

# BREAKING DOWN BARRIERS



Using Youth Suicide-Related  
Surveillance Data from State Systems



SPRC | Suicide Prevention Resource Center



# Acknowledgments

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*Breaking Down Barriers: Using Youth Suicide-Related Surveillance Data from State Systems* was developed by the Suicide Prevention Resource Center (SPRC) under a grant from the Substance Abuse and Mental Health Services Administration.

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The Suicide Prevention Resource Center at EDC is supported by a grant from the U.S. Department of Health and Human Services (HHS), Substance Abuse and Mental Health Services Administration (SAMHSA), Center for Mental Health Services (CMHS), under Grant No. 5U79SM062297. The views, opinions, and content expressed in this product do not necessarily reflect the views, opinions, or policies of CMHS, SAMHSA, or HHS.

Suggested citation:

Suicide Prevention Resource Center. (2017). *Breaking down barriers: Using youth suicide-related surveillance data from state systems*. Waltham, MA: Education Development Center, Inc.

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# Executive Summary

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In the public health field, surveillance means the collection of data for use in planning, implementation, and evaluation of public health efforts (WHO, 2017). In order to have a significant impact on reducing youth suicide, we must better understand the trajectory toward suicide of those who die, including understanding the systems with which they have contact before they die. This makes surveillance data from state systems that serve youth with a large number of suicide-related risk factors critically important. Specifically, a better understanding is needed of the opportunities and barriers for using data from the juvenile justice, child welfare, and public behavioral health systems.

To address this need, the Suicide Prevention Resource Center (SPRC) conducted key informant interviews, surveys of Garrett Lee Smith Memorial Act (GLS) grantees, and an analysis of archival data. This report highlights existing opportunities and successes from the field, while also providing recommendations on overcoming specific barriers that state GLS grantees may face in accessing, analyzing, and ultimately using suicide surveillance data. Recommendations address the following issues:

- **How to overcome a lack of data availability**, including dealing with narrative data, data-sharing agreements, and a lack of system resources
- **How to address data quality concerns**, including a lack of standardized definitions for suicide-related behaviors and difficulty tracking youth across systems and time
- **How to consider the extent to which prevention efforts are systemwide** before using system-level outcome data to measure success
- **How to interpret trends** when there are a small number of in-system suicide deaths and/or a small overall size of in-system populations
- **How to address other system-unique barriers** (e.g., discrepancies in how suicide-related data are defined and collected in different parts of the same system)

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# Introduction

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## Why focus suicide prevention and surveillance efforts on juvenile justice, child welfare, and public behavioral health systems?

In the public health field, 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. As the suicide prevention field continues to develop, it generates a growing need to gather suicide surveillance data to inform decision making, mobilize momentum for change, and ultimately demonstrate the effectiveness of prevention programs in reducing suicidal behaviors. In order to have a significant impact on reducing youth suicide, we must better understand the trajectory of youth who die by suicide, including the systems they touch before their death.

Funded by the Substance Abuse and Mental Health Services Administration (SAMHSA), state Garrett Lee Smith Memorial Act (GLS) grantees are tasked with planning, coordinating, implementing, and evaluating suicide prevention efforts for youth aged 10–24 years. To have the broadest impact possible during the grant, SAMHSA encourages state GLS grantees to focus prevention efforts on systems that serve youth at high risk. Research suggests that youth who are involved with the juvenile justice, child welfare, and public behavioral health systems often have multiple risk factors for suicide, including history of mental illness (Teplin, Abram, McClelland, Dulcan, & Mericle, 2002); substance use disorders (OJJDP, 2014), physical or sexual abuse (U.S. Department of Justice, 2009); and/or poverty (Knitzer & Lefkowitz, 2006).<sup>1</sup> Despite a clear need for suicide surveillance data from these systems for prevention purposes, little is known about how or whether these systems collect suicide-related data and the potential for data sharing between these systems and GLS grantees.

## What is the purpose and scope of this report?

In response to the need for suicide surveillance data from youth-serving systems,<sup>2</sup> this report will do the following:

- **Explore the opportunities and barriers that state GLS grantees face in accessing and using suicide surveillance data from juvenile justice, child welfare, and public behavioral health youth-serving state systems for planning, building political and community support, quality improvement, and measuring impact**
- **Provide resources and recommendations for state GLS grantees to overcome identified barriers**

While we recognize that the juvenile justice, child welfare, and public behavioral health systems are diverse in terms of population(s) served, organizational structure, and overall purpose, their suicide surveillance systems share similar challenges and opportunities. We will focus on these common aspects throughout this report. Because a primary purpose of this report is to help state GLS grantees access data from these systems, we will focus specifically on the state GLS priority population of youth between the ages of 10 and 24 years. Since other resources already exist on suicide surveillance in public behavioral health systems,<sup>3</sup> child welfare and juvenile justice systems will receive more focus in this report.

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<sup>1</sup> See Pilowski & Wu (2006) for more in-depth research on the connection between suicide and child welfare. See Grey et al. (2002) and Gallagher & Dobrin (2006) for more in-depth research on the connection between suicide and juvenile justice.

<sup>2</sup> In this report, the term *youth-serving state systems* will refer to three state systems: juvenile justice, child welfare, and public behavioral health.

<sup>3</sup> See p. 30 for links to SPRC's suicide *Surveillance Success Stories*.

## What approaches were used to gather information about suicide surveillance data in the juvenile justice, child welfare, and public behavioral health systems?<sup>4</sup>

To inform recommendations in this report, SPRC performed the following:

- ▶ Interviewed key informant juvenile justice and child welfare administrators, asking them about current collection of suicide-related data, barriers to collecting this data, and barriers and opportunities for sharing the data with state GLS grantees
- ▶ Administered a GLS State Systems Surveillance Survey for state GLS grantees whose funding began in 2013–2015, capturing information on their current system-level prevention activities in youth-serving state systems, access to suicide surveillance data from these systems, barriers to data access, and relevant technical assistance (TA) needs on suicide surveillance in these systems
- ▶ Reviewed archival data, including state GLS grant proposals, to gather information about how grantees had proposed to conduct system-level work and surveillance in youth-serving state systems
- ▶ Reviewed interview transcripts (also archival data) from SPRC's series of *Surveillance Success Stories* to gather information about innovative data partnerships and existing resources, including strategies for accessing and using public behavioral health suicide surveillance data

## What successes and supports are already available to help state GLS grantees access and use suicide surveillance data from youth-serving state systems? What barriers exist, and how can state GLS grantees overcome those barriers?

Based on these methods, we found a few successes and supports already available to help state GLS grantees access and use suicide surveillance data from youth-serving state systems, which we describe in **Section 1**. Despite those opportunities for data collection, however, a number of challenges remain that affect the access and use of suicide-related data from youth-serving state systems. In **Sections 2–6**, we discuss the common barriers to accessing data in these systems, make recommendations for how to overcome them, and offer related resources and examples.

<sup>4</sup> A full record of the methods and findings for the key informant interviews and Garrett Lee Smith State Systems Surveillance Survey can be found in the accompanying technical report, *Breaking Down Barriers: Using Youth Suicide-Related Surveillance Data from State Systems – Technical Report*: <http://www.sprc.org/resources-programs/breaking-down-barriers-using-youth-suicide-related-surveillance-data-state>.

## SECTION 1

### Existing Successes and Supports



**Our methods revealed the following existing supports for suicide surveillance in specific systems.**

### JUVENILE JUSTICE SYSTEM

- ▶ **Performance-based Standards:** The Performance-based Standards (PbS) system is operated privately through a nonprofit organization on a fee-for-service basis. The PbS system, which is active in select detention centers, correction facilities, and community-based programs in over 35 states, collects information twice a year on various aspects of juvenile justice residential centers, including safety and services provided. Field experts serve as PbS coaches and guide facility staff along the three-part cycle: (1) collect data, (2) analyze results, and (3) use the information to develop data-informed improvement plans.
- ▶ To ensure consistent collection, PbS provides a glossary of standardized data definitions, which includes a broad definition of *suicidal behavior*. Participants log all incidents of self-harm, both fatal and nonfatal, as suicidal behavior during the months of April and October. The adoption of common definitions allows PbS to provide a national field average that the individual facilities use to compare rates of suicidal behavior with and without injuries to other similar facilities. However, participation in PbS is voluntary and not all juvenile justice systems have adopted the system.

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**State GLS grantees and others looking to link with a state's PbS data can contact their state's juvenile justice administrator to assess availability.**

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**RESOURCE: *Performance Based Standards Website.*** The PbS website offers links to programs, resources, and contact information. <http://pbstandards.org/>

### PUBLIC BEHAVIORAL HEALTH SYSTEM

- ▶ **Zero Suicide in Health and Behavioral Health Initiative:** Zero Suicide, a model for health systems change to improve suicide care, is a key part of the National Action Alliance for Suicide Prevention's (Action Alliance's) priority of transforming health systems. The Suicide Prevention Resource Center (SPRC) at EDC provides secretariat support to the Action Alliance, and EDC's Zero Suicide Institute is the implementation lead for the Zero Suicide Initiative. The foundational belief of Zero Suicide is that suicide deaths for individuals under care within health and behavioral health systems are preventable. The Zero Suicide framework includes a focus on data-driven quality improvement, and a number of health systems implementing Zero Suicide have collaborated with state suicide prevention leadership to crosswalk patient data with vital statistics records to assess impact.

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**GLS grantees are encouraged to review Zero Suicide resources for innovative ideas on linking with health records, even if their public behavioral health system is not implementing the Zero Suicide approach.**

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**RESOURCE: *Zero Suicide Toolkit: Improve.*** Zero Suicide introduces a data-driven, quality improvement approach to addressing suicide care based on process and outcome evaluation data. <http://zerosuicide.sprc.org/toolkit/improve>

## ALL THREE YOUTH-SERVING SYSTEMS

- Child Death Review Boards:<sup>5</sup> Every state has a Child Death Review (CDR) program. Often using a multidisciplinary, collaborative process, the CDR investigates child deaths and uses the resulting information to inform local-, state-, and national-level prevention efforts. CDR programs may be convened at different levels (e.g., state, community) and with varied funding levels, age ranges, causes for which deaths are reviewed, and adherence to identified best practices. A small number of states or counties have formed Suicide Death Review Teams,<sup>6</sup> which are specifically focused on deaths by suicide and not limited to the investigation of deaths by minors.

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**State GLS grantees are encouraged to link with their state's CDR and/or Suicide Death Review Team as potential sources of information about the involvement in state systems of youth who have died by suicide.**

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- In some cases, collaboration with CDR programs has resulted in more consistent or focused review of suicide deaths, while also allowing CDR teams to link their efforts to specific prevention activities implemented by the GLS grant.

### RESOURCES:

***The National Center for Fatality Review and Prevention.*** This link provides state-specific CDR contacts. GLS grantees can contact their state program for recent reports, data, and information on how their CDR can connect with GLS activities. <https://www.ncfrp.org/cdr-programs/u-s-cdr-programs/>

***The SPRC Suicide Surveillance Success Story Series: Montana.*** This suicide surveillance success story highlights lessons learned from Montana, a state with a high-functioning Suicide Mortality Review Team. <http://www.sprc.org/resources-programs/surveillance-success-stories-montana>

- National Violent Death Reporting System (NVDRS): Funded by the Centers for Disease Control and Prevention (CDC), NVDRS is a surveillance system that gathers in-depth data on all suicides, homicides, deaths from legal intervention, deaths of undetermined intent involving trauma or poisoning (including drug-related poisoning), and unintentional firearm fatalities in an effort to inform prevention efforts. At the time of this report, 40 states, the District of Columbia, and Puerto Rico receive federal support for NVDRS implementation, although in some areas, implementation may not yet be fully functional. Required primary sources for NVDRS include death certificates, coroner/medical examiner reports, and law enforcement reports. Optional additional sources include hospital data, crime lab data, and data from CDR programs.
- NVDRS records include two institutional commitment variables that indicate whether the deceased was currently in involuntary commitment or had been voluntarily or involuntarily committed during the 30 days prior to his or her death.

<sup>5</sup> Also Child Mortality Review Boards, Child Fatality Review Boards

<sup>6</sup> Also Suicide Fatality Review Committees

Commitment could include incarceration, foster care placement, commitment to any psychiatric hospital (not specific to the public system), or legal home confinement.<sup>7</sup> Although not required, some NVDRS systems collect the following additional data:

- » Contact with the juvenile justice or mental health system in the past 12 months
- » Historical child welfare involvement (information on sexual or physical violence or neglect, substantiation of the child welfare report, etc.)
- » Residence type (including juvenile detention center, foster home)
- » History of psychiatric treatment (including history of inpatient psychiatric hospitalization, current use of psychiatric medications)

The quality of NVDRS data depends on the completeness and accuracy of the local death investigation. National-level NVDRS data releases occur after approximately 18 months after the calendar year, and state-level data may not be released until investigations are fully concluded, thereby limiting the utility of the data for making timely planning decisions, although the data may still be useful for other purposes.

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**GLS grantees are encouraged to connect with their NVDRS system (if available) to learn more about the availability of data on suicide deaths of system-involved youth.**

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#### RESOURCES:

**Centers for Disease Control and Prevention. National Violent Death Reporting System: Web Coding Manual (2015 revision).** This manual provides state GLS grantees with an understanding of the data fields collected within NVDRS. [https://www.cdc.gov/violenceprevention/pdf/nvdrs\\_web\\_codingmanual.pdf](https://www.cdc.gov/violenceprevention/pdf/nvdrs_web_codingmanual.pdf)

**Centers for Disease Control and Prevention. National Violent Death Reporting System: State Profiles.** This website provides state GLS grantees with their state-specific NVDRS contacts. GLS grantees can contact their representatives for recent reports, data, and information on how the team's work can connect with GLS activities. <https://www.cdc.gov/violenceprevention/nvdrs/stateprofiles.html>

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<sup>7</sup> If recently released from more than one institution (e.g., past month stay in prison, released to foster care), this will be coded according to the most recent release.

## SECTION 2

### Lack of Available Suicide-Related Data in Youth-Serving State Systems



**BARRIER:** Lack of available data is a significant barrier to accessing suicide-related data in youth-serving state systems.

**Background on Challenge:** Although a leading cause of death among youth, suicide is a relatively rare event and may not be a top priority for youth-serving state systems. Some key informant administrators from these juvenile justice and child welfare systems have reported that they have not been aware of any in-custody deaths in their systems for many years. They are also likely unaware of suicide deaths that occur among those who have touched, but are not currently involved in, their system. For this reason, the motivation to improve infrastructure for tracking suicide deaths may not exist in these systems.

Even when data collection infrastructure does exist, the data are often not easily shared, aggregated, or analyzed. Key informant administrators from these systems reported that suicide-related data, particularly on attempts, are generally collected in narrative form through incident reports. Narrative data may include personally identifiable information and are often not easily aggregated, so preparing this data for sharing and/or surveillance use may be too time consuming to be practical.

Since many GLS grants are housed in state behavioral health agencies, these grantees may have relatively easy access to the public behavioral health system, making it a logical place for intervention and data access. However, while some state public behavioral health systems collect suicide-related data on those individuals under their care, the definition of *under care* may vary by state. Additionally, when attempt-related data are collected, they are generally based on self-report, which may be incomplete or unreliable. Further, special permissions may be needed to share attempt data with others because of identifiers. In fact, linking attempt data across state systems could require informed consent or extensive privacy assurances, which might be another barrier in understanding suicide behavior among youth in overlapping systems.

Data on suicide-related deaths can also be challenging to collect, particularly when individuals are not currently engaged with a state system. Some public behavioral health systems have reported gathering data on client suicide deaths by routinely scanning obituary columns, documenting occasional notifications from family members or clients' insurance carriers, and attempting to verify community word-of-mouth reports. Data on suicide-related attempts for youth who have touched, but are not currently involved in, a state system are even more challenging to collect.

Suicide death data are available from State Child Death Review and Suicide Death Review teams, who are likely to know about current system involvement among youth who have died by suicide for the deaths they review. Unfortunately, even these committees may not have information about prior system involvement, particularly if that involvement was less recent. Additionally, the capacity of these committees varies from state to state. States may not review all suicide deaths or may not review suicide deaths at all, and many have an age cutoff of 18 years or younger, limiting the richness and completeness of the data in many states for GLS purposes.



## Recommendations for State GLS Grantees on Understanding and Improving Data Availability:

### 2.1. Do your homework before meeting with your juvenile justice, child welfare, or public behavioral health system.

This should include:

- a. A vision of who would use the data, how it would be used, and how data sharing might be sustained over time
- b. An understanding of the capacity of the existing data collection system
- c. An understanding of the ownership of the existing data system
- d. An understanding of related available data from outside of the state system in question (e.g., Child Death Review program)
- e. An understanding of how data systems could be improved

#### RESOURCES:

- ***Epidemiological Profiles for States and Jurisdictions.*** Substance abuse prevention profiles from each state and jurisdiction are developed by a collaboration of state agencies and local researchers. Although over 40 states are represented in this resource, not all have updated profiles. However, this resource can still aid GLS grantees in understanding what data may already be publicly available. The lead agency for epi-profile development is listed in each state report:
  - » <https://www.samhsa.gov/capt/programs-campaigns/center-application-prevention-technologies/practicing-effective-prevention-0>
- ***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, 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, suicide ideation), the demographic setting, and the Web link where the data can be found:
  - » <http://annals.org/article.aspx?articleid=2558371>
- See Section 1: Existing Successes and Supports (p. 3–6), for recommendations on connecting with Child Death Review programs, Suicide Death Review Boards, and NVDRS programs in the state.
- ***Appendix I: Worksheets on Starting and Continuing Dialogue on Data Sharing in Youth-Serving Systems, Worksheets 1-4*** (See p. 33 in this report.)

## 2.2. Increase leadership buy-in for prioritizing suicide-related data collection.

Before approaching state systems with specific requests for data partnerships, research the risks and benefits of suicide-related data collection for state systems. While there can be some economic benefit to data sharing (e.g., new funding opportunities, opportunities to pilot new projects), finding out and documenting for the first time that the youth in a system are attempting (and possibly dying by) suicide invites further scrutiny at high levels, from state leadership to the press. Build relationships with leadership to determine their needs and reservations, and look for mutually beneficial solutions.

Once the partner is engaged, do not underestimate the importance of continued relationship building for ongoing access to and improvement of data from the system. Further, where possible, encourage cross-system partnerships, building partnerships among youth-serving state systems engaged in suicide prevention. In this way, we can work toward improving the tracking of youth across systems.

### RESOURCES:

- **Appendix I: Worksheets on Starting and Continuing Dialogue on Data Sharing in Youth-Serving Systems, Worksheet 1** (See p. 34 in this report.)
- **SPRC Substance Abuse and Suicide Prevention Collaboration Continuum.** 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>
- **So Much at Stake: Lessons on Stakeholder Engagement from the Washington State Suicide Prevention Plan.** A 1-hour recorded webinar on the process of developing the Washington State Suicide Prevention Plan with more than 250 stakeholders:
  - » <http://www.nwcphp.org/training/opportunities/webinars/stakeholder-engagement-for-suicide-prevention>
- Moskos, M. A., Halbern, S. R., Alder, S., Kim, H., & Gray, D. (2007). Utah youth suicide study: Evidence-based suicide prevention for juvenile offenders. *Journal of Law and Family Studies*, 10, 127–145. (See p. 141–142 for specific information on cost savings.)
- **From the Field: Utah's Story of Comprehensive State System Engagement in Suicide Surveillance** (See p. 30 in this report.)

## 2.3. Set a strong foundation with clear communication.

Reach early agreement with partners on core issues of data sharing, including intended use of the data, transmission procedures, confidentiality assurances, and other procedural and logistical issues. Assure data owners that they will not lose control of the data by creating clear agreements that address the following:

- The right to review results and presentations before public release
- Assurances that data will be used for planning and quality improvement purposes and not for blame
- Agreements to list data owners as authors in publications and presentations

**RESOURCES:**

- **Appendix I: Worksheets on Starting and Continuing Dialogue on Data Sharing in Youth-Serving Systems, Worksheets 2-4** (See p. 36-40 in this report.)
- **Research Practice Partnerships: Developing Data Sharing Agreements.** Examples and resources on creating data-sharing agreements:
  - » <http://rpp.wtgrantfoundation.org/developing-data-sharing-agreements>
- **Human Resources Information System (HRIS) Strengthening Implementation Toolkit.** Discusses why agencies might share data, what data might be shared, the elements of a data-sharing agreement, and what to do if an agreement has been violated:
  - » <http://www.ihris.org/toolkit/tools/data-sharing.html>
- **Key Elements of Data Sharing Agreements.** Summary of common elements found in data-sharing agreements:
  - » <http://www.neighborhoodindicators.org/library/guides/key-elements-data-sharing-agreements>

**FROM THE FIELD****Ohio's Story of "Fertile Ground" for Data Sharing between the Department of Mental Health and Addiction Services and the State Juvenile Justice System**

Mental health and juvenile justice have a long history of collaboration in Ohio, beginning with a 1990s project sponsored by the U.S. Department of Justice that brought together stakeholders from a diverse set of state systems. In the early 2000s, the Ohio's behavioral health agency enhanced its use of least restrictive, appropriate care for youth involved in the state's juvenile justice system. As more low-to-medium risk offenders were diverted to evidence-based alternatives to incarceration, partnerships grew even stronger between Ohio's Department of Mental Health and Addiction Services, local community mental health center (CMHC) partners, and the juvenile justice system. Today, Ohio has a uniform tracking system of all deaths in the juvenile justice system, including county jails and the juvenile prison system. Data sharing is possible between the juvenile justice's behavioral health project and the GLS grant, with current exchange of aggregate data and ongoing negotiation between agencies of how more detailed data could be shared as well. According to Jane Timmons Mitchell, senior research associate and associate clinical professor of psychology at Case Western Reserve University, the long-term relationships that started in the 90s have made the current shared access to data possible. Dr. Timmons Mitchell says that a next step for Ohio will be to follow juvenile justice youth more closely as they interact with behavioral health providers, but this will take additional time and resources. She noted that data access is made easier when cross-system, long-term relationships are fostered and shared system benefits are identified.

**FROM THE FIELD****New Hampshire's Story of Unique Linkages for Access to Real-Time Data**

Recognizing a need for access to real-time data on suicide, New Hampshire assigned a designated liaison from the Department of Health and Human Services (DHHS) to the Office of Chief Medical Examiner (OCME) and to the New Hampshire National Guard. This role allows DHHS access to real-time suicide death data, enabling immediate postvention response at the local level. Upon learning of a suicide-related death, the local community mental health center (CMHC) can immediately be contacted and activated to provide support to the community and to prevent contagion. If a CMHC client is the decedent, targeted outreach can be provided to loved ones and early internal case review of patient management can begin. Targeted outreach occurs to the schools for suicide deaths of youth. The liaison also monitors media coverage of the event, watching for best practices in reporting. In addition to using the data in real-time for immediate action, de-identified aggregate data are shared with CMHCs for quality improvement and planning purposes.

**FROM THE FIELD****Tennessee's Story of Accessing and Utilizing Narrative-Based Data from the Juvenile Justice System**

Through Tennessee's second GLS grant, the evaluation team at Centerstone Research Institute, in partnership with the Tennessee Department of Mental Health and Substance Abuse Services, the Mental Health Association, and the Department of Juvenile Justice, developed a suicide prevention training for juvenile justice facilities. Specifically, following an evaluation of Applied Suicide Intervention Skills Training (ASIST), the team used evaluation data to build the Shield of Care Suicide Prevention Training, which is customized to juvenile justice settings and now available on the SPRC website see <http://www.sprc.org/resources-programs/shield-care-system-focused-approach-protecting-juvenile-justice-youth-suicide>.

**The Shield of Care's *S-Plan* teaches staff to:**

- > **S**ee early warning signs of suicide
- > **P**rotect youths' safety
- > **L**isten to concerns contributing to suicidal thoughts
- > **A**ssess youths' needs
- > **N**etwork together to prevent suicide

To assess client-level outcomes from their program, Dr. Jennifer Lockman, program evaluator for Centerstone Research Institute, and her team planned to use an interrupted time series design and to evaluate the number, timing, and quality of serious incident reports before and after the training in each youth development center across the state. The evaluation team accessed serious incident reports in participating juvenile justice facilities from before and after implementation. They

used qualitative methods (i.e., grounded theory, content analysis) to develop a coding tool, and coded the narrative-based incident reports, checking periodically for inter-rater agreement. A research assistant pre-screened the reports, redacted confidential information, and delivered the reports to the evaluation team. Although mid-course implementation changes in the collection of incident reports in the juvenile justice system prevented the team from being able to use these reports for outcome purposes (as was the original intent of the study), they were able to provide feedback to improve information collected during a suicide-related incident, resulting in better data. Dr. Lockman and her team were also able to use the incident reports to generate a classification tool to gauge client risk and to classify staff's intervention response.

Through this project, Dr. Lockman and her evaluation team identified several tips for accessing existing data from youth-serving systems, including the need for critical stakeholder buy-in (such as buy-in from the project's funder to cover the cost of evaluation services), the need for early and frequent conversations with the partner system on when and how the data will be used, and the need to stretch evaluation dollars by relying on interns for time-consuming tasks.

## SECTION 3

# Data Quality Issues in Youth-Serving State Systems



**BARRIER:** Data quality can be a significant barrier to using suicide-related data from youth-serving state systems.

**Background on Challenge:** Key informant administrators from juvenile justice and child welfare systems reported that even when suicide-related data are collected in their systems, accuracy and data quality remain a challenge. Juvenile justice and child welfare systems often lack standard definitions and/or consistent protocols or training to support on-the-ground staff in accurately and consistently identifying and recording suicide-related events. These inconsistencies may be present even within a single state system; for example, a state's privately run jails may have different suicide-related data collection protocols and definitions than the state's prison or probation system. In the child welfare system, staff monitoring youth in foster care may define and report suicide differently than those serving youth in-home.

Culture and training can also impact whether staff decide to code an event as suicide-related. For example, in the juvenile justice system, some teams may be more likely to call for emergency service assistance for a suicide-related event, which would necessitate incident documentation. Other teams may have more capacity to handle an event in-house, and thus be less likely to call for emergency services and complete an incident report. Consistency problems are compounded when youth cross systems (e.g., from juvenile justice to child welfare).

Public behavioral health systems are more likely than juvenile justice and child welfare systems to have standard definitions and consistent data collection protocols because these are defined by the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) and the International Classification of Diseases (ICD-10) codes. However, the accuracy of ICD-10 codes, specifically, is dependent on (a) the quality of communication between the client and the intake staff and clinician(s), (b) the training and experience of the coder, and (c) whether codes have been altered to accommodate billing needs, or (d) if critical information has been omitted (O'Malley et al., 2005).

National data sets that supplement system-collected information, such as the NVDRS, may not provide enough detail to make up for these data quality and collection challenges. For example, although the NVDRS tracks whether a person who died by suicide transitioned from an involuntary or voluntary commitment (e.g., jail, foster care, or a psychiatric institution) in the past 30 days, it does not have specific variables in the system to capture multiple transitions. This means that if a youth transferred from foster care to jail within 30 days of his or her death, for example, only the jail involvement would be recorded in the system. If a youth transitioned from a commitment in a psychiatric institution to foster care within 30 days of his or her death, only the contact with foster care would be recorded. The NVDRS also does not capture all less-intensive system involvement (e.g., child welfare investigations not requiring removal from the home). In some cases, more detailed information about transitions might be available in abstractor narratives.



## Recommendations for State GLS Grantees on Understanding and Improving Data Quality:

### 3.1. Offer investment and/or in-kind consultation to youth-serving systems to enhance their ability to collect quality suicide-related data

This could include assistance in creating common definitions for suicide-related behavior (e.g., ideation, attempt) and/or assistance in building helpful suicide-surveillance infrastructure (e.g., adding quantitative fields on suicidal ideation, attempt, and death). When building or enhancing suicide-surveillance infrastructure, state GLS grantees should be sure to address ways to sustain these efforts by planning for staff turnover, instituting ongoing training, and/or developing manuals and updating policies. These efforts could ensure consistency in data collection even when turnover is high or when administrative changes in governing bodies cause shifting priorities.

#### RESOURCES:

- **National Center for Injury Prevention, Division of Violence Prevention's Self-Directed Violence Surveillance: Uniform Definitions and Recommended Data Elements.** Designed to promote and improve consistency of self-directed violence surveillance; reduce data incompatibility; and reduce the high costs of collecting, linking, and using data:
  - » <http://www.cdc.gov/violenceprevention/pdf/self-directed-violence-a.pdf>
- **International Statistical Classification of Diseases and Related Health Problems (10th revision).** The ICD-10 is used to guide medical coding practices and may be useful for creating consistent definitions in systems for coding suicide attempts:
  - » <http://www.who.int/classifications/icd/en/>
- **Medical Examiners' and Coroners' Handbook on Death Registration and Fetal Death Reporting.** This resource offers guidance on how coroners and medical examiners distinguish between deaths that are accidental, homicides, suicides, and undetermined. This process may be useful for other state systems looking to develop their own suicide-related definitions:
  - » [https://www.cdc.gov/nchs/data/misc/hb\\_me.pdf](https://www.cdc.gov/nchs/data/misc/hb_me.pdf)

### 3.2. Become familiar with state system priorities for data collection.

- When suicide surveillance is tied to existing state system priorities, suicide-related data can be collected in a way that adds the least amount of burden.

### 3.3. Connect with critical players in suicide surveillance data collection, including Child Death Review programs, Suicide Death Review teams, and coroners or medical examiners to strengthen consistency of data collection and explore how connections between suicide surveillance groups and youth-serving systems might be strengthened:

- See Section 1: Existing Successes and Supports (p. 5–6), for information on Child Death Review programs, Suicide Death Review teams, and NVDRS.



#### FROM THE FIELD

### Michigan's Story of Enhanced, Centralized Screening in Foster Care to Build a State-Level Suicide Surveillance System

In response to challenges in consistently identifying and recording information about youth at risk for suicide in the child welfare system, the Michigan GLS grant is piloting a collaboration with state- and local-level child welfare staff to create screening protocols designed to meet the needs of local staff, foster families, youth, and families of origin. According to Pat Smith, principle investigator/program director for Transforming Youth Suicide Prevention GLS grant in Michigan, in the proposed process, the foster care worker assigned to a youth entering the system will administer a brief screening measure on a computer tablet to obtain information on depressive symptoms, substance use, and suicidal ideation. While the foster care worker reviews these results, the youth will complete a comprehensive risk assessment on risk and protective factors. All information entered by the youth will be uploaded to a central database to be used for, among other things, conducting de-identified suicide-related surveillance among youth entering foster care. In this way, Michigan is improving their data collection infrastructure, centralizing data collection within the foster care system, and allowing for shared definitions of suicide-related risk between their GLS grant and foster care. This pilot system is designed to investigate the usefulness of conducting suicide-related surveillance among youth entering foster care in Michigan, and it will offer unique information on the degree of suicidal ideation in a child welfare system.



#### FROM THE FIELD

### Montana's Story of Improving Consistency of Reporting at the Ground Level

Concerned about inconsistency in reporting of deaths by suicide, Karl Rosston, the Montana Department of Public Health and Human Service's suicide prevention coordinator, examined the cultural, procedural, and logistical barriers that impact death coding. To fully understand the death coding system, Mr. Rosston first met the educational requirements to become a certified medical examiner. This certification allowed him to provide more effective technical assistance to medical examiners to increase the quality and consistency of suicide death coding, which allowed him to more confidently rely on this data for suicide-related planning, quality improvement, and impact measurement.

## SECTION 4

Limitations of Using Surveillance Data to Measure Impact when Prevention Efforts Are Not Systemwide



**BARRIER:** Because GLS grantees are not always involved in systemwide prevention activities in juvenile justice, child welfare, and/or public behavioral health systems, impact may be limited, even if grantees are able to access surveillance data from these systems.

**Background on Challenge:** To effect change in deaths and attempts over time, prevention efforts need to have adequate delivery and reach. GLS grantees involved in comprehensive suicide prevention in a system, such as Zero Suicide, using a multi-strategy, system-tailored approach, are well positioned to use system-level surveillance data. However, more limited prevention efforts that do not result in systems change and have less reach should not expect that system-level data, even if it is accessible, will demonstrate change.



## Recommendations for State GLS Grantees on Understanding When to Use Surveillance Data to Measure Impact

### 4.1. Conduct an environmental scan to understand existing prevention efforts in these systems.

Remember that juvenile justice, child welfare, and public behavioral health systems may already have suicide prevention activities and supports happening in-system. Conducting an environmental scan can give you more information on activities already occurring in the system so that you can select complementary prevention activities to fill in existing gaps and create a system-wide approach.

### 4.2. Use a systems-level prevention approach.

The suicide prevention field in general, and SPRC specifically, offer well-established best practices in general comprehensive prevention for systems change. In public behavioral health systems (as well as other health and behavioral health systems), these practices have been operationalized through the Zero Suicide model. Several resources and programs are also available for juvenile justice systems, and additional comprehensive approaches for child welfare settings could be created based on similar principles.

#### RESOURCES:

- ***SPRC's Comprehensive Approach to Suicide Prevention.*** Adapted from a model developed for campuses by SPRC and the Jed Foundation, this model provides a vision of nine strategies that contribute to comprehensive suicide prevention:

- » <http://www.sprc.org/effective-prevention/comprehensive-approach>

- **Zero Suicide Toolkit.** Introduces a comprehensive, data-driven, quality improvement approach to addressing suicide care:
  - » <http://zerosuicide.sprc.org/toolkit>
- **Zero Suicide Data Elements Worksheet.** Provides a list of data elements to consider, including outcomes measures:
  - » <http://zerosuicide.sprc.org/resources/zero-suicide-data-elements-worksheet>
- **National Action Alliance for Suicide Prevention: Youth in Contact with the Juvenile Justice System.** Offers information on creating a comprehensive approach to prevention within the juvenile justice system:
  - » <http://actionallianceforsuicideprevention.org/youth-contact-juvenile-justice-system>
- **National Action Alliance for Suicide Prevention: The 2012 National Strategy for Suicide Prevention: Individuals in Justice and Child Welfare Settings.** A resource list on recommendations for preventing suicides among individuals in juvenile justice and child welfare settings:
  - » [http://actionallianceforsuicideprevention.org/sites/actionallianceforsuicideprevention.org/files/NSSPFact-Sheet\\_IndividualsJusticeChildWelfareSettings.pdf](http://actionallianceforsuicideprevention.org/sites/actionallianceforsuicideprevention.org/files/NSSPFact-Sheet_IndividualsJusticeChildWelfareSettings.pdf)



## FROM THE FIELD

### Indiana's Story of Suicide Surveillance for Quality Improvement

Indiana is using their surveillance data to engage in a coordinated, systemwide quality improvement effort. According to Marc Kniola, Division of Youth Services program director for the Indiana Department of Correction (DOC), youth correctional facilities in Indiana track suicide ideation and suicide attempts via Performance-based Standards (PbS) incident reports. Each morning, facility teams, including executive members and mental health staff, meet to review any incidents from the night before and make recommendations regarding follow-up and corrective action. Incidents are aggregated and reviewed monthly to look for patterns, such as repeated incidents involving the same offender or staff member, or trends in locations, times, or shift rotations. Quarterly tracking reports are also generated and submitted to a central office to determine if corrective action, such as staffing, operational, or functional process changes, is necessary.

Suicide deaths are treated as critical incidents. The Operations Center of the DOC is notified of all critical incidents within one hour of the incident. Notifications are also sent to core decision makers, including appropriate directors, no later than the first business day following the date of the critical incident. A corrective plan of action must be developed for all critical incidents and submitted within 30 days through the appropriate chain-of-command.

Each correction and detention facility in Indiana also has a Suicide Prevention Committee that meets regularly to discuss trends, incidents, corrective action progress, and staff training needs. Each facility also has its own Health Care Services Directive, which is charged with providing guidance on (1) the identification and management of youth who are at risk for suicide or self-injurious behavior and (2) the development and modification of incident management protocols. In this way, surveillance data are being used to direct improvements.

## SECTION 5

### Analyzing Small Numbers



**BARRIER:** There are few youth deaths by suicide in juvenile justice, child welfare, and public behavioral health systems, limiting the utility of suicide death surveillance data to assess GLS grant impact.

**Background on Barrier:** Suicide is a relatively rare event, and the number of suicides is even smaller when we look at only a small slice of the population (such as youth involved in the juvenile justice, child welfare, or public behavioral health system). When working with a relatively rare event, it is difficult to determine whether changes that happen over time are a result of prevention efforts or simply the result of chance. If a population is large, we can be more certain that changes in suicide rates are meaningful (assuming that broader contextual factors, such as policy-based changes or demographic shifts, have been accounted for), since big data sets with large populations are less vulnerable to chance fluctuation. In a smaller data set, suicide rates are more likely to go up and down randomly, so a drop in the number of suicides from one year to the next may not indicate a real change, and rates may go up again the following year. If we make major changes to our prevention efforts because of a chance fluctuation in a small population, we will be constantly shifting our prevention plans, when in fact these changes are likely random and not connected to the success or failure of our efforts.

Since youth-serving state systems generally have small populations and few deaths by suicide, suicide data from these systems in small or mid-sized states may be too small to analyze for meaningful change, particularly over a short term of three to five years. For this reason, we should use caution in interpreting changes in youth suicide data from juvenile justice, child welfare, or public behavioral health systems. A skilled evaluator or epidemiologist should be an integral part of any project team, as they can help look for chance fluctuations and advise program staff on interpreting data sets for small populations.

### Additional Challenges Related to This Issue

**Short(ish) time period for the GLS grant:** When you have a small number of events, one way to look for meaningful change over time is by combining a few years of data to produce a larger number. For example, if a state system has four suicides each year for three years, and five suicides each year for the next two years, all five years of data could be combined to produce 22 suicides in a five-year period. This increases the size of the numbers to be analyzed, which helps to filter out possible random fluctuations. We could then analyze changes over time by continuing to look at five-year increments. But because the GLS grant is not that long (i.e., five-year maximum, unless grantees are awarded back-to-back funding), combining years may not be feasible if we want to show change over time resulting from our efforts.

**Presence of extreme observations:** Suicide clusters sometimes occur among youth engaged in youth-serving state systems, and these can cause inflations, or “blips,” that do not indicate an ongoing trend. These types of “extreme observations” can have a big impact on small numbers and distort the analysis of potential trends.

**The impact of broader, contextual factors:** In juvenile justice, child welfare, and public behavioral health systems, youth frequently cycle into and out of the system. The populations each system serves can also change with funding, policy changes, and political agendas. This means that the number and demographics of individuals served in any system may vary from year to year, as different policies are implemented. Population changes can have a particularly large impact when looking at a relatively rare event, such as suicide, over time. For example, if a system begins serving more youth who live in

poverty or providing more service to youth who were previously unable to access service, the population served changes in a non-random way. If the overall size of the population served grows, particularly when it expands to include more youth at greater risk, a relatively rare event, such as suicide, may grow as well.

For a more concrete example, imagine that a public behavioral health system receives increased funding one year to serve more at-risk individuals. Because the system would be serving more at-risk youth, suicide rates might go up. Looking at these increasing rates without understanding the broader context might lead us to conclude that our suicide prevention efforts are not working. In reality, the changing population may have had more to do with the changing rates.

Statistical methods can help adjust for changes in basic demographics (e.g., race or income), but it is harder to accommodate the impact of policy-based change.

**Confidentiality/Anonymity:** When a system has only a small number of events or a small overall population, release of data can lead to unintentional personal identifiers. For example, suppose a rural area had only one youth residing in the state's detention system, and that youth attempted suicide. Release of geographic indicators with suicide attempt data would allow others to easily identify that youth. This would mean a serious, if unintentional, violation of that youth's privacy.



## Recommendations for State GLS Grantees on Analyzing Small Numbers

### 5.1. Consider the following alternatives when analyzing youth system data involving either a small population or few suicides:

- a. Use alternative measures for planning, quality improvement, motivating stakeholders, and impact purposes. This can include data on suicidal ideation, suicide attempts, or risk factors for suicide. Consider conducting a smaller-scale, pre-/post-test evaluation with a random sample of prevention participants and an equivalent control group to determine impact. Self-constructed evaluation measures have many benefits, including more precise, relevant outcome measures. Talk to your evaluator to explore this option.
- b. If appropriate, combine data points over time (e.g., 2–3 years) to increase the number of suicide-related events and the size of the population.<sup>8</sup>
- c. In data presentations and materials, acknowledge the possible influence of random fluctuations by showing confidence intervals.
- d. Use data from a single point in time to motivate change and engage new partners and influencers. This kind of data can also inform quality improvement efforts within the system, especially when triangulated with other information (such as key informant interviews). Data from a single point in time can provide critical information about gaps in a system or point to fairly easy procedural changes that can prevent similar incidents, especially when these changes can be easily added into existing GLS work with partner systems.

<sup>8</sup> If combining years, be sure that the data collection and the population were generally similar over time. For example, if a juvenile justice system changed its definition of suicide attempt over time, or if it had a significant policy change that impacted the number or type of youth involved in the system during the time period to be analyzed, combining data across several years may not be appropriate.

- e. When looking at raw numbers for planning purposes, remember that raw numbers are likely to be higher in larger communities simply because the overall size of the population is bigger. Rates, in contrast, account for the size of the community. Adjusted rates account for the size of the community and for other confounding factors, such as age. Consult with your epidemiologist or evaluator on how to convert data into a meaningful measure that can allow you to compare suicidal behaviors in your community with other communities or states.
- f. Limit further “drilling down” of the data to discourage the creation of even smaller sample sizes (e.g., examining youth-serving state system data by geographic or demographic factors). This will also help to preserve confidentiality.

**RESOURCES:**

- **North Carolina Department of Health and Human Services Statistical Primer: Problem with Rates Based on Small Numbers** (p. 1). A statistical primer on random error and why small numbers create analysis challenges:
  - » [http://www.schs.state.nc.us/schs/pdf/primer12\\_2.pdf](http://www.schs.state.nc.us/schs/pdf/primer12_2.pdf)
- **National Association of Health Data Organizations Statistical Approaches for Small Numbers: Addressing Reliability and Disclosure Risk**. Addresses guidelines established by the CDC in using and releasing public health data on a small number of events and/or a small population, particularly through Web-based dissemination systems:
  - » [https://www.nahdo.org/sites/nahdo.org/files/Data\\_Release\\_Guidelines.pdf](https://www.nahdo.org/sites/nahdo.org/files/Data_Release_Guidelines.pdf)
- **Utah Department of Health Data Suppression Decision Rules Work Group: Report of Guidelines for Data Result Suppression from October 5, 2009**. Sample guidelines from a single state on considerations for working with a small number of events and/or a small population:
  - » <http://health.utah.gov/opha/IBIShelp/DataSuppression.pdf>
- **Interpreting Suicide Data: Special Considerations for Small Populations (SPRC Resource Sheet)**. Other policies and practices for protecting confidentiality with small  $n$ 's; addresses interpretation of suicide-related data when working with a small number of events and/or a small population:
  - » <http://www.sprc.org/sites/default/files/migrate/library/Interpreting%20Suicide%20Data%20Special%20Considerations%20for%20Small%20Populations.pdf>

**5.2. Remember that data on suicide attempts, even when  $n$ 's are small, can be useful for quality improvement purposes.**

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**RESOURCES:**

- **Zero Suicide Toolkit**. Introduces a comprehensive, data-driven, quality improvement approach to addressing suicide care:
  - » <http://zerosuicide.sprc.org/toolkit>

› **Zero Suicide Data Elements Worksheet.** Provides a list of data elements to consider, including outcomes measures:

» <http://zerosuicide.sprc.org/resources/zero-suicide-data-elements-worksheet>



## FROM THE FIELD

### Rhode Island's Story on Augmenting Existing Data with Alternative Data Sources

Given its small geographic size and population, Rhode Island is familiar with system surveillance challenges stemming from small numbers. However, smaller state systems can use non-traditional partnerships and non-traditional measures to work towards demonstrating impact. According to Jeffery Hill, program manager for the Violence and Injury Prevention Program in the Rhode Island Department of Health and project director for the Rhode Island GLS project, Rhode Island's small size has facilitated the formation of new partnerships and allowed for the use of different data sources—including judiciary court databases—to triangulate and augment information gathered from more traditional sources (e.g., NVDRS and Child Death Review Team, or CDRT). The state also has plans to further augment its traditional suicide surveillance records (i.e., vital records) through a new school-based partnership and utilizing EMS ambulance run form data. Rhode Island's GLS program, the Rhode Island Youth Suicide Prevention Project, is a multi-component triage system focused on youth and young adults living in identified at-risk geographical areas—cities characterized by high rates of poverty, neglect, homelessness, and family incarceration. Through this program, Rhode Island will be able to collect suicide surveillance data on youth at high risk, including those who may be involved in child welfare and other youth-serving systems, and use data from the Department of Children, Youth, and Families, Child and Adolescent Needs and Strengths assessments for planning purposes. Rhode Island is also working to supplement NVDRS and CDRT data back to 2008 to verify any child welfare or juvenile justice involvement prior to a youth suicide, including those 18–24 years who died during that time whose case would not have been heard by the CDRT, essentially looking back to 2001–2002 for a history of child welfare involvement.

## SECTION 6

### Unique Considerations for Juvenile Justice, Child Welfare, and Public Behavioral Health Systems



**BARRIER (SPECIFIC TO JUVENILE JUSTICE AND CHILD WELFARE SYSTEMS):** These systems with their diverse subdivisions often have discrepancies in the quality and availability of existing data.

**Background on Barrier:** The juvenile justice system is composed of different parts, sometimes under different jurisdictions (e.g., a municipal drug court, a county jail, and state-run prison system). The child welfare system is sometimes similarly fragmented into different divisions—such as investigation units or family services units. Such fragmentation can create differences in the availability and quality of existing suicide-related data (e.g., a county jail may collect suicide-related data differently from the state’s probation system), making in-system data comparisons challenging and limiting how the combined data might be used for planning or impact purposes in these youth-serving systems



## Recommendations for Suicide Surveillance in Juvenile Justice and Child Welfare Systems

### 6.1. Use key informant data for filling in data gaps. Key informant interviews can have the added benefit of building relationships and identifying solutions.

#### RESOURCES:

- ***Tips for Conducting Key Informant Interviews.*** A resource developed by SAMHSA’s Center for the Application of Prevention Technologies on best practices in conducting key informant interviews:
  - » <https://www.samhsa.gov/capt/tools-learning-resources/conducting-key-informant-interviews>
- ***State and Tribal Evaluator’s Community of Learning: Challenges and Recommendations for Evaluating Suicide Prevention Programs.*** A SPRC-developed resource on challenges and resources for measuring impact of suicide prevention programs (see p. 4, 6, and 15 for the benefits of qualitative data, including key informant interview data from the perspective of GLS evaluators):
  - » <http://www.sprc.org/sites/default/files/resource-program/ChallengesRecommendationsEvaluatingSPPPrograms.pdf>

## 6.2. Understand the many “doors of entry” in the child welfare and juvenile justice systems. Begin improving data infrastructure in the area that is most receptive.

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For example, if the probation system is most receptive to data improvements within the juvenile justice system, start there. If the foster care system is most receptive within the child welfare system, start there.

### RESOURCES:

- ***Child Welfare Information Gateway: How the Child Welfare System Works.*** Includes an appendix with a flow chart following a referral through the child welfare system:
  - » <https://www.childwelfare.gov/pubpdfs/cpswork.pdf>
- ***Office of Juvenile Justice and Delinquency Prevention (OJJDP): Juvenile Justice System Structure and Process.*** Presents a flow chart diagramming the stages of delinquency case processing in the juvenile justice system:
  - » [http://www.ojjdp.gov/ojstatbb/structure\\_process/case.html](http://www.ojjdp.gov/ojstatbb/structure_process/case.html)

## 6.3. Work with your state’s child welfare administrator to see whether, when, and how suicide-related surveillance might be added into existing systems to improve data collection.

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There are many federally required and voluntary national data sources for information on children involved in state child welfare systems, and some of these might allow suicide-related data points to be added relatively easily. These include the State Automated Child Welfare Information System (SACWIS; a state-managed, federally supported database for managing foster care and adoption cases) and the National Youth in Transition Database (NYTD; a federally required, national data set that captures information, services, and outcomes for youth transitioning out of the child welfare system).

### RESOURCES:

- ***Introduction to Cross-System Data Sources in Child Welfare, Alcohol and Other Drug Services, and Courts.*** A SAMHSA-produced resource highlighting available data sources in child welfare, alcohol and drug treatment and prevention services, and juvenile courts:
  - » <http://store.samhsa.gov/shin/content/SMA11-4630/SMA11-4360.pdf>

**BARRIER (SPECIFIC TO PUBLIC BEHAVIORAL HEALTH SYSTEMS):** The usefulness of public behavioral health data for measuring impact depends on where prevention efforts are directed and on the structure of the overall system.

**Background on Barrier:** For some GLS grantees, prevention work in the public behavioral health system is focused in a single county or small geographic area, making systemwide data inappropriate for assessing impact. In these cases, it may be difficult to disaggregate data to the county-level, and even when that is possible, small numbers of events and populations remain an issue, particularly when the data are narrowed further to focus solely on youth.

Complicated coding systems used in public behavioral health systems may require extensive GLS in-house capacity building to understand which data to ask for and/or to receive shared data.

Recent successes in suicide-related surveillance data sharing between public behavioral health and suicide prevention systems are documented in *SPRC's Surveillance Success Stories* (See Section 6.5, "Resources"), some of which highlight public behavioral health systems that have partnered with state suicide prevention leadership to collect and use suicide-related data. These success stories, although focused mainly on adults or full lifespan data, present many lessons learned that may be applied to youth suicide surveillance challenges in public behavioral health.



## Recommendations and Resources in Suicide Surveillance in Public Behavioral Health

### 6.4. Gain familiarity with the coding system used in public behavioral health systems.

#### RESOURCES:

- **National Center for Health Statistics International Classification of Diseases, Tenth Revision, Clinical Modification (ICD-10-CM).** This site 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>

### 6.5. Network with other states that have demonstrated success in suicide surveillance in public behavioral health systems.

#### RESOURCES:

- **Suicide Prevention Resource Center: Surveillance Success Stories.** These stories detail how states and/or counties have partnered with public behavioral health systems to collect and use suicide-related data:
  - » Kentucky: <http://www.sprc.org/resources-programs/surveillance-success-stories-kentucky>
  - » Ohio: <http://www.sprc.org/news/ohio-surveillance-success-story>
  - » Vermont: <http://www.sprc.org/news/vermont-surveillance-success-story>
  - » Montana: <http://www.sprc.org/resources-programs/surveillance-success-stories-montana>
  - » Texas: <http://www.sprc.org/news/surveillance-success-stories-%E2%80%93-texas-denton-tarrant-counties>

### 6.6. Use existing international resources to guide surveillance development.

#### RESOURCES:

- **World Health Organization: Practice Manual for Establishing and Maintaining Surveillance Systems for Suicide Attempts and Self-Harm.** A tool for the design and implementation of a public health surveillance system to support long-term monitoring of information related to attempted suicide and self-harm in health systems:
  - » [http://www.who.int/mental\\_health/suicide-prevention/attempts\\_surveillance\\_systems/en/](http://www.who.int/mental_health/suicide-prevention/attempts_surveillance_systems/en/)



#### FROM THE FIELD

### Utah's Story of Comprehensive State System Engagement in Suicide Surveillance

In 1996, Utah's Department of Health (DOH) allocated approximately \$300,000 of additional funding to suicide prevention. After consulting with top suicidologists, Dr. Doug Gray, professor and vice-chair for education and training in the Department of Psychiatry at the University of Utah School of Medicine, opted to pilot a data-informed approach to prevention programming. With DOH at the helm and a galvanized base of public support, state systems were primed to engage in a cross-agency data-sharing effort to identify youth at highest risk for suicide. Equipped with death certificates for 151 consecutive youth suicides (ages 13–21) from 1996–1999 and access to a centralized database from the Office of the Medical Examiner (including toxicology screens, demographics, and cause of death/method), Dr. Gray's team sought to determine where decedents had contact with state systems prior to their deaths. Engaged systems included the following:

- a. The juvenile justice system, offering access to a number of referrals and type of offense(s) for decedents
- b. State psychiatric hospitals and public behavioral health systems (3 counties only), offering information on lifetime system engagement for decedents
- c. Department of Education (through the board of superintendents), offering access to school records for decedents
- d. Child Protective Services, who were able to crosswalk their records with social security numbers of known decedents to affirm system involvement

Of the 151 consecutive youth suicides investigated, 65 percent had interacted with the juvenile justice system at some point in their lifetime. Most of these were engaged in juvenile justice through the probation system only. The research team published the finding that having four to six referrals to the court increased suicide risk three-fold, and seven or more referrals increased risk of completed suicide five-fold. Dr. Gray and his team used this information to advocate for a targeted prevention approach, by designing a screening program for the Utah juvenile courts and a unique program to treat juvenile offenders with mental illness who were living at home. This program consisted of the following, all offered free of charge:

1. In-home behavioral services (parent training model)
2. Psychiatric evaluation and treatment
3. Case management
4. Web-based continuous evaluation of treatment (the Youth Outcomes Questionnaire)

Compared with matched controls, this program reduced the number and severity of offenses, improved the youths' mental health, and saved money. The financial savings was largely due to members of the control group ("community treatment as usual") ending up in residential placements. At that point, the Utah research team was able to secure a SAMHSA grant to provide services to a wider group of adolescents with mental illness who were on probation. The team published the results in *Psychiatric Services*.

For more information:

- Gray, 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), p. 427–434.
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- Moskos, M. A., Olson, L., Halbern, S. R., & Gray, D. (2007). Utah suicide study: Barriers to mental health treatment for adolescents. *Suicide and Life-Threatening Behavior, 37*(2), p. 179–186.

## Conclusion

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Obtaining suicide-related surveillance data from systems that serve youth at higher suicide risk—including juvenile justice, child welfare, and public behavioral health systems—can allow for enhanced prevention planning, new momentum to engage partners and leadership, data-informed decision making, directed quality improvement, and, in some cases, assessment of impact. This document introduces resources and opportunities for GLS grantees on accessing and using suicide-related surveillance data from these youth-serving state systems. While there are many challenges involved in working with and obtaining surveillance data from these systems, SPRC continues to be available to GLS grantees interested in moving forward with the recommendations from this report.

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## Appendix I: Worksheets on Starting and Continuing Dialogue on Data Sharing in Youth-Serving Systems

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*The following worksheets were designed to help State Garrett Lee Smith (GLS) grantees start or continue a dialogue on accessing and/or using suicide-related data from youth-serving state systems.*

**Download these in writeable format at** <http://www.sprc.org/resources-programs/breaking-down-barriers-using-youth-suicide-related-surveillance-data-state>.



## WORKSHEET 1: Before Connecting with Partner Agencies to Explore Data-Sharing Possibilities

1. Assess your current relationship with the identified partner.
  - a. Do you have an existing relationship? What existing linkages already exist?
  
  
  
  
  
  
  
  
  
  
  - b. Which stakeholders/agency leaders from that state system need to be brought on board to generate approval for data sharing? Which stakeholders/agency leaders can facilitate data-sharing agreements (e.g., are there in-system champions, agency personnel with connections to the suicide field)? How can they be brought on board?
  
2. Develop a clear vision of your data-related needs.
  - a. What kind of suicide-related data would you be looking to receive (e.g., deaths, attempts, ideation)?
  
  
  
  
  
  
  
  
  
  
  - b. How would you like to use the information (e.g., for planning, quality improvement, impact)?
  
3. Assess your capacity to handle incoming data.
  - a. What is your existing capacity for accessing, analyzing, and using the data? Where are your gaps? How can these gaps be filled?

4. Describe the benefits of data sharing for you and for the partner agency. Consider the following:

a. Economic benefits

b. Programmatic benefits

c. Benefits to leadership

d. Benefits to staff

e. Benefits to individuals being served



g. How has the partner used the data for planning? How has the partner used the data to show impact? To whom has the partner communicated its results, and in what format?

2. Assess whether it is possible for you to use the data for your identified purpose.

h. Are there enough deaths by suicide (or attempts) to be able to use the data for your purposes? In systems with few suicide deaths or attempts, for example, it might not be possible to use the data for impact. (See Section 5: Analyzing Small Numbers, p. 21–25). If the number of suicide deaths or attempts is too small impact, what other data might be available?

3. Assess barriers to data sharing for your partners.

a. What is the estimated cost of establishing and sustaining a data-sharing system between the partner system and the suicide prevention system?

b. What challenges exist between the partner system and the suicide prevention system in protecting the confidentiality of youth in data sharing?

c. What technical challenges might exist in sharing this data (e.g., difficulties matching identifiers)?



f. Are there conditions about dissemination? For example, is there a specific citation that should be used when the data are used in a report?

g. What are the financial costs of data sharing, and who will be responsible for the expenses?

h. How often does the agreement need to be renewed? What is the amendment process?



## Appendix II: Additional Resources

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### Resources for Strategic Planning

- **Effective Prevention Model.** Developed by the Suicide Prevention Resource Center (SPRC), this online resource features models and guidance on current knowledge of suicide prevention.
  - » <http://www.sprc.org/effective-suicide-prevention>
- **A Strategic Planning Approach to Suicide Prevention.** Developed by SPRC, this online course is designed to illustrate a strategic planning approach that incorporates evaluation planning.
  - » <http://training.sprc.org/enrol/index.php?id=7>

### Resources for Understanding Available Data

- **Locating and Understanding Data for Suicide Prevention.** Developed by SPRC, this online course presents accessible sources of data to help states and communities understand the extent of suicide-related behaviors in their localities.
  - » <http://training.sprc.org/enrol/index.php?id=2>
- **Wide-ranging ONline Data for Epidemiological Research (WONDER).** This online query system is for county-level public health data on underlying cause of death. It uses a wide range of data sources and can be analyzed at the county level.
  - » <https://wonder.cdc.gov/>
- **Web-based Injury Statistics Query and Reporting System (WISQARS):** This online query system is for regional-level public health data on underlying causes of death.
  - » <https://www.cdc.gov/injury/wisqars/index.html>
- **Youth Risk Behavior Surveillance System (YRBSS) or equivalent state youth health behavior survey.** Designed to monitor the health-risk behaviors that contribute toward death among youth and young adults, the YRBSS is administered in schools bi-annually. Although this survey will not capture institutionalized populations, it is useful for providing broader context.
  - » <https://www.cdc.gov/healthyyouth/data/yrebs/>

### Resources for Evaluation Research

- **RAND Suicide Prevention Evaluation Toolkit.** Developed by RAND, this toolkit is designed to help program staff understand how to evaluate and plan for improvements to their programs.
  - » <http://www.sprc.org/resources-programs/rand-suicide-prevention-evaluation-toolkit>
- **Getting to Outcomes 2004 (Chapter 1).** This e-book was designed to help hone prevention practitioner skills in using data to plan, implement, and evaluate their own programs. Chapter 1 focuses on using data to conduct a needs assessment (archival, suicide-surveillance system-level data are part of this analysis).
  - » [http://www.rand.org/pubs/technical\\_reports/TR101.html](http://www.rand.org/pubs/technical_reports/TR101.html)

### Resources for Dissemination Planning

- **Strategic Communication Planning: A Workbook for Garrett Lee Smith Memorial Act State, Tribal, and Campus**

**Grantees.** This manual uses the 8-Step Communication Planning Model to provide a blueprint for site-specific, actionable communication plans.

» <http://www.sprc.org/resources-programs/strategic-communication-planning-workbook-garrett-lee-smith-memorial-act-state>

➤ **Agency for Healthcare Research and Quality (AHRQ) Dissemination Planning Tool.** Developed to help researchers design an appropriate dissemination plan, this resource includes components of a dissemination plan, along with tips on identifying end users, selecting messages, identifying dissemination partners, and developing a strategy for identifying “next steps” post-dissemination.

» <https://www.ahrq.gov/professionals/quality-patient-safety/patient-safety-resources/resources/advances-in-patient-safety/vol4/planningtool.html>

### Resources for Data Visualization

➤ **Tableau Public.** A free tool that helps turn data files into interactive data visualizations

» <https://public.tableau.com/s/>

➤ **ChartBlocks.** A free online tool for designing charts

» <http://www.chartblocks.com/en/>

➤ **Piktochart.** A free online tool for developing infographics

» <https://piktochart.com/>

➤ **Noun Project.** Offers free icons that can be used in infographics

» <https://thenounproject.com/>

