Drugs, Depression, and Dating Violence: Partnering With Schools to Collect and Use Data on Adolescent Risky Behaviors

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**Introduction: The Need for Local Data**

The greatest threat to the health of American adolescents is not illness or chronic disease: It is the consequences of risky behaviors that can lead to disability, social problems, and even death. These behaviors include unsafe or impaired driving, violence, substance use, sexual activity, and suicide. In 2010, there were 10,887 deaths among adolescents ages 15-19; the leading causes of death were unintentional injury, including motor vehicle crashes (41 percent), homicide (20 percent), and suicide (17 percent) (U.S. Department of Health and Human Services, 2013).

The good news is these behaviors are largely preventable. The federal Substance Abuse and Mental Health Services Administration lists more than 140 adolescent mental health and substance-abuse interventions in its National Registry of Evidence-Based Programs and Practices (U.S. Department of Health and Human Services, 2014). In addition, countless other programs across the country focus on reducing risk factors and promoting protective factors associated with adolescent risky behaviors.

But how valuable are these national statistics when it comes to addressing risks within a community? Individual communities and school districts do not routinely have access to localized data from the Youth Risk Behavior Survey (YRBS), conducted by the Centers for Disease Control and Prevention (CDC) and individual states, nor are the school-level samples large enough to provide meaningful local data (Centers for Disease Con-
trol and Prevention, 2014). What is really important in driving change at the local level is just how many adolescents in a community are engaging in risky behaviors, at what age certain behaviors tend to emerge, and the trends.

**Background: How the Foundation Became Involved in Local Data Collection**

The MetroWest Health Foundation, in Framingham, Mass., has had a particular interest in child and adolescent health since its founding in 1999. The foundation’s first strategic plan targeted children and elders as its priorities. In its first five years of grantmaking, the foundation funded a variety of responsive projects focused on youth, such as a school-based dental sealant program, self-injury and suicide prevention training for school personnel, a crisis stabilization program for deaf students, and the creation of several wellness centers in schools.

In 2004, the foundation launched its first major proactive initiative, a six-year, $2 million investment in reducing youth substance abuse in 11 communities. The MetroWest region, comprised of 25 cities and towns west of Boston, is generally considered the healthiest in Massachusetts, but high rates of adult binge drinking were identified through the Center for Disease Control and Prevention’s annual Behavioral Risk Factor Surveillance Survey. While each of the 11 communities identified short-term outcomes to measure changes in knowledge and behavior, the foundation realized it needed a tool to measure the longer-term outcome of changes in substance-use rates to evaluate the results of the initiative itself. The foundation also understood that having a way to measure other health and risk behaviors would help with evaluation of subsequent funding efforts focused on adolescents.

The following year, the foundation began to look into conducting a survey like the YRBS among all high school students in its 25-town region. The foundation viewed this as an extension of its commitment to health data sharing, which included its MetroWest Health Data Book and Atlas and subsequent online Community Health Database. Foundation staff asked the region’s school superintendents if they would be interested in a shared measurement tool that would give them information on their student population and how it compared to the region. The responses were mixed. Some had concerns about the time such a survey would require, legal questions, the impact of its findings on real estate values, or potential backlash from parents. Others, however, indicated interest – especially if they had some local control of the survey questions and data and could compare themselves with the MetroWest region as a whole.

**Methodology: Finding the Right Partner and Doing It the Right Way**

*Project Launch and First Year*

Given the interest of some of the superintendents, the foundation’s board of trustees approved a 10-year plan to implement an adolescent health survey every other year at the high school level. In response to districts’ concerns about the public release of data comparing communities with one another, a critical decision was made that the local data would be owned and disseminated by the individual school districts and not the foundation. To this day, the foundation does not have access to individual school- or district-level data sets.
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In April 2006, the foundation contracted with Education Development Center (EDC), a global nonprofit organization in Waltham, Mass., to undertake the scope of work. The elements of the initiative, called the MetroWest Adolescent Health Survey (MW AHS), included school recruitment, survey development, data analysis, regional and district-level data reporting, and technical assistance to schools on how to interpret and use the data. To lead the project, EDC appointed two staffers with extensive experience in conducting large-scale surveys of adolescent health for research and evaluation.

Leading up to the first survey in the fall of 2006, EDC worked closely with school superintendents and other administrators to maximize district participation. Though initially only a high school effort, the foundation responded to requests from multiple school districts to collect data on middle school youth by approving a survey of seventh- and eighth-grade students, therefore capturing data during the crucial years of initiation and experimentation with substance use and when school bullying is often at its peak. Out of 26 school districts in the region served by the foundation, EDC secured the participation of 18 high schools, including two vocational schools, and 13 middle school districts—a number that was much higher than expected for the initial survey year.

Developmentally appropriate “core” middle and high school surveys were designed by EDC and then customized for individual districts to address topics of local concern. These “core” surveys were based on the YRBS and covered topics related to violence and bullying, tobacco use, alcohol and other substance use, impaired driving, suicide, risky sexual behavior, poor nutrition, and lack of physical activity. Responding to the needs of multiple school districts, questions on stress, school attachment, adult support, and cyberbullying were also developed and became part of the “core” survey that was administered to all districts. These supplemental questions not only responded to the districts’ concerns, but also enabled the foundation to collect data on emerging trends, like cyberbullying, that were not being captured on most state and national surveys at the time.

To further customize their surveys, districts were given a menu of additional subjects to allow them to address a new topic (such as gambling) or to gather more in-depth information about a topic of great concern (such as impaired driving). These questions, where possible, were curated from other validated surveys. The result was a common set of questions that yielded both district and regional data, with additional questions on local concerns tailored to each school district. Fourteen of the 18 high school districts and nine of the 13 middle school districts customized their questions in this way during the first survey; in 2006; it proved to be an invaluable asset to districts that were looking to build on past survey efforts and
FIGURE 1 MetroWest Adolescent Health Survey School and Student Participation Rates, 2006-2012

*2008, 2010, and 2012 middle schools had the option to include 6th grade in their surveys. Three did so in 2008, 13 in 2010, and 14 in 2012.
New questions have been added to the survey each year to collect data on emerging behaviors and topics of interest in the region, including sexting, cyberbullying, help-seeking behaviors around mental health, and distracted driving. When marijuana was decriminalized in Massachusetts in 2010, questions were added on perceptions of risk and behaviors related to driving under the influence of marijuana.

In the first year, surveys were collected from 23,555 students during a four-week period from mid-October through mid-November 2006. The 2005 Massachusetts YRBS, in contrast, surveyed only 3,522 high school students.

In late spring of 2007, each district received detailed, customized reports that contained an executive summary of key findings and demographic trends. The reports also included the prevalence of various behaviors as well as associations of interest (e.g., the relationship between mental health and violence and the relationship between protective factors – school attachment and adult support – and various risk behaviors). Comparisons to MetroWest regional data as well as state and national data, where applicable, were provided. EDC then held trainings for district representatives to discuss how the data could be used and disseminated, and provided technical assistance with interpretation and dissemination, including how to work with the media.

Subsequent Iterations
Since year one, the survey administration process has remained unchanged to maintain consistent methodology. A few important changes and advancements, however, have taken place.

By far the most important development has been the increase in district participation. (See Figure 1.) By 2012, every eligible high school and middle school district – 55 schools – participated in the survey. The total number of high school students surveyed in 2012 was 24,459, an 89.6 percent participation rate, and 15,605 middle school students, a 92.4 percent participation rate. These high levels of student participation mean that the data are highly representative of the student populations in each district as well as youth across the region.

The option of surveying sixth-grade students was added in 2010 based on feedback from school administrators. This option was of particular interest to districts whose sixth grades were located in the same building as seventh and eighth grades and who wanted to capture data on all middle school youth to inform their health curriculum and other programs and policies at that level.
As surveys have been collected, regional and school reports began to include trend data to show how behaviors are changing and where advances are being made. With each additional survey administration, trend data have become more reliable, and EDC has provided assistance to districts in understanding the degree to which changes in prevalence are indicative of meaningful trends. As of the 2012 survey, districts that have participated from the beginning have data at four time points to help them identify emergent and priority issues as well as measure progress toward health-related goals.

In 2010 and 2012, EDC developed customized special-topic fact sheets, which serve as ready-to-distribute materials for general audiences to increase awareness and convey information in a concise and accessible format. These special topics have included substance use, bullying and cyberbullying, mental health, and impaired driving. In addition, EDC created an interactive chart-making tool that allows districts to easily explore their data electronically and to create customized charts for presentations. The tool allows districts to select measures of their choice to display graphically so they can explore trends, gender patterns, and grade patterns for areas of interest.

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**Validity and Reliability**

The foundation and EDC are often asked whether students respond truthfully. Research on the validity and reliability of self-report surveys among school-based populations suggest that surveys are reliable methods of collecting data from young people. Research on the national YRBS, in fact, indicates that adolescents are just as credible as adults when answering this kind of survey. These studies show that young people respond truthfully when participation is voluntary, when students perceive the survey as important, and when they feel that measures have been taken to preserve their privacy and ensure anonymity.

The MWAHS follows procedures to assure students that participation is voluntary and anonymous: Students are instructed not to write their name on the survey and are informed that their answers will be kept private. The MWAHS instructions also call attention to why it is important to hear directly from students, stating that findings will be used to improve health education and services for young people.

Two other steps are taken to improve validity. First, all surveys are reviewed for implausible or frivolous responses. If it appears that a survey was answered frivolously, it is omitted from all analyses. Second, analyses are conducted to test for the reasonableness of responses and for the consistency of responses across related items. Very few problems—in only 1 percent to 2 percent of surveys—are found each year.

The validity of the survey is further bolstered by using a questionnaire based largely upon the CDC’s Youth Risk Behavior Surveillance System, a standardized instrument developed by the CDC in collaboration with other national and local health-education agencies. A number of published articles address the validity and test-retest reliability of the instrument (Center for Disease Control and Prevention, 2013).

**Results: It Don’t Mean a Thing If No One Uses the Data**

MetroWest Health Foundation has invested more than $2.6 million in this project to date. While there is no doubt the MWAHS has helped the foundation evaluate the work of its funded initiatives (e.g., youth substance abuse and bullying) and identify emerging adolescent health issues, it is also clear that school districts have become more willing to share the data and have used the data to promote change. Schools have given
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<table>
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<th>TABLE 1</th>
<th>Examples of Utilization of the 2006-2012 MWAHS data</th>
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<td><strong>To improve health and wellness programming</strong></td>
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- “Using the MWAHS data, my colleagues and I have been able to advocate successfully for some critical improvements to our health and physical education curriculum, including development of a new health curriculum at the middle school with a full-time certified health teacher for all students in grades 8-12 [and] a new wellness program, which consists of one semester each year of developmentally appropriate and engaging health and physical education units.”
- “We had a suicide in June and another last year, so we used the data to show that there are a lot more kids thinking about it than we see in the counseling office. It showed we need to do something more, that counselors should be in the classrooms, we need to take a broader approach.”

| **To influence school and district policies and actions** |

- “We use it to validate the budget within the school and to support our needs. We just had a 40% cut, and some of the sexual health items were cut. When we looked at the data we were able to speak to the needs of students and it was reinstated.”
- “We used the data to convince our new superintendent that we needed a more cohesive department that had all the student support services together (e.g., nurses, guidance, mental health counselors). The [new] department supports students who have issues not necessarily directly academically related, but social and medically related.”

| **To engage students in learning about and discussion of health-related issues** |

- “We always share the data with the kids during the health curriculum when it fits in with the topics we’re covering. During that time, we also explain how reliable and valid the survey is. … They really feel invested after that.”
- “The data is used throughout our entire school. Our students review the data in Health, PE & Wellness, Statistics Class, and next year we are including the data in our freshmen Social Studies classes. Our students create posters, public service announcements, statistics projects, role plays – just to name a few of the ways they use the data.”

| **To improve school climate and change norms** |

- “We create social marketing campaigns for adults and youth and use the data from the survey to share the messages.”
- “We’ve been looking a lot as a faculty at school connectivity and adult relationships. The data has been surprising and telling for us as a faculty. … We worked in more time to make those connections between students and faculty. Since then we have looked at those kids that have been reached and we’re seeing some great results.”

| **To raise awareness among and engage parents in addressing risky behaviors** |

- “Our coalition has seen an increase in parent participation at our events and we believe this is in part due to the community-specific information we have received from the surveys.”
- “We had a mandatory meeting last year for parents whose children were attending a dance, and the principal used the data on alcohol. Once they heard it, they thought it was very valuable. … Parents think they know everything that’s going on, but they don’t.”

| **To engage community members and organizations in active change** |

- “Our Department of Health and School Department work closely together to analyze the results around substance use and then come up with community and school-based programs. … The collaboration between the two departments has resulted in programs integrated in community and school settings. The data really was the vehicle for that.”
- “Every time we get a survey back, we present to different groups – school administrative council, to all the leadership at each school, to our youth advisory council, the governing body for mental health in town. We always have a community forum to discuss the new numbers, bring parents in, and invite everyone to come together and look at the data and ask questions and hear more about the programming that we’re doing.”
- “On the district level, the superintendent uses the data to communicate to the school committee and the general community about areas of concern for middle school through high school with everything we survey the kids on, as well as strategizing the things we need to address in middle school or high school.”
- “Based upon the data we have received from the surveys, our coalition was able to secure unanimous support to move forward with a social norming campaign to see if we can norm positive behavior in our community.”

| **To write successful grants** |

- “We refer to the data often in grant applications that we put together for health-related money. Most recently, we used the mental health data for a grant to fund a clinical care coordinator and a person that would arrange counseling after school for high school students. It has been a real coup for us.”
- “The trends in mental health have been really helpful to see, especially when budgets get tight and schools are looking for more support. We have data that suggests students are struggling with mental health, and having the data does help when we’re talking about cuts to resources for students.”
- “It helps us evaluate programs, develop every logic model we write for a grant, it backs up every logic model so it’s all data-driven. We are engaged in data-driven decision-making – it’s scientific and we can demonstrate where gaps are and where needs are and where we are making improvements.”
greater emphasis to health and wellness, including expanding time devoted to health education, adjusting curricula to reflect local health issues, and introducing programs focused on mental health, substance use, and bullying. The data have also led to improvements in social norms, increased parent awareness, and new collaborations between parents, schools, and community-based organizations to address adolescent health issues. (See Table 1.) Numerous school districts have used the data to secure external funding, including federal Drug Free Communities grants, which require documentation of substance-use rates as well as a methodology for measuring the change in rates throughout the grant period.

The data have also come to the attention of state and national policymakers. During the spring of 2012, when New York City was debating whether to raise the tobacco-purchase age to 21, city leaders cited the MetroWest data for evidence to support the initiative. Needham, Mass., which increased its tobacco-purchase age to 21 in 2005, agreed to share its MWAHS tobacco data showing notable decreases in current and lifetime smoking rates from 2006 to 2010. Needham’s data were mentioned in New York City’s hearings about the proposed ordinance. While the MWAHS was in no way designed or intended to evaluate Needham’s initiative, it represented the best data available to understand changes in tobacco use in the town since the local law was passed.

The MWAHS data is also of great value to the field of adolescent health. With four time points and tens of thousands of surveys collected at each administration, the resulting data allow for analysis of risk behaviors among small sociodemographic groups (e.g., sexual minority youth) and associations with low-prevalence behaviors (e.g., suicide attempts). EDC has published analyses on the links between school bullying and cyberbullying and psychological distress (Kessel Schneider, O’Donnell, Stueve, & Coulter, 2012), and presented data at several national conferences. Several publications on emerging issues and trends are being completed to share with the broader scientific community.

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**Results**

**The MetroWest region is home to some of the highest-rated schools and most expensive real estate in the state. Consequently, the cultural norm in the region can discourage the sharing of information that would tarnish school and community reputations.**

**Lessons Learned**

**Ownership and Control Matter**

As with any public health intervention, it is important to understand that cultural norms matter. Massachusetts, with its home rule petition and lack of county governments, has an affinity for local control. In addition, the MetroWest region is home to some of the highest-rated schools and most expensive real estate in the state. Consequently, the cultural norm in the region can discourage the sharing of information that would tarnish school and community reputations.

When MetroWest first encountered concern from local superintendents about how the MWAHS data would be used, it made a critical decision to allow districts to own and control the data. This was extremely important in eventually garnering support from all superintendents. If a journalist, researcher, or community resident wants town-specific data, that information must come directly from the school district. The foundation does not have it, nor does it have a real need for it. For the most part, MetroWest is interested in regional trends, though it often requires local data to support grant applications and the evaluation of funded school-based interventions.

**Informed Consent**

Another lesson can be appreciated through the experience of a school district in nearby Bedford,
A third and final important lesson: While schools may teach statistics and math, they are often overwhelmed by public health data. In the earliest survey administrations, EDC provided customized data reports as well as the actual raw data. It soon became apparent that most districts did not know what to do with the raw data or did not have the resources to analyze it.

N.H., that failed to follow a protocol similar to that employed by MWAHS in conducting its own youth survey. An adolescent health survey administered there included questions about sexual behavior, but the consent letter sent to parents omitted that information. When parents found out about the sexual behavior questions, there was a backlash. While including such questions addresses an important adolescent health issue, it is ultimately more important that the community be comfortable with the questions and the reasons why they are being asked. In the MWAHS, questions on sexual behavior are standard at the high school level and parents are informed of that. At the middle school level, each district decides whether to include questions related to sexual behavior and parents are notified if such questions appear on the survey.

During each MWAHS survey iteration, EDC sends a sample parental consent letter to each school district. Each school uses this template to personalize its letter while keeping intact key information, including the anonymous and voluntary nature of the survey and the topics being covered. Each district must send its letter to EDC for approval before distributing it to parents. In the eight years the survey has been conducted, fewer than 2 percent of parents have opted out. Parents who wish to see the survey in advance may go to the school to do so; to prevent advance circulation of the survey, which could influence the validity of student responses, electronic copies are not provided.

Drowning in Data

A third and final important lesson: While schools may teach statistics and math, they are often overwhelmed by public health data. In the earliest survey administrations, EDC provided customized data reports as well as the actual raw data. It soon became apparent that most districts did not know what to do with the raw data or did not have the resources to analyze it. EDC now provides extensive technical assistance to enhance use of the data, including one-on-one meetings to discuss how to interpret the data and its implications for local planning; supplemental analysis of local data; and guidance and feedback on local data presentations to school staff, school committees, and community audiences. It developed a web-based platform for encouraging participating schools to ask questions, share resources and materials, and discuss successful strategies.

EDC also offers a three-part intensive workshop for school personnel. It walks schools through the process of understanding and presenting their data; selecting issues that the school and community are interested in and ready to address; working with community partners to ensure the issue is not just a “school problem”; and selecting interventions that are shown to be effective.

For six under-resourced school districts, additional one-on-one technical assistance is offered through in-person meetings and telephone consultations. For 2012, EDC provided additional cross-tabulations, assistance with data presentations, and guidance on community engagement and messaging. Four of the six communities were fully engaged in the enhanced technical assistance, but two felt they did not have enough internal capacity to
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take full advantage of the support. The lesson learned is that selecting districts for technical assistance does not necessarily mean they have the resources to work with EDC or that the timing is right. Many districts in communities with more resources expressed interest in technical assistance and EDC accommodated their requests.

Benefits to the Foundation

It is clear that MWAHS has assisted the 25 towns served by the MetroWest Health Foundation by offering data and training to improve their curriculum, policies, and programs. It is equally true, however, that the $2.6 million investment has benefited the foundation. The three most significant ways are:

• Visibility. Local media coverage has been extensive. Town newspapers routinely cover data presentations to the community. The MetroWest Daily News, the largest regional newspaper, has published more than 50 articles about the survey data as they are released and discussed in various communities; 13 articles have appeared in The Milford Daily News, a smaller area paper. The Boston Globe has included three feature articles in its print edition and eight pieces online. The foundation’s increased media presence has bolstered its reputation as a provider of support beyond grants and has showcased its efforts to encourage local agencies to use data to drive their decision-making.

• School relationships. Prior to the MWAHS, the foundation’s relationship with local schools was primarily that of a grantor. Schools looked to the foundation, if at all, as a potential source of funding. Following implementation of the survey, schools began to view MetroWest as a partner and ally in garnering attention to adolescent health issues. Superintendents, principals, and wellness staff now proactively approach the foundation regarding emerging issues. In one case, the principal of the largest high school in the region contacted the foundation regarding fractured relationships with community-based mental health providers; the foundation convened a working group of school and mental health providers that ultimately produced a new model of early identification and intervention for students with mental health issues.

• Evaluation. The MWAHS allowed the foundation to evaluate the results of its youth substance abuse and antibullying initiatives. The survey has also established baselines for numerous behaviors, which will allow the foundation to measure its impact in future grantmaking areas. The foundation has recently embarked on an adolescent mental health initiative, for example, and data will be used to track changes in rates of depressive symptoms, self-injury, and suicidal ideation. These are data that schools would not have been able to collect in such a robust way on their own.

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Future Directions and Considerations for Other Funders

The 2014 survey will mark the 10th year of data collection, thus completing the Metro-West trustees’ initial commitment to the project. While it is not possible to predict with certainty whether they will approve future iterations, there is no doubt the survey has made a significant and demonstrated impact on the foundation and the region.

This project demonstrates how funders can, in the words of Michael Porter and Mark Kramer (1999), “create value” – not merely funding programs,
but leading social progress. Foundations can create value, they write, by generating “social benefits that go beyond the mere purchasing power of their grants” (p. 123), and they outline four approaches, advancing the state of knowledge and practice being the most substantive. This approach, they say, creates a framework “that shapes subsequent work in the field” (p. 125).

Second, it is important to take the long view and to meet people where they are, even if it means starting a project on a smaller scale than hoped for. In the case of the MWAHS, some school superintendents were initially worried about lack of control over their local data. Given the foundation’s sizable investment in the project, the trustees could have rigidly required the local data be available to them. It was ultimately more important to the foundation to maximize school participation than it was to own school-level data. The foundation understood that this measured approach would allay fears, build trust and buy-in, and result in greater participation down the road. Indeed, the majority of school districts now share their data widely with the foundation to seek funding for local programs, and with their communities to raise awareness of health issues and prompt local action.

Last, a project like the MWAHS can generate significant publicity. It is important for funders to consider this when undertaking major public health data-collection projects, especially those involving children and adolescents. For the MetroWest Health Foundation, the publicity has been extremely positive. Foundation staff are very clear about messaging and keep the focus on what the data reveal about adolescent behavior and what communities can do about it. In areas where there is a paucity of accurate, current data, the media can be very receptive to running stories about the issues surrounding the data. For funders interested in expanding their visibility, this can be an effective way of publicly demonstrating leadership and showcasing value beyond just grants.

References


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