. While these requirements may be well-intentioned, their data from my study provide preliminary evidence that they may be inadvertently restricting access to individuals who are able to navigate them—that is, high functioning individuals with lots of human capital. To truly meet their mission, safety-net health agencies should critically assess the costs and benefits of maintaining onerous administrative requirements to become a client.

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