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## Stand Up for Science

### Angela DeJulius

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The Ohio Public Health Association and this journal have made it our mission to advance the science and practice of public health in Ohio. As professionals, our readers rely on rigorous evidence to practice prevention and work towards a healthier state and nation.

Without reliable data, we risk endangering human health by making decisions based on assumptions, ideology, or fear. The current federal administration's cuts to research and programs that support health should alarm us all.

For decades, the United States has invested in being the world leader in health science research and innovation. But as we watch the defunding of the NIH (where so far, cuts are estimated at \$2.7 billion), the CDC, and our universities, we will see the US lose its credibility and leadership of the global health research community. Our science workforce and infrastructure won't be quickly or easily rebuilt.

Science is a complex, self-correcting process of inquiry that, to many Americans, may seem obscure or abstract and, therefore, easy to defund. But behind every breakthrough there is a team of humans dedicating their careers to the work, and if we don't fund them today, we'll never have the miracle treatments of tomorrow. In 1980, glucagon-like peptide-1(GLP-1) was discovered, and it wasn't until 45 years later that the first GLP-1 drug was approved by the FDA. A revolution in diabetes treatment and weight loss was launched. With an estimated 14.7% of adults having diabetes, and 2/3 of us either overweight or obese, it's not surprising that 1 in 6 Americans are now taking a GLP-1 medication such as Ozempic or Wegovy! The long-term impact on cardiovascular disease and mortality isn't known yet (so we must continue to fund research), but the point is that basic science happens decades before we see the innovations that improve our daily lives and health.

Meanwhile, the outside world is not standing still. The European Union recently announced its Choose Europe for Science initiative, budgeting €500 million (\$570 million) in new money in the years 2025–2027 "to make Europe a magnet for researchers" who want to continue their work outside the US rather than struggle under the current administration. France has committed an additional €100 million (\$114 million) to recruit scientists from abroad. No doubt, the brain drain will accelerate.

It's one thing to abandon science, another to actively deny and undermine it. Sometimes there is a clear motivation based on politics and profits – such as the deletion of the Surgeon General's 2024 Advisory on gun violence, disregarding the frankly alarming truth that firearm-related injuries are the leading cause of death for children and adolescents in this country. At other times, there seems to be no reason other than fixed beliefs and opinions about issues such as fluoride (now banned from public water supplies in Utah and Florida), or childhood lead exposure risks (apparently no longer a concern since the CDC's National Center for Environmental Health was gutted). Denying scientific data won't change the reality of these or countless other health threats.

Science is complex, our knowledge of the truth evolves, and communication of this is hard. But because science continuously pursues truth, because argument and debate are baked into the process, it will endure. You don't have to love basic science to appreciate what it does for us—our profession relies on the evidence to understand the truth and build new knowledge. As public health professionals, we need to stand up for science even if it sometimes feels like we're standing alone. We cannot succumb to the comfort of silence or despair. It's time for us to listen to our hearts, use our brains, and find our courage.



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### **RESEARCH ARTICLE**

## Serious and Persistent Mental Illness Treatment and Support Services in Ohio: Perceptions from Consumers, Family Members, and Service Providers

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### **ABSTRACT**

**Background:** Given the prevalence of unaddressed mental health conditions in the United States, and the unique challenges that mental health service providers face in their therapeutic work with people living with serious and persistent mental illness (SPMI), it is imperative to understand how and where current services are meeting or falling short according to consumers of SPMI services, their family members, and service providers.

**Methods:** Utilizing a mixed-methods approach, SPMI recovery-oriented practices were assessed throughout Ohio. Data were collected from 332 participants (consumers of SPMI services, their family members, and SPMI service providers) via focus groups and surveys from June through November 2020.

**Results:** Overall, consumers and family members were satisfied with current services but felt negative about the process of finding services. Family members discussed that the behavioral health system did not do a good job of explaining what services were available and how to access those services. While participants generally held a positive perception that the mental health treatment system embraced the core principles of recovery, they overwhelmingly reported that service expansion was needed, both in terms of additional services and a higher volume of existing services, and they discussed the need to combat stigma. Most participants reported that they had perceived negative attitudes toward persons living with SPMI. Two-thirds of service providers perceived negative attitudes in service delivery.

**Conclusion:** Findings illustrate aspects of SPMI treatment and support services as possible areas for improvements, such as heightening community outreach and education, employing navigators, expanding transportation and telehealth options, and expanding crisis services. To address stigma, there were many calls across participant types for increased community education on SPMI and what it means to live with SPMI, with an outreach focus on reframing and positive community messaging.

Keywords: SPMI; Recovery-oriented practices; Stigma; Mental health; Mixed-methods

### INTRODUCTION

Properly managed mental health is an integral component of overall health and well-being, yet unaddressed mental health conditions are prevalent. Among adults in the United States in 2020, 21.0%, or 52.9 million people, experienced any mental illness, while 5.6%, or 14.2 million people, experienced serious mental illness in the past year.¹ Among the 14.2 million adults living with

serious mental illness, 35.5% did not receive inpatient or outpatient mental health services or take prescription medication for a mental health issue in the past year, and 49.7% perceived an unmet need for mental health services.<sup>1</sup>

Given the prevalence of mental health conditions in the United States, the need for treatment is great. Mental health service providers face unique challenges in their therapeutic work with



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people living with serious and persistent mental illness (SPMI), including clients' persistent, and sometimes sudden, recurrence of symptoms, loss of developmental achievements, and regressive behavior, as well as stigma from the community.<sup>2</sup> Therefore, it is imperative to understand how and where current services are meeting or falling short for individuals living with SPMI.

While there has been previous research focusing on perceptions of SPMI treatment and support services among individuals participating in those services, their family, and their treatment providers, to our knowledge this is the first research to assess SPMI services from all 3 groups in a single study. And, although states have published case studies reviewing the development/implementation of new mental health service/treatment models,<sup>3,4</sup> a statewide assessment of SPMI treatment and support services was nonexistent at the time of this present study.

Through the utilization of a mixed-methods research approach, the present study was designed to assess knowledge and availability of SPMI recovery-oriented practices throughout Ohio. The specific objectives were: assess knowledge of persons living with SPMI and their family members as to the availability of community treatment and support services, as well as knowledge of how to access needed services; assess community professional perceptions of treatment and support service needs, as well as their program/agency/organization's ability to provide appropriate services to persons living with SPMI; identify barriers and gaps in SPMI services; and assess current community messaging related to SPMI in examination of stigma of persons living with SPMI. The results from this study may inform policy to develop and improve accessibility to SPMI treatment and support services.

### **METHODS**

From June through November 2020, a total of 6 regional epidemiologists (REPIs) collected survey data and conducted focus groups. A REPI was assigned to each of Ohio's 6 state psychiatric hospital catchment areas. The state operates a psychiatric hospital in each of its geographical regions: Northeast, Northwest, Central, Southeast, and Southwest. The Northeast region, due to its dense population, has 2 state psychiatric hospitals, and thus, consists of 2 catchment areas. The REPIs were professionals with at least a master's degree in social science.

The study's principal investigator (PI) trained REPIs on the implementation of study protocols as well as provided REPIs with ongoing monitoring and technical assistance. Prior to focus group/interview (FGI) start, REPIs obtained participant informed consent, administered a brief survey of participant background, and administered assessments of SPMI recovery-oriented practices in participant communities. The REPIs conducted FGIs following scripted protocols and audio recorded all FGI proceedings with participant knowledge and informed consent. Study participation was voluntary. Focus groups were no larger than 11 participants and were 1 to 2 hours in duration. An applicable institutional review board approved this study.

### **Participants**

Participants for this research needed to have lived experience, ie, persons who had lived experience in having SPMI (ie, bipolar disorder, borderline personality disorder, major depressive disorder, schizoaffective disorder, schizophrenia), persons who had lived experience in having a family member/loved one with SPMI, and persons who had lived experience in providing treatment/support services to persons living with SPMI (eg, case managers, counselors, law enforcement officers, psychiatrists, and social workers). The REPIs were required to interview, per catchment area, a minimum of 15 persons living with SPMI, a minimum of 15 family members/loved ones of persons living with SPMI, and a minimum of 30 community professionals who provided SPMI services. Since the study's objectives included assessing treatment/support needs of persons living with SPMI and their family members, both consumers of services, 15 respondents of each were targeted. Thus, 30 consumers of services and 30 community professionals who deliver services were targeted for recruitment per catchment area. The study's overall target sample size was 360 participants.

Our sample size was determined based on the time allotted and resources available for the study. Note, since persons living with SPMI were recruited from treatment/support programs, they are referred to as 'consumers' in this study (ie, consumers of SPMI treatment/support services). In addition to biological relations, the term 'family member' includes loved ones of persons living with SPMI (ie, non-biologically related significant other, eg, spouse or romantic/domestic partner, relation by adoption/marriage, close friend). Also, participating family members may or may not have been connected to a participating consumer; they may have referenced a loved one not enrolled in this study.

Our sampling plan was based on strategies for mixed purposeful sampling. Purposeful sampling is selecting information-rich cases for in-depth study with sample size and specific cases dependent on the study's purpose.<sup>5</sup> The purpose of this research initiative was to conduct a statewide assessment of SPMI treatment and support services. Our sampling combined the strategies of maximum variation sampling and convenience sampling. Maximum variation sampling picks a wide range in variation among persons of interest. Our sample size was determined based on time allotted and resources available for the study.

Consumers were recruited to participate in the study through treatment/support programs. The REPIs and the study coordinator contacted community agencies by phone or email within each of the 6 psychiatric hospital catchment areas to invite study participation of agency staff, treatment clients, and family members of persons living with SPMI who participated in agency family programming. Other community professionals who provided treatment/support services to persons living with SPMI were also contacted by phone or email and solicited for study participation within each hospital catchment area. The REPIs also contacted local chapters of NAMI (National Alliance on Mental Illness) Ohio

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to assist with advertisement of the study and recruitment of consumers and family members. Due to difficulty in obtaining parental consent for minor participants, only individuals aged 18 years or over were invited to participate in this study.

All study data were primary data, and most data were collected via focus groups. Note, focus groups were used to allow for a larger number of study participants within the study timeframe. Most data were collected via focus groups. Interviews were conducted when only one participant showed for a scheduled focus group, or in the case of service providers, when mutual time among a group of service providers could not be found for a focus group.

### Instrumentation

Participants completed a brief demographic survey prior to FGI start. The researchers wrote these pencil and paper surveys to capture the following participant information: sex, ethnicity, race, age, level of education, as well as additional characteristics by participant type. Participants also completed the Recovery Self-Assessment Revised (RSA-R) questionnaire prior to FGI start. The RSA-R is a self-reflective, self-administered pencil and paper questionnaire designed to identify strengths and target areas for improvement in the provision of recovery-oriented care.6 There are 4 versions of RSA-R: Person in Recovery (administered to consumers), Family Member/Significant Other (administered to family members), Provider (administered to treatment/service providers), and Administrator (not administered due to too few administrator participants). Each RSA-R version is comprised of 32 to 40 items designed to gauge the degree to which programs implement recovery-oriented practices. Participants are presented with a list of statements and instructed to indicate how accurately each statement describes the activities, values, policies, and practices of the provider.

Each version of the RSA-R is comprised of 6 domains: client choice, consumer involvement, diversity of treatment option, individually tailored services, inviting space, and life goals. In addition, the Family Member/Significant Other version includes a seventh domain, family involvement. The RSA-R scoring consists of an overall score and a score for each domain. Each item is scored from 1 to 5, with 5 indicating the most positive perception that a program/agency/organization engages in recovery-oriented practices. For a more detailed description of RSA-R domains and scoring, refer to O'Connell et al.<sup>7</sup>

In FGIs, all participants were asked open-ended questions to assess community messaging related to SPMI in examination of per-

ceived stigma of persons living with SPMI. Consumers and family members were asked a series of open-ended and Likert-scale questions to assess their knowledge of available SPMI treatment/ support services, as well as questions to assess their knowledge of how to access needed services. Providers were asked a series of open-ended and Likert-scale questions to assess their perceptions of community treatment/support service needs, as well as their program/agency/organization's ability to provide appropriate services to address the needs of persons living with SPMI. For focus group questions (scripted protocols), see Appendix.

### **Data Analysis**

All analyses of quantitative data were conducted using the Statistical Package for the Social Sciences (SPSS) (SPSS Inc., Chicago, IL) and were descriptive and inferential in nature, consisting of counts, frequencies, and comparisons of means (one-way ANOVA). An alpha level of 0.05 was used for inferential testing. Qualitative data analysis was informed by grounded theory, with response categories generated to reflect the viewpoints of participants. Through an iterative, nonlinear process of discovery, response categories are identified and defined.8 The REPIs independently analyzed FGI transcripts, coded for participant responses, identified recurrent responses, and aggregated response categories across FGIs to write a data summary report for each assigned catchment area. The study's PI and coordinator independently analyzed FGI transcripts and data summary reports for each catchment area, then aggregated thematic categories across catchment areas to compile a summary report of major findings. They reviewed and discussed any discrepancy in thematic coding until consensus.

### **RESULTS**

A total of 332 participants enrolled in FGIs, 92.2% of the study's target enrollment goal (332/360). The number of individual interviews and focus groups stratified by participant type are shown in Table 1. For results of the participant background surveys, see demographic tables in Appendix.

### **Status of Treatment and Support Services**

When surveyed on the types of SPMI treatment/support services provided/utilized during the past 12 months, participants noted many (Table 2). Across participant types, medications, counseling (individual/group therapy), case management, and peer support services were most often mentioned. When asked to identify the treatment and support services currently available in their

Table 1. Number of Interviews, Focus Groups, and Participants by Participant Type

| Participant<br>type | Number of individual interviews | Number of focus groups | Number of focus group participants | Focus group<br>participant mean | Total number of participants |
|---------------------|---------------------------------|------------------------|------------------------------------|---------------------------------|------------------------------|
| Consumer            | 20                              | 15                     | 56                                 | 3.7                             | 76                           |
| Family              | 21                              | 13                     | 51                                 | 3.9                             | 72                           |
| Providers           | 65                              | 34                     | 119                                | 3.5                             | 184                          |
| Total               | 106                             | 62                     | 226                                | 3.6                             | 332                          |

communities for persons living with SPMI, participants named an array of services that varied by community type, agreeing that counties with urban centers had the most services, while service availability in less-populated counties was considerably lower. In some rural areas, there was limited knowledge of community offerings for managing SPMI. One consumer in a rural area reported, "I know there are a lot of things that aren't widely available."

Most participants (81.2%; N=234) agreed that current treatment/support services met the needs of persons living with SPMI. Figure 1 provides the proportional breakdown of affirmative responses by participant type. Most consumers reported that they had received the kind of services they thought they needed, however, many discussed that in the past this had not always been the case. Comments included: "Eventually [I received needed services], but it took a long time; Has it been as responsive or as fast or as insightful as it could have been? No. I ultimately got what I needed, but sometimes I really had to fight for it." Greater than half of responding family members indicated that they thought their loved one had received the type of services needed, although

family members also noted that this had not consistently been the case.

Most providers agreed that the services their agency/program delivered met the expressed needs of their clients living with SPMI. However, nearly all providers also felt that their agency had room to improve, or that they did the best they could with the resources they had. Treatment providers acknowledged barriers often outside their control that inhibited service delivery, such as disagreements with guardians or payees, number of available resources, and availability of doctors. They responded: "We do what we can ... but there are [service] gaps because of workforce shortage; Intensive case management can only be offered to so many people."

When asked to describe the level of satisfaction with the services/care they/their loved one received, consumers reported overall high satisfaction, while family members expressed differing levels of satisfaction, with half of family members reporting general dissatisfaction with the services/care their loved one received. Family members assigning low satisfaction scores stated personal

Table 2. Types of Treatment/Support Services Offered/Utilized During Past 12 Months by Respondent Type<sup>a</sup>

| Types of Treatment/Support Services Offered/Utilized   | Providers<br>(N = 183)  | Family<br>(N = 64)    | Consumers<br>(N = 72)  |
|--|-------------------------|-----------------------|------------------------|
| Assessment services  | 99 (54.1%)              | X <sup>b</sup> (X.X%) | X (X.X%)               |
| Case management  | 109 (59.6%)             | 28 (43.8%)            | 38 (52.8%)             |
| Financial services   | 37 (20.2%)              | 17 (26.6%)            | 12 (16.7%)             |
| Housing/supervised living/group homes  | 81 (44.3%)              | 3 (4.7%)              | 15 (20.8%)             |
| Individual/group therapy (public/private)  | 96 (52.5%)              | 43 (67.2%)            | 55 (76.4%)             |
| Inpatient substance use disorder (SUD) treatment   | 30 (16.4%)              | 4 (6.3%)              | 1 (1.4%)               |
| Medications (psychiatry and medication assisted treatment [MAT])                                 | 85 (46.4%)              | 54 (84.4%)            | 68 (94.4%)             |
| Outpatient SUD treatment, including intensive outpatient program (IOP)                           | 64 (35.0%)              | 2 (3.1%)              | 7 (9.7%)               |
| Partial psychiatric hospitalization  | 20 (10.9%)              | 5 (7.8%)              | 5 (6.9%)               |
| Peer support services  | 84 (45.9%)              | 15 (23.4%)            | 39 (54.2%)             |
| Psychiatric hospitalization  | 16 (8.7%)               | 15 (23.4%)            | 9 (12.5%)              |
| Referrals to serious and persistent mental illness (SPMI) services/supports                      | 117 (63.9%)             | X (X.X%)              | X (X.X%)               |
| Services for dual diagnosis  | 83 (45.4%)              | 4 (6.3%)              | 5 (6.9%)               |
| Other specified service(s)/support(s) <sup>c</sup>   | 49 <sup>d</sup> (26.8%) | 6 <sup>e</sup> (9.4%) | 8 <sup>f</sup> (11.1%) |
| Advocacy and mental health education/training  | 7                       |                       |                        |
| Clubhouse psych rehab/day treatment program  | 2                       |                       | 1                      |
| Crisis hotlines  | 2                       |                       |                        |
| Crisis services, including mobile  | 7                       |                       |                        |
| Employment/vocational services   | 7                       |                       |                        |
| Family support services  | 2                       | 1                     |                        |
| Funding source (ADAMHS—Alcohol, Drug Addiction and Mental<br>Health Services board and Medicaid) | 4                       |                       |                        |
| Primary care (medical)   | 4                       | 2                     |                        |
| Support/12-step/recovery groups  | 3                       |                       | 3                      |
| Supported employment   | 4                       |                       |                        |
| Transportation, including medical cab service, bus pass  | 4                       |                       |                        |
| Youth services, including school-based counseling  | 2                       |                       |                        |

<sup>&</sup>lt;sup>a</sup>Responses are not rank ordered.

<sup>&</sup>lt;sup>b</sup>X denotes response option not provided for respondent type.

Cother specified service/support with only 1 response across respondent types are not listed in the table.

The following 6 other services/supports were each provided by 1 professional: assertive community treatment (ACT teams), crisis intervention training (CIT) for police, food assistance (pantry), reentry services, SBIRT (screening, brief intervention and referral to treatment) and street outreach. The total number of other responses are greater than 49 as providers were able to specify more than 1 other service/support.

<sup>&</sup>lt;sup>e</sup>The following 3 other services/supports were each provided by 1 family member: assistance with activities of daily living (ADLs), guardianship, and unspecified other service/support.

The following 4 other services/supports were each provided by 1 consumer: art therapy, telehealth, NAMI—National Alliance on Mental Illness/ADAMHS board sponsored programs, and unspecified other service/support.



Figure 1. Proportion of Respondents Who Agreed Current Services Meet Needs of Persons Living with Serious and Persistent Mental Illness (SPMI)

difficulties in accessing care, inconsistent quality of care, and lack of some services as precluding them from rating satisfaction as high. Some dissatisfied family members acknowledged that their loved one's course of illness made it harder for services to work with them but thought the system should be more equipped to deal with this scenario, as it is common. Consumers referenced the services they were currently receiving and indicated high satisfaction with the level of these services. Several consumers noted that their satisfaction had increased over time, or that previous services had been lacking in comparison.

A large proportion of consumers (44.6%; N = 56) and most family members (82.1%; N = 56) reported that they had had unmet service needs. When asked to indicate the level of need for additional treatment/support services in their community for persons living with SPMI, participants overwhelmingly reported that additional services were needed a great deal. There was consensus that service expansion was critical to meet unmet needs, both in terms of additional services and a higher volume of existing services.

### Service Accessibility

When asked to rate how easily persons living with SPMI accessed treatment/support services, participants of all types most often reported moderate ease. However, almost universally, participants reported that there was insufficient community knowledge of the availability of behavioral health and recovery support services. Treatment providers generally thought that care was available but that people needing help did not always know how to access it. Treatment providers reported, "Part of the problem is a lot of people don't know how to access services, but once they figure out how to access it, then I think services are fairly readily available; The public doesn't always understand the system.... Our responsibility is to help them understand."

Family members also discussed that the behavioral health system did not do a good job of explaining what services were available and how to access those services. One family member shared, "The system is very crisis-oriented. When somebody is in crisis or hospitalized, they're going to get treatment. But they have to be in crisis. It's much more difficult for somebody to find treatment before they're in crisis." Consumers expressed dissatisfaction with the process of accessing treatment; often cited were difficulties in knowing what to do, long wait times for appointments, and a struggle to find providers who accepted their insurance. They noted that accessing services and moving through systems was

made easier by referrals, usually from a doctor to a behavioral health system that worked well together.

### **Thoughts on Improving Service Accessibility**

In addition to workforce development and increasing service capacity at all levels of care, participants offered many ideas as to what could be done to make accessing SPMI treatment/support services easier. Table 3 shows a list of participant recommendations for improving service accessibility. These recommendations

### Table 3. Participant Recommendations for Improving Service Accessibility<sup>a</sup>

Workforce development (recruit/retain staff)

Increase service capacity

Heighten community outreach/education

**Employ navigators** 

Provide immediate care (ie, treatment on demand)

Expand crisis services

Make follow-up care after crisis standard

Expand transportation/telehealth options

Open insurance options

Increase access to injectable long-acting medications

were responses aggregated across participant types and they did not vary by participant type. The most frequently discussed ideas are detailed below.

Heighten community outreach and education. Most participants generally thought that while care was available, people needing help did not always know about treatment/support options or how to access them. To increase general awareness of behavioral health services, participants prescribed heightened community outreach. One treatment provider stated, "How do people know what they don't know?" Providers discussed behavioral health outreach and engagement on the streets, in homeless camps, and around communities as highly important, including outreach to other systems (ie, hospital and criminal justice systems). Law enforcement advocated for 'in-reach' into jails, connecting people to needed services upon jail release. Family members called for more education: both about mental illness and about how to navigate treatment services. Consumers thought that better advertising of services, especially no-cost services, was needed throughout their communities. For instance, not all participants reported awareness of a 24-hour crisis hotline, although most discussed the utility of around-the-clock crisis and informational services.

<sup>&</sup>lt;sup>a</sup>Data collected from focus group/interviews (FGIs).

Employ navigators. There was consensus that there was a need for providers (ie, case managers) and peers that could act as navigators. Treatment providers noted success with having peer supporters help others navigate the behavioral health system. In fact, providers mentioned peer support most often as a necessary component to linking consumers to services. There was a shared belief that a network of relationships with people with similar experiences was crucial to long-term treatment/recovery. A provider remarked, "I think what we have done with client navigation is amazing ... having someone able to walk through the whole process with the client, from the beginning to the end...." Family members felt the most successful path was when they had gotten connected with one service or provider that then helped them navigate the system at large. Family members reported, "When he left [hospital commitment], he was able to get help and resources. If we hadn't had him committed, we would not have known what kind of resources there were; We didn't get hooked up with [a wraparound service provider] for 3 to 4 years, and once we did, everything got easier." Consumers concurred that case management and peer support were extremely valuable in connecting to needed services.

Expand crisis services. Providers discussed that crisis services not only address an immediate crisis, but they were also instrumental in linking persons with SPMI to ongoing treatment and support services. Moreover, providers noted a need for care that would prevent people from decompensating to a crisis level. Some treatment providers saw this as more wraparound support in the community, a 24-hour crisis center, or a level of care between hospitalization and people living on their own. Providers also advocated for crisis stabilization units, stabilizing a person in crisis to conduct a needs assessment and make appropriate linkages to services.

### Perceived Stigma of Persons Living with SPMI

When asked if there is any prejudice against persons living with SPMI when receiving services, 6 out of 10 participants reported that they had perceived negative attitudes (59.9%; N = 274). Figure 2 illustrates the proportion of each participant type that agreed prejudice existed.

Providers, consumers, and family members reported hearing consistent negative messaging about SPMI. All groups recognized that negative messaging reinforced stigma and prejudice against per-

sons living with SPMI, further creating feelings of shame, and discouraging people from openly discussing mental health and seeking services. A support services provider stated that many family members and consumers would rather not discuss SPMI diagnosis, remarking their preference often is to, "keep it quiet because they're ashamed." Family members discussed still working to overcome their feelings of shame regarding their loved one's SPMI diagnosis. One family member explained, "The first thing people do is drop their voice [when talking about SPMI]. After getting involved with [family supports], I no longer drop my voice." Several consumers reported dealing with feelings of shame around their SPMI primarily triggered by the reactions they received from others. A consumer shared, "I've been hurt by discrimination pretty badly, so I am always worried by what other people are thinking." Table 4 displays the most offered preferred messages across participant types.

Table 4. Participants Preferred Community Messaging Related to Serious and Persistent Mental Illness (SPMI)<sup>a</sup>

SPMI is a chronic illness and should be viewed as other chronic illnesses.

SPMI is an "unseen wound" but the need for care is real.

SPMI can be managed.

Recovery is a long-term process, but it is possible.

People living with SPMI function in and contribute to society.

SPMI does not define a person.

There is help available.

There is hope in recovery.

It is okay to talk about mental health/SPMI.

### **RSA-R Results**

The RSA-R scores paralleled the level of satisfaction expressed by participants above. When compared with consumers and providers, family members' mean overall RSA-R scores, as well as each domain score, were the lowest, indicating that family members were not only the least satisfied with services, but they also held the least positive perception of recovery-oriented practices. Generally, professional mean scores were slightly higher than consumer scores, but both scores indicated a positive perception of the treatment system and its providers and agreement that the

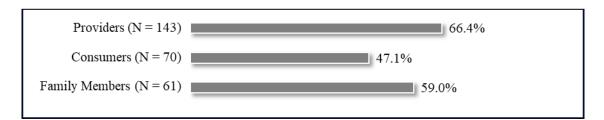


Figure 2. Proportion of Respondents Who Perceived Prejudice Against Persons Living with Serious and Persistent Mental Illness (SPMI) When Receiving Services

<sup>&</sup>lt;sup>a</sup>Data collected from focus group/interviews (FGIs).

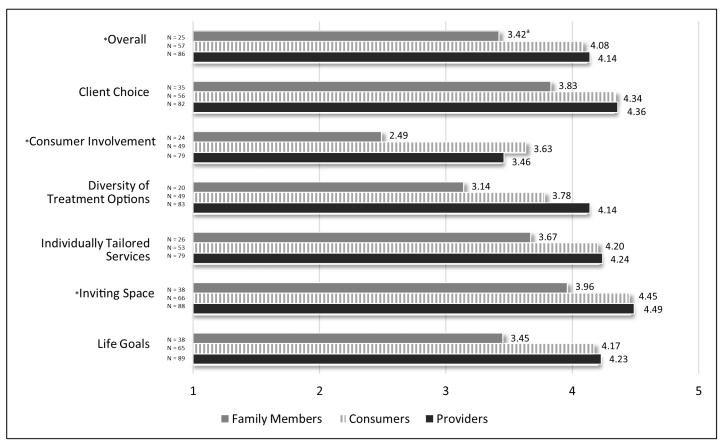
treatment system embraced the core principles of recovery. Figure 3 shows a comparison of RSA-R mean scores across participant types.

To determine if there were statistically significant mean differences between participant types for RSA-R overall score and for each domain score, a series of one-way ANOVAs was performed. Statistically significant mean differences were found between participant types and RSA-R overall scores: (F(2,165) = 8.878, p <0.001). In addition, statistically significant mean differences were found between participant types and 'Consumer Involvement' mean scores: (F(2,149) = 9.840, p < 0.001); and participant types and 'Inviting Space' mean scores: (F(2,189) = 5.805, p = 0.004). Post hoc comparisons using LSD (least significant difference) tests revealed significantly lower mean RSA-R overall scores for family members (M = 3.42, SD = 0.94) than for consumers (M = 4.08,SD = 0.85) and providers (M = 4.14, SD = 0.64); significantly lower mean scores on 'Consumer Involvement' for family members (M = 2.49, SD = 1.17) than for consumers (M = 3.63, SD = 1.12)and providers (M = 3.46, SD = 1.02); and significantly lower mean scores on 'Inviting Space' for family members (M = 3.96,SD = 0.96) than for consumers (M = 4.45, SD = 0.85) and providers (M = 4.49, SD = 0.76).

#### DISCUSSION

This study was unique in conducting a statewide assessment of SPMI treatment and support services. While previous research has focused on perceptions of SPMI services among individuals participating in those services,<sup>9,10</sup> their family,<sup>11</sup> and their treatment providers,<sup>11</sup> our study presents perceptions of SPMI services from all 3 groups in a single study. In addition, our study contributes to the research of stigma affecting persons living with SPMI with its focus on reframing and positive community messaging.

Study results found that consumers and family members had considerable knowledge of available SPMI services; however, almost universally, participants reported that there was insufficient community knowledge. Family members discussed that the behavioral health system did not do a good job of explaining what services were available and how to access those services. Most consumers expressed that the process of finding, applying for, and accessing services could be overwhelming for a person living with SPMI. They often cited difficulties in knowing where to start and what to do. Participants of all types advocated for a way to assist people living with SPMI to navigate the behavioral health system. Most providers thought that current services addressed the needs of persons living with SPMI, but there was consensus that there was



<sup>\*</sup>Significant difference at p < 0.05.

Figure 3. Mean Recovery Self-Assessment Revised (RSA-R) Scores

<sup>&</sup>lt;sup>a</sup>Overall mean score for family members does not include the additional 'Family Involvement' domain.

always room for improvement and additional services. A large proportion of consumers and most family members reported that they had unmet service needs.

In terms of stigma, most participants reported that they perceived negative attitudes toward persons living with SPMI. Two-thirds of providers discussed negative attitudes toward persons living with SPMI in service delivery. Providers noted exemptions in current housing and employment services that disqualified persons living with SPMI. Treatment providers said staff were not always appropriately trained on SPMI diagnoses, often leading to stigmatizing attitudes. Treatment providers also pointed out that staff burnout and compassion fatigue could lead to negative attitudes. Consumers reported instances of not being believed/heard by providers, their concerns being dismissed, and being judged unfairly due to their SPMI. Most family members reported that they have perceived negative attitudes toward their loved one when receiving treatment. Providers, family members, and consumers all recognized that the stigma and prejudice against persons living with SPMI elicited feelings of shame and discouraged people from openly discussing mental health and seeking services.

In this study, participants described the importance of accessible and effective recovery-oriented SPMI services. However, people with SPMI are more likely to experience barriers accessing services and receive lower quality care. 12,13 Social determinants of health were sometimes noted as contributing factors, including lack of information and access challenges (especially in rural areas), health payor barriers, limited resources, workforce shortages, and stigma. Individuals with SPMI are also at higher risk for other health concerns, 14 so access to recovery-oriented care is essential not only for mental well-being but overall health. Therefore, a public health approach is needed to support individuals living with SPMI.

### PUBLIC HEALTH IMPLICATIONS

The RSA-R results are useful when identifying strengths and target areas for improvement.<sup>15</sup> To strengthen recovery-oriented care, programs should consider communicating more clearly with family members and loved ones about how consumers are involved in their treatment plans as well as in program and organization-level decisions. Previous research has shown that, of the 6 subscale domains, programs that score high on 'Consumer Involvement' consistently score higher on overall recovery orientation.15 Family members scored this domain the lowest. Increasing communication would likely increase the perception of consumer involvement, as well as increase family involvement. The 'Diversity of Treatment Options' domain had the largest difference in scores between consumers and providers. In addition to increasing awareness of current treatment options offered, programs may want to consider offering additional treatment options and/or other resources/activities in which consumers are interested.

To improve access to SPMI treatment and support services, programs should consider heightening community outreach and education, employing navigators, expanding transportation and telehealth options, and expanding crisis services. In-person community outreach can be an effective way to connect with people with SPMI, particularly in rural areas. Research has shown that navigators can help consumers overcome barriers to access care, improve adherence to care, reduce hospital readmissions, and increase consumer satisfaction through effective referrals to services, care coordination, medication access assistance, and supportive listening. 17,18

To address stigma in the general public, there were many calls for increased community education on SPMI and empathy for what it means to live with SPMI. Providers noted that a lack of understanding about mental illness has led to many misconceptions and prejudices. Participants highlighted that SPMI should be seen in the same light as physical illnesses and that those living with SPMI should not be defined by their diagnosis. This would improve understanding and decrease the stigma around seeking help and normalize open discussion of mental health. It is also important to communicate messages of hope, such as "recovery is possible." Participants emphasized that not only should there be no shame in living with and seeking treatment for SPMI, but also mental health services are for everyone. Participant messaging recommendations could be incorporated into various anti-stigma strategies. Contact-based initiatives facilitating contact between people living with and without mental illness are most effective at reducing stigma; communication campaigns can reduce stigma if goals are well-defined and target audiences are reached consistently over time.19

### Limitations

This study has limitations. Our sampling plan might have created selection bias due to the exclusive recruitment of persons living with SPMI from treatment programs. The experiences of persons receiving treatment might have differed from persons living with SPMI who were not in treatment or from those who had never accessed treatment. To minimize this bias, consumer data were corroborated with data collected from family members of persons living with SPMI, many of whom shared experiences of loved ones not in treatment or of loved ones who had never accessed treatment. Also, although study epidemiologists were assigned to each of Ohio's psychiatric hospital catchment areas to create a geographic representative sample, findings of this study may not have fully captured the experiences, feelings, and beliefs of the state's diverse populations since our sample was predominately White, female, and older. Diverse populations might have different pathways and preferences for mental health services.

### Conclusion

The assessment objectives of this research study were met. Key findings indicated that, overall, consumers and family members

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were satisfied with current services but felt negative about the process of finding services. They generally held a positive perception that the mental health treatment system embraced the core principles of recovery. Participants overwhelmingly reported that service expansion was needed, both in terms of additional services and a higher volume of existing services, and they discussed the need to combat stigma. The data generated through this study may inform community strategies to reduce stigma and enhance treatment and support services for persons living with SPMI and for their families.

### CONFLICTS OF INTEREST

The authors report there are no competing interests to declare.

### **AUTHOR CONTRIBUTION**

R. Thomas Sherba designed the study, wrote protocols, coordinated data collection, conducted data analysis, summarized findings, and wrote manuscript. Julia Ashwood conducted data analysis, summarized findings, and wrote manuscript. Sarah Kriebel and Hannah MacDowell summarized findings and wrote manuscript.

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### APPENDIX—Scripted Protocols of Focus Group Questions, Demographics Tables

### Consumer Focus Group Questions

- What treatment services are currently available in your community for persons living with a mental health disorder?
- 2. How well do you think current treatment services address the needs of persons living with a mental health disorder on a scale from '1' to '7,' where '1' is 'not well at all' and '7' is 'extremely well'? <u>Please explain</u>.
- 3. What is the ease in which people access mental health treatment services on a scale from '1' to '7', where '1' is 'very difficult/felt I could not access treatment' and '7' is 'very easy/felt I had no trouble accessing treatment at all'? Please explain.
- 4. How would you describe the need for additional treatment services in your community for persons living with a mental health disorder on a scale from '1' to '7', where '1' is 'not needed at all' and '7' is 'needed a great deal'? <u>Please explain</u>.
- 5. Are there support services available to assist persons living with a mental health disorder (educational, vocational, housing, etc)? *If yes, please describe.*

### Consumer Experiences in Accessing/Utilizing Services

- 6. Think about how you currently connect with treatment/support services and *please describe* the way in which you access services.
  - How did you find your current treatment provider?
  - How were you linked with support services?
  - What, if any, were the <u>barriers</u> you encountered when trying to access services?
  - What might be different that would make it easier or more helpful to you?
- 7. <u>Please describe</u> what your life in recovery consists of, keeping in mind the following: employment/work, school, housing, family/friend relationships, volunteering, parenting, fitness, hobbies, etc.
- 8. What mental health treatment services are you currently receiving? What support services are you currently receiving? Please explain the benefit of these services to your recovery.
- 9. Of the treatment/support services you receive now, which are most valuable in helping you meet your recovery goals? Please explain.
- 10. Have you received the kind of services you needed? <u>Please explain</u>.
- 11. Were the services you received the right approach for helping you? If yes, why? If no, why not? Please explain.
- 12. If a friend or loved one were in need of similar help, would you recommend the same services? *If yes, why? If no, why not?* Please explain.
- 13. Was there any type of service that you felt you needed from the program/agency/organization but had not received? *If yes, what?* Please explain.
- 14. Please describe your level of satisfaction with the services/care you have received on a scale from '1' to '7', where '1' is 'completely dissatisfied' and '7' is 'extremely satisfied.' Please explain.
- 15. How much input do you have in setting the goals and priorities on your treatment plan?
- 16. Whom do you call or contact first (or most often) if you have a question or concern about your treatment/recovery?
- 17. Whom do you call or contact if you have a mental health crisis?

### Coordination of Care

- 18. In your opinion, how well do treatment/support programs/agencies/organizations in your community work together, on a scale from '1' to '7', where '1' is 'they don't seem to work together at all' and '7' is 'they work together completely'? <u>Please explain</u>.
- 19. How smoothly do medical services (eg, family doctor), addiction treatment services (eg, medication assisted treatment (MAT) prescriber) and mental health services (eg, your current mental health counselor or case manager) work together on a scale from '1' to '7', where '1' is 'they don't seem to work together at all' and '7' is 'they work together completely'? <u>Please explain</u>.
- 20. In your opinion, why do some people drop out of mental health treatment?
- 21. What roles have your family members played in your treatment and recovery?
- 22. In addition to the family roles you've described, what other roles in general do family members play in the treatment and recovery of persons living with mental health disorders?

### **Cultural Considerations**

- 23. Do you feel that there is any prejudice against you or negative attitude about you when receiving treatment? If so, please explain why you feel this way? What do you think can be done about it?
- 24. Are service providers sensitive to accommodating your ethnic background? If so, how? Please explain.
- 25. Do service providers respect your beliefs about your mental health? If no, please explain.

### Perceived Stigma

- 26. What is the most consistent message you hear about mental health disorders and persons living with mental health disorders?
- 27. What messaging about mental health disorders would you want people in your community to hear? *If you were to reframe the messages, what would they say?*

### **Closing Question**

28. What other thoughts or ideas would you like to share?

### Family Member Focus Group Questions

- 1. What treatment services are currently available in your community for persons living with a serious and persistent mental illness (SPMI)? <u>Please describe</u>.
- 2. How well do you think current treatment services address the needs of persons living with SPMI on a scale from '1' to '7,' where '1' is 'not well at all' and '7' is 'extremely well'? Please explain.
- 3. What is the ease in which persons living with SPMI access treatment services on a scale from '1' to '7', where '1' is 'very difficult/ felt my loved one could not access treatment' and '7' is 'very easy/felt my loved one had no trouble accessing treatment at all'? <a href="Please explain">Please explain</a>.

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- 4. How would you describe the need for additional treatment services in your community for persons living with SPMI on a scale from '1' to '7', where '1' is 'not needed at all' and '7' is 'needed a great deal'? <u>Please explain</u>.
- 5. Are there support services available to assist persons living with SPMI (educational, vocational, housing, etc)? If yes, please describe.

### Family Member Experiences in Accessing/Utilizing Services

- 6. Think about how your loved one (living with SPMI) currently connects with treatment/support services and <u>please describe</u> the way in which they access services.
  - *How did they find their current treatment provider?*
  - How were they linked with support services?
  - What, if any, were the <u>barriers</u> they encountered when trying to access services?
  - What might be different that would make it easier or more helpful to them and others living with SPMI to access/utilize treatment/support services?
- 7. Have you ever had to act on behalf of your loved one living with SPMI to get them help/services during a mental health crisis? *If* yes, whom did you call or contact? Please discuss your experience.
- 8. In lieu of services, or while awaiting services, what are things families do to help their loved one living with SPMI cope/manage psychiatric symptoms? <u>Please describe</u>.
- 9. What treatment/support services is your loved one (living with SPMI) currently receiving? <u>Please describe</u>.
- 10. Of the services your loved one (living with SPMI) receives now, which are most valuable in helping them meet their recovery goals? Please explain.
- 11. If no current receipt of services: How is your loved one managing their SPMI? Please explain.
- 12. Did your loved one (living with SPMI) receive the kind of services they needed? Please explain.
- 13. Were the services your loved one (living with SPMI) received the right approach for helping them? *If yes, why? If no, why not?* Please explain.
- 14. If a friend or another loved one living with SPMI were in need of similar help, would you recommend the same services? *If yes, why?* If no, *why not?* Please explain.
- 15. Was there any type of service that you felt your loved one (living with SPMI) needed but had not received? If yes, *what?* Please explain.
- 16. Please describe your level of satisfaction with the services/care your loved one (living with SPMI) received on a scale from '1' to '7', where '1' is 'completely dissatisfied' and '7' is 'extremely satisfied.' <u>Please explain</u>.

### Coordination of Care

- 17. In your opinion, how well do treatment programs/agencies/organizations in your community work together in meeting the needs of persons living with SPMI, on a scale from '1' to '7', where '1' is 'they don't seem to work together at all' and '7' is 'they work together completely'? Please explain.
- 18. How smoothly do medical services (eg, family doctor), addiction treatment services (eg, MAT prescriber) and mental health services (eg, mental health counselor or case manager) work together to provide the best services to persons living with SPMI on a scale from '1' to '7', where '1' is 'they don't seem to work together at all' and '7' is 'they work together completely'? Please explain.
- 19. In your opinion, why do some persons living with SPMI drop out of treatment?
- 20. What role do you play in the treatment and recovery of your loved one (living with SPMI)?
- 21. In addition to the family role you've described, what other roles in general do family members play in the treatment and recovery of persons living with SPMI?

### Family Member Supports

- 22. Where do you get support to help you cope with having/living with a loved one with SPMI? Please describe.
- 23. Are there services/supports specific to loved ones of persons living with SPMI in your community? *If yes, what are they and are you accessing them?* Please describe your experiences with accessing services/supports. *If you are not accessing available services/supports, why not?* Please explain.
- 24. What services/supports would be helpful to family members if available? Please describe.
- 25. Do you participate in a family support group for loved ones of persons living with SPMI? If yes, what? How often does this group meet? Is it beneficial to you? Please describe your experiences with family support groups.

### **Cultural Considerations**

- 26. Do you feel that there is any prejudice against your loved one (living with SPMI) or negative attitude about them when receiving treatment? *If so, please explain why you feel this way? What do you think can be done about it?*
- 27. Are service providers sensitive to accommodating the ethnic background of your loved one (living with SPMI)? If so, *how?* <u>Please explain</u>.

### Perceived Stigma

- 28. What is the most consistent message you hear about SPMI and persons living with SPMI?
- 29. What messaging about SPMI would you want people in your community to hear? If you were to reframe the messages, what would they say?

### **Closing Questions**

- 30. Have you participated in any trainings/classes/conferences related to SPMI and persons living with SPMI? If yes, *what, when and where?* Please describe.
- 31. What other thoughts or ideas would you like to share?

### Community Professional Focus Group Questions

1. What treatment services are currently available in your community for persons living with serious and persistent mental illness (SPMI)?

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- 2. How well do you think current treatment services address the needs of persons living with SPMI on a scale from '1' to '7,' where '1' is 'not well at all' and '7' is 'extremely well'? Please explain.
- 3. What is the ease in which persons living with SPMI access mental health treatment services on a scale from '1' to '7', where '1' is 'very difficult/felt they could not access treatment' and '7' is 'very easy/felt they had no trouble accessing treatment at all'? <u>Please explain</u>.
- 4. How would you describe the need for additional treatment services in your community for persons living with SPMI on a scale from '1' to '7', where '1' is 'not needed at all' and '7' is 'needed a great deal'? <u>Please explain</u>.
- 5. Are there support services available to assist persons living with SPMI (educational, vocational, housing, etc)? If yes, please describe.
- 6. In your opinion, what can be done to make accessing treatment/support services easier for persons living with SPMI?

### Your Community's Mental Health Treatment System

- 7. In your opinion, how well do treatment programs/agencies/organizations in your community work together to provide the best services to persons living with SPMI on a scale from '1' to '7', where '1' is 'they don't seem to work together at all' and '7' is 'they work together completely'? Please explain.
- 8. How well do you think these stakeholders communicate with each other about the needs of persons living with SPMI on a scale from '1' to '7,' where '1' is 'not well at all' and '7' is 'extremely well'? <u>Please explain</u>.
- 9. How efficient do you think persons living with SPMI move into, through and out of the various community help systems, on a scale from '1' to '7', where '1' 'completely inefficiently' and '7' is 'completely efficiently'? <u>Please explain</u>.
- 10. What are the gaps that you perceive in your community mental health treatment system? *In your opinion, what could be done to fill these gaps?*
- 11. In terms of recovery supports, what supports do persons living with SPMI need? In your opinion, which recovery supports are the most beneficial to long-term recovery? Please describe/explain.

### Coordination of Care

- 12. Has your program/agency/organization been successful in linking persons living with SPMI to needed treatment/other community services? Please explain, describing success(es) and to what/whom do you attribute success(es)?
- 13. Have you referred persons living with SPMI to needed treatment/support services in the past? *If yes, why and where? If no, why not?* Please explain.
- 14. What criteria are used to determine appropriate referrals?
- 15. How satisfied are you with the way the staff of different programs/agencies/organizations work together to ensure that persons living with SPMI get the help they need on a scale of '1' (completely dissatisfied) and '7' (completely satisfied)? Please explain.
- 16. How smoothly do medical services (eg, family doctor), addiction treatment services (eg, MAT prescriber) and mental health services (eg, mental health counselor or case manager) work together to provide the best services to persons living with SPMI on a scale from '1' to '7', where '1' is 'they don't seem to work together at all' and '7' is 'they work together completely'? Please explain.
- 17. What roles do loved ones (family members) play in the treatment and recovery of persons living with SPMI? Please explain.

Ask questions 18-21 of treatment/support professionals only. Skip to Cultural Considerations questions for all other community professionals (Q. 22). Ask questions 22-29 of ALL community professionals.

- 18. How much input do persons living with SPMI have in setting the goals and priorities on their treatment plan?
- 19. Do the services your program/agency/organization deliver meet the expressed needs of your clients living with SPMI? *If no, why not?* Please explain.
- In your opinion, are the services offered by your program/agency/organization for persons living with SPMI of good quality? <u>Please explain</u>.
- 21. If your program/agency/organization were to close, where would your clients living with SPMI go to receive treatment/support services?

### **Cultural Considerations**

- 22. Do you feel that there is any prejudice against persons living with SPMI or negative attitude about them when receiving treatment? *If* so, <u>please explain</u> why you feel this way? What do you think can be done about it?
- 23. Are service providers sensitive to accommodating the ethnic background of persons living with SPMI? If so, how? Please explain.
- 24. Do service providers respect the personal beliefs of persons living with SPMI regarding their mental health? *If yes*, how so? *If not, why not?* Please explain.

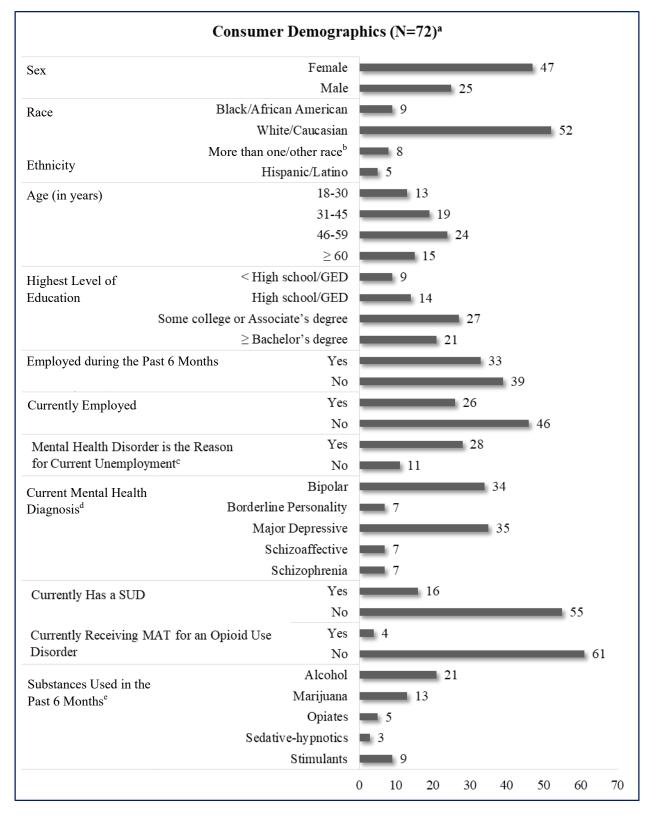
### Perceived Stigma

- 25. What is the most consistent message you hear about SPMI and persons living with SPMI?
- 26. What messaging about SPMI would you want people in your community to hear? *If you were to reframe the messages, what would they say?*

### **Closing Questions**

- 27. In your opinion, why do some persons living with SPMI drop out of treatment?
- 28. Have you participated in any trainings/classes/conferences related to SPMI and treating/providing services to persons living with SPMI? *If yes, what, when and where? If not, why not?* Please describe/explain.
- 29. What other thoughts or ideas would you like to share?





<sup>&</sup>lt;sup>a</sup>Due to missing or excluded invalid responses, variable totals may not equal 72.

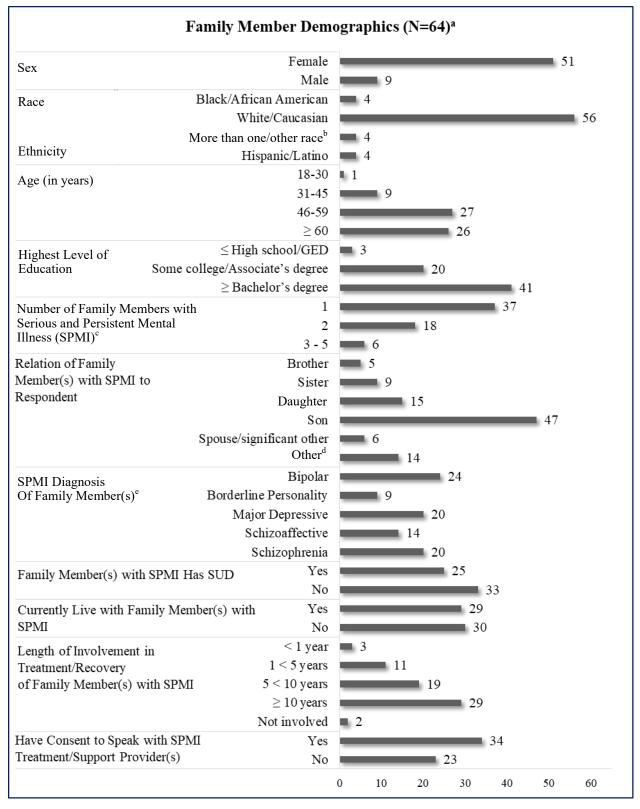
b"Another race" includes a respondent who did not specify their racial identity.

<sup>&</sup>lt;sup>c</sup>Question was only asked to respondents who indicated that they were not currently employed.

dRespondents were allowed to choose more than 1 diagnosis. Diagnoses are not mutually exclusive.

<sup>&</sup>lt;sup>e</sup>Respondents were allowed to choose more than 1 substance. Substances are not mutually exclusive.





<sup>&</sup>lt;sup>a</sup>Due to missing or excluded invalid responses, variable totals may not equal 64.

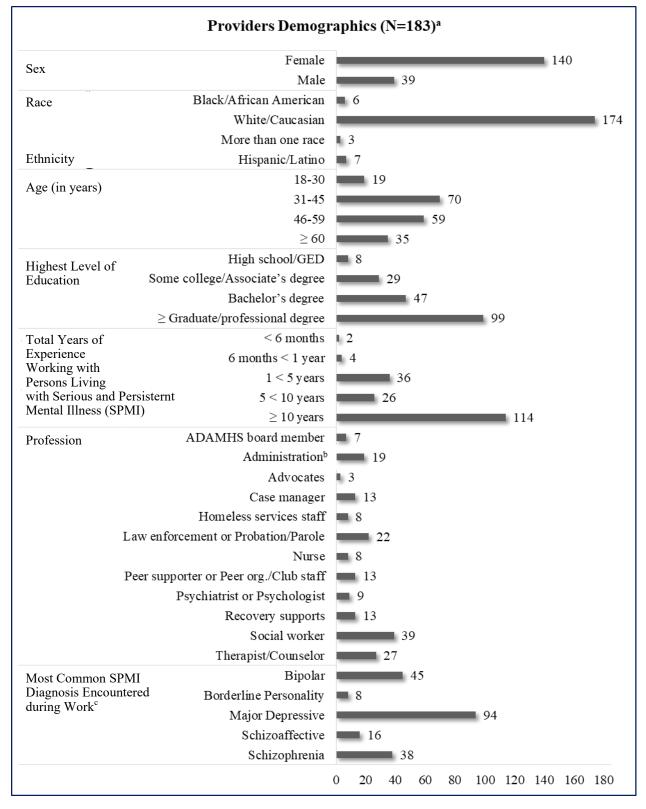
b"Another race" includes American Indian or Alaska Native.

<sup>&</sup>lt;sup>c</sup>Respondents were allowed to list more than 1 family member. Family members are not mutually exclusive.

d"Other" includes niece, mother, cousin, grandson, nephew, and aunt.

<sup>&</sup>lt;sup>e</sup>Respondents were allowed to state up to 4 diagnoses. Diagnoses are not mutually exclusive.





<sup>a</sup>Due to missing or excluded invalid responses, variable totals may not equal 183.

<sup>c</sup>Some respondents selected more than 1 diagnosis. Diagnoses are not mutually exclusive.

b"Administration" includes executive directors, chief executive officers, and chief clinical officers, as well as program managers, facility mangers, and respondents in Human Resources and operational roles.



### **RESEARCH ARTICLE**

## Results of Outreach Referral Program After Failed In-School Eye Examinations

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### **ABSTRACT**

**Background:** The absence of childhood vision care has detrimental consequences on development and learning. <sup>1</sup> The Vision Health Initiative Committee (VHI) was established by the Centers for Disease Control and Prevention (CDC) to mandate school vision screenings. <sup>2</sup> Improved detection does not translate into vision care. Poor compliance for follow-up remains an issue. This study evaluates the effectiveness of an outreach referral program specializing in assisting families with recommended follow-up care for children following in-school eye examinations.

**Methods:** A mobile vision van provided in-school eye examinations and dispensed eyeglasses to at-risk children. Referrals for in-office evaluation were generated for children with more serious medical conditions. Each family was contacted via phone call and/or text message to assist in scheduling their child with an eye examination. Results of the communications were tabulated and analyzed.

**Results:** The mobile vision van program completed 13 260 vision screenings and provided 2185 eye examinations to children in Northeast Ohio. Out of the 2185 examinations, 238 (11%) students required further evaluation. Of those 238, the families of 165 (70%) were successfully contacted; 75 (45%) families had scheduled their own follow-up appointment, 77 (47%) families needed assistance to schedule an examination, and 13 (8%) families were not interested in further assistance. Of the 77 receiving assistance with scheduling, 54 (70%) families kept the scheduled appointment and received care at no cost.

**Conclusion:** This study further substantiates the health disparity in eye care. It demonstrates the importance of in-school vision examinations and the value of an outreach referral program which includes education and assistance with scheduling appointments.

**Keywords:** Pediatrics; Vision care; Eyeglasses; Referral; Retrospective review

### INTRODUCTION

Health equity continues to be a topic of conversation for doctors and policymakers in the United States. According to the Centers for Disease Control and Prevention (CDC), health equity can be defined as the ability of all members of a community to receive fair and equal opportunities to the highest level of health care. However, access to fair health care in the United States is widely determined by socioeconomic status. Vision care needs for school-age children tend to follow this trend. Without early detection and

treatment, uncorrected vision disorders can impair child development, interfere with learning, and even lead to permanent vision loss.<sup>2</sup> The CDC recognizes that vision problems substantially impact the quality of life for these children and, thus, established the Vision Health Initiative (VHI).<sup>3</sup> The VHI's mission is to create cost-effective public health interventions to improve quality of life, increase access to needed eye care, and reduce health disparities among people with or at high risk for vision loss.<sup>4</sup> According to Wahl et al and the work of the VHI, school vision screenings have



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been mandated in 38 of the 50 states; Ohio is 1 of the 38 states that require vision screenings for school-age children.<sup>5</sup> This allows vision problems to be identified at a much higher rate.

Unfortunately, identification of a vision problem does not guarantee a child will receive adequate care. Studies have shown that up to 62% of children never receive the recommended eye examinations after failing their school vision screening.<sup>6</sup> Previous studies have identified insurance coverage, cost, and transportation as barriers to care. These barriers can be impacted, and vision care disparities improved, if complete eye examinations and eyeglasses are provided inside these high-risk schools. This was proven successful with the initiation of in-school examinations in Southeast Ohio.8 However, even with in-school eye examinations, children with more serious eye conditions are still being left with unmet needs. The number of parents who heed the referral recommendations and the number of high-risk children left with unmet vision needs is unknown. This study evaluates the impact an outreach referral program has on the number of students that receive the recommended follow-up care when instituted in at-risk communities in Northeast Ohio.

### **METHODS**

Through the collaboration of 2 non-profit organizations, a mobile vision van program was established and funded in Northeast Ohio. This program was instituted to bridge the gap in vision services for underserved schools and communities in this region. School districts were hand-selected for mobile vision services based on financial need defined as greater than 50% of the students receiving free and/or reduced lunches.

The vision van spent nearly 190 days of the 2022-2023 school year on the road visiting underserved schools. Every child in kindergarten through 12th grade had their vision screened (Figure 1:A). Students failing the vision screening received an eye examination with a licensed optometrist, at the school, on the mobile van (Figure 1:B). Vision, refractive error, anterior ocular health, posterior ocular health, and intraocular pressure were assessed during this mobile clinic visit. Students in need of refractive error correction received eyeglasses at no cost to the family or school (Figure 1:C).

Children identified with a more serious eye condition such as strabismus, amblyopia, or anterior or posterior segment health concerns were referred for further evaluation and care with a community eye doctor (Figure 1:D). The standard procedure for a referral used in other national mobile vision clinics includes a letter sent home to the family notifying them of their child's ocular health problem. Additional efforts were at the discretion of the van optometrist and school nurse and varied widely. Due to lack of time and resources, this left many children, with more serious eye health complications, with unmet need.

For this study, after the standard referral letters were sent home following the in-school eye examination, a complete list of chil-

dren requiring follow-up was provided to the outreach assistant at a partnering local non-profit organization. The outreach assistants had experience and training as ophthalmic technicians and possessed general knowledge of eye diseases and treatments and were familiar with local eye doctors, making it simple to assist families with scheduling appointments. The outreach assistant received information about the family such as parent's name and phone number as well as the presumed diagnosis from the inschool eye examination. Every child needing a referral examination was included in the list to the outreach assistant. No child was excluded. The outreach assistant contacted the family via phone call or text message. Contact was attempted with each family at least 4 times.

Once contact was made, an in-depth conversation took place using the diagnosis supplied from the referral (Figure 1:E). The family was educated on the importance of follow-up care and the possible treatment options. See Appendix for a more in-depth look at conversation scripts and text message templates The outreach assistant assigned the child to 1 of 3 categories: compliant with referral recommendations (Figure 1:F), assisted with referral recommendations (Figure 1:G), or the family was not interested in any further assistance (Figure 1:H).

The outreach assistant then focused on the subgroup of families who had not yet scheduled an appointment for an eye examination. The outreach assistant worked with the family to schedule an appointment with local eye doctors while minimizing barriers to care such as cost and transportation (Figure 1:J). These children were seen by an eye doctor close to their school district at no cost to the doctor or family. Financial responsibility for the referral examination was covered by the non-profit organization overseeing the outreach assistants. The final assessment and treatment plan was relayed back to the outreach assistant to assist in any follow-up questions the family might have.

At the conclusion of the school year, data regarding the number of children screened, examined, referred, and seen for an in-depth eye examination were tabulated and reviewed. Each child was placed in 1 of the 3 subgroups: compliant with referral recommendations, assisted with referral recommendations, or the family was not interested in any further assistance. Each subgroup was assigned a percentage based on the total number of children recommended for a referral. The effectiveness of the referral program was evaluated by analyzing the percentage of children within each subgroup and the effect of having an outreach assistant on the subgroup percentages. In the discussion, presumed and final diagnoses were analyzed to hypothesize which diagnoses are more likely to prompt the families to seek follow-up care.

### **RESULTS**

In one school year, 13 260 students were screened at 25 schools in Northeast Ohio. These students ranged from kindergarten through 12th grade. Of those children screened, 2185 (16%) failed their

screening and received an eye examination on the mobile vision van with 1670 (13%) students receiving eyeglasses. Of the 2185 eye examinations, 238 (11%) children were referred for further evaluation. The contact information and presumed diagnosis for all 238 children was provided to the outreach assistant. The presumed diagnoses were divided into 4 main categories including strabismus [84 (35%) students], amblyopia [75 (32%) students], difficulty with refraction [64 (27%) students], and medical conditions [15 (6%) students] such as elevated intraocular pressure, retinal abnormalities, or optic nerve abnormalities. (Figure 2)

The outreach assistant attempted to reach all 238 families via phone call and/or text message. Of the 238 children referred, 165 (70%) families were successfully contacted and a conversation occurred with the outreach assistant. On average, 2 attempts were

needed to successfully reach the family. Of the families that were reached, the most successful form of communication was text message with a return phone call. Of the 165 families that were reached, 75 (45%) were compliant with referral recommendations and 13 (7.9%) families were not interested in discussing their child's vision further. Seventy-seven (47%) families needed assistance with referral recommendations. After educating the families, our outreach assistant scheduled these children for an examination with local eye doctors (Figure 1).

Of the 77 families that were assisted through the outreach referral program, 54 (70%) children were successfully seen by a local eye doctor. Documentation of these examinations included the ocular evaluation, eyeglasses prescription, and final assessment and plan. In review of these results, 9 (17%) students were identified as

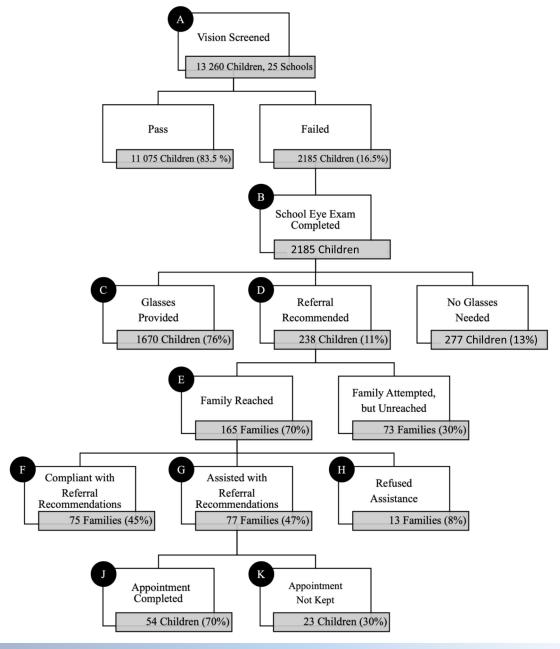


Figure 1. Referral Program Flowchart

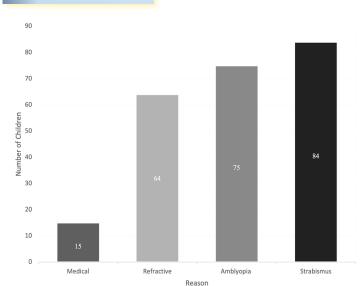


Figure 2. Reason for Referral

having strabismus, 17 (32%) students were identified as ambly-opic, 18 (33%) students were given eyeglasses prescriptions which allowed them to be corrected to 20/20 in both eyes, and 3 (6%) students were seen for a medical condition. Of the 54 students receiving an eye examination, 7 (13%) students were completely healthy, and did not require eyeglasses.

Seventeen (31%) children required subsequent visits for continued care. Fourteen (26%) children required a 3-month follow-up for diagnoses such as amblyopia or strabismus. Three (6%) children received subspecialty referral for a more serious medical problem such as surgery for strabismus or cataracts. Thirty (56%) children required a yearly examination for continued monitoring of vision and refractive error.

Twenty-three (30%) families failed to bring their child to their scheduled appointments. These families received a reminder call and text before the appointment, coming from both our outreach assistant and the doctor's office. Attempts to reach the families for rescheduling the appointments were unsuccessful.

### **DISCUSSION**

This program demonstrates the importance of additional intervention regarding recommended follow-up care after a failed school eye examination. Historical data demonstrate that nearly two-thirds of children are never seen by an eye doctor following a failed school screening.<sup>6</sup> When this statistic is applied to our population of children, 1400 children would have been left without care. This unmet need for eye care can have a serious long-term impact on a child, including poor academic performance, ultimately leading to higher rates of unemployment and incarceration.<sup>9</sup> The establishment of a mobile vision clinic has made great strides to remove this barrier by providing eye examinations and eyeglasses to children directly at the school. During the 2022-2023 school year, 2100 examinations took place on the vision van, and 1670 children received free eyeglasses. On-site examinations al-

low for immediate intervention following a failed vision screening and the on-site dispensing of free eyeglasses to any child in need produces improved test scores, and greater confidence and participation in the classroom.  $^{10}$ 

While in-school eye examinations create a tremendous impact on health equity for children, even with the mobile vision van more serious eye diseases are still being left untreated due to the continued lack of follow-up care after being seen on the van. This study is the first of its kind to provide insight into a parent's response to referral recommendations following in-school eye examinations. Many previous studies show the parent's response following a screening, but in our search there were no published studies looking at the parent response to a referral following an in-school eye examination.11 Of the children screened and examined, 238 children were referred for further evaluation for more serious eye conditions such as strabismus, amblyopia, and medical problems. The outreach assistants were able to reach 165 of those families. After conversations with these families, our study demonstrated that only 45% of parents act on a school referral for additional care. In addition, 47% of parents either did not receive the referral letter or did not act on the referral letter after a problem was identified with their child's sight. This study confirms that a significant number of parents do not respond to recommended follow-up care following a screening or an in-school eye examination. The data of this study mirror previously published data regarding response to follow-up care following in-school vision screenings and further substantiate the need for outreach assistance to continue to stress the need for follow-up care.6

The statistics uncovered through this study are alarming because it leaves at-risk children with unmet vision needs. When needed medical care is not heeded, these children can develop lifelong debilitating vision and even a negative social impact.<sup>12</sup> Families reacted to the referral recommendation differently based on the presumed diagnosis from the mobile eye examination. Families scheduled an appointment at a higher rate when the presumed diagnosis had a noticeable visual appearance, such as strabismus, or a visual threatening effect, such as amblyopia. When the presumed diagnosis had no cosmetic effect or threat to vision, the chance of the family acting on the recommendation for follow-up care decreased (Figure 3). The data support previously published data by Yu et al regarding the prevalence of an eye examination for school-age children based on diagnosis showing strabismus and amblyopia had much higher rates of a previous eye examination, while hyperopia, anisometropia and astigmatism were at much lower rates<sup>13</sup> (Figure 4).

Although we contacted 70% of families recommended for followup care, which is considered a significant improvement from baseline, 30% of the 238 families were still unreachable. Of these 73 families, 13 had phone numbers that were incorrect or not in service. In efforts to reach more children, it is important to evaluate issues with contacting parents such as wrong phone



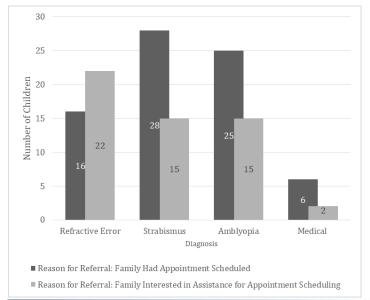


Figure 3. Comparison of Reason for Referral for Families Who Acted on Referral Recommendations Versus Families Who Did Not Act

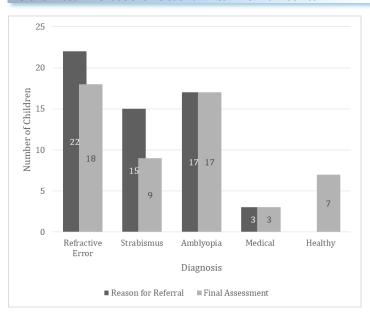


Figure 4. Comparison of Presumed Diagnosis Versus Final Assessment for Children Seen by Partnered Eye Doctors in the Community

numbers and language barriers. Home addresses, as a part of the data collection, would allow for letters to be sent to alleviate the complication that arises from incorrect/inactive phone numbers.

One of the major limitations we had when reviewing the data was the lack of demographic information. Outside of age and phone number, no other data was provided from the mobile vision van. Efforts to extract this information from the families, such as insurance status, race, primary language, education status, was challenging and often led to poor response. To increase our response rate, our team decided to forgo discussion of demographic information, but this information would be very valuable and improve the social implications of this study.

Another limitation this study has is the small geographic location that this project was able to impact. We believe that this model

could be replicated to other in-school eye examination programs across the state of Ohio, and even nationally, to ensure the next generation has adequate eye care.

### **PUBLIC HEALTH IMPLICATIONS**

The outreach referral program had a positive impact on health equity for at-risk children in Northeast Ohio. This study shows how an in-school vision van program improves vision outcomes by addressing barriers such as scheduling and cost. When inschool examinations are paired with the outreach referral program, the impact of serious eye conditions on children's vision is greatly reduced. When an outreach assistant educated the family concerning their presumed diagnosis, follow-up rates improved. This outreach referral program is the first of its kind to work directly with a mobile van and community eye doctors to close the gap for medical care. An outreach referral program augments the VHI by not just enhancing visual defect detection rates but by also increasing medical care and treatment, thus improving public health in a population. This can be seen through long-term health for these children by increasing parent understanding and improving doctor-patient relationships.

### **CONFLICTS OF INTEREST**

The authors have none to report.

### **ACKNOWLEDGMENTS**

Sight for All United is a 501(c)(3) nonprofit organization in Youngstown, Ohio, established in 2016 with the mission of helping every person reach his/her visual potential while lifting barriers for access to care.

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### **Author Contribution**

Tahir Kuraan: data acquisition. Kayla Tucker: data analysis, data interpretation, manuscript development. Sergul Ayse Erzurum: manuscript review, senior advisor.

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### **APPENDIX**—Outreach Assistant Templates

| ۹. | Convers<br>a. | "Hello, n | ny name is<br>mination | e outreach assistant's initial call to the families of children in need of a referral examination.  (referral counselor's name) from Sight for All United once again reaching out in regards to (child's name)  (child's name) was seen on the vision van several weeks ago, and during that examination Dr (vision van |
|----|---------------|-----------|------------------------|---|
|    |               |           |                        | your child might have (select from the list below that fits the child's reason for referral in layman terms). This  |
|    |               |           |                        | t explanation from below) which could mean (select corresponding consequence.) Sight for All United is a non-   |
|    |               |           | •                      | helping families make follow-up eye examinations for kids. The follow-up eye examination is important because it  |
|    |               |           | •                      | vell your child sees for the rest of their life. The follow-up examination could be with's (child's name) previous  |
|    |               | •         | •                      | u do not already have an eye doctor, we could help you schedule an appointment with one of our partner eye doc-   |
|    |               |           |                        | ors near where you live and you would receive an eye examination at no cost. Please call our office back to let us  |
|    |               | _         | (child                 | 's name) already has an appointment scheduled or if you are interested in scheduling an appointment with our assis-   |
|    |               | tance."   |                        |   |
|    |               | i.        |                        | e (Layman Terms)  |
|    |               |           |                        | Amblyopia (Medical Term on Referral)  |
|    |               |           |                        | This means that one of your child's eyes is not as strong as the other eye  |
|    |               |           | 3.                     | This could lead to long term poor vision in that eye and risk of blindness if something were to happen to the good  |
|    |               |           |                        | eye.  |
|    |               | ii.       |                        | n (Layman Terms)  |
|    |               |           | 1.                     | Strabismus (Medical Term on Referral)   |
|    |               |           | 2.                     | Esotropia (Medical Term on Referral)  |
|    |               |           | 3.                     | Exotropia (Medical Term on Referral)  |
|    |               |           | 4.                     | Convergence Insufficiency (Medical Term on Referral)  |
|    |               |           | 5.                     | Nystagmus (Medical Term on Referral)  |
|    |               |           | 6.                     | This means that one of your child's eyes is not pointing in the same direction- either facing in or facing out  |
|    |               |           | 7.                     | This could cause your child to see poorly in that eye long term. It could also mean that your child could be more   |
|    |               |           |                        | prone to headaches or eye strain and that could affect how well they do in school.  |
|    |               | iii.      | Eyeglass               | ses Prescription (Layman Terms)   |
|    |               |           | 1.                     | Hyperopia (Medical Term on Referral)  |
|    |               |           | 2.                     | Myopia (Medical Term on Referral)   |
|    |               |           | 3.                     | Astigmatism (Medical Term on Referral)  |
|    |               |           | 4.                     | Anisometropia (Medical Term on Referral)  |
|    |               |           | 5.                     | Cycloplegic Examination Needed (Medical Term on Referral)   |
|    |               |           | 6.                     | This means that because of the limited time on the vision van for examinations, Dr (vision van doctor) was  |
|    |               |           |                        | not able to adequately assess your child's eyeglasses prescription and they believe a more in-depth eye examina-  |
|    |               |           |                        | tion would give better results.   |
|    |               |           | 7.                     | This is important because it could mean that your child is at-risk of a lazy eye or an eye turn if their eyeglasses   |
|    |               |           |                        | prscription is not determined properly.   |
|    |               | iv.       | Health o               | f the Eye (Layman Terms)  |
|    |               |           | 1.                     | Pupillary Defect (Medical Term on Referral)   |
|    |               |           | 2.                     | Intraocular Pressure (Medical Term on Referral)   |
|    |               |           | 3.                     | Glaucoma (Medical Term on Referral)   |
|    |               |           | 4.                     | Cataract (Medical Term on Referral)   |
|    |               |           | 5.                     | Retina (Medical Term on Referral)   |
|    |               |           | 6.                     | This means that Dr (vision van doctor) is worried about something like glaucoma, high eye pressure, a cata-   |
|    |               |           |                        | ract in the eye, or something wrong with the retina. All of these things are very serious and should be evaluated   |
|    |               |           |                        | and monitored in an eye doctor's office regularly.  |
|    |               |           | 7.                     | This could lead to blindness as an adult if the medical condition is not managed properly now.  |
|    |               |           |                        |   |
| 3. | Text me       | ssage tem | iplate for th          | e outreach assistant's initial call to the families of children in need a referral examination.   |
|    | a.            |           | •                      | (referral counselor's name) from Sight for All United. Sight for All United is a non-profit organization helping  |
|    |               |           |                        | w-up eye examinations for kids (child's name) was seen on the vision van and Dr(vision van doctor)  |
|    |               | recomm    | ended a fo             | llow-up eye examination because of (select from the list below that fits the child's reason for referral in layman  |
|    |               | terms).   | The follow-            | up eye examination is important because it could impact how well your child sees for the rest of their life. You should   |
|    |               | receive   | a letter in tl         | ne mail soon with more information. Sight for All United would like to help you schedule an eye examination for your  |
|    |               | child. Pl | ease call o            | r text our office at this number for more information or assistance with scheduling an appointment."  |
|    |               | i.        | Lazy Eye               | e (Layman Terms)  |
|    |               |           | 1.                     | Amblyopia (Medical Term on Referral)  |
|    |               | ii.       | •                      | ı (Layman Terms)  |
|    |               |           | 1.                     | Strabismus (Medical Term on Referral)   |
|    |               |           | 2.                     | Esotropia (Medical Term on Referral)  |
|    |               |           | 3.                     | Exotropia (Medical Term on Referral)  |
|    |               |           | 4.                     | Convergence Insufficiency (Medical Term on Referral)  |
|    |               |           |                        |   |

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### APPENDIX—continued

- 5. Nystagmus (Medical Term on Referral)
- iii. Eyeglasses Prescription (Layman Terms)
  - 1. Hyperopia (Medical Term on Referral)
  - 2. Myopia (Medical Term on Referral)
  - 3. Astigmatism (Medical Term on Referral)
  - 4. Anisometropia (Medical Term on Referral)
  - 5. Cycloplegic Examination Needed (Medical Term on Referral)
- iv. Health of the Eye (Layman Terms)
  - 1. Pupillary Defect (Medical Term on Referral)
  - 2. Intraocular Pressure (Medical Term on Referral)
  - 3. Glaucoma (Medical Term on Referral)
  - 4. Cataract (Medical Term on Referral)
  - 5. Retina (Medical Term on Referral)



### **RESEARCH ARTICLE**

# Gauging Risk and Protective Factors Contributing to e-Cigarette Use Among Multiracial Youth

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### **ABSTRACT**

**Background:** Currently, e-cigarettes are the most common form of nicotine consumption among youth in the United States. There is a lack of research focusing on e-cigarette use among multiracial youth, yet the sparse literature points toward the adverse consequences of e-cigarettes on multiracial youth. Multiracial youth tend to have higher addiction and prevalence rates of e-cigarette use compared to other racial/ethnic groups. The current research focuses on analyzing e-cigarette use based on parental factors, school factors, prosocial behavior, ease of access, risk behaviors, perception of harm, and sociodemographic differences among multiracial youth.

**Methods:** A secondary data analysis of the 2020 Student Drug Use Survey (N = 38048) was performed. Of these, n = 3340 self-identified as multiracial. Descriptive analysis, univariate logistic regression, and logistic regression were performed.

**Results:** Results indicate that the odds of using e-cigarettes among multiracial youth increase 2 times when not perceived as harmful, 2 times if one is employed, 18 times if involved in high-risk behaviors, and 2 times if in 9th through 12th grade. Additionally, logistic regression demonstrates that parental factors may not be significant in e-cigarette use among multiracial youth.

**Conclusion:** It is crucial to investigate the association between e-cigarette use and multiracial youth, as they may be disproportionately affected by chronic conditions and fatal diseases linked to tobacco use. Understanding the specific risk and protective factors influencing e-cigarette use within this demographic can help design targeted interventions, particularly for multiracial youth in the Greater Cincinnati region.

Keywords: e-Cigarette; Youth; School; Tobacco use; Multiracial; Adolescents

### **INTRODUCTION**

Electronic cigarettes (e-cigarettes) have become a significant public health concern, particularly among youth, with a marked increase in usage since 2014.¹ Recent data indicate a concerning prevalence of e-cigarette use among middle and high school students, with approximately 1 out of 35 middle school students and 1 out of 9 high school students reporting e-cigarette use in the past 30 days.² This trend necessitates an examination of the factors contributing to the widespread adoption of e-cigarettes among young individuals and the identification of groups at higher risk. Among these groups, multiracial youth have emerged as an essen-

tial demographic to study.<sup>2</sup> The escalating prevalence of e-cigarette use among youth, especially among multiracial adolescents in grades 7th through 12th, has emerged as a pressing public health issue.<sup>3</sup> This demographic, characterized by its unique intersectionality of age and race, presents a critical area of study due to its susceptibility to substance use initiation and progression.<sup>4</sup>

Use of e-cigarettes is influenced by many risk and protective factors, with accessibility being a key driver of its prevalence. Parental factors play a significant role in shaping a child's behavior, including their propensity to engage in e-cigarette use. Parental attitudes toward smoking, parental smoking behavior, and the



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<sup>&</sup>lt;sup>2</sup>Boise State University, Boise, ID

access, perceived harm to self, perceived harm to others, and demographics (sex, age, employment status, and grade) among mul-

degree of parental monitoring can all impact a youth's likelihood of using e-cigarettes.5 In 2021, approximately 32.8% of youth obtained e-cigarettes from friends, while 31.3% purchased these products.2 The school environment can also contribute to e-cigarette use among youth. Factors such as peer influence, school policies on tobacco use, and prevention programs can all play a role.5 Engagement in risky behaviors, such as substance use or risky sexual behavior, can increase the likelihood of e-cigarette use among youth.5 These behaviors often co-occur, and comprehensively addressing them can be an effective strategy for prevention.5 The ease of accessibility has undoubtedly played a significant role in the popularity of e-cigarettes among youth. Moreover, the perception of harm associated with the intermittent use of tobacco has been identified as a noteworthy factor, with a striking 16.6% of e-cigarette users reporting that they believe such use causes little to no harm.2

According to the Centers for Disease Control and Prevention (CDC), e-cigarette usage is currently at 20.8% among non-Hispanic multiracial students. In comparison to their peers, these numbers are higher; 18.4% of non-Hispanic White students, 18.2% of Hispanic students, 15.4% of non-Hispanic American Indian/Alaska native students, and 12.9% of non-Hispanic Black or African American students are reported to use e-cigarettes.6 Furthermore, the 2021 Youth Risk Behavior Survey indicates that electronic vapor products (EVPs) are used by 36.8% of multiracial high school students.7 These rates are comparable to the usage rates among White students (36.7%) and Hispanic students (40.4%) but higher than the rates among Black students (33.6%) and American Indian/Alaska native students (33.5%).7

A significant concern is the emerging pattern of high e-cigarette use among multiracial youth, particularly among multiracial girls.8 This phenomenon is underscored by a report based on the 2014-2017 National Youth Tobacco Surveys (NYTS), which revealed that multiracial youth ranked third highest in terms of ever using any tobacco products, following only Native Hawaiians/Other Pacific Islanders and American Indian/Alaska native youth.9 These findings indicate a pressing need to investigate the prevalence and underlying factors contributing to e-cigarette use within this demographic.

Given the growing concerns surrounding e-cigarette use among multiracial youth and the evolving landscape of risk and protective factors, the current study aims to address these issues through a secondary data analysis of the 2020 Student Drug Use Survey. 10 By examining the prevalence of e-cigarette use and identifying the factors associated with its uptake among multiracial youth, the research study seeks to contribute valuable insights into the ongoing discourse on youth tobacco product use and to inform targeted interventions and policy measures to address this pressing public health concern. Specifically, the research questions analyzed are (1) What is the extent of e-cigarette use among multiracial youth? (2) Does e-cigarette use differ based on parental factors, school factors, involvement in risky behaviors, ease of

### **METHODS**

### **Study Design**

tiracial youth?

The current cross-sectional study utilizes a secondary data analysis from the biannual Student Drug Use Survey conducted by the Coalition for a Drug-Free Greater Cincinnati Interact for Health.<sup>10</sup> The questionnaire assesses various health risk behaviors among adolescents, including substance use, gang involvement, and violence. Institutional review board review for nonhuman research was obtained before analyzing the data.

### **Participants**

The participants included adolescents in the 7th through 12th grades recruited from 77 local and private schools in the Greater Cincinnati area. This study's sample was restricted to multiracial adolescents, resulting in a total sample size of 3340.

### Instrument

The Student Drug Use Survey for grades 7th through 12th, a nationally recognized tool for evaluating substance use and other high-risk behaviors, was administered to students. The current study utilized data from the 2020 survey, focusing on specific sections related to e-cigarette use, prosocial and risky behaviors, parental factors, school factors, ease of access, perceived harm to others and self, and sociodemographic factors among multiracial youth. Past-year e-cigarette use: participants' e-cigarette usage in the past year was assessed using the question, "Within the past year, how often have you used an electronic vapor product?" Prosocial factors and risky behaviors: the survey assessed 5 items each for prosocial, such as taking part in school sports teams, and risky behaviors, such as taking part in gang activities. Parent and school factors: the parent factors section included parent communication, rules, and enforcement. The school factors section also included 3 items about school rules, teacher discussions about rules, and rules enforcement. Ease of access, perceived harm to others, and perceived harm to self: perceived harm to self and others was analyzed by asking students how electronic vapor products harm them and other people. Ease of access was assessed by asking participants how easy it was to get all tobacco products such as cigarettes, e-cigarettes, smokeless tobacco, etc. Demographic and background information included race, sex, age, employment status, and grade.

### **Data Analysis**

All data analyses were conducted using IBM SPSS statistical software package (version 28.0). The data were dichotomized, with 1 indicating involvement in the behavior and 0 indicating nonparticipation. Descriptive statistics, including frequency distributions, means, standard deviations, and ranges, were calculated for demographic characteristics and the prevalence of e-cigarette

use. Univariate logistic regression analyses were performed to compute odds ratios, specifically examining the relationship between e-cigarette use and various risk and protective factors. Significant variables were retained and incorporated into a final logistic regression model.

### RESULTS

Table 1 provides the demographic bifurcation and descriptive characteristics of the participants. The sample comprised 3340 participants, with an approaching equal distribution between females and males. Specifically, 1708 participants (52%) identified as female, and 1575 (48%) identified as male. Participants were distributed across 2 grade categories: 7th and 8th grades and 9th through 12th grades. There were 1357 participants (40.6%) in the 7th and 8th grades category and 1983 participants (59.4%) in the 9th through 12th grades category. Regarding employment status, 2520 participants (76.9%) reported not having a job, while 759 participants (23.1%) reported having a job. Furthermore, the ease of access to e-cigarettes was assessed, with 1772 participants (58.8%) indicating no ease of access and 1241 participants (41.2%) indicating ease of access. The reported percentages reflect valid responses for each demographic characteristic, with missing data excluded from the denominator.

Among the total sample, a notable proportion of 667 (20%) reported using e-cigarettes in the past year. Further examination of the data revealed gender disparities, with 375 (23.1%) females reporting e-cigarette use compared to 218 (19.4%) males. Additionally, e-cigarette use appeared to increase with higher grade

levels, as 511 (27.8%) youth in 9th through 12th grades reported usage, whereas 156 (12.1%) in 7th and 8th grades reported the same. Employment status also played a role, with 226 (32.4%) of those with jobs reporting e-cigarette use compared to those without employment. Moreover, 396 reported low parental factors (26.7%), and 356 reported school factors (22.9%) were associated with higher rates of e-cigarette use among multiracial youth.

The univariate logistic regression was employed to analyze the e-cigarette use against the risk and protective factors (Table 2). There was a significant difference in past-year e-cigarette use by gender ( $\chi^2 = 6.243$ , p = .012). Female respondents reported a significantly higher usage rate (23.1%) than males (19.4%). Of the participants who perceived e-cigarette use as harmful to others, 14.7% reported using e-cigarettes in the past year, whereas 34.8% of those who did not perceive harm reported past-year use. The odds ratio indicates that those who do not perceive harm are 3.1 times more likely to use e-cigarettes (OR = 3.103, 95% CI [2.586, 3.723]). Similarly, among respondents who perceived e-cigarette use as harmful, 15.8% reported past-year use, compared to 35.4% of those who did not perceive harm. The odds of using e-cigarettes were almost 3 times higher for those who did not perceive harm (OR = 2.911, 95% CI [2.421, 3.500]). Among those who found it easy to access e-cigarettes, 37.6% reported past-year use, compared to 9.5% of those who did not find it easy. The odds of pastyear use were significantly higher for those with easier access (OR = 5.753, 95% CI [4.725, 7.005]). Higher-grade students (9th-12th) reported a higher usage rate (27.8%) compared to 7th/8th grade students (12.1%). The odds of past-year use were higher for

**Table 1. Demographic Characteristics of the Multiracial Youth** 

| Variable                 |                                   | Frequency (n) | Percent (%) |
|--------------------------|-----------------------------------|---------------|-------------|
| Sex                      |                                   |               |             |
|                          | Female                            | 1708          | 52.0        |
|                          | Male                              | 1575          | 48.0        |
| Grade                    | 41- 41-                           |               |             |
|                          | 7 <sup>th</sup> -8 <sup>th</sup>  | 1357          | 40.6        |
|                          | 9 <sup>th</sup> -12 <sup>th</sup> | 1983          | 59.4        |
| Employment status        |                                   |               |             |
|                          | No                                | 2520          | 76.9        |
|                          | Yes                               | 759           | 23.1        |
| Parent factors           |                                   |               |             |
|                          | High parent factors               | 1440          | 48.3        |
|                          | Low parent factors                | 1543          | 51.7        |
| School factors           |                                   |               |             |
|                          | High school factors               | 1448          | 47.2        |
|                          | Low school factors                | 1623          | 52.8        |
| Prosocial activities     |                                   |               |             |
|                          | High prosocial factors            | 1430          | 46.8        |
|                          | Low prosocial factors             | 1626          | 53.2        |
| Risky behaviors          |                                   |               |             |
|                          | Low risky behaviors               | 1337          | 44.8        |
|                          | High risky behaviors              | 1646          | 55.2        |
| Perceived harm to self   |                                   |               |             |
|                          | Harmful                           | 2226          | 73.3        |
|                          | No harm                           | 809           | 26.7        |
| Perceived harm to others |                                   |               |             |
|                          | Harmful                           | 2049          | 68.4        |
|                          | No harm                           | 947           | 31.6        |
| Ease of access           |                                   |               |             |
|                          | No ease of access                 | 1772          | 58.8        |
|                          | Ease of access                    | 1241          | 41.2        |



Table 2. Univariate Logistic Regression Analysis Reporting Odds Ratios for e-Cigarette Use in Past Year

| Variables  | χ²      | р     | Odds Ratio<br>(OR) | 95% Conf<br>Lower | idence Interval<br>Upper |
|--|---------|-------|--------------------|-------------------|--------------------------|
| Perceived harm to others (Harmful/No Harm)                                   | 156.415 | <.001 | 3.10               | 2.58              | 3.72                     |
| Perceived harm to self (Harmful/No Harm)                                     | 135.731 | <.001 | 2.91               | 2.42              | 3.50                     |
| Ease of access (No/Yes)  | 344.478 | <.001 | 5.75               | 4.72              | 7.00                     |
| Sex (Female/Male)  | 6.243   | .012  | 0.80               | 0.67              | 0.95                     |
| Grade (7 <sup>th</sup> -8 <sup>th</sup> /9 <sup>th</sup> -12 <sup>th</sup> ) | 110.122 | <.001 | 2.78               | 2.28              | 3.38                     |
| Employment status (No/Yes)   | 64.602  | <.001 | 2.15               | 1.78              | 2.60                     |
| Parental factors (High/Low)  | 37.913  | <.001 | 1.75               | 1.46              | 2.10                     |
| School factors (High/Low)  | 1.652   | .199  | 1.12               | 0.94              | 1.33                     |
| Prosocial activities (High/Low)  | 19.752  | <.001 | 1.49               | 1.25              | 1.79                     |
| Risky behavior ( <i>Low/</i> High)   | 477.224 | <.001 | 18.24              | 13.10             | 25.39                    |

Except for school factors (p = 0.199), all the variables were significant at p < 0.05. The italics denote reference categories.

older students. Employment status was also significantly related to past-year e-cigarette use ( $\chi^2$  = q64.602, p < .001). Those with low parent factors reported higher usage (26.7%) than those with high (17.2%). The odds ratio for low versus high parent factors was 1.756 (95% CI [1.466, 2.103]). Both high and low school factors groups showed similar usage rates, with no substantial difference in odds ratios (OR = 1.121, 95% CI [0.942, 1.335]). A significant relationship was observed between prosocial activities and past-year e-cigarette use ( $\chi^2$  = 19.752, p < .001). Those with low prosocial activities had higher usage rates (24.6%) than those with high prosocial activities (17.9%). Students with high risk behaviors reported much higher usage rates (36.7%) compared to those with low risky behaviors (3.1%). The odds ratio for low versus high risky behaviors was 18.240 (95% CI [13.102, 25.395]), indicating a strong correlation.

A logistic regression analysis (Table 3) evaluated the association between various predictor variables and past-year e-cigarette use among students. The predictor variables included sex, grade, employment status, parent factors, prosocial activities, risky behaviors, perceived harm of e-cigarettes, perceived harm to others from e-cigarettes, and ease of access to e-cigarettes. The final model was statistically significant,  $\chi^2$  (9, 2344) = 705.030, p < .001. The model explained 26.0% (Cox-Snell R<sup>2</sup>) to 39.9% (Nagelkerke R<sup>2</sup>) of the variance in the past-year of e-cigarette use and correctly classified 82.0% of cases. Significant predictors of past-year's e-cigarette use included sex, grade, employment status, prosocial activities, risky behaviors, perceived harm of e-cigarettes, perceived harm to others from e-cigarettes, and ease of access to e-cigarettes. Male students were less likely to use e-cigarettes in the past-year than female students. Students in higher grades, those with jobs, and those engaged in fewer prosocial activities were more likely to use e-cigarettes. High risky behavior scores significantly increased the likelihood of e-cigarette use. Additionally, students who perceived e-cigarettes and their effects on others as less harmful and those who found e-cigarettes easier to access were more likely to use them. Parental factors were not a significant predictor in this model.

### **DISCUSSION**

The present study examined the demographic and psychosocial factors associated with e-cigarette use among a sample of 3340 multiracial youth. The findings uncovered a significant proportion (20%) of participants reporting past-year e-cigarette use, reflecting a concerning trend among this sample. Notably, gender disparities emerged, with a higher percentage of females (23.1%) reporting e-cigarette use compared to males (19.4%), aligning with previous research indicating gender differences in e-cigarette use. This finding suggests a need for targeted interventions tailored to the unique risk profiles of female youth. Use of e-cigarettes was higher with higher grade levels and older students, which was consistent with prior studies. Employment status also played a role, with employed individuals exhibiting higher odds of e-cigarette use, indicating that employment may facilitate both the means and opportunity for e-cigarette use.

The univariate logistic regression analysis further elucidated significant differences in past-year e-cigarette use by various factors, including gender, perceived harm of e-cigarettes, ease of access, grade level, and employment status. Notably, perceptions of harm and accessibility emerged as influential factors, underscoring the importance of addressing misconceptions and regulating access to e-cigarettes among youth.<sup>8</sup> The subsequent logistic regression analysis confirmed the significance of these predictors in predicting past-year e-cigarette use, explaining a substantial proportion of the variance in usage. Interestingly, parental factors did not emerge as significant predictors in this model, suggesting that other factors may play a more prominent role in influencing e-cigarette use among multiracial youth.<sup>9</sup>

The presence of functional peer networks was identified as a crucial factor influencing e-cigarette use behavior, highlighting the significance of peer influence in shaping youth behavior. Adolescents with peers who use e-cigarettes may be more susceptible to engaging in e-cigarette use themselves, emphasizing the need to address peer influence in prevention efforts.<sup>5</sup> Despite the observed influence of peer networks, parental factors did not



Table 3. Logistic Regression Model Assessing E-Cigarette Use as Dependent Variable

| Variable                 | β      | SE    | Wald    | р      | Adjusted<br>Odds Ratios | 95% CI          |
|--------------------------|--------|-------|---------|--------|-------------------------|-----------------|
| Sex                      | -0.431 | 0.121 | 12.676  | <.001* | 0.650                   | [0.513, 0.824]  |
| Grade                    | 0.406  | 0.140 | 8.390   | .004*  | 1.501                   | [1.140, 1.975]  |
| Employment status        | 0.373  | 0.133 | 7.837   | .005*  | 1.452                   | [1.118, 1.886]  |
| Parental factors         | 0.056  | 0.121 | 0.213   | .644   | 1.058                   | [0.834, 1.341]  |
| Prosocial activities     | 0.278  | 0.121 | 5.271   | .022*  | 1.320                   | [1.041, 1.674]  |
| Risky behaviors          | 2.325  | 0.198 | 138.182 | <.001* | 10.223                  | [6.938, 15.062] |
| Perceived harm to self   | 0.505  | 0.146 | 11.959  | <.001* | 1.658                   | [1.245, 2.208]  |
| Perceived harm to others | 0.734  | 0.141 | 27.092  | <.001* | 2.082                   | [1.580, 2.745]  |
| Ease of access           | 1.339  | 0.127 | 111.636 | <.001* | 3.815                   | [2.976, 4.891]  |

<sup>\*</sup> denotes variables significant at p < 0.05, df = 1 for all variables.

significantly predict e-cigarette use in the final model. This finding underscores the need for further exploration of cultural influences and parenting styles that may moderate the association between parental factors and e-cigarette use among multiracial youth.

In conclusion, this study sheds light on the complex interplay of demographic and psychosocial factors in e-cigarette use among multiracial youth. The findings underscore the need for targeted interventions addressing gender-specific risk factors, perceptions of harm, accessibility, and peer influence to mitigate the rising prevalence of e-cigarette use in this population. Future research should prioritize this demographic to develop more effective prevention and intervention strategies tailored to the unique needs of multiracial youth.<sup>7</sup>

### PUBLIC HEALTH IMPLICATIONS

The findings carry significant implications for addressing e-cigarette use among multiracial youth and potentially mitigating multiple health risk behaviors. Current results underscore the potential effectiveness of strengthening protective factors to combat e-cigarette use and other health risk behaviors among multiracial youth.5 By enhancing prosocial factors, parental engagement, and school support systems, interventions can be tailored to empower multiracial youth to make healthier choices. Schools can play a pivotal role by implementing programs designed to build resilience, promote positive peer relationships, and educate on the risks associated with e-cigarette use. There is a pressing need for targeted parental education sessions within schools to raise awareness about the impact of secondhand smoke and how parental actions can influence e-cigarette use among youth. Parents influence their children's attitudes and behaviors, including their choices regarding e-cigarettes. Equipping parents with knowledge and strategies to address this issue can lead to more informed decision-making within families and potentially reduce e-cigarette use among multiracial youth.

Moreover, integrating culturally sensitive approaches into prevention and intervention efforts is essential for effectively addressing e-cigarette use among multiracial youth. Acknowledging and respecting diverse cultural backgrounds can enhance the relevance and acceptability of interventions within these communities. Col-

laborative efforts involving community stakeholders, cultural leaders, and health care professionals are vital for developing culturally tailored strategies that resonate with multiracial youth and their families. Furthermore, leveraging digital technologies and social media platforms can enhance the reach and impact of prevention efforts targeting multiracial youth. Interactive online resources, social media campaigns, and mobile applications can provide accessible and engaging platforms for delivering evidence-based information, promoting healthy behaviors, and fostering peer support networks. Harnessing digital tools can facilitate proactive engagement with diverse youth populations and facilitate ongoing communication and support.

In conclusion, addressing e-cigarette use among multiracial youth requires a comprehensive, multifaceted approach that integrates protective factors, parental involvement, cultural sensitivity, and innovative digital strategies. By implementing targeted interventions and fostering collaborative partnerships across sectors, we can work toward reducing e-cigarette use and promoting the health and well-being of multiracial youth now and in the future.

### **Recommendations for Future Research**

The current study provides valuable insights into the demographic and psychosocial factors associated with e-cigarette use among multiracial youth. However, several avenues for future research warrant exploration to deepen the understanding of this complex phenomenon and inform more effective prevention and intervention strategies. Longitudinal designs would enable researchers to examine how these factors evolve and their impact on e-cigarette initiation, frequency, and cessation behaviors. Qualitative research methods, such as focus groups and in-depth interviews, can provide valuable insights into the underlying motivations, perceptions, and social dynamics influencing e-cigarette use among multiracial youth. Qualitative approaches allow for a deeper exploration of subjective experiences and contextual factors that quantitative measures may not capture fully.

Furthermore, investigating the role of cultural factors and ethnic identity in e-cigarette use among multiracial youth is crucial. Cultural beliefs, values, and norms may shape attitudes toward e-cigarette use and influence behaviors differently across diverse

ethnic groups. Future research should adopt a culturally sensitive approach to examine how cultural factors intersect with other risk and protective factors to influence e-cigarette use patterns. Additionally, exploring the impact of targeted interventions and policy measures on reducing e-cigarette use among multiracial youth is imperative. Intervention studies evaluating the effectiveness of school-based programs, community outreach initiatives, and regulatory policies can provide valuable insights into the most efficacious strategies for preventing and reducing e-cigarette use in this population. Moreover, given the rapid evolution of e-cigarette products and marketing strategies, ongoing surveillance and monitoring efforts are essential to track trends in e-cigarette use and mized. identify emerging patterns of use among multiracial youth. Longi-CONFLICTS OF INTEREST tudinal surveillance studies can inform timely interventions and

In conclusion, future research should adopt a multidisciplinary approach integrating quantitative and qualitative methods to comprehensively understand the determinants of e-cigarette use among multiracial youth comprehensively. By addressing the knowledge gaps identified in this study, researchers can develop more nuanced and practical strategies to combat the growing public health threat posed by e-cigarette use in diverse youth populations.

policy responses to address evolving e-cigarette prevention and

### Limitations

control challenges.

Despite the valuable insights gained from this study, several limitations must be acknowledged when interpreting the results. Firstly, the cross-sectional nature of this study prevents the establishment of causal relationships. While there are identified associations between various factors and e-cigarette use among multiracial youth, the causation cannot be inferred. Longitudinal studies are needed to explore the temporal sequence of these relationships and provide a more robust basis for causal inferences. Secondly, the possibility of social desirability bias must be acknowledged. Some participants may have responded to survey questions in a manner they perceived as socially desirable rather than providing completely accurate information. This bias could potentially influence the reported prevalence of e-cigarette use and the factors associated with it. Lastly, the generalizability of our findings may be limited to multiracial youth in the specific geographical location where the study was conducted. Multiracial populations can exhibit significant diversity in terms of cultural, social, and environmental factors, which may affect their patterns of e-cigarette use differently in other regions. Therefore, caution should be exercised when applying these results to multiracial youth populations in different locations.

### Conclusion

In summary, the present study contributes valuable insights into e-cigarette use among youth, emphasizing the critical roles of peer networks, parental influences, and perceptions of harm as determinants of this behavior. These findings underscore the imperative for a holistic approach to tackling e-cigarette use among multiracial youth, centered on fostering positive peer dynamics and strengthening parental involvement while simultaneously addressing factors that contribute to the allure and accessibility of e-cigarettes. Through collaborative efforts in public health interventions, policymakers, educators, and health care professionals can strive to mitigate the health disparities linked to e-cigarette use within this vulnerable demographic. By prioritizing multifaceted strategies targeting individual and environmental influences, we can endeavor toward a healthier future for multiracial youth, where e-cigarette use is minimized and overall well-being is opti-

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**Competing Interests** 

Data Availability. The data can be requested from PreventionFirst! (https://www.prevention-first.org/home/).

Ethics Approval. This study uses secondary data. No ethical approval is required for this secondary analysis.

Ethics Declarations. All procedures performed in this study were under the ethical standards of the University of Cincinnati institutional review board and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. The author and the coauthors completed the National Institutes of Health (NIH) "Protecting Human Research Participants" before conducting the study.

Consent to Participate. This study uses secondary data. The Prevention-First! provided consent to the participants to participate during their data collection period, but this research project did not need it.

### **AUTHOR CONTRIBUTION**

All authors contributed to the study's conception and design. The corresponding author wrote the first draft of the manuscript, and coauthors commented on previous versions. Rebecca Vidouek conducted the data analysis and was responsible for conceptualizing the manuscript. Kruti Chaliawala wrote the first draft. Rebecca Vidouek and Keith King reviewed and revised the manuscript before submission. All authors read and approved the final manuscript.

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### **RESEARCH ARTICLE**

## Ohio Beyond the Mean: Socioeconomic Inequality in Body Mass Index Among Adults 2008-2021

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### **ABSTRACT**

**Background:** Obesity is a serious public health problem in Ohio. This study evaluated the heterogeneous relationship between socioeconomic status (SES) and body mass index (BMI) across the BMI distribution and examined the evolution of the gradient across time.

**Methods:** The analyses were conducted using data from the 2008 Ohio Family Health Survey (OFHS) and the 2021 Ohio Medicaid Assessment Survey (OMAS). These surveys are repeated cross-sectional random probability samples of noninstitutionalized adults used to monitor the health and well-being of residential Ohioans. The sample consists of nonpregnant adults aged 19 years and older.

**Results:** The change in BMI between 2008 and 2021 was most dramatic for women, with the entire distribution shifting to the higher range of values with the largest percentage change occurring at the 75th and 90th percentiles. The results showed a persistent educational and income gradient in BMI especially among women. While the income gradient is steepest at higher levels of BMI, the main impact of educational attainment occurs around the median BMI. The difference across the BMI distribution between those with and without a 4-year degree is most striking among women.

**Conclusion:** Overall, women experienced the most significant shift in BMI compared to men. However, rates of BMI vary across socioeconomic indicators, with educational attainment having the greatest impact on BMI.

**Keywords:** Body mass index; Obesity; Health disparities; Socioeconomic inequality; Unconditional quantile regression

### INTRODUCTION

In the last 15 years, Ohio experienced one of the steepest increases in the United States in the prevalence of adults with obesity, increasing from 28.1% in 2007 to 38.1% in 2022, making it the seventh most obese state in the union. This is concerning given that obesity has been linked not only to other serious chronic diseases such as hypertension, heart disease, and diabetes, but also to lowered life expectancy. Obesity is associated with increased health care expenditures and a decline in economic productivity, with recent estimates suggesting a loss of \$20 million annually due to the high rates of obesity among Ohio's labor force. At the same time, many studies have found that the burden of obesity falls along a socioeconomic gradient, with excess weight occurring among adults with lower educational attainment or less access to

economic resources.<sup>8</sup> However, these studies may mask differences in the relationship between education and obesity at the upper and lower ends of the body mass index (BMI) distribution.

While understanding the prevalence of obesity is essential to monitor population health, this measure may mask differences at the upper and lower end of the BMI distribution. Most studies on the socioeconomic gradient of obesity examine how risk factors are associated with average differences in the prevalence of obesity (ie, using linear regression) or with the odds of obesity (ie, using logistic regression), while relatively few US studies examine whether the socioeconomic gradient varies differentially across the distribution of BMI.<sup>8-10</sup> One exception is a study utilizing multiple years of the National Health and Nutrition Examination Survey (1971-2006). This study found that the strongest



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relationship between income and BMI occurs at the tails of the BMI distribution such that the gradient was negative at the obesity threshold (BMI in kg/m2 at 30 or higher) and positive at the underweight threshold (BMI < 18.5).<sup>11</sup> However, this study did not consider whether a similar gradient might occur across levels of educational attainment, nor was it able to examine patterns at a subnational level. This is an important omission for 2 reasons. The first reason is that recent research has demonstrated that health inequality is increasing in Ohio, particularly along educational lines.<sup>5</sup> The second reason is that the population of Ohio has experienced a more rapid increase in obesity in recent years compared to most other states, the degree to which may not be reflected in national data that does not allow for state-level investigation. Given these reasons, a study on the evolving socioeconomic gradient of BMI in Ohio is warranted.

Traditional methods of measuring socioeconomic inequalities in the prevalence of obesity typically take a single measure representing the average or mean of the population. For example, in annual reports issued by the Ohio Department of Health, obesity prevalence is captured as the percentage of adults with BMI that places them at or above the obesity threshold (ie, BMI greater than or equal to 30). This mean level is then presented across levels of household income and education.12 Using this method implies that the relationship between socioeconomic status (SES) and BMI is the same for all adults regardless of body mass. However, focusing on the mean level may mask substantial heterogeneity in the association between BMI and socioeconomic indicators across the population. This paper examines the relationship between 2 critical socioeconomic indicators (educational attainment and income) and BMI across the full range of BMI using unconditional quantile regression (UQR) on a population-based sample of residential Ohioans. A second goal is to examine the evolution of this relationship over time.

### **METHODS**

Data for the study come from the 2008 Ohio Family Health Survey (OFHS) and the 2021 Ohio Medicaid Assessment Survey (OMAS). These data are cross-sectional population-based samples of residential Ohioans that provide valuable information on their health status (including self-reported height and weight), socioeconomic characteristics such as household income and educational attainment, and their use and access to health insurance and health services. More detailed information on the survey procedures and the publicly available data used in this project can be found at https:// grc.osu.edu/OMAS. The study population consisted of nonpregnant adults aged 19 years and older, including 48 267 respondents in 2008 and 31861 respondents in 2021, with valid measures of BMI and SES indicators. A critical advantage of using these data compared with the only other state-based data that includes measures of BMI, the Behavioral Risk Factor Surveillance Survey (BRFSS), concerns sample size. To examine the relationship between our socioeconomic indicators and BMI across the full range

of values stratified by sex, a large sample size is needed. The OF-HS/OMAS sample is substantially larger than the BRFSS which gives us the statistical power to examine this relationship in Ohio, a state that is particularly burdened by high rates of obesity. Other data that may include measures of BMI, such as the National Health Interview Survey or the National Health and Nutrition Survey do not release state-level identifiers. This analysis was considered exempt by the authors' university institutional review board (IRB). The IRB approved a waiver of the consent process, as this study comprised deidentified, publicly available secondary data.

### **Empirical Strategy**

Unconditional quantile regression was used with BMI as the dependent variable. All models control for age, age-squared, and race/ethnicity. We use an approach developed by Firpo and colleagues based on a linear approximation of the unconditional quantiles through a recentered influence function (RIF).<sup>13</sup> More specifically, the RIF is defined as follows:

$$RIF(y; q_{\tau}) = q_{\tau} + \frac{\tau - \mathbf{1}\{y \le q_{\tau}\}}{f_{Y}(q_{\tau})}$$
 (1)

where y is BMI,  $\tau$  indicates a specific quantile (eg, 0.10 or 0.90),  $q_{\tau}$  is the value of y at that specific quantile,  $1\{y \leq q_{\tau}\}$  is a function that equals 1 when a respondent's value of y is less than or equal to the value of y at quantile  $\tau$ , and 0 otherwise; and  $f_{Y}(q_{\tau})$  is the density of y at quantile  $\tau$ . Once the RIF estimates were obtained, the following regression was then estimated using ordinary least squares (OLS):

$$RIF(v; q_{\tau}) = X\beta^{UQR} + \varepsilon$$
 (2)

Importantly, the explanatory variables do not contribute to the transformation of equation (1), even though the Xs in the model change, the interpretation of the estimated effects does not vary across models, so alternative models can be compared.14 Using UQR allows an examination of how each measure of SES varies in strength and association across the full BMI distribution. Unconditional quantile regression differs from conditional quantile regression in which the interpretation of the coefficients is related to the quantiles of the distributions defined by the covariates (the conditional distribution), instead of the unconditional distribution of BMI.15 Another advantage of UQR is that the estimates are robust to BMI outliers. 16 Recentered influence function estimates were obtained from both years of the data, and UQR was used to reveal the heterogeneity in the predictors (ie, educational attainment, household income) at various levels of the BMI distribution for 2008 and 2021. Complex sample design weights were applied to all analyses, and missing values were assumed to be missing at random.

### **Variables**

The dependent variable is BMI, defined as an individual's weight divided by their height squared, typically expressed in kg/m². We use the natural logarithm transformation of BMI to adjust for skewness and to estimate relative or proportion changes across the full range of values. Supplementary analyses were conducted using BMI without a transformation and the findings were

substantively similar. Two measures of SES used to measure the socioeconomic gradient in BMI were educational attainment and equivalized household income. Educational attainment was measured in 4 categories: less than a high school degree, a high school degree or some college, a 2-year associate degree, and a 4-year college degree or higher. The public versions of the OFHS/OMAS do not include a continuous measure of household-income-topoverty ratio. However, they do include continuous measures of household income, the number of adults, and the number of children. Using this information, we created an equivalence-adjusted household income estimate based on a 3-parameter scale weighted on household size and composition, often used by the United States Census Bureau to measure household income inequality.<sup>17</sup> The 3-parameter adjustment is calculated as follows: One or two adults: scale = (number of adults) 0.5; Single parents: scale = (number of adults + 0.8\*first child + 0.5 other children)0.7; All other families: scale = (number of adults + 0.5\*number of children)0.7. To standardize across years of the surveys, we defined 5 intervals of equivalence-adjusted household income (ie, lowest 20% to highest 20%). Given that prior research has found a stronger association between socioeconomic indicators and obesity prevalence among women, as compared to men, we stratify the analysis by sex.8,18 Race/ethnicity was captured as non-Hispanic White, non-Hispanic Black, non-Hispanic of other races, and Hispanic of any race.

### **RESULTS**

Table 1 presents descriptive statistics of changes in percentiles of BMI between 2008 and 2021 for both males and females. Among men, there was almost no change in the left-tail distribution, a minimal shift at the median, and the largest change at the 90th percentile. For women, the change in BMI is more dramatic, with the entire distribution shifting to the right, with the largest percentage change occurring at the 75th and 90th percentiles.

Tables 2 and 3 present the OLS coefficients and the UQR estimates showing the association of the SES variables with logged BMI at the 10th, 25th, 50th, 75th, and 90th percentiles for 2008 and 2021 for males and females, respectively, controlling for age, age-squared, and racial/ethnic group. We set the reference categories as a 4-year college degree and the highest equivalized household income.

Among men (Table 2, Panel A), the OLS estimates do not suggest a 'traditional' SES gradient in BMI, with BMI dropping as education-

al attainment increases, but a bifurcation between those with and without a 4-year degree. For example, in 2008 the OLS coefficients for less than high school, high school, and associate degree are larger and statistically different from those with a 4-year degree, all else equal, meaning that those with a 4-year degree have lower BMI on average than those with each of the educational categories shown. However, the significance tests between educational categories (ie, high school degree compared with associate degree) show no meaningful differences. On the other hand, the UQR estimates suggest that the gradient was primarily driven at the median BMI or above, where the gradient was steeper at the upper BMI values. To illustrate, in 2008, the OLS estimates show that men lacking a high school degree had a BMI that was, on average, 3% higher than men with at least a 4-year college degree. The OLS estimates are independent of the quantile of BMI considered, so no matter if the respondent has a low or high BMI, the difference between those with the lowest and highest education is roughly 3%. However, the UQR estimates show that the difference between the men with the lowest and the highest educational attainment is much larger as we move to the right tail of the BMI distribution. At the 75th percentile, men lacking a high school degree had a BMI that was 12% higher than men who held at least a 4-year college degree.

The results for 2021 (Table 2, Panel B) show a similar association between education and BMI as found in 2008, with the key differences occurring between men with and without a 4-year college degree. However, the UQR estimates provide some evidence of a positive gradient for men who were close to underweight; those in the 10th percentile with a 4-year degree had a 12% higher BMI than those without a high school degree, illustrating a protective effect of education at the extreme left-tail of the distribution.

Examining the quintiles of equivalence-adjusted household income shows that for both years, most of the differences across income levels are driven by men at the higher levels of BMI, namely the 50th percentile and above. However, among men, there is some evidence of a positive gradient for those below the median BMI (eg, the 10th and 25th quantiles). In 2008 and 2021, men at the highest level of income had relatively higher BMI than men with the lowest income. At the same time, the gradient for men in right-tail of the BMI distribution (the 90th percentile) follows the expected pattern with those at the highest incomes having slightly lower BMI than those at lower incomes. In contrast, the OLS estimates showed minimal differences across income levels,

Table 1. Body Mass Index at Selected Percentiles, 2008 and 2021

|                  | Males |      |            |          | Females |      |            |          |
|------------------|-------|------|------------|----------|---------|------|------------|----------|
| Percentile       | 2008  | 2021 | Difference | % Change | 2008    | 2021 | Difference | % Change |
| 15 <sup>th</sup> | 23.0  | 23.1 | 0.09       | 0.4%     | 21.5    | 22.2 | 0.76       | 3.5%     |
| 30 <sup>th</sup> | 25.1  | 25.1 | 0.02       | 0.1%     | 23.5    | 24.9 | 1.35       | 5.7%     |
| 50 <sup>th</sup> | 27.3  | 27.9 | 0.57       | 2.1%     | 26.5    | 28.3 | 1.86       | 7.0%     |
| 75 <sup>th</sup> | 31.0  | 32.3 | 1.27       | 4.1%     | 31.0    | 34.3 | 3.28       | 10.6%    |
| 90 <sup>th</sup> | 35.3  | 37.4 | 2.18       | 6.2%     | 37.1    | 41.0 | 3.89       | 10.5%    |

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highlighting the importance of examining the gradient across the full BMI distribution.

Among women (Table 3), the protective effect of a 4-year college degree has remained relatively stable across the BMI distribution between 2008 and 2021. The OLS estimates for both years show that women with less than a high school degree had BMI 7% higher than women with a 4-year college degree, on average. However, the UQR estimates reflect a somewhat inverted U-shaped relationship at different parts of the BMI distribution, with the most sub-

stantial impact found near the median and less at the extreme ends of the distribution. For example, in 2021, the difference in BMI at the 50th percentile between a woman with a 4-year degree and a woman with less than a high school degree was 26% but was 7% at the 90th percentile.

The gradient of obesity, according to equivalence-adjusted house-hold income, was steeper for women than for men in both years. The OLS estimates show that in 2008 and 2021, women in the lowest income group had a BMI that was, on average, 6% higher

Table 2. Association Between Socioeconomic Status Indicators and Body Mass Index (logged) Among Ohio Males Aged 19 Years and Older, 2008 Ohio Family Health Survey and 2021 Ohio Medicaid Assessment Survey

|                                    | OLS estimates difference in E |     | Uncon<br>quantil |     | quantile | regres | sion estir | mates (d | differenc | e in BM | I at speci | ific |
|------------------------------------|-------------------------------|-----|------------------|-----|----------|--------|------------|----------|-----------|---------|------------|------|
| Panel A: 2008                      |                               |     | q10              |     | q25      |        | q50        |          | q75       |         | q90        |      |
| Educational attainment             |                               |     |                  |     |          |        |            |          |           |         |            |      |
| Less than high school              | 0.03                          | *** | 0.00             |     | 0.05     |        | 0.12       | ***      | 0.12      | ***     | 0.07       | ***  |
| High school or some college        | 0.03                          | *** | 0.03             | *   | 0.06     | **     | 0.11       | ***      | 0.09      | ***     | 0.06       | ***  |
| Associate degree                   | 0.04                          | *** | 0.05             | **  | 0.09     | **     | 0.13       | ***      | 0.13      | ***     | 0.07       | ***  |
| (ref cat: 4-year college degree)   |                               |     |                  |     |          |        |            |          |           |         |            |      |
| Equalized household income         |                               |     |                  |     |          |        |            |          |           |         |            |      |
| Income 20-lowest income quintile   | -0.01                         | +   | -0.10            | *** | -0.15    | ***    | -0.06      | *        | 0.01      |         | 0.05       | **   |
| Income 40                          | 0.01                          |     | -0.04            | *   | -0.03    |        | 0.02       |          | 0.07      | **      | 0.05       | **   |
| Income 60                          | 0.01                          | *   | 0.00             |     | 0.00     |        | 0.02       |          | 0.04      | *       | 0.04       | **   |
| Income 80                          | 0.01                          |     | -0.01            |     | 0.00     |        | 0.02       |          | 0.03      |         | 0.03       | *    |
| (ref cat: highest income quintile) |                               |     |                  |     |          |        |            |          |           |         |            |      |
| Panel B: 2021                      |                               |     |                  |     |          |        |            |          |           |         |            |      |
| Educational attainment             |                               |     |                  |     |          |        |            |          |           |         |            |      |
| Less than high school              | -0.01                         |     | -0.12            | **  | -0.08    |        | -0.01      |          | 0.06      |         | 0.03       |      |
| High school or some college        | 0.03                          | *** | -0.02            |     | 0.03     |        | 0.12       | ***      | 0.14      | ***     | 0.08       | ***  |
| Associate degree                   | 0.03                          | *** | 0.03             |     | 0.06     | *      | 0.08       | *        | 0.11      | ***     | 0.06       | **   |
| (ref cat: 4-year college degree)   |                               |     |                  |     |          |        |            |          |           |         |            |      |
| Equalized household income         |                               |     |                  |     |          |        |            |          |           |         |            |      |
| Income 20-lowest income quintile   | 0.00                          |     | -0.07            | **  | -0.09    | **     | 0.01       |          | 0.03      |         | 0.03       |      |
| Income 40                          | 0.03                          | **  | -0.01            |     | 0.03     |        | 0.05       |          | 0.09      | **      | 0.09       | ***  |
| Income 60                          | 0.02                          | *   | 0.01             |     | 0.02     |        | 0.08       | *        | 0.05      | +       | 0.04       | *    |
| Income 80                          | 0.02                          | +   | -0.01            |     | 0.00     |        | 0.04       |          | 0.04      |         | 0.05       | **   |
| (ref cat: highest income quintile) |                               |     |                  |     |          |        |            |          |           |         |            |      |

<sup>+</sup> p < .10, \*p < 0.05, \*\*p < 0.01, \*\*\*p < 0.01. Models are weighted and control for age, age-squared and racial/ethnic group.

Table 3. Association Between Socioeconomic Status Indicators and Body Mass Index (logged) Among Ohio Females Aged 19 Years and Older, 2008 Ohio Family Health Survey and 2021 Ohio Medicaid Assessment Survey

|                                    | OLS estimate difference in |     | quanti |     |      | e regres |      | mates (d | difference | e in BM |      | fic |
|------------------------------------|----------------------------|-----|--------|-----|------|----------|------|----------|------------|---------|------|-----|
| Panel A: 2008                      |                            |     | q10    |     | q25  |          | q50  |          | q75        |         | q90  |     |
| Educational attainment             |                            |     |        |     |      |          |      |          |            |         |      |     |
| Less than high school              | 0.07                       | *** | 0.09   | *** | 0.16 | ***      | 0.23 | ***      | 0.17       | ***     | 0.11 | *** |
| High school or some college        | 0.05                       | *** | 0.06   | *** | 0.14 | ***      | 0.16 | ***      | 0.11       | ***     | 0.06 | *** |
| Associate degree                   | 0.05                       | *** | 0.07   | *** | 0.13 | ***      | 0.17 | ***      | 0.08       | ***     | 0.06 | *** |
| (ref cat: 4-year college degree    |                            |     |        |     |      |          |      |          |            |         |      |     |
| Equalized household income         |                            |     |        |     |      |          |      |          |            |         |      |     |
| Income 20-lowest income quintile   | 0.06                       | *** | 0.01   |     | 0.09 | ***      | 0.16 | ***      | 0.17       | ***     | 0.11 | *** |
| Income 40                          | 0.04                       | *** | 0.01   |     | 0.07 | **       | 0.13 | ***      | 0.12       | ***     | 0.03 | *   |
| Income 60                          | 0.03                       | *** | 0.02   |     | 0.09 | ***      | 0.09 | ***      | 0.09       | ***     | 0.04 | **  |
| Income 80                          | 0.01                       |     | 0.01   |     | 0.03 |          | 0.03 |          | 0.04       | *       | 0.00 | *   |
| (ref cat: highest income quintile) |                            |     |        |     |      |          |      |          |            |         |      |     |
| Panel B: 2021                      |                            |     |        |     |      |          |      |          |            |         |      |     |
| Educational attainment             |                            |     |        |     |      |          |      |          |            |         |      |     |
| Less than high school              | 0.07                       | *** | 0.03   |     | 0.11 | **       | 0.26 | ***      | 0.14       | ***     | 0.07 | **  |
| High school or some college        | 0.06                       | *** | 0.05   | **  | 0.13 | ***      | 0.22 | ***      | 0.12       | ***     | 0.06 | *** |
| Associate degree                   | 0.06                       | *** | 0.06   | *** | 0.17 | ***      | 0.20 | ***      | 0.11       | ***     | 0.03 | *   |
| (ref cat: 4-year college degree    |                            |     |        |     |      |          |      |          |            |         |      |     |
| Equalized household income         |                            |     |        |     |      |          |      |          |            |         |      |     |
| Income 20-lowest income quintile   | 0.06                       | *** | 0.02   |     | 0.08 | **       | 0.12 | ***      | 0.19       | ***     | 0.10 | *** |
| Income 40                          | 0.08                       | *** | 0.02   |     | 0.12 | ***      | 0.19 | ***      | 0.22       | ***     | 0.11 | *** |
| Income 60                          | 0.05                       | *** | 0.04   | *   | 0.09 | ***      | 0.12 | ***      | 0.15       | ***     | 0.08 | *** |
| Income 80                          | 0.03                       | *** | 0.01   |     | 0.06 | **       | 0.08 | **       | 0.09       | ***     | 0.05 | *** |
| (ref cat: highest income quintile) |                            |     |        |     |      |          |      |          |            |         |      |     |

<sup>+</sup> p < .10, \* p < 0.05, \*\* p < 0.01, \*\*\* p < 0.001. Models are weighted and control for age, age-squared and racial/ethnic group.

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than women in the highest income group. The UQR estimates show substantial heterogeneity for women across the BMI distribution. The gap between the lowest and highest income group was the largest among overweight or obese women (ie, at the 75th percentile), with estimates showing a 17% difference in 2008 and a 19% difference in 2021.

Overall, socioeconomic inequalities in BMI remain a reality in Ohio, but most predominately for women. The OLS estimates show (with the reference categories set as the highest educational attainment and highest income group) a general direction of higher levels of BMI for those with less than a 4-year degree and high BMI at successively lower levels of household income. However, the UQR estimates reflect heterogeneity in these relationships, with stronger associations between SES and BMI at the upper ends of the BMI distribution.

#### **DISCUSSION**

The findings from this study demonstrate that BMI has shifted to the right-tail of the distribution in Ohio, particularly for women, with the largest percentage change occurring at or above the 75th percentile. Indeed, the 2021 OMAS shows that 42% of women in Ohio experienced obesity, up from 30% in 2008. However, these rates varied widely across indicators of SES. We found that income had a more substantial impact among women with obesity (ie, at the upper tail of the unconditional BMI distribution). In contrast, education level had the greatest impact on the median level of BMI, particularly in 2021. This increasing importance of education for women's healthy BMI supports recent research on the widening health gap between those with low and high levels of educational attainment. Numerous national studies show that the gains in health and longevity are eroding among those with the least education, and Ohio is no exception. 19,20

The strengths of this study include a large and sufficient sample size from a population-based sample of Ohioans, which allowed for the examination of socioeconomic gradients across the full range of BMI for males and females separately and across different time periods. Unconditional quantile regression showed changes along with socioeconomic inequalities across the full BMI spectrum. However, this study does have some limitations. The sample size, while sufficient to examine a full range of BMI, did not allow for stratified analyses by racial/ethnic group. Nonetheless, our statistical models controlled for race/ethnicity and age. Another limitation is that the OFHS/OMAS does not include detailed measures such as physical activity, nutrition quality, or local food environment that may affect the distribution of social inequality and BMI. To address this shortcoming, we performed supplemental analyses using a measure of local food environment made available at the county level by the United States Department of Agriculture (USDA) Food Environment Atlas. More specifically, we included a measure of 'food swamps' described as counties with a high-density of restaurants and stores selling high calorie fast/ junk foods, relative to more healthy options. Prior research conducted at the county-level has shown that food swamps are associated with prevalence rates of obesity. Because county identifiers are available on the public versions of the 2008 OFHS and the 2021 OMAS, we were able to attach the percentage of food retail outlets that were characterized as food swamps to the county in which the respondents of our samples resided. We included this measure of local food environment in our models and, importantly, the results showing the relationship between SES and BMI remain unchanged. Finally, our results may not be interpreted in terms of causality, given the cross-sectional nature of the data. Nonetheless, the findings suggest income-related and education-related inequalities of excess weight are a reality in Ohio, particularly among women, and this could aggravate the socioeconomic

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gradient in health even further into the future.

The results presented here support recent calls in the public health literature to extend investigations into population health beyond the average and focus on the determinants of distributions.<sup>22</sup> Here, we demonstrated the importance of examining the socioeconomic gradient in BMI across the full range of the distribution, finding larger effect sizes in the right tail. By limiting research to often used overweight or obesity cut points and estimating just average effects through linear regression, we underestimate the effects of SES, particularly among those in the worst health (ie, those at upper levels of BMI). This clouds our understanding of how to target obesity prevention programs. Our findings also point to the widening gap in BMI among women by educational attainment, particularly the gap between those with a 4-year college degree and those without.

Education serves a dual role as both a driver of opportunity and a reproducer of health inequality.<sup>23</sup> State-level investment in education and the health and well-being of children early in the life course could disrupt the expanding health inequality found in Ohio. For example, the Ohio Healthy Programs (OHP) initiative supports training on healthy eating and physical activity for young children in childcare settings with the goal of reducing obesity and preventing later physical and mental health problems. More research is needed on the long-term impacts of programs such as these in Ohio, as they could inform future models and interventions across all ages.

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#### **Author Contribution**

Kelly Stamper Balistreri: literature review, designed the study, data analysis, manuscript drafting/editing. Rachael Ioele: literature review, manuscript drafting/editing.

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#### **RESEARCH ARTICLE**

## Addressing Donated Lead-Contaminated Meats within the Ohio Food Bank System

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#### **ABSTRACT**

**Background:** Lead contamination in game-hunted meat (GHM) remains a health risk due to common use of lead bullets in hunting, affecting meat donated to food banks. This qualitative study examined these risks in Ohio and Minnesota food bank systems, focusing on stakeholders' roles, awareness, and safety measures.

**Methods:** Semistructured telephone interviews were conducted with 26 stakeholders, including meat processors, meat distribution organizations, state meat inspectors, food banks, and food pantries in Ohio and Minnesota. Participants were interviewed about their knowledge and practices related to lead contamination in donated game meat.

**Results:** Significant disparities in awareness and safety measures were found between states. Ohio food banks and pantries exhibited minimal awareness of lead contamination risks (0/18 participants) and relied heavily on meat processors for safety, with few processors employing comprehensive safety measures beyond basic bullet removal. In contrast, Minnesota has a robust system with mandatory x-ray screening of this meat in place, albeit with financial and logistical challenges. Notably, approximately 5-15% of donated meat in Minnesota is discarded annually due to lead contamination. Food banks and pantries in Ohio expressed a strong willingness to learn and implement safety changes when informed about the risks.

**Conclusion:** This study highlights health risk within the Ohio food bank system due to lead-contaminated game meat, necessitating increased awareness and targeted interventions. Willingness of Ohio stakeholders to implement changes underscores the need for educational campaigns and policy discussions to enhance food safety. Collaborative efforts between states could further refine these interventions and promote nationwide food safety standards.

Keywords: Lead; Food banks; Bullets; Qualitative

#### **INTRODUCTION**

For more than half a century, concerns have been raised over the use of lead ammunition in US hunting.¹ Beginning with the documentation of waterfowl experiencing lead poisoning from consuming lead shotgun pellets, efforts were made to limit the use of ammunition containing lead, leading to enactment in 1991 of the first nationwide regulation restricting this ammunition's usage.².³ Nevertheless, other forms of lead ammunition are still regularly used for hunting in the United States. With roughly 57 000 pounds donated annually to Ohio charity organizations,

lead-contaminated hunted meat poses a potential food safety issue for those with low food security.  $^4$ 

Several studies have shown that lead ammunition leaves fragments in meat, often too small/distant from the bullet entrance site to be detected.<sup>5-7</sup> Research has documented elevated lead levels in game meat, with resulting detectible lead concentrations varying widely.<sup>8,9</sup> Thus, meat hunted with lead ammunition can contribute to elevated blood lead levels among at-risk groups such as children and pregnant women.<sup>10-13</sup>



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Despite these risks, there has been minimal discussion regarding food bank clients, a common consumer group of GHM. A study in Wisconsin found 15% of donated 1-pound ground venison samples from state food banks had visible lead fragments on x-ray analysis. A recent call to action highlighted the need for primary prevention actions to limit exposure. However, Minnesota and Iowa are currently the only states with regulations specific to this lead exposure risk. Minnesota requires x-ray screening of donated meat and discarding of samples with visible lead contaminants, while Iowa issues warning labels with distributed venison packages.

The purpose of this project was to examine the practice of donated hunted meat in a state with one of the highest rates of donated GHM, Ohio,<sup>15</sup> in order to identify possible areas of intervention that would be effective feasible and acceptable in making this food safer for at-risk populations.

#### **METHODS**

One-time semistructured telephone interviews were conducted with 26 individuals familiar with one or more roles in the donation and distribution of hunted meats (n=19 in Ohio; n=7 in Minnesota, see Table 1), including meat processors, meat distribution organizations, state meat inspectors, food banks, food pantries, and the Ohio Association of Food Banks (OAFB), which oversees most food banks in Ohio.

#### **Recruitment and Data Collection**

Participants were recruited through convenience sampling using various search engines and publicly available food safety net resources to identify suitable candidates (inclusion/exclusion criteria in Table 1).

Initial recruitment information was sent to relevant parties via publicly available emails. If no email was found, a message was sent through the organization's website contact form. In cases where neither method was possible, a phone call was made to obtain a contact email for sending the recruitment letter. Verbal consent was obtained for the interview with permission for audio recording. Recruitment ceased when thematic saturation (no new emerging themes or ideas) was reached for each role within each state.

Interviews addressed the use of lead ammunition in hunting game meat, food safety practices for donated meat, risks associated with consuming GHM and the organization-specific safety measures in place. Interviews also explored participants' willingness to learn more about food safety issues, share knowledge of safety practices used by other organizations, and advocate for changes within their own organizations. Participants were asked 2 structured questions, "On a scale of 0-10, how interested would you be in learning about some of the safety methods other organizations have put in place?" and "On a scale of 0-10, how interested would you be in advocating for your organization to try and promote some of the practices in improving donated hunted meat safety?" The responses were then interpreted as either promoters (ratings 9-10), passives (ratings 7-8), or detractors (ratings 0-6), following conventions of the net promoter score (NPS), a validated measure of intent to act.17 No questions, prompts, or guides were provided to participants prior to the interview. For the full interview guide, see Appendix.

Interviews were conducted by a research assistant who held a master of health science (MSH) degree with experience conducting semistructured interviews. The interviewer was not previously known to study participants. No one else was present during the interviews besides the participants and researcher. All data including original MP3 audio files were stored using unique study identifiers in an encrypted electronic database, REDCap (Research Electronic Data Capture). To help maintain confidentiality, written transcriptions were deidentified by replacing personal identifiers with generic signifiers, for example "Mr. Smith" replaced with "Foodbank Administrator." Only the deidentified written transcriptions were retained for analysis.

#### Table 1. Inclusion/Exclusion Criteria for Study Enrollment

#### **Inclusion**

- 1. Age range: 18 years or older.
- 2. Must be employed or actively volunteering at 1 of the following in Ohio or Minnesota:
  - food bank, food pantry, or related organization
  - meat distribution facility involved with processing of game-hunted meat
  - game-hunted meat donation organization
  - meat inspection organization or associated entities
- 3. Knowledgeable regarding at least 1 of the following:
  - demographics that their organization serves
  - food that their organization donates
  - meat inspection practices of their respective organization
- 4. Comfortable conversing in English.

#### Exclusion

1. Does not meet the inclusion criteria as stated above.

ceptualization, a diagram illustrating the process was created based on interview findings (Figure 1).

This protocol for this project was reviewed by the University Hospitals institutional review board (IRB) and was determined to meet criteria for exemption from IRB review.

#### Analysis

The study applied content analysis, a methodological orientation that allows for the systematic categorization and analysis of qualitative data. 18 This approach was chosen because it facilitates the identification of patterns and themes within narrative responses and open-ended data.

One data coder was involved in data analysis. The coding tree for data analysis was developed to systematically categorize and analyze the qualitative data collected from the interviews, allowing for a comprehensive and nuanced analysis and providing a deeper understanding of the issues related to lead contamination in donated GHM. Transcripts were manually coded and tracked. Participants did not provide feedback on the findings, and transcripts were not returned to participants for comment or correction.

#### RESULTS

Of 94 individuals invited to participate in the study, 4 declined to participate, 26 agreed, and the remainder did not respond to investigator outreach. Participants represented 8 food banks, 5 meat processors, 3 meat inspectors, 1 GHM donation organization, and 5 food pantries. Of these 26 participants, 25 reported their role within the organization. All that responded were employed within their organization, with 21 of these respondents having a leadership role (eg, director, owner, CEO). Nineteen interviewees were located in Ohio, while the remaining 7 were located in Minnesota. Interviews averaged 25 minutes in length.

#### Overview of Process-Ohio

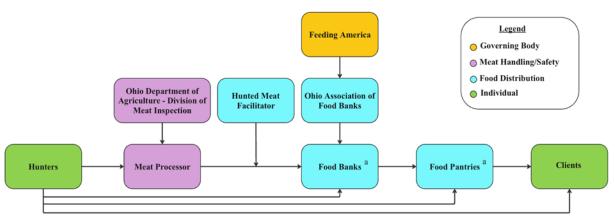
An understanding of the GHM distribution process in Ohio was formulated entirely from interviews with study participants, as no official resources showing this entire process exist. To aid in conWithin Ohio, venison is donated to families through food pantries with no restrictions or warning labels regarding the danger of lead, indication the meat was hunted, etc. Food banks and food pantries that are governed by the OAFB and hunted meat facilitators rely on US Department of Agriculture approved meat processors to handle safety measures. However, these processors follow different guidelines for donated meat compared to grocery storeintended meat, with the only reported lead safety measures being the removal of bullet entrance areas and, in one case, newer meat processing technology. The GHM that is donated will sometimes have labels that read "Not for Sale" and the type of meat (eg, ground venison), but do not describe the manner in which the meat was harvested. These safety measures are not required of those food banks and pantries that are not governed by the OAFB.

#### Overview of Process-Minnesota

The GHM distribution process in Minnesota, confirmed by prior work,15 is similar to Ohio's but incorporates complex measures to limit lead contamination. These extra measures are coordinated by the Department of Natural Resources (DNR) and the Minnesota Department of Agriculture (MDA).

Hunters obtain licenses with a surcharge that funds the venison donation program. Deer carcasses are donated to licensed processors under the MDA, which inspects these facilities for safety. The meat undergoes x-ray scanning for lead contamination, with contaminated batches discarded and safe meat distributed to regional food banks. The MDA tracks and reports on the donated meat, providing feedback to processors.

The DNR funds the program through hunting license surcharges and collaborates with the MDA. Additional efforts include training processors on safe practices, with food banks providing warning labels to families about the risks of consuming game meat.



<sup>a</sup> Some food banks/pantries operate independently of governing bodies.

Figure 1. The Game-Hunted Meat Distribution Process in the Ohio Food Bank System

m [meat processors]

Annually, 5-15% of firearm-related venison meat is discarded due to lead contamination, with no decrease in donated venison quantity due to these regulations.

Three main themes emerged from interviews. First, awareness and knowledge of lead contamination of GHM differs between Ohio and Minnesota. Second, the overall buy-in of stakeholders to addressing the topic of lead-contaminated meats is role-specific. Finally, Minnesota has a robust system in place to address lead-contaminated meats, but drawbacks exist. Quotes from interviews are noted in Table 2.

## Theme 1: Awareness and Knowledge of Lead Contamination in Donated Game-Hunted Meat Differs Between Ohio and Minnesota

Interviews revealed significant disparities in awareness and knowledge about lead contamination in donated GHM between stakeholders in Ohio and Minnesota. In Ohio, there was a prevalent lack of awareness among food banks and pantries regarding the risks associated with lead contamination in GHM. When queried about this issue, one food bank acknowledged, "This is the first time that I've heard of it being contaminated with lead due to bullets...I've heard of lead in water, but not through hunted meat for example." Additionally, the existing safety measures in Ohio were minimal with assumptions that other parties were responsible for maintaining appropriate safety measures. One food bank

noted "...[We're] pretty much banking on them [meat processors] that it's good to go."

In contrast, stakeholders in Minnesota demonstrated a higher level of awareness about lead contamination issues with multiple parties citing the concern of consumption with this product. However, there was an overall ambiguity regarding the distribution flow of donated meat. One processor even suggested this uncertainty was leading to a decrease in willingness to donate meat, saying, "I know before the DNR were coming to pick everything up I think there was a lot more places willing to do it and now that there's more regulation on it and it's tighter and it's not going to your local food shop." Of note, this contradicts the meat inspector from Minnesota who noted that amount of donated game meat "ebbs and flows [year over year]" with no notable trend.

## Theme 2: Overall Buy-In of Stakeholders to Addressing the Topic of Lead-Contaminated Meats is Role-Specific

The buy-in from stakeholders to address lead-contaminated meats varied significantly across different parties. In Ohio, the willingness to change was notably high among food banks and pantries once they were informed about the issue. Among these 2 groups, there was an overall interest in learning more and advocating for their organization to improve policies surrounding this issue, NPS = 8.3 and 36.4, respectively (Table 3).

## Table 2. Emerging Themes Through Discussions Regarding Lead-Contaminated Meats From Food Bank System Participants in Ohio and Minnesota

#### Theme 1: Disparities in Awareness and Knowledge of Lead Contamination in Donated Game-Hunted Meat Between Ohio and Minnesota

Ohio

- "...it's a solid, one-piece bullet... anything it hits gets destroyed ...I can't imagine that would affect anything of the integrity of the meat of anything."
- "...[We're] pretty much banking on them [meat processors] that it's good to go. Unless there's something that's glaring...we're pretty much trusting that person."
- "We've been working with Ohio Department of Natural Resources for so many years, and they've pretty much approved us, so I don't think we have any real issues at all on that."
- "I think we're about as safe as we can be with the deer meat at this point."

#### Minnesota

"I know before the DNR were coming to pick everything up I think there was a lot more places willing to do it and now that there's more regulation on it and it's tighter and it's not going to your local food shop."

#### Theme 2: Overall Buy-In of Stakeholders to Addressing the Topic of Lead-Contaminated Meats is Role-Specific

Food Bank/Pantries

- "Just because people are in need doesn't mean that they have to get the worst of the worst...I totally would advocate [for change]..."
- "You just put me on game and opened my eyes to something that we've been missing that we should really be more cognitive of."

Meat Processors

- "I would say I'm not really that interested because I really don't have time to learn about it and I don't think that's really...a danger."
- "...I really don't have the time to learn about it, and I don't think there's really that big of a danger."
- I mean on the deer end, it's kind of like we're just doing it as a favor [anyways]..."

#### Theme 3: Minnesota Has a Robust System in Place to Address Lead-Contaminated Meats but Drawbacks Exist

Food Bank/Pantries

"I would say it's a good program. It might be too much controlled. I suppose they're afraid of little kids eating the venison and getting lead poisoning."

Meat Processors

"People should know about it [lead contamination], but...you don't need to have all these little [surveillance] steps...we don't even know where it [donated meat] is going."

"I don't think it's bad...[but] I think it might be a waste of money.

advocate for change suggests that the absence of specific safety measures is due to a statewide lack of awareness. This contrasts with Minnesota, where many stakeholders are aware of the risks associated with lead exposure through GHM and have implement-

ed safety measures to mitigate these risks.

Interviews revealed multiple potential barriers to implementing safety measures. A significant issue is the lack of appropriate funding for intervention targets in Ohio, whereas Minnesota has a surcharge system in place to account for these increased costs. If a system is eventually put in place by Ohio, they are likely to be met with similar sentiments of many interviewed Minnesota stakeholders who felt the entire process of donating meat was convoluted and may be leading to a decrease in overall willingness to participate in this program. Nevertheless, 7 replicable strategies identified by interviewees follow.

Educational Campaigns. Educational campaigns can increase awareness about the risks of lead contamination in game meat among all stakeholders. By raising awareness, these campaigns can lead to better safety practices and greater buy-in for other interventions. Ohio food banks and pantries showed a high willingness to learn and implement changes once informed about the issue, suggesting a significant impact of targeted information on this topic. These campaigns can also involve training for meat processors and collaboration with health care providers to disseminate information on safe consumption practices. Of note, one of the initial studies revealing elevated lead content in donated GHM was noted as a source of motivation for change both in our interview with the MDA, and in Iowa. 16

Labels for Food Pantries and Food Banks. Another approach would be to implement warning labels on donated game meat for both food pantries and food banks. This low-cost intervention could raise awareness among clients and organizations without directly reducing contamination rates, though it would require consistent implementation across various locations for maximum effectiveness. These warning labels could serve as an initial step to inform and protect clients, and increase awareness among Ohio's food banks and pantries regarding the risks of lead contamination. Given that interviewees expressed a willingness to learn and advocate for safer practices, warning labels are likely to be both acceptable and feasible. Some meat processors already provide

On the other hand, meat processors in Ohio showed mixed responses with some expressing concerns about the financial burden of implementing new safety measures or a reluctance to acknowledging this issue. Time constraints were also highlighted by this party, especially during busy times such as hunting season (eg, "I would say I'm not really that interested because I really don't have to time to learn about it and I don't think that's really... a danger"). Responses regarding an interest in learning more or advocating for their organization to improve policies surrounding this issue were much more negative compared to food banks/pantries, NPS = -50 and -50, respectively (Table 3).

#### Theme 3: Minnesota Has a Robust System in Place to Address Lead-Contaminated Meats but Drawbacks Exist

Minnesota's system to address lead-contaminated meats is comprehensive and involves multiple steps to ensure safety as described above. This system significantly reduces the risk of lead contamination reaching consumers, particularly those relying on food banks and pantries.

However, this robust system is not without its drawbacks. The increased costs associated with these safety measures, including the transportation of meat to x-ray facilities and the subsequent storage and handling, pose financial challenges that are not fully offset by funding generated by the DNR through the hunting license program. For instance, the cost of storing meat at processors while awaiting x-ray results can strain smaller operations. Challenges with understanding meat flow distribution, as mentioned in Theme 1, also have led to hesitancy in participating in the donation program. Additionally, some meat processors and food pantries reported concerns regarding the loss of donated meat due to discarding and its downstream effects on food security, with one pantry expressing they were "bothered with [the] amount of meat that is wasted from this process."

#### **DISCUSSION**

This study reveals a significant health risk within the Ohio food bank system and identifies multiple factors contributing to inadequate safety measures for GHM. While implementing a proper safety model presents various challenges, it is evident that the system as a whole is largely unaware of this issue. The strong willingness of interviewed food banks and pantries to learn more and

Table 3. Ohio Stakeholder Net Promoter Scores on Topic of Lead-Contaminated Meats

|                     | Question                   | Promoters | Passives | Detractors | Net promoter score (NPS) <sup>a</sup> |
|---------------------|----------------------------|-----------|----------|------------|---------------------------------------|
| Food Banks/Pantries | Learning More <sup>b</sup> | 6         | 1        | 5          | 8.3                                   |
|                     | Advocating <sup>c</sup>    | 6         | 3        | 2          | 36.4                                  |
| Meat Processors     | Learning More <sup>b</sup> | 1         | 0        | 3          | -50                                   |
| weat Processors     | Advocating <sup>c</sup>    | 1         | 0        | 3          | -50                                   |

a Net promoter score (NPS) = (number of promoters - number of detractors) / total respondents) × 100. Promoters: scores 9-10, passives: scores 7-8, detractors: scores 0-6

b Learning more="On a scale of 0-10, how interested would you be in learning about some of the safety methods other organizations have put in place?"

Advocating="On a scale of 0-10, how interested would you be in advocating for your organization to try and promote some of the practices in improving donated hunted meat safety?"

labels indicating the type of meat given to food banks and pantries, so adding or revising a label would not be especially burdensome.

Upgrading Meat Processing Equipment. Upgrading meat processing equipment, such as meat grinders, could significantly reduce lead contamination rates, ensuring safer donated game meat. However, this poses a financial burden on meat processors, potentially limiting their willingness to adopt these changes, particularly as meat processors were less willing to learn about this topic overall compared to other players in the system. A potential solution to this barrier could be implementing funding models similar to Minnesota's hunting license surcharge to help alleviate the financial burden on processors.

Engaging Health Care Providers. Engaging health care providers by alerting them to the exposure risk from lead-contaminated game meat can also help spread awareness. Providers can screen at-risk populations based on their dietary habits, and council families regarding strategies to mitigate adverse impact, such as directing donated game meats to nonpregnant adults and older children.

Restricting Game Meat Donations. Restricting game meat donations to pregnant women and children, who are the most at-risk populations, can significantly reduce health risks. However, full enforcement is challenging, requiring staff education, member buy-in, and alternative food resources for affected clients.

X-Ray Screening. A more comprehensive solution involves mandatory x-ray screening to detect and discard contaminated meat. Effective, x-ray screening incurs high costs for transportation, screening, and additional personnel and facilities. Minnesota's robust system, which includes x-ray screening funded by a surcharge on hunting licenses, serves as a model that Ohio could consider. This intervention ensures that contaminated meat is identified and removed before reaching consumers, significantly reducing the risk of lead exposure. The success of Minnesota's system, despite its financial and logistical challenges, underscores the potential effectiveness of this intervention.

Limiting Lead Ammunition. Promoting the use of non-lead ammunition among hunters is another intervention with significant potential impact. Reducing lead ammunition use can decrease lead contamination in donated game meat. However, previous attempts to limit lead ammunition have met with minimal success due to long-standing hunting traditions, pushback from organizations like the National Rifle Association, and the higher costs of alternative ammunition materials.<sup>19</sup>

#### Limitations

This study acknowledges several limitations. First, the use of convenience sampling may introduce selection bias, limiting the generalizability of the findings. Participants who were more accessible or willing to participate might have different perspectives

than those not included. Additionally, the study relied on self-reported data from stakeholders, which could be influenced by social desirability bias or recall bias, potentially affecting response accuracy.

The qualitative nature of the study also presents limitations. While semistructured interviews provided in-depth exploration of stakeholders' views and practices, the findings are not generalizable to all food bank systems or meat processors. The study focused on stakeholders within Ohio and Minnesota, which may not fully represent the diversity of practices and perspectives in other states. Furthermore, differences in themes between states, such as awareness of lead-contaminated meats as a health risk, may be attributed to the implementation of systems in Minnesota compared to Ohio.

Efforts were made to achieve saturation in the interviews; however, additional insights might have been gained with a larger sample size or the inclusion of other relevant stakeholders not part of the study. Despite these limitations, the study provides valuable insights into the practices and perceptions regarding lead contamination in donated GHM within the Ohio food bank system, highlighting areas for potential intervention and improvement.

#### **PUBLIC HEALTH IMPLICATIONS**

The findings from this study highlight the urgent need to address lead contamination in donated GHM, particularly within Ohio's food bank system. This issue poses serious health risks for at-risk populations such as children and pregnant women, for whom even low-level lead exposure can have long-term health consequences. Incorporating additional safety measures—ranging from warning labels and enhanced screening to educational campaigns—would likely benefit not only clients of food pantries and food banks but also the broader public. Given the willingness of many Ohio stakeholders to learn more about this topic and advocate for safer practices, there is a strong foundation for implementing strategies that have been successfully used elsewhere, as demonstrated by Minnesota's robust system.

These results can be used by state-level policymakers, public health officials, food assistance organizations, and health care providers in Ohio to develop or strengthen programs that minimize the risks associated with GHM. Stakeholders throughout the donation and distribution chain could benefit from clear guidance and consistent regulations, including funding models to offset any financial burden. Ultimately, these interventions would contribute to the reduction of lead exposure among food-insecure populations, safeguarding the well-being of individuals who rely on donated GHM for protein while promoting a healthier, more informed community.

#### CONFLICTS OF INTEREST

On behalf of all authors, the corresponding author states that there is no conflict of interest.

#### **AUTHOR CONTRIBUTION**

Jared Lebron: conceptualization, methodology, formal analysis, investigation, data curation, writing—original draft, writing—review and editing, visualization. Marie Masotya: conceptualization, methodology, writing—review and editing, supervision. Sarah Ronis: conceptualization, methodology, formal analysis, writing— review and editing, resources, supervision, project administration.

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#### Appendix—Interview Guide

Addressing Donated Lead-Contaminated Meats within the Ohio Food Bank System

- 1. Tell me about your organization.
- 2. Do you have data for how many children and women are served through your services?
- 3. If not, do you have any rough estimates of these measures?
- 4. Tell me about your organization's role in helping the process of donated game-hunted meat eventually reaching those in need.
- 5. I'm curious about the types of donated meats that you receive, could you tell me more about that?
- 6. Does this change depending on the time of year? How so?
- 7. What methods do the donators use to hunt?
- 8. What types of materials are used in the ammunitions?
- 9. Has this always been the case, or have there been any changes in methods of hunting in recent years? If yes, could you tell me about some of the reasons for this?
- 10. Are there any risks to these donations, such as bullet fragments?
- 11. Certain organizations proposed/utilized modes of intervention to try and limit distribution of potentially lead-contaminated meats. Which if any the following applies to your organization?
  - a. Limiting of meat donation that have been hunted with lead ammunition
  - b. Screening meat after it had been donated, but before brought to food banks
  - c. Limiting donation of game-hunted meat to children and pregnant women
- 12. If yes to any of the above, how does your organization make this happen?
- 13. In addition to any of the methods just described, what else does your organization do to help make sure the meat being donated is safe to eat?
- 14. What motivated the policies you have in place for food safety in your organization?
- 15. Are there any areas of limiting contaminated-meats that you think your organization could improve in? If yes, what are they?
- 16. On a scale of 0-10, how interested would you be in learning about some of the safety methods other organizations have put in place?
- 17. On a scale of 0-10, how interested would you be in advocating for your organization to try and promote some of the practices in improving donated hunted meat safety?



#### **RESEARCH BRIEF**

# Drowning in Disparities: Health Equity in Ohio Childhood Drowning Rates

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#### **ABSTRACT**

**Background:** Drowning, a common unintentional injury, is a leading cause of death among children in the United States. The morbidity and mortality of childhood drowning are not uniform across American society but, rather, subject to profound racial disparities. These inequities are reflected in Ohio's pediatric drowning rates.

**Methods:** Data from the 2015-2020 Franklin County Child Fatality Report and the Centers for Disease Control and Prevention Web-based Injury Statistics Query and Reporting System (WISQARS) database were synthesized with information from the 2020 US Census to calculate standardized mortality ratios (SMRs) comparing observed drowning deaths among Black children in the state of Ohio to expected deaths based on national data. The SMRs were additionally calculated for Franklin County, Ohio, and compared to state and national rates.

**Results:** Standardized mortality ratios show that Black children in Franklin County were 21% more likely to drown than expected based on Ohio state rates and 41% more likely to drown than expected based on national rates between 2015 and 2020. Black children in the state of Ohio were 16% more likely to drown than expected based on national data during this time frame.

**Conclusion:** Existing inequalities in childhood drowning rates are rooted in historical racism. This legacy has resulted in significantly higher drowning rates among Black American children and, alarmingly, higher-than-expected rates in Ohio specifically. Understanding these disparities is crucial to protecting vulnerable members of our communities from these avoidable tragedies. Interventions should account for social determinants of health, including race and ethnicity, when attempting to decrease pediatric drowning rates.

Keywords: Drowning; Health equity; Social determinants of health; Standardized mortality ratios

#### INTRODUCTION

Drowning is a common cause of death among American children, with approximately 11 fatal drownings occurring every single day in the United States.<sup>1</sup> These unintentional injury deaths are largely preventable, yet they continue to occur, making pediatric drowning a critical public health concern.<sup>2</sup> Moreover, these drowning rates are subject to profound racial disparities.<sup>1,2</sup> Childhood drowning is therefore a matter of equity and social justice.

While drowning rates among American White and Hispanic children have declined in recent years, rates among Black children

have been consistent for the past 2 decades. Today, Black Americans remain 1.5 times as likely to drown as White Americans—a disparity that has not improved since 1999.<sup>3</sup> This inequality has primarily been attributed to racial differences in access to swimming education and safe swimming facilities, an issue with historical roots in American racism.<sup>4</sup>

Historically, Black Americans have struggled to access the facilities and education needed to learn to swim because of racist legislation and structural violence. During racial segregation, few pools or beaches allowed Black families to swim, and desegregation coincided with a shift toward privatization of these



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facilities. Public pools deteriorated and closed or were torn down and replaced by private establishments, eliminating the possibility of gaining swimming competence via free communal facilities. The economic and social legacy of racial discrimination prevented many Black families from joining private clubs, perpetuating a lack of swim education among African American families.<sup>5</sup> As a result, 64% of Black American children cannot swim.<sup>6</sup> This trend is reflected in Ohio's childhood drowning rates, as well as in rates specific to Franklin County.<sup>7</sup>

#### **METHODS**

Data were extracted from the 2015-2020 Franklin County Child Fatality Report<sup>7</sup> and the Centers for Disease Control and Prevention Web-based Injury Statistics Query and Reporting System (WISQARS)<sup>8</sup> database. The proportional racial breakdown of pediatric drowning deaths was calculated for the United States, the state of Ohio, and Franklin County, Ohio (Figure 1).

This data was then synthesized with information on the racial makeup of the overall pediatric population from the 2020 US Census<sup>9</sup> to calculate standardized mortality ratios (SMRs) accounting for different racial demographics. These SMRs compare the true number of events within a population to expected events based on the mortality rate of a standard population (in this case, that of the United States). Calculated SMRs show geographic disparities between observed and expected drowning deaths among Black children during the 2015-2020 period. These inequalities are analyzed in the context of social determinants of health.

#### **RESULTS**

Childhood drowning rates in Ohio reflect a broader national pattern wherein Black children are significantly more likely to drown than White children. From 2015-2020, Black children accounted for 55% of childhood drowning victims in Franklin County, compared to 29% in Ohio as a whole and 25% nationally during this period. Accounting for differences in racial demographics reveals a Franklin County drowning rate of approximately 15.88 per 100 000 Black children during this period, compared to 13.08 per 100 000 for the state of Ohio, and 11.28 per 100 000 nationally. The SMR calculations for the 2015-2020 time frame, provided (Table 1), show that observed child drowning

deaths among Black children in Franklin County were 21% higher than expected based on Ohio state rates (SMR=121.08) and 41% higher than expected based on national rates (SMR=140.99). Observed child drowning deaths among Black children in Ohio as a whole were also 16% higher than expected based on national rates during this period (SMR=115.97).

#### **DISCUSSION**

Ohio faces a heavy burden of racial disparities in drowning. These standardized mortality rates illustrate higher-than-expected pediatric drowning deaths among Black children in Ohio compared to the United States, as well as higher-than-expected rates in Franklin County compared to the entirety of Ohio. Additionally, in Franklin County, specifically, immigrant children accounted for half of all childhood drowning victims between 2015 and 2020. This adds another layer of vulnerability for certain minority children.<sup>7</sup>

Numerous factors might be proposed to account for these inequalities. Among these are the material conditions in which individuals live and work, psychosocial factors, behavioral and biological factors, and the health system itself. The economic impacts of decades of discrimination have resulted in a poverty rate among Black Americans that is 1.8 times that of the general population, preventing access to formal swimming lessons which have been shown to reduce the risk of drowning in children by as much as 88%. Acceptable 13.14 Lack of safe swimming facilities is an additional issue—many US cities, including Columbus, Ohio, legally require pools to be surrounded by a fence or barrier; however, studies show that most cities do not routinely inspect pool barriers or enforce safety regulations. These lapses in safety inspections are more likely to affect lower-income communities.

Psychosocial determinants of drowning include an absence of attentive, effective supervision which is associated with a 3-fold increase in drownings.<sup>4</sup> Numerous stressors may compromise caregiver attention including health concerns, working long hours, and performing shift work. These determinants disproportionately affect marginalized individuals, particularly racial minorities and individuals with lower socioeconomic status.<sup>16</sup> Additionally, if a caregiver cannot swim, they are limited in their ability to provide proximity during water supervision. This perpetuates

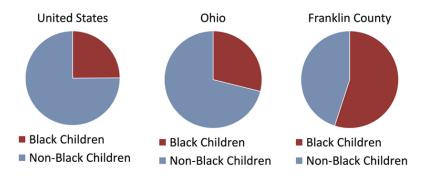


Figure 1. Racial Makeup of Pediatric Drowning Deaths<sup>7,8</sup>



Table 1. Standardized Mortality Ratios (SMRs) for Black Pediatric Drowning Victims in Franklin County, Ohio and the State of Ohio, 2015-2020

| Data: 2015-2020   | United States | Ohio   | Franklin County, Ohio |
|---|---------------|--------|-----------------------|
| Black children as a percentage of pediatric drowning victims              | 24.9%         | 28.9%  | 54.5%                 |
| Drowning rate among Black children (drownings per 100 000 Black children) | 11.28         | 13.08  | 15.88                 |
| Standardized mortality ratio (SMR) versus the state of Ohio               |               |        | 121.08                |
| Standardized mortality ratio (SMR) versus national data                   |               | 115.97 | 140.99                |

drowning risk among families belonging to marginalized groups, where parents may have faced their own challenges in accessing swim education.<sup>4</sup>

Health infrastructure also has significant impacts on drowning prevention and resuscitation. Previous studies that have examined the relationship between emergency medical services (EMS) response time and demographic factors in the United States have consistently reported that racial minorities, rural residents, and individuals living in low-income areas experience longer wait times for EMS arrival. 17,18 Before EMS arrival, racial and ethnic minorities are additionally less likely to receive bystander support, including cardiopulmonary resuscitation (CPR). 17 These systemic issues augment elevated risks of experiencing drowning among these communities, creating further susceptibility to poor outcomes.

Understanding these root causes may pave the way for better, more comprehensive policies and practices to combat preventable childhood drownings. Given that swim lessons are highly effective at preventing drowning, increasing access to swim education among vulnerable populations is essential.<sup>14</sup> Mandatory water safety education in elementary schools has been proposed as one possible intervention that has been successfully implemented in other countries, such as the United Kingdom. 19 Subsidizing schoolbased programs in low-income neighborhoods in the United States could enhance equity in swim education, tackling socioeconomic disparities in drowning. Subsidy of adult swim education in high-risk areas should also be a key policy goal, knowing that parental swimming ability prevents childhood drowning.4 These programs would also benefit from incorporating inclusive water safety outreach campaigns to educate families about effective swim supervision, drowning risks, and the importance of swim education.4

Culturally competent swim education should be a priority to ensure the accessibility of swim lessons among at-risk populations. Barriers to swimming competency in higher-risk groups should be defined and addressed using input and leadership from within these communities, ensuring adequate understanding of needs and values. Considerations for better, more inclusive swim education and outreach may include accommodations for ethnic hair-styles and hair protection, religious clothing and headwear, and cultural beliefs about mixed-gender physical activity. <sup>20,21</sup> In addition to designing programs with inclusivity in mind, ensuring that staff are knowledgeable about cultural needs and differences can

facilitate more comprehensive swim education. These actions address social determinants of drowning, creating a more just and inclusive approach to drowning prevention.

#### PUBLIC HEALTH IMPLICATIONS

An analysis of Ohio-specific childhood drowning data compared to national trends reveals important disparities and challenges within the state. While systemic racism and the historic legacy of racial segregation may partially explain discrepancies in drowning rates among different racial groups, these issues are not specific to Ohio. More research is needed to understand the factors contributing to disproportionately high rates of pediatric drowning deaths among Black and immigrant children in Ohio and Franklin County. Knowledge of these disparities should also guide drowning prevention. To address these challenges, interventions will need to be tailored to the most vulnerable children and their communities. Policy recommendations include increasing equity in swim education by requiring and sponsoring mandatory water safety education in elementary schools;19 subsidizing adult swim education programs through community centers, gyms, and schools, recognizing that parental swimming ability prevents childhood drowning;4 and utilizing culturally competent, inclusive water safety outreach campaigns in multiple languages to educate families about effective swim supervision, drowning risks, and the importance of swim education.4

By acknowledging and acting upon the social determinants of childhood drowning, we can create better, more comprehensive prevention practices and systems. This approach safeguards the well-being of all children, regardless of their social circumstances.

#### **CONFLICTS OF INTEREST**

None declared.

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#### **COMMENTARY/POLICY**

## Vaccination, Adolescents, and the Mature Minor Standard in Ohio

### Kathryn Poe

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#### **ABSTRACT**

Controversy in recent years surrounding the vaccination of minors and the stories of adolescents like Ohioan Ethan Lindenberger, who went viral for a Reddit post in 2019 in which he asked for advice after discovering that he had never been vaccinated, have raised questions about whether allowing adolescents to vaccinate without parental consent is acceptable. This article discusses the mature minor doctrine, Kantian philosophy, and principlism to argue that not only is it acceptable to do so, but there is already precedent in Ohio law, and doing so would be beneficial to public health in Ohio.

**Keywords:** Vaccination; Adolescents; Mature minor; Parental consent

#### INTRODUCTION

Vaccines are perhaps the best modern example of a medical innovation's success being its own worst enemy. Those who remember the scourge of diseases such as polio and measles in the United States are dwindling in population, and with them often goes the memory of their fear, panic, and desperation. Estimates from the World Health Organization (WHO) place the lives saved from vaccinations at 3.5 million to 5 million each year,¹ and many Americans are far removed from the realities many developing nations face when accessing vaccines. Yet, vaccines have been followed by criticism, suspicion, and fear since their creation,² often for good reason. The history of vaccine testing on children is fraught with controversy and ethical violations; from the first vaccine being tested on a child to the American hepatitis experiments at Willowbrook.³ Young children have often been at the center of discussions about vaccination for terrible reasons.

During the COVID-19 pandemic, some of that focus shifted to the gray area of adolescence as families grappled with whether to vaccinate their teens. In Ohio, stories on the topic of vaccination in adolescence have made national headlines, like the story of Ohioan Ethan Lindenberger who went viral for a Reddit post in 2019 in which he asked for advice after discovering that he had never been vaccinated.<sup>4</sup> Other stories from nearby states made headlines in the aftermath of COVID-19, like that of Nicolas Montero who used a law in Philadelphia to be vaccinated for COVID-19 against his

parents' wishes, have grabbed headlines in recent years as antivaccination sentiment has spread in the United States.<sup>4</sup> In the age of the internet, teenagers are able to access more health information than ever before, and it's no surprise that young adults feel more empowered to make these kinds of choices. Adolescents in Ohio (from age 15 years and above) should be able to pursue routine vaccination from a licensed physician without the consent of a parental guardian given the already established precedent in state laws for special circumstances. While consequentialist frameworks are commonly used to encourage vaccination for the benefit of everyone and justify the use of mandates, these arguments won't be the focus of this paper. Instead, this paper will cover a Kantian framework focused on the universalization principle and acting for the benefit of others as well as the autonomy of a mature minor and the minimal risk of harm.

#### **Medical Literature and Past Discussion**

Evidence has shown that vaccine refusals correlate to outbreaks of vaccine preventable diseases such as measles and pertussis, emphasizing the importance of giving adolescents another opportunity after a parental refusal earlier in life. Lower childhood vaccination rates are generally tied to outbreaks of childhood infections, putting not only the young children without vaccines at risk, but also their peers. Despite this risk, more and more parents are choosing the opt-out every year. The Centers for Disease Control and Prevention (CDC) data shows that more



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kindergarteners did not have all required vaccines in 2021 compared to 2019.7,8 Many parents forget the real impact of some of these preventable diseases because of the effectiveness of modern vaccines and public health initiatives, making it easier to justify a refusal. For example, diphtheria, a bacterial infection, can have mortality rates of 20% in children under 5 years of age.9 Other diseases, like measles, can have long-term consequences for children such as intellectual disabilities caused by encephalitis.10 When this reality is not the everyday lived reality for parents, it can be easy to minimize the impact. Ultimately, exposure to these kinds of pathogens can happen at any point in someone's life, making any opportunity, even later in adolescence, to reverse a vaccine refusal an important opportunity for changing course. In a state like Ohio, this kind of expansion could put the state closer to herd immunity. Ohio's vaccination rates at 24 months are generally on par with the rest of the country, but could be slightly improved.11 For example, herd immunity for measles is around 94% of the population (or 94 out of every 100 people).12 In Ohio, at 24 months, 91.5% of children are given the measles, mumps, and rubella (MMR) vaccine.11 Expanded access in adolescence could give that number an important bump.

Questions about allowing minors to consent to vaccines without parental approval are not new in medical literature, and the discussion is usually spurred by a concern about a specific vaccine such as the human papillomavirus (HPV) vaccine. 13 The Society for Adolescent Health and Medicine published a position paper on the topic in 2013 encouraging states to allow for exceptions to parental consent for adolescents in certain circumstances, 14 and other studies around that time suggested that some medical professionals believed this could help improve access. 15 Studies have found that physicians and adolescents seem to be on the same page about adolescent involvement, with physicians surveyed supporting minor consent to vaccination15 and other surveys showing support for involvement among adolescents.16 An article published in The New England Journal of Medicine in 2019 about measles outbreaks shows that the issue of adolescents and consent to vaccination has been slowly building over time as more and more parents opt-out of childhood vaccines.<sup>17</sup> However, much of the literature on the topic comes from the recent pandemic era, spurred by both the cultural divisions and other events such as the authorization of the Pfizer-BioNTech COVID-19 vaccine for adolescents in 2021.18 Some of the discussion emphasizes the reality that due to social media, some adolescents are more informed about vaccination than their parents.<sup>19</sup> The COVID-19 vaccines also presented unique circumstances that separated the literature on the topic from other vaccines, specifically the balance between personal autonomy and an ongoing public health emergency. 13

#### The Legal Landscape for Minors

For most of the history of vaccination in the United States, the discussion has focused on the allowability of vaccine mandates broadly. The 1905 Supreme Court case *Jacobson v Massachusetts* 

ruled that states are allowed to enact a vaccination mandate to protect public health.<sup>20</sup> Interestingly, the Supreme Court also ruled that "the legislature may exempt children from the law without violating the equal protection rights of adults if the law applies equally among adults."20 Various public health crises throughout the last century have had a disproportionate impact on children and families, leading to an emphasis on vaccinating young children. For example, the rollout of the polio vaccine in the 1950s heavily focused on children, leading to the Vaccines for Children (VFC) program later on (in 1994).<sup>21</sup> As standards around informed consent have developed for adults, an understanding that parental permission is required has also developed for children.<sup>22</sup> Since informed consent is a term reserved for a competent, autonomous adult, parents cannot give consent for their children, but can, rather, give their permission. For all adults, the standard age of consent is 18 years, which is standard practice for most medical treatment in the United States with few exceptions.<sup>22</sup> In addition, it is important to highlight the 1977 National Commission's definition of a child when considering pediatric research. The National Commission defined a child as "persons who have not attained the legal age of consent to general medical care as determined under the applicable law of the jurisdiction in which the research will be conducted."23 This definition highlights that a "child's" legal status is directly dependent on the laws where the child in question resides. Simply, the definition of a child is malleable to a certain extent, allowing for exceptions and changes.<sup>23</sup>

While these exceptions vary state by state, minors are generally only able to make their own medical decisions before the age of 18 years in instances of emancipation, specific special enumerated circumstances (such as sexually transmitted infection (STI) testing, pregnancy, etc), and when the mature minor doctrine is applied.<sup>22</sup> The mature minor doctrine is the common-law rule that allows an adolescent who is mature to give consent for medical care when necessary.24 While this doctrine is vague and contains a number of possible factors, there are general commonalities in the interpretation from the legal system, such as the ability to understand and communicate information, the ability to understand the risks and benefits, and that a minor understands their diagnosis, among many others.<sup>25</sup> These guidelines echo the standards found in many informed consent processes for adults, such as a person's comprehension, voluntariness, and the impact to someone's health.<sup>26</sup> When determining whether a minor is competent enough to make their own medical care in a pediatric setting, this is often the framework that is used. The doctrine is also supported by commonly cited evidence suggesting that minors above the age of 14 years make decisions in a similar way to adults.<sup>27</sup>

The mature minor doctrine is commonly used in situations where state or local law allows for exceptions or special circumstances. In Ohio, so-called special circumstances include testing for STI, HIV/AIDS testing, mental health care, and abortion-related health care.<sup>28</sup> Other states have a similar list of exceptions, including allowing a minor to be vaccinated without parental permission.<sup>29</sup>

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Alabama allows minors above the age of 14 years to be vaccinated without parental permission, and Oregon allows for minors 15 years of age and up to receive certain kinds of care (including vaccines) without parental permission.<sup>29,30</sup> In Delaware, anyone above the age of 12 years can get vaccines related to STI.<sup>31</sup> Other states, such as California, allow for only certain vaccinations (the HPV vaccination and hepatitis B vaccination) while municipalities within the state might differ.<sup>29</sup> In all of these cases, the concept of the mature minor standard is a cornerstone in laying the argument for why vaccination is legally permissible.

#### Vaccination as an Individualized Treatment

In discussions surrounding vaccination in public health, consequentialist (specifically utilitarian) reasoning is a common justification due to the realities of herd immunity. Typically, the logic is that the more people are vaccinated, the more effective the vaccine will be, and the safer society-at-large remains.<sup>32</sup> This is not an objectionable position. However, in this circumstance, consequentialist reasoning does not seem to be the driving force behind an adolescent patient's decision. Herd immunity is important, but many teenagers also cite wanting to protect themselves as one of their primary concerns. In the minds of most people, vaccination is a treatment and that's still an individual choice, with the secondary benefit of herd immunity for others.<sup>33</sup> It's worth focusing on the benefit to the individual as a treatment and personal prevention in this specific situation.

Commonly, the conflict surrounding adolescents and vaccination arises from a conflict between the teen and the family, specifically due to religious or ethical beliefs. While parents are typically given precedence in decisions about their child's health care, this decision-making power is not unlimited.34 In modern pluralistic society, it also cannot be assumed that a family always acts as a single unit with unified beliefs. For a long time, physicians have been able to safely assume that children and their parents share a moral community,35 but in the age of the internet and expanded access to information this may not be the case. Adolescents may genuinely hold different moral, political, and health-based beliefs about their care than their parents—sometimes radically different! The advocacy group Teens for Vaccines includes the stories of many ambassadors on their website, including the stories of young people whose parents are strongly anti-vaccine or believe in conspiracies surrounding QAnon, while they themselves do not.33

For mature adolescents, this combination can cause not only moral distress but also serious concerns about their own health. This is not a unique concern to vaccination. In other situations, special exceptions within state law exist for this exact reason (like HIV/AIDS testing). It is well understood that young adults may not pursue treatment if they believe a parent will punish them or disagree. In these situations, it is recommended that physicians treat the adolescent patient in the interest of what is best for the patient, and then initiate a discussion about informing their parents later on.<sup>22</sup> While it has been previously argued that immunizations

may not meet the threshold for this kind of legal protection or intervention based on the lack of immediate threat presented,36 this is not necessarily true. As we discovered during the COVID-19 pandemic, the exposure risk to a pathogen is constantly shifting in a world in which people are constantly traveling. Being unvaccinated may make a normal activity, like domestic air travel, much more dangerous for a teenager. Additionally, there are more risks than just the physical risk to an adolescent's well-being. Adolescents may be substantially restricted by these parental choices in college admissions choices, work environment, K-12 public school requirements, participation on sports teams, and other situations where a minor may be not allowed to participate if unvaccinated. This is the current standard in Ohio, although there are some exceptions. In situations where the adolescent may be able to participate, they will likely create a threat to others—such as adolescents with disabilities. There need not be an ongoing pandemic or measles outbreak to create an immediate threat when the reality of living a 'normal life' as an unvaccinated person may be a threat on its own. Given the relatively minimal risk of vaccination when compared to the real possibility of an unvaccinated adolescent contracting measles or chicken pox (or giving it to others),37 the risks and benefits to a young person become clear. Requiring an adolescent to go without vaccination due to a parental belief is far more dangerous than allowing a mature adolescent to make the choice to vaccinate.

#### **A Kantian View**

Another possible ethical approach is to turn to the works of Immanuel Kant whose deontological framework often fits well into public policy-based approaches due to its structure. There are 2 lines of thinking within Kant's work that can be used to justify this type of action. First is the maxim that all moral rules should be universalizable (apply to everyone) to justify their use.<sup>38</sup> In public health and policy, it is important to highlight that a law must be applicable and appropriate for everyone. In this situation, the question is simple: If all adolescents (age 15 and above) were able to make the choice to vaccinate themselves (without parental permission), what kind of world would that be? The answer is that it would be a world with much more autonomy for adolescents and broadening access to vaccination across the country. While all vaccination carries a risk, adolescents would be able to choose this risk for themselves—perhaps a real trial-run to full medical decision-making. Allowing a young adult to access the HPV vaccine before they are sexually active or a student to opt-in to the MMR vaccine before applying to colleges could be a strong on-ramp to future choices. This is simply not a world where parental decisionmaking falls apart, but rather a recognition of the transitory nature of adolescence.

Second, Kant is most well-known for his belief that people should not be treated as a means to an end, but rather have inherent human worth.<sup>38</sup> As noted in the stories of minors who disagree with the beliefs of the parent(s), whether that be religious, ethical, or

affiliations with QAnon, it is clear that children in these situations are often asked to represent their parents beliefs in a way that might be harmful to them. Adolescents in this situation are asked to fulfill their parent's duties and moral obligations over their own, therefore asking a teenager to act as a means for their parents ends. But parental decision-making is not unlimited. As noted by Hickey and Lyckholm, there are several situations in which parental autonomy is limited by the state in medical decisionmaking such as courts overruling parents in Jehovah's Witnesses in blood infusion cases.34 There are also gray area cases in the law, like the laws that protect Christian Scientists who wish to use faith -based healing on their children.<sup>34</sup> But the mature minor doctrine, when applied to each of these situations, allows for nuance when there is a notable disagreement between parent and child, especially a mature adolescent. For vaccination, a situation that is far more low-stakes in comparison, it seems allowable to give an adolescent the space to make this decision and live out their own values. In a situation where a minor is a young child and their values have not yet formed, it is understandable to assume that the family has unified values. However, once a young adult starts developing their own values it would be wrong to require them to live out values that could plausibly put them in danger.

#### Principlism, Harm, and Best Interests

While Beauchamp and Childress's theories of principlism as laid out in Principles of Biomedical Ethics have their limits, the framework can still be useful for sifting through the different scenarios and conflicts that might emerge when combined with other theories and considerations.<sup>39</sup> First, respect for autonomy, or selfownership, requires that a competent individual's choices are respected. Beauchamp and Childress write about autonomous actions as those that are intentional, with understanding, and without controlling influences that determine their actions.<sup>39</sup> For minors, all 3 of these may come into question. However, a case can be made that older adolescents meet many of these qualifications. An adolescent who is purposefully seeking vaccination, assuming this act may be against a parent's wishes, is not likely to be making an impulsive or easy choice. Adolescents often understand their parents' concerns and deeply held beliefs, and may also fear anger, retribution, and creating division within the family. And yet, they are seeking out medical attention, treatment, and guidance an act that shows intentionality, understanding, and acting without controlled influence. For these mature minors, they are clearly autonomous enough, despite their age, to make this choice.

The 3 other principles of beneficence, nonmaleficence, and justice also come into play in vaccination. Beneficence and nonmaleficence, which are often paired together for good reason, speak to a physician's obligation to both do good by a patient and not to do evil. Beneficence can best be described as a moral obligation to intervene on behalf of a patient's best interests, while nonmaleficence is more so a requirement not to needlessly cause harm to a patient.<sup>39</sup> In the case of an adolescent seeking to be vac-

cinated without parental permission, the patient at the center of the question remains the minor. While they are not yet a legal adult, they have decided what they believe their best interest to be and are acting accordingly to get medical treatment. Vaccination not only protects the minor and their values, but also protects everyone around them from potential harm. As for nonmaleficence, the question becomes the risk of serious harm to the adolescent patient. While risk varies by vaccine, the harm of being infected by the disease is often much greater than the risk posed by the vaccine. For example, in recent years concerns about the safety of the HPV vaccine have grown in the United States due to political discourse and social media misinformation, despite HPV being the most common sexually transmitted disease in the United States.40 The HPV vaccine "protects against six different kinds of cancer (cervical, anal, back of the throat, penile, vaginal, and vulvar),41 "at a time where there are global concerns about the growing number of cancer cases.42 While parental concern is a normal part of medicine, there are strong data over 15 years of extensive testing to suggest that the HPV vaccine is incredibly safe.41 In this situation, it is absolutely permissible to ensure that a young person has access to preventative treatment given a physician's beneficence and nonmaleficence-based duties to the patient. Lastly, while there are many theories of justice, bioethics is often focused on distributive justice in health care. Ensuring that access to vaccination is just must include adolescents who wish to receive it for their personal benefit and the benefit of others. It would not be just or equitable to deny an autonomous person a treatment that could potentially save their life based on another person's values, even if that person is a parent.

#### **PUBLIC HEALTH IMPLICATIONS**

In the United States, most children are vaccinated as young children and infants,<sup>43</sup> but for those that are not, taking the step to get vaccinated can be a major choice. Ethan Lindenberger, the Ohio teen who first posted on Reddit about his journey in 2019 to get vaccinated,<sup>44</sup> was successful in getting vaccinated once he turned age 18 years and has since testified before Congress on the topic. During the testimony he told lawmakers that, as he "approached high school and began to critically think for myself, I saw that the information in defense of vaccines outweighed the concerns heavily."<sup>45</sup> This sentiment about the importance of the high school years (15-18 years of age in the United States) is echoed by many of the teenagers who share this experience.<sup>33</sup>

While state law in Ohio required Ethan to wait to turn age 18 years, this doesn't have to be the case for others like him. The state of Ohio should make routine, medically recommended vaccination a 'special circumstance' for minors above the age of 15 years without their parents' consent. This law would open the possibility for high school students to receive vaccinations through routine clinics in high school and colleges across the state, as well as the possibility for expanded clinical trials on adolescents (after institutional review board approval). But states aren't

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the only level of government that can intervene. Municipalities can also create this law, which could encourage vaccination drives in major cities with denser populations. At a time where vaccine misinformation is rapidly spreading among parents, lawmakers should allow young adults to make this choice for themselves to improve public health outcomes and catch adolescents who may otherwise fall through the cracks. Given the national political environment, state action on expanding access to vaccination may play a pivotal role in keeping communities safe.

#### **CONFLICTS OF INTEREST**

There are not reported conflicts of interest.

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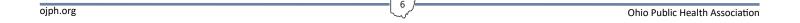
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#### **COMMENTARY/POLICY**

## Improving Public Health in Ohio by Refining Measurement of Paid Sick Leave

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#### **ABSTRACT**

Paid sick leave is an active health policy consideration. Publicly and privately funded datasets have been used to evaluate paid sick leave in relation to business, employment, and health outcomes. These findings have informed 40 states and localities that have passed legislation since 2006 that requires paid sick leave to be available to certain employees. During the same time frame, 24 states, including Ohio, enacted preemptive laws prohibiting the adoption of a local paid sick leave regulation by a local city or county. The present investigation organizes, compares, and evaluates the implications of how paid sick leave is measured in 9 datasets. Findings from this investigation can be used to refine the measurement of paid sick leave to inform this ongoing public health policy debate in Ohio and countrywide.

Keywords: Measurement; Paid sick leave; Paid sick days; Health policy

#### INTRODUCTION

Some families struggle to make ends meet as they balance work and health. As a remedy, paid sick leave is an employment benefit designed to allow workers to manage their personal and familial health without jeopardizing their income or employment. Since the United States lacks a guaranteed paid sick leave policy, access to paid sick leave disproportionately lies with full-time workers employed by large businesses, with the lowest rate of benefit among Hispanic, low-income, and service sector workers. The proportion of employees with access to paid sick leave has increased by 15% over the last decade, with 79% of US workers in private industry in 2024 having access to this workplace benefit. After 12 months on the job, most civilian workers with access to paid sick days have a mean of 8 days available each year.

#### Review of the Literature

Over the last 10 years, a robust literature has developed that establishes the personal, familial, and public health benefits of paid sick leave. For example, employees with paid sick leave are more likely to promptly access necessary medical care than workers without paid sick leave. Workers with paid sick leave are also more likely to engage in preventive health care screenings for can-

cer,<sup>7</sup> diabetes, high cholesterol, and high blood pressure, and they are also more likely to receive an annual influenza vaccination.<sup>8</sup> Having paid sick leave is related to higher sleep quality,<sup>9</sup> lower indicators of psychological distress,<sup>10</sup> and even lower mortality from all causes.<sup>11</sup> There are also benefits to general public health in that workers with paid sick days are less likely to contribute to the spread of contagious illness,<sup>12</sup> partly because they are more likely to stay home from work when ill. Employees with paid sick leave are safer since occupational injuries are decreased among workers with access to paid sick leave benefits.<sup>13</sup>

Families also benefit when a working adult has paid sick leave benefits. For example, when a parent has paid sick leave benefits, their family members are more likely to receive prompt medical care when necessary.<sup>6</sup> In the United States, employees with paid sick leave have an increased ability to afford prescription medications, prescription eyeglasses, and dental visits.<sup>14</sup> Families with paid sick leave also have decreased health care expenses and, thus, decreased economic anxiety,<sup>15</sup> greater retirement wealth,<sup>16</sup> and they are less likely to be in poverty.<sup>14</sup> Correspondingly, workers with paid sick leave are less likely to need welfare benefits for food, housing, childcare, and transportation.<sup>17</sup>



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These findings have directly influenced policy. For example, when the United States was faced with the most impactful public health crisis in a century during the COVID-19 pandemic, the US government relied on published paid sick leave research findings<sup>18</sup> to inform their decision to pass the Families First Coronavirus Response Act (FFCRA), which was the first US federal law that guaranteed access to paid sick leave from April 1 to December 31, 2020, for most US employees.<sup>19</sup> The FFCRA is credited with reducing the spread of COVID-19 by 400 cases each day in the early stages of the pandemic.<sup>20</sup> In addition to this federal law, 18 states and 22 localities have passed laws since 2006 mandating that certain workers be eligible for paid sick leave.21 It is important to note that not all recent legislative activity regarding paid sick leave has supported access to this benefit. Specifically, 24 states, including Ohio, since 2011, have passed a paid leave preemption law prohibiting localities from enacting a paid sick leave mandate.22

#### Gaps in the Literature and Purpose

While individual published studies include the methods and measurements used to assess paid sick leave, the literature lacks a collective examination of how this vital concept is measured in published research. To fill this gap, the current investigation aims to catalog some frequently cited measures of paid sick leave in the literature. Insights from this investigation are valuable and will allow researchers to engage more efficiently in paid sick leave research by identifying the ideal dataset to answer specific questions of importance to society. These findings can also be used to improve the measurement of paid sick leave in future data collection efforts. Refining how we measure paid sick leave will allow researchers to answer more precise questions consistent with the priority health outcomes stated in the State Health Improvement Plan 2020-2022.<sup>23</sup> Examples of such questions are "What are the specific number of paid sick days that are needed to achieve a reduction in infant mortality?" or "Do employees who are allowed to use their paid sick leave benefits for preventive health care (not just for injury or illness) have lower rates of heart disease?" Refining the measurement of paid sick leave is particularly valuable as these findings can directly inform policy in this active paid sick leave policy-making environment. Indeed, findings from this research will help to build a path toward answering specific questions that were the subject of a 2023 bipartisan bicameral Congressional working group request for information about "what types of [paid] leave should a potential federal program cover, at what length, and why?"24

#### **METHODS**

A purposive list of measures used to study paid sick leave in the United States was derived from a 2021 systematic review by Lamsal and colleagues and a 2023 systematic review by Vander Weerdt and colleagues.<sup>25,26</sup> These are the most recent systematic reviews identified in the literature that contain published US studies focused on paid sick leave as a predictor variable. Da-

tasets with at least 2 studies in either systematic review were included in the present analysis; an additional publicly available dataset was also included.

In their systematic review, Vander Weerdt and colleagues identified the data sources for the paid leave variable included in each of the 43 studies they reviewed. The most frequent data source identified in the review by Vander Weerdt and colleagues was the Medical Expenditure Panel Survey (MEPS; 6 studies),13,27-31 followed by the National Health Interview Survey (NHIS; 4 studies), 6,8,11,32-34 the Centers for Disease Control and Prevention (CDC; 3 studies),35-37 and 2 studies each from the American Time Use Survey (ATUS),38,39 Bureau of Labor Statistics (BLS),40,41 National Core Indicators (NCI),42,43 and The Shift Project.44,45 Of the 12 papers included in the systematic review by Lamsal and colleagues, the most common dataset used was the NHIS (7 papers), 6,8,33,46-49 followed by the MEPS (3 papers)48,50,51 and the National H1N1 Flu Survey (NHFS; 2 papers).51-53 While the National Longitudinal Survey of Youth (NLSY) had only a single paper in the review by Lamsal and colleagues, it was included in the current examination due to its unique measurement of paid sick leave.<sup>54</sup> An exception to our stated inclusion criteria is merited since the NLSY is a compelling option for future paid sick leave research, given it is nationally representative, has ongoing data collection, provides panel data that allows for longitudinal analysis and is publicly available. The NLSY has also measured the number of paid sick leave days in 2 distinct ways, enriching this discussion. Collectively, 9 datasets that include a paid sick leave variable were identified for inclusion in this review.

#### **Findings**

Medical Expenditure Panel Survey (MEPS)

The US Department of Health and Human Services Agency for Healthcare Research and Quality has collected MEPS data since 1996.55 The MEPS includes data on the cost and utilization of health care services and health insurance in the United States. The most recent data collected in 2022 included 21747 respondents from 10 034 families.56 The household component of the survey included a nationally representative subsample of households in the NHIS sample in the previous year. While the survey is generally cross-sectional, the paid sick leave variable is collected in the household component survey on 5 occasions over 24 months.55 One dichotomous question assesses paid sick leave status, "Does a current main job offer paid sick leave?" Responses include yes, no, do not know, and refused. The MEPS has been used to evaluate paid sick leave in relation to job flexibility,<sup>57</sup> absenteeism, health,<sup>58</sup> use of health care services,<sup>27</sup> and welfare benefits.<sup>59</sup> The MEPS does not collect data about how many days of paid sick leave respondents have access to nor how they use their leave.

National Health Interview Survey (NHIS)

The data available via the National Health Interview Survey are collected by the CDC. This cross-sectional survey has been

collected monthly since 1957, with an update to the questionnaire in 2019.60 Geographically clustered sampling techniques are utilized to select a nationally representative sample. The average annual sample size is 85 000 respondents, representing 35 000 households, with an adult and up to 1 child respondent from each household. The NHIS includes 1 categorical question about paid sick leave, "Do you have paid sick leave at this main job?" Available responses are yes, no, refused, or do not know. The NHIS data are available free of charge online. Impactful papers have used the NHIS to evaluate paid sick leave in relation to cancer screenings<sup>49</sup> and other health care screenings,8 health care utilization by adults46 and children,61 injuries at work,61,62 and prompt access to medical care when needed.6 The categorical measurement of paid sick leave limits the conclusions drawn in these studies as no information is collected via NHIS regarding how many paid sick days employees can access.

#### Centers for Disease Control and Prevention (CDC)

At first glance, it appears the CDC measures paid sick leave since papers that use CDC data include paid sick leave as a variable. However, upon closer examination, it is apparent that the CDC does not measure or collect data on paid sick leave benefits or usage. Instead, researchers utilize the CDC for health-related variables, such as influenza spread and mortality statistics. They then combine this information with other data to examine the availability of sick leave. For example, Pichler and colleagues and Wolf and colleagues measure paid sick leave as an independent variable using records of public law to identify and compare geographic areas with and without a paid sick leave mandate.

#### American Time Use Survey (ATUS)

The American Time Use Survey is a cross-sectional annual survey of respondents who completed 8 rounds of current population survey interviews. The US Department of Labor, Women's Division sponsors the survey<sup>64</sup> while the US Census Bureau conducts it. The module on benefits was collected in 2011, 2017-2018, 2024 and will likely be conducted in 2025. The survey is unique in that it asks questions about which family members the respondent can take paid leave to attend to, "Can you take paid leave for your own illness or medical care and/or the illness or medical care of a family member?" The survey lists many reasons why a person may potentially take paid leave, such as for caregiving, birth/adoption, or personal/vacation time. The survey also quantifies leave-taking by asking, "In the past 7 days, how many hours of leave have you taken?" "Did you use paid leave for any time you took off from work in the past 7 days?" "Did you use paid leave for all of this time off or just some of it?" The survey quantifies the amount of leave that a respondent has taken in the last 7 days and ties that quantitative data to the reason for the leave (ie, paid sick time) via this question, "Thinking about your longest period of leave off in the last 7 days, what was the main reason you had to take off from work?" By pairing these questions, it is possible to infer the number of hours a respondent took paid leave to care for themself or a

family member in the 7 days before the survey. The ATUS also collected data on access to unpaid leave. Past research using the ATUS has explored paid sick leave in relation to presenteeism,<sup>65</sup> absenteeism,<sup>38</sup> and childcare.<sup>66</sup> The ATUS provides some of the most detailed data on paid sick leave access; however, it has not been collected on a consistent annual basis.

Bureau of Labor Statistics (BLS) National Compensation Survey (NCS)

The US Bureau of Labor Statistics fields a monthly survey collected by the US Department of Labor.<sup>67</sup> Multistage probability-based sampling is conducted to achieve a representative civilian noninstitutionalized population. The National Compensation Survey gathers information from private and governmental employers on the wages and benefits of American workers, including paid leave. Employers are asked about benefits provided to specific sampled workers based on occupational code, including "paid (sick) days at 100%," "unpaid days," "sick leave plan days paid as needed," and "sick leave plan max days per year." They are also asked the "number of days for waiting period" to access the leave and whether employees can access "unlimited days." 68,69 In March 2022, a total of 17 750 establishments were surveyed. 70 The BLS data are commonly used in published research to establish the percentage of the US population with access to paid sick leave. Prior research using BLS data has also been used to evaluate paid sick leave in relation to occupational injuries<sup>40</sup> and the labor market impacts of sick leave mandates.<sup>41</sup> A significant strength of this data collection is that the survey asks about the number of paid sick days an employee can access by industry.

#### National Core Indicators (NCI)

The National Core Indicators survey is an initiative sponsored jointly by the National Association of State Directors of Developmental Disabilities Services, the Human Services Research Institute, and various state developmental disabilities authorities. Weighting is used to increase the cross-sectional survey's representativeness. The respondents are professionals who provide support to adults with developmental disabilities. Paid sick leave is measured in 2 ways in this survey.<sup>71</sup> A "pooled" paid time off variable collectively measures sick, vacation, and personal days. A second variable measures only paid sick time. The specific paid sick leave questions are not publicly available as they are copyrighted. Past paid sick leave research that has utilized NCI has examined topics such as worker retention.<sup>43</sup> Lack of access to the specific questions that measure paid sick leave reduces researchers' ability to critique these measures.

#### The Shift Project

The Shift Project is a cross-sectional private survey which uses nonprobability sampling to collect data from food and service industry workers via Instagram and Facebook advertisements.<sup>72</sup> The data are subject to stratification weighting and are not publicly available. The measurement instrument is available upon

request. The survey also collects information about child health, length of employment, state (and locality) of employment, resignations, income, receipt of welfare benefits, income, savings, vaccination status, and workplace culture. Questions asked to measure paid sick leave include, "Please look at the following list of benefits that employers sometimes make available to their employees. Which of the benefits on this list can you receive as part of your job at [EMPLOYER NAME]? Please mark all that apply." "Paid sick days" is an answer choice. The survey also includes questions about working while sick, the reasons for working while sick such as "I did not have paid sick leave" and "I wanted to save my sick days," retaliation for leave-taking, paid family medical leave, and how a shift is covered when a worker calls off work. There are separate questions about paid leave related to a "serious" medical condition that typically falls under the umbrella of paid family medical leave policy rather than paid sick leave ("How many weeks of leave did you take from your job at [EMPLOYER NAME] to recover from your serious health condition or illness?"). Past research has utilized Shift Project data to examine paid sick leave access in relation to gender,73 presenteeism,45 and work-life conflict.44 The Shift Project contains perhaps the most detailed measurement of employee use of paid sick leave. The major limitation of the Shift Project data is that they are not publicly available.

#### The National Longitudinal Survey of Youth (NLSY97)

The National Longitudinal Survey of Youth 97 is a survey of paneled respondents representing the US population aged 12 to 16 years in 1980 when the survey was first deployed. Since then, 21 rounds of data have been collected by the US Bureau of Labor Statistics, with 6748 respondents in the most recent data collection. 74 Paid sick leave has been measured differently at various points in time. For example, from 2000-2011, respondents were asked, "How many days of paid sick or personal leave [are/were] you entitled to per year?" However, the survey was modified in 2013, 2015, and 2017 to ask, "How many total days of paid sick, vaca-

tion, or personal leave [are/were] you entitled to each year?" A notable strength of this survey is that it employs a higher level of measurement by asking the question in a way that renders paid sick leave as a quantitative variable for analysis. The measurement change in 2013, 2015, and 2017, while retaining the number of days, is disadvantageous because it does not allow data consumers to parcel out the unique relationship between paid sick leave independent of vacation and personal time. A single study has utilized this dataset to analyze the number of paid sick days needed to increase the use of preventive health care services.<sup>54</sup>

#### National H1N1 Flu Survey (NHFS)

The National H1N1 Flu Survey (NHFS) was a nationally representative, cross-sectional data collection effort by the National Center for Immunization and Respiratory Diseases, CDC, and National Center for Health Statistics.<sup>75</sup> This one-time survey was fielded alongside the annual National Immunization Survey and focused on flu vaccination rates among children and adults in 2010 during the H1N1 flu epidemic. A socioeconomic status module was fielded that year to assess barriers to immunization. Questions about wages and benefits, including paid sick leave, were added. The question included in the survey asks, "Workers sometimes receive benefits in addition to wages. Whether you receive them or not, tell me if you are eligible to receive sick leave with full pay. If the respondent receives paid time off (PTO) that can be used for sick time off, vacation, or another purpose, code ves." The survey also asked a follow-up question, "In addition to using sick days for your illness, can you use your paid sick days for a sick child or family member?" Past research has utilized the NHFS to examine paid sick leave in relation to flu vaccination<sup>52</sup> and utilizing sick time to care for an influenza-like illness.30,53 Strengths include the large sample size (a total of 45 599 adults and 11 240 children were surveyed), the data are available for public use, and the survey clarifies if paid sick leave can be used for the worker, child, or family member. The limitation of this dataset is that the

**Table 1. Summary of Dataset Characteristics** 

| Survey  | Nationally representative?                           | Design  | Level of measurement of paid sick leave    | Data publicly available? |
|---|--|---|--|--------------------------|
| Medical Expenditure Panel<br>Survey (MEPS)                          | Yes  | Cross-sectional with longitudinal components over 2 years | Nominal                                    | Yes                      |
| National Health Interview Survey<br>(NHIS)                          | Yes  | Cross-sectional   | Nominal                                    | Yes                      |
| Centers for Disease Control and Prevention (CDC)                    | Yes  | Cross-sectional   | N/A  | Yes                      |
| American Time Use Survey (ATUS)                                     | Yes  | Cross-sectional   | Nominal and Numeric                        | Yes                      |
| Bureau of Labor Statistics (BLS) National Compensation Survey (NCS) | Yes  | Cross-sectional   | Nominal and Numeric                        | Yes                      |
| National Core Indicators (NCI)                                      | No, weighting is used to increase representativeness | Cross-sectional   | Nominal                                    | No                       |
| Shift Project   | No, weighting is used to increase representativeness | Cross-sectional   | Nominal and Numeric                        | No                       |
| National Longitudinal Survey of<br>Youth (NLSY97)                   | Yes  | Longitudinal  | Numeric (2000-2011)<br>Nominal (2013-2017) | Yes                      |
| National H1N1 Flu Survey (NHFS)                                     | Yes  | Cross-sectional   | Nominal                                    | Yes                      |

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sick leave variable was collected only in 2010 and was not subsequently added to the National Immunization Survey core questionnaire.

#### Discussion

Information from this study enlightens the past, current, and future research landscape surrounding paid sick leave. The methodology used to measure paid sick leave in existing surveys is influenced by many factors. For example, a survey's question design is carefully considered to optimize response rates; fewer questions can improve the response rate. Similarly, the wording of questions is crucial, as questions asked in a way that requires more details may lead to respondents indicating uncertainty and answering that they "do not know" which could lead to an increase in missing data. Furthermore, survey length is a significant factor, as longer surveys result in higher costs related to data collection.

#### How Much Paid Leave is Permitted?

Within the 18 states that have legislated a paid sick leave mandate, variations in policy exist that are worth examining.21 Notably, the entitlement of eligible employees to a specific number of paid sick days varies across states, ranging from 3 to 8 days, with an average of 5.8 days.<sup>21</sup> Yet, most research on paid sick leave examines paid sick leave as a nominal variable, comparing the absence or presence of paid sick leave to health, economic, and work-related outcome variables. Only 1 study was found that analyzed the number of paid sick days needed to observe a change in an outcome variable. In the identified study,54 10 days of paid sick leave was needed to observe increased odds of obtaining 5 separate preventive health screenings. This type of research, scrutinizing the specific number of days needed to observe crucial societal outcomes, is indispensable for informing future policy considerations. However, this research can only be undertaken if available data collection initiatives measure paid sick leave at an ordinal or ratio level of measurement. A minor yet impactful modification involves rephrasing survey questions to inquire about the number of paid sick days accessible annually.

#### Who Paid Sick Days Can Be Used For?

Gathering data about who paid sick leaves can be used to care for is necessary. Among the 18 states with a paid sick leave mandate, the majority allow its utilization for personal health reasons and to attend to the health needs of a spouse, child, or parent. However, exceptions exist, such as in Connecticut, where paid sick leave for caring for a parent is not permitted. In data collection efforts, it is beneficial to include specific questions to inquire if a respondent's paid sick time may be used to provide health-related care to family members to gain insights into which relationships should be included in future paid sick leave policies. In Ohio, some public education employees have access to paid sick time as defined in Chapter 3319 of the Ohio Revised Code. This legislative code

specifies that paid sick leave can be used to manage the personal health or the health of immediate family members.

#### Acceptable Purpose for Leave

It is beneficial for surveys to ask respondents the specific purposes for which paid sick days can be taken. In some states, eligible workers are granted the option to use paid sick days for various purposes, including acute illness, injury, preventive health care visits, and situations related to domestic or sexual violence or unexpected closures of a school or day care. A specific question that measures the acceptable purpose for paid sick leave is suggested to facilitate a comprehensive evaluation of the potential value of these provisions. This question could inquire, "For what purpose(s) are you allowed to use paid sick leave with response choices of "illness," "injury," preventive health care," "sexual/ domestic violence," and "unexpected school/day care closure." Including such detailed inquiry can provide a more nuanced understanding of the allowable use of paid sick leave. This will allow researchers to tie the possible uses of paid leave to various public health outcomes. For example, do employees who are permitted to use paid sick time to manage situations related to domestic violence experience a lower hospitalization or mortality rate? If the rate is lower, this could inform future policy.

Noticing, measuring, and assessing differences in paid sick leave policies may be important in promoting public health. For example, in Ohio, public education employees have access to paid sick leave as defined in Chapter 3319 of the Ohio Revised Code and may use paid sick leave for purposes related to illness, injury, pregnancy, contagious illness, and death (in the immediate family). Of note, preventive health care and well-child visits are absent from this list of allowable uses.

#### **Strengths and Limitations**

Strengths of this investigation include identifying a research question with important implications for informing an active public health policy debate, utilizing 2 recently published systematic reviews to select studies for inclusion, and including a variety of private and publicly available data sources in this review. The scope of this study did not include an examination of the reliability and validity of these measures, which is a limitation. A further limitation is that we could not access the specific question used to measure paid sick leave in the NCI.

#### **PUBLIC HEALTH IMPLICATIONS**

Research has consistently shown employees' and their families' financial, physical, and emotional well-being improves with access to paid sick leave. To help future research determine the ideal number of paid sick days needed to achieve desired public health outcomes, we must refine how we measure paid sick leave.

High-quality, nationally representative data are essential for researchers and community stakeholders to comprehensively evaluate the relationship between paid sick leave and its impact on

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public health outcomes. This review encompassed 9 datasets measuring paid sick leave. The analysis of these datasets revealed that many publicly available data only provide a nominal measure of paid sick leave, limiting the depth of insights that can be gained from research findings. Refining the measurement of paid sick leave, such as inquiring about the number of days of paid sick leave available to workers annually, could inform policy and, by extension, public health. Nominal measurement of paid sick leave hinders our ability to draw precise conclusions about the number of paid sick days needed to improve health. Similarly, data should be collected that specifies who paid sick leave can be used for and for what specific purposes. Overall, future efforts to create or revise datasets should prioritize gathering more comprehensive information about a respondent's access and usage of paid sick leave. This will enable more nuanced and informed public health policy decisions in Ohio.

#### **CONFLICTS OF INTEREST**

No conflicts of interest to declare.

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#### **AUTHOR CONTRIBUTION**

Both authors contributed equally to all facets of this publication.

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