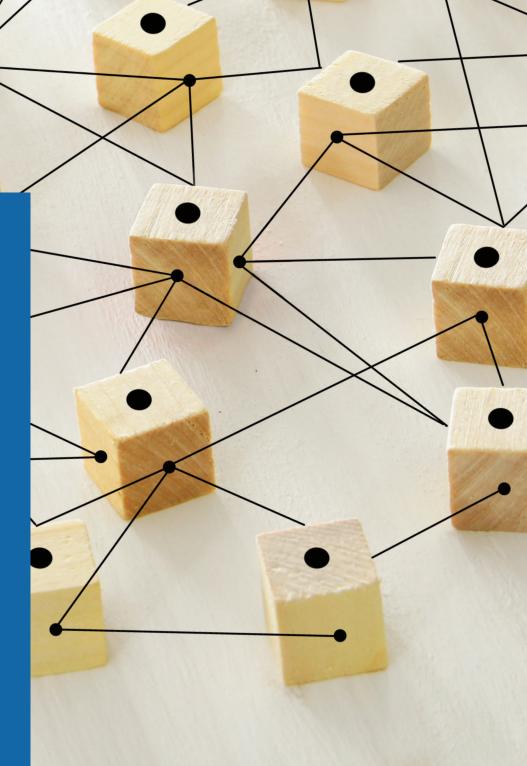
# Data Infrastructure:

Recommendations for State Suicide Prevention







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# Introduction

In 2019, the Suicide Prevention Resource Center (SPRC) released <u>Recommendations for State</u> <u>Suicide Prevention Infrastructure</u> (Infrastructure Recommendations), an overview of critical infrastructure elements that states need to have in place for effective and sustained suicide prevention efforts. Recommendations for the report were generated, in part, through contributions from topic-specific work groups. The Data Work Group created data infrastructure recommendations that are broadly summarized in the Infrastructure Recommendations' <u>Examine</u> essential element. As part of this process, the Data Work Group also established very specific recommendations beyond the scope of the broader report. These specific recommendations are included in this supplement.

The broader "Examine" section of the Infrastructure Recommendations includes the following recommendations:

#### At a minimum

- Allocate sufficient funding and personnel to support high-quality, privacy-protected suicide morbidity and mortality data collection and analysis
- Identify, connect with, and strengthen existing data sources
- Ensure that high-risk and underserved populations are represented in data collection
- Develop the skills and a plan for regularly analyzing and using data to inform action at the state and local levels

#### To further strengthen your infrastructure

• Link data from different systems while protecting privacy

See details and examples of these recommendations under the <u>Examine</u> essential element on the SPRC website. Other sections of the Infrastructure Recommendations also contain relevant recommendations and are noted in this supplement where relevant.

## Who is this supplement for?

The recommendations in this supplement can help state and local leaders tasked with advancing suicide prevention planning to understand the resources and systems needed to effectively identify, share, analyze, and use data to direct prevention efforts. Because those who lead state and local suicide prevention planning may not be epidemiologists, this report offers concrete recommendations and resources to encourage the creation of an infrastructure that will support data-driven decision-making. These recommendations can be brought to epidemiologists and other stakeholders to create a stronger data infrastructure.

# What will you find in this supplement?

The Data Work Group's detailed recommendations on data infrastructure can be grouped into six main sections:

- Establish core leadership positions and leadership buy-in for building data infrastructure to support suicide prevention
- Establish partnerships, coalitions, and/or prevention centers to support data infrastructure
- Establish a system for identifying data sources and sharing data
- Establish a system for analyzing data
- Establish a system for using data
- Collect, analyze, and use data from state systems

Within each of these categories, recommendations are grouped into "at a minimum" and "to further strengthen your infrastructure":

- At a minimum. These recommendations identify the data-related infrastructure that is *minimally necessary* to support successful implementation and longevity of effective suicide prevention efforts.
- **To further strengthen your infrastructure.** These recommendations identify additional data-related infrastructure to bolster comprehensive and successful implementation and longevity of effective suicide prevention efforts.

# Data Supplement Recommendations at a Glance

	At a minimum	To further strengthen your infrastructure
1. Establish Core Leadership Positions and Leadership Buy-In for Building Data Infrastructure to Support Suicide Prevention	<ul> <li>Establish a suicide prevention coordinator position that transcends grant funding sources.<sup>1</sup></li> <li>Ensure that the suicide prevention coordinator is well versed in data- driven decision-making and is committed to act on data-based findings.</li> <li>Identify a "data champion" in addition to the state suicide prevention coordinator.</li> <li>Informally build the capacity of state leadership to understand the basics of data-driven decision- making and to be open to shifting priorities based on data findings.</li> <li>Systematize data infrastructure planning so that it continues beyond staff transitions.</li> </ul>	<ul> <li>Identify a role or entity within the state suicide prevention office that will advance these recommendations.</li> <li>Ensure that high-level leaders receive formal training in data-driven decision-making.</li> <li>Demonstrate at the state department leadership level explicit commitment to integrating suicide prevention data and surveillance into existing efforts.</li> </ul>
2. Establish Partnerships, Coalitions, and/or Prevention Centers to Support Data Infrastructure	<ul> <li>Ensure that community voices are present in determining data-related priorities and needs.</li> <li>Connect state and local stakeholders to state suicide prevention leadership to explore data sharing and use (see body of the recommendations below).</li> </ul>	<ul> <li>Create a system where the child fatality and/or suicide fatality review committee can provide technical assistance to the state suicide prevention office on data collection procedures.</li> <li>Connect additional groups to state suicide prevention leadership to explore data sharing and use (see body of the recommendations below).</li> </ul>

<sup>&</sup>lt;sup>1</sup> Where a recommendation in this supplement overlaps with the main Infrastructure Recommendations, it is noted in the respective narrative section below.

	At a minimum	To further strengthen your infrastructure
3. Establish a System for Identifying Data Sources and Sharing Data	<ul> <li>Ensure data availability for local- level analysis. When unavailable, create an action plan to build local data availability.</li> <li>Connect with underrepresented communities to locate population- specific data and explore data gaps in traditional data sources.</li> <li>Reduce reliance on the slow release of data from national systems though local workarounds.</li> <li>Encourage data providers to sign formal statements of commitment to support suicide prevention.</li> <li>Garner state-level leadership support to collect and report on health care encounters related to suicide.</li> <li>Develop technical and legal infrastructure to link program systems through available linking variables (e.g. memoranda of understanding, business associate agreements).</li> </ul>	<ul> <li>Develop or enhance policies to support surveillance. 2</li> <li>Work with state and local boards of health to ensure that suicide deaths and health care encounters are reported to state health departments.</li> <li>Ensure access to real-time data.</li> <li>Develop a system for identifying innovative, community-level data systems.</li> <li>Ensure that state and county data sources are explained well to stakeholders.</li> </ul>

<sup>&</sup>lt;sup>2</sup> "Surveillance" means the collection, recording, and analysis of data for use in planning, implementation, and evaluation of public health efforts (WHO, 2017). Surveillance data is often generated from vital statistics, government and disease monitoring reports, health service records, and disease registries.

	At a minimum	To further strengthen your infrastructure
4. Establish a System for Analyzing Data	<ul> <li>Employ a data analyst to perform targeted analyses.</li> <li>Establish a mechanism and personnel within broader state or regional public health data structures to provide analyses for suicide prevention.</li> <li>Create a quality control system for suicide-related data.</li> <li>Budget for software, hardware, and personnel needs for a well-functioning data system.</li> <li>Interpret real-time data meaningfully. Data-related caveats should be reported and understood.</li> <li>Encourage data providers to educate their audiences on interpretation of statistical results.</li> <li>Ensure that underserved communities are well represented in analyses and that health disparities are examined (when applicable).</li> </ul>	<ul> <li>Establish a dedicated state or regional public health structure and personnel to provide analyses specifically for suicide prevention.</li> <li>Enable access to a data analyst well versed in qualitative design and analysis.</li> </ul>

	At a minimum	To further strengthen your infrastructure
5. Establish a System for Using Data	<ul> <li>Establish general infrastructure to support data use, and a system for regularly reporting data to the suicide prevention coordinator.</li> <li>Develop capacity to respond immediately to public questions related to suicide using existing data systems.</li> <li>Establish a system to explore how the state infrastructure might be built or changed to address emerging questions through data.</li> <li>Communicate data locally. When local data are unavailable, create an action plan to build local capacity to address questions.</li> <li>Communicate data regularly to stakeholders. Collect information about the data's utility to stakeholders and pass this information back to data providers.</li> <li>Use culturally and linguistically appropriate writers and translators when creating data briefs.</li> <li>Require an annual high-level report that includes multiple data sources and suicide-related metrics.</li> <li>Build capacity of local leadership to understand the fundamentals of data-driven decision-making and to be open to shifting priorities based on data findings.</li> </ul>	Establish a coordinating body to collaborate with the suicide prevention coordinator to support data use.

	At a minimum	To further strengthen your infrastructure
6. Collect, Analyze, and Use Data from State Systems	<ul> <li>Establish a formal data-sharing connection between the suicide prevention coordinator, public behavioral health care system, and public health care system.</li> <li>Work toward a common definition of suicide and suicide-related behaviors, but be careful not to let the lack of a common definition be an excuse for not collecting suicide-related data.</li> <li>Ensure that executive branch leadership supports the state systems' collection of suicide-related data.</li> <li>Establish champions within state systems who can support the systematic collection and use of suicide-related data (see narrative for additional details).</li> <li>Ensure that there is a forum or process for reporting on state system suicide-related data.</li> <li>Engage in suicide-related data sharing with adult-serving state crisis providers.</li> </ul>	<ul> <li>Require state systems to be involved in sharing suicide-related data.</li> <li>Require that an annual report be submitted to the governor on suicide-related indicators in state systems.</li> </ul>

# Section 1: Establish Core Leadership Positions and Leadership Buy-In for Building Data Infrastructure to Support Suicide Prevention

## At a minimum

For successful implementation and longevity of suicide prevention efforts, states should have an established suicide prevention coordinator position that transcends grant funding sources. (See Infrastructure Recommendations, "Lead: Maintain a dedicated leadership position" for further details.) The suicide prevention coordinator should be well versed in data-driven decision-making and have affirmed a commitment to act on emerging trends from the data. The suicide prevention coordinator should identify a data champion outside of the suicide prevention office who will ensure that data infrastructure planning remains a state priority even if staff turnover occurs. The process of data infrastructure planning should be embedded within the state system, ensuring that it remains a priority over time. The suicide prevention coordinator, the data champion, and other stakeholders should inform key leadership (e.g., the governor, legislators, commissioners) about the importance of data-driven decision-making and secure the commitment of key leaders to act on information from data.

## To further strengthen your infrastructure

States should identify (or create) the role within the state suicide prevention office that will work to advance the data recommendations contained in this report. Leadership at the appropriate state department level should demonstrate explicit commitment to integrating suicide prevention data and surveillance into existing efforts. Trainings might be offered to high-level leaders on the fundamentals of data-driven decision-making.

#### Resource

U.S. Department of Health and Human Services. *Guide to Data-Driven Decision-making: Using Data to Inform Practice and Policy Decisions in Child Welfare Organizations*. This guide explains data-driven decision-making (the information is not specific to child welfare organizations), including the requirements for it and the steps for applying data-driven decision-making concepts to organizations and service systems.

https://www.acf.hhs.gov/sites/default/files/cb/guide\_to\_dddm.pdf

#### Example

The Virginia Department of Health houses an injury and violence prevention program (IVPP) with two full-time staff devoted to data epidemiology and evaluation. The IVPP team creates data briefs on suicide and self-harm that provide state decision makers with an understanding of suicide prevention data and the impact of suicide prevention efforts in the state. The IVPP's data analysis guides the Department of Health's suicide prevention efforts to better identify where strategies and resources should be focused across populations in the state. The Department of Health also staffs a suicide prevention coordinator within the IVPP who collaborates with other state agencies and community partners to develop and implement these data-driven suicide prevention strategies.

# Section 2: Establish Partnerships, Coalitions, and/or Prevention Centers to Support Data Infrastructure

# At a minimum

For successful implementation and longevity of suicide prevention efforts, states must make sure that community voices are present in determining data-related priorities and needs. Publicprivate partnerships can be powerful tools in supporting suicide prevention data and should be systematized within the state. At a minimum, the state suicide prevention leadership should be connected to the following groups to explore opportunities for data sharing, analysis, and use:

- Child Fatality Review Team/Suicide Fatality Review Committee
- State injury prevention branch
- Veteran's system and services (e.g., Veteran's Commission, veteran-serving agencies, VA Suicide Prevention Coordinators)
- Advocates, including suicide prevention organizations (e.g., AFSP)
- Hospitals and emergency departments
- National Violent Death Reporting System state team and sources, including medical examiners, coroners, and local law enforcement
- Center for Health Statistics, including the National Vital Statistics System, Behavioral Risk Factor Surveillance System, Pregnancy Risk Assessment Monitoring System, Youth Risk Behavior Surveillance System, state-sponsored health surveys (particularly when housed within a state health department)
- Local health and public health offices

# To further strengthen your infrastructure

States would benefit from having regionally organized suicide prevention centers situated throughout the state, mirroring the infrastructure of many states' substance abuse prevention efforts. In some states, community coalitions run suicide prevention centers that the state finances and provides with resources. The state also delivers technical assistance to these centers. This model could be boosted by having the state's Child Fatality Review Team (CFRT) or Suicide Fatality Review Committee (SFRC) deliver technical assistance on best practices in collecting suicide death data. This technical assistance might include an annual or semi-annual report from the CFRT or SFRC on its procedures and findings. Involving the CFRTs and SFRC in suicide prevention efforts ensures that the data collected by these groups are used and that CFRTs pay close attention to suicide in their investigations.

Suicide prevention leadership should be well connected with the following organizations to explore opportunities for data sharing, analysis, and use:

• Councils and governing boards of Community Mental Health Centers

- National Suicide Prevention Lifeline and other crisis centers
- State epidemiological workgroup (funded through SAMHSA)
- Funeral homes, Local Outreach to Suicide Survivors (LOSS) teams or other postvention teams
- Higher education suicide prevention programs or grantees
- EMS registry /trauma registry
- National Guard
- Veteran Integrated Service Networks (VISNs) or VA
- Council of communities
- Tribal communities/ Indian Health Services

#### Resource

"SPRC Substance Abuse and Suicide Prevention Collaboration Continuum." This webpage provides tools and resources to establish and strengthen collaborative relationships with partners in different health fields and settings, including substance abuse prevention. http://www.sprc.org/states/collaborationcontinuum

#### Example

In 2016, Minnesota released <u>Legislative Report: Suicide-Related Data Plan: Improving the</u> <u>Timeliness, Usefulness, and Quality of Data</u>, which called for Minnesota to create a suicide statewide epidemiological outcomes workgroup (S-SEOW). The S-SEOW brings together diverse partners who analyze a variety of data sources related to suicide and who are involved in the creation and maintenance of a central Minnesota suicide data dashboard. Members of the S-SEOW commit to a two-year term and include the Minnesota Department of Health, the Wilder Foundation, the Minnesota Department of Human Services, the University of Minnesota, the Great Lakes Inter-Tribal Epidemiology Center, county public health departments, health care associations, and more. The S-SEOW regularly discusses the implementation of the ongoing analysis of each organization's data and how it applies to the progress of Minnesota's Suicide-Related Data Plan, and provides updates from the group to Minnesota's statewide suicide prevention planning committee.

# Section 3: Establish a System for Identifying Data Sources and Sharing Data

# At a minimum

For successful data infrastructure, states should have locally available data and connections with underrepresented communities to ensure a complete data picture. States should have an action plan in place to address data gaps and build the data capacity of local communities to ensure the availability of representative data. To reduce reliance on the slow release of data from national systems, states should develop local workarounds, with formal, established connections to local data providers committed to supporting suicide prevention. States will need state-level leadership support to collect and report on health care encounters related to suicide and have the technical and legal infrastructure to link data across systems as needed (e.g., memoranda of understanding).

# To further strengthen your infrastructure

States should have policies in place to support surveillance efforts like the National Violent Death Reporting System and Enhanced State Opioid Overdose Surveillance. This might include working with local and state boards of health to ensure that suicide deaths and medically treated suicide attempts are reported to state health departments so that states can have access to near real-time data. States would also benefit from having a system in place to identify innovative, community-level data systems, including tribal data collection systems. Lastly, it would be important for states to ensure that their state- and county-level data sources are explained well to stakeholders. Such explanations would include easily accessible information on what the data sources include, where to find them, and what their caveats may be. The explanations could be structured as an online resource or one-page handout.

#### Resources

SPRC's Accessing Data about Suicidal Behavior among American Indians and Alaska Natives. This information sheet discusses key local, state, and regional sources of data on suicide (deaths, attempts, other behavior, and thoughts) in American Indian/Alaska Native populations. It also briefly discusses ways to improve access to American Indian/Alaska Native data. <u>http://www.sprc.org/sites/default/files/Handout-</u>

AccessingDataAboutSuicideBehaviorAmongAmericanIndianAndAlaskaNatives.pdf

"Data Linkage Strategies to Advance Youth Suicide Prevention: A Systematic Review for a National Institutes of Health Pathways to Prevention Workshop." This article describes a systematic review, an environmental scan, and a targeted search designed to identify data systems that can be linked to data from prevention studies to advance youth suicide prevention research. A supplemental content page offers a list of national-, state-, and local-level data systems, including the type of suicide-related data collected (i.e., suicide deaths, suicide attempts, suicidal ideation), the demographic setting, and the web link where the data can be found. <u>http://annals.org/article.aspx?articleid=2558371</u>

Research-Practice Partnerships: Developing Data Sharing Agreements. This website section offers examples and resources on creating data sharing agreements. <u>https://rpp.wtgrantfoundation.org/topic/developing-data-sharing-agreements/</u>

"Key Elements of Data Sharing Agreements." This information sheet provides a summary of common elements found in data sharing agreements. http://www.neighborhoodindicators.org/library/guides/key-elements-data-sharing-agreements

SPRC's Locating and Understanding Data for Suicide Prevention. This free, online course can help with thinking critically about the strengths and limitations of various data sources. <u>https://training.sprc.org/enrol/index.php?id=35</u>

#### Example

HarrisLogic, LLC, based in Dallas, Texas, has integrated event and services data from jails, courts, state repositories, psychiatric hospitals, mental health clinics, crisis hotlines, and mobile crisis outreach teams into one platform called <u>Stella</u>. This platform provides a privacy-compliant digital space for multiple agencies to coordinate care and has enabled detection and risk stratification of individuals involved in the justice system with behavioral health problems. Stella has made it possible for Dallas to remove operational silos by making these individuals' comprehensive records available. Ultimately, Stella has allowed Dallas to rapidly detect and provide targeted services for individuals at heightened risk of jail recidivism, failure to engage in aftercare, inpatient and emergency department re-admissions, and suicide.

# Section 4: Establish a System for Analyzing Data

#### At a minimum

For successful implementation and longevity of suicide prevention efforts, states should employ a data analyst who can perform targeted analyses and offer ideas on data sources and analytics. Ideally, the analyst would be dedicated to suicide prevention, but at minimum, they would be part of a state or regional structure that provides analyses for suicide prevention along with other public health programs.

States should have the budgetary support to meet software, hardware, and personnel needs for a well-functioning data system. When real-time data are used, they should be interpreted meaningfully, with caveats that are reported and understood.

For all data, there should be a system of quality control in place to ensure that the data are appropriately collected, stored, cleaned, and analyzed. Data providers should offer resources on correct interpretation of statistical results to ensure that data are not misunderstood or used inappropriately. When data on underserved communities can be obtained reliably and in large enough quantity, data analysts should ensure that underserved communities are well represented in analyses and that health disparities are examined when applicable. When data on underserved populations is not being accessed or collected in this fashion, the state suicide prevention program should work to address these gaps (See Infrastructure Recommendations, "Examine: Ensure that high-risk and underserved populations are represented in data collection" for further details.) The data analyst should be skilled in quantitative research.

# To further strengthen your infrastructure

States should establish a dedicated state or regional mechanism with personnel to provide analyses specifically for suicide prevention. Ideally, the state would also have access to an analyst who is well versed in qualitative design and analysis.

#### Resource

National Syndromic Surveillance Program Fact Sheet. This sheet provides information on near real-time data offered through CDC's ESSENCE system. <u>https://www.cdc.gov/nssp/documents/NSSP-fact-sheet-508.pdf</u>

#### Example

Denton and Tarrant Counties in Texas have created strong and timely data snapshots for their Zero Suicide-specific and broader county suicide prevention efforts. By collaborating with medical examiner offices, Local Mental Health Authorities, and Local Outreach to Suicide Survivors teams, the counties were able to access real-time suicide death data, which they used

to strengthen and track the impact of their prevention efforts. <u>https://www.sprc.org/resources-programs/surveillance-success-stories-texas-denton-tarrant-counties</u>

# Section 5: Establish a System for Using Data

## At a minimum

For successful implementation and longevity of suicide prevention efforts, states should have an established infrastructure to support data use with a system for regularly reporting data to the suicide prevention coordinator. States should be able to respond to public questions related to suicide and communicate data locally. (See Infrastructure Recommendations, <u>"Lead: Develop capacity to respond to information requests from officials, communities, the media, and the general public</u>" and <u>"Examine: Develop the skills and a plan for regularly analyzing and using</u> <u>data to inform action at the state and local levels</u>" for further details.)

When states cannot answer public questions with existing data, or when local data are not available, they should develop an infrastructure plan that builds state and local capacity to address emerging questions. Data should be clearly communicated to stakeholders, and information about the usefulness of the data to stakeholders should be sent back to data providers to ensure accountability. High-level reports to the governor and other important stakeholders should be mandated and contain multiple data sources and suicide metrics. (See Infrastructure Recommendations, <u>"Authorize: Require an annual progress and needs report to the legislature or governor</u>" for further details.) Reports and data briefs should be culturally and linguistically appropriate.

# To further strengthen your infrastructure

States might establish a coordinating body to work in collaboration with the suicide prevention coordinator.

#### Resource

SPRC's Locating and Understanding Data for Suicide Prevention. This free, online course can help with thinking critically about the strengths and limitations of various data sources. <u>https://training.sprc.org/enrol/index.php?id=35</u>

#### Example

States like New York, Oregon, and Colorado have created interactive data tools to drive suicide prevention education and planning efforts at the local, regional, and statewide levels. These online data tools draw on information from their state's violent death reporting system and are publicly available for use by a variety of stakeholders.

 Oregon Violent Death Reporting System Data Dashboard: <u>https://www.oregon.gov/oha/PH/DISEASESCONDITIONS/INJURYFATALITYDATA/P</u> <u>ages/nvdrs.aspx</u>

- New York State Health Connector, Suicide and Self-Harm Dashboard: <u>https://nyshc.health.ny.gov/web/nyapd/suicides-in-new-york</u>
- Colorado Violent Death Reporting System (scroll down to Data section to access Colorado Suicide Data Dashboard): <a href="https://www.colorado.gov/pacific/cdphe/colorado-violent-death-reporting-system">https://www.colorado.gov/pacific/cdphe/colorado-violent-death-reporting-system</a>

# Section 6: Collect, Analyze, and Use Data from State Systems

## At a minimum

For successful implementation and longevity of suicide prevention efforts, states should have a formal, established connection between the suicide prevention coordinator, the public behavioral health care system, and the public health care system. States should also establish champions within state systems who can support the systematic collection and use of suicide-related data. This could include on-the-ground staff who can provide recommendations on improvements in data collection procedures, data analysts who can find ways to integrate suicide data into the existing data system, and executive level leadership who can create new policies to prioritize the collection and use of suicide-related data. Data sharing should occur between the office of suicide prevention and adult-serving crisis systems, (such as state hospitals, crisis respite services, and crisis residential services), and youth-serving systems (such as juvenile justice and child welfare). State systems should not let the lack of a common definition be an excuse for not collecting suicide-related data.

## To further strengthen your infrastructure

States would require data sharing between state systems for suicide-related data and require that an annual report be submitted to the governor on suicide-related indicators in state systems. (See Infrastructure Recommendations, <u>"Examine: Link data from different systems</u> while protecting privacy" for further details.)

#### Resources

CDC's "International Classification of Diseases, Tenth Revision, Clinical Modification." To allow for more familiarity with the coding systems used in public behavioral health, this webpage provides background on the history and current use of the ICD-10-CM, including a link to the coding manual used by behavioral health systems for billing purposes. https://www.cdc.gov/nchs/icd/icd10cm.htm

SPRC's Breaking Down Barriers: Using Youth Suicide-Related Surveillance Data from State Systems. This report was developed for SAMHSA and Garrett Lee Smith state grantees to highlight challenges and opportunities for data sharing between youth-serving state systems and state suicide prevention efforts. <u>https://www.sprc.org/resources-programs/breaking-down-barriers-using-youth-suicide-related-surveillance-data-state</u>

#### Example

Researchers in Utah<sup>3</sup> examined data from 151 consecutive youth suicides (ages 13-21) to determine where decedents had contact with state systems prior to their death. The researchers drew on data from a variety of systems, including juvenile justice, public behavioral health, department of education, and child protective services. The researchers found that 65% of these suicide decedents had interacted with the juvenile justice system at some point in their lifetime. The researchers used this information to advocate for a targeted prevention approach.

<sup>&</sup>lt;sup>3</sup> Grey, D., Achilles, J., Keller, T., Tate, D., Haggard, L., Rolfs, R., & McMahon, W. M. (2002). Utah youth suicide study, Phase 1: Government agency contact before death. *Journal of the American Academy of Child and Adolescent Psychiatry*, *41*(4), 427–434. This study describes the work of Douglas Grey and colleagues examining suicide in youth-serving state systems in Utah.

