

## 7. Community Coalition Considers Sharing Aggregate Data Related to Student Test Scores, Youth Risk Behavior Survey Results, Truancy, Crime, Mental Health Services, and Drug Use



The mayor and city council of a mid-size city have established a Youth Violence Prevention Coalition that includes representatives from 20 community organizations, including the school district, the juvenile court, afterschool programs, community-based mental health providers, and a substance abuse treatment program.

The coalition members agree that their first step should be to get a clear picture of the scope and depth of problems that the community's youth face. To do this, the coalition makes the following requests for aggregate data:

- The school superintendent is asked to carry out the Youth Risk Behavior Survey (YRBS), a national survey that explores high-risk behaviors among youth, and to share those data with the coalition. She is also asked to share truancy data and students' aggregated test scores for the state's standardized tests.
- The juvenile court is asked to share data on crimes that involve minors.
- The community mental health providers are asked to share the number of youth they serve and the most common diagnoses.
- The substance abuse treatment program is asked to provide the number of youth who participate in the program annually and to describe the illicit drugs most commonly used by the community's youth.

The response from the community agencies and organizations is less than favorable. The superintendent of schools says that the school department does not intend to carry out the YRBS because it asks questions about "protected" issues such as sexual activity and drug use. She's concerned that surveys like YRBS might violate the Protection of Pupil Right Amendment, and she's hesitant to share aggregate information with an informal organization like the coalition, which is not a government agency or a registered 501(c)(3) nonprofit organization.

The juvenile court administrator says that the court won't share information about youth crime without a guarantee that all 20 participating organizations will handle the sensitive data appropriately, respecting relevant confidentiality and privacy regulations. The administrator recommends that all 20 organizations sign a memorandum of understanding that specifies how the information will be shared and with whom, and how the security of the data will be protected.

The community mental health providers say that they are unwilling to share aggregate data about youth mental health diagnoses because these data might contain personally identifiable information (for example, if there

were one diagnosis of schizophrenia in a minor).

The substance abuse treatment program representative is only willing to share with the coalition the number of youth who participate in the program annually. The representative explains that the program's legal counsel is concerned about the program possibly revealing confidential information and being sued.

## Who has the information?

The school district, the juvenile court, the community mental health providers, and the substance abuse treatment program.

## Who wants the information?

The Youth Violence Prevention Coalition, whose members represent 20 community organizations.

## What information is being requested?

- The school superintendent is being asked to carry out the YRBS and to share those data with the coalition. She is also being asked to share truancy data and students' aggregated test scores for the state's standardized tests.
- The juvenile court is being asked to share data on crimes that involve minors.
- The community mental health providers are being asked to share the number of youth they serve and the most common diagnoses.
- The substance abuse treatment program is being asked to provide the number of youth who participate in the program annually and to describe the illicit drugs most commonly used by the community's youth.

## What does the requester want to do with the information?

The coalition wants to more fully understand the scope of the city's youth violence problem.

## Which laws are relevant in this situation?

The school information is governed by FERPA. The juvenile court data is governed by state law. The mental health information is governed by HIPAA. The substance abuse treatment information is governed by 42 CFR Part 2.

## What do the laws permit, and what do they prohibit?

Because the coalition seeks only aggregate data that does not contain personal identifiers, the general requirement of obtaining signed consent found in these laws is not applicable.

Under FERPA, aggregate data may be obtained without parental authorization. FERPA's prohibition on disclosure of "personally identifiable information" allows agencies and institutions to aggregate data and disclose statistical information from education records without parental consent so long as each student's identity is not easily traceable. FERPA also has a studies exception, which allows for the disclosure of information from education records without consent to organizations conducting studies for, or on behalf of, schools, school districts, or postsecondary institutions. Studies may be for the purpose of developing, validating, or administering predictive tests, administering student aid programs, or improving instruction.

State laws and regulations governing the juvenile court data differ by state, though typically there are few restrictions on de-identified data.

HIPAA does not place restrictions on the use of de-identified information in aggregate form. However, in order to ensure that information is properly de-identified, it must undergo a process that involves a formal determination by a qualified expert or the removal of specified individual identifiers as well as the absence of actual knowledge by the covered entity that the remaining information could be used alone or in combination with other information to identify the individual.

The federal drug and alcohol laws contained in 42 CFR Part 2 do not place restrictions on de-identified data in the aggregate form.

## How can the schools and other community agencies proceed legally to share aggregate data about youth risk behaviors?

As long as the community agencies and the school district de-identify the data prior to sharing them in the aggregate form, the data may be shared with the coalition.