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Guidance on Using Syndromic Surveillance for Adverse Childhood Experiences

Guidance on Using Syndromic Surveillance for Adverse Childhood Experiences (ACEs)

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Overview

This guidance focuses on potential uses and known limitations of utilizing syndromic surveillance (SyS) data to identify or characterize trends in Adverse Childhood Experiences (ACEs). It will review the background for current public health interest in ACEs, point to resources on how ACEs could be defined using SyS data, and describe potential limitations. Additionally, it will offer recommended best practices for maximizing the utility of SyS data on ACEs by state, territorial, local, and tribal (STLT) public health practitioners.

Background

In 1998, a landmark study established the first link between self-reported history of childhood experiences of abuse, family violence, and household instability (Adverse Childhood Experiences, or ACEs), and current health conditions among a survey of adult health maintenance organization (HMO) members (Felitti, Anda, Nordenberg, et al.). Since that publication, public health interest in understanding how childhood experiences influence health across the lifespan has continued to grow.

Currently, the Centers for Disease Control and Prevention (CDC) identifies ACEs prevention as one of three priority focus areas for the National Center for Injury Prevention and Control (NCIPC) (https://www.cdc.gov/injury/priorities/index.html). With new funding being directed to state, territorial, local, and tribal (STLT) jurisdictions to address ACEs at the population level, there is increased interest in using SyS data systems to better understand and respond to local trends in ACEs. While these data systems have the advantage of real time reporting, jurisdictions must carefully weigh which types of ACEs can be reliably tracked in SyS data to leverage this critical data source to support population health.

Defining ACEs

In the original ACEs study, Felitti et al. developed a questionnaire to document recalled instances of ACEs among adults. This questionnaire contained items capturing prior experiences of psychological, physical, or sexual abuse, as well as exposure to household mental health issues, substance abuse, divorce, incarceration of a family member, or witnessing violence against their mother (or stepmother) during childhood. The second wave of the ACEs study incorporated measures of physical and emotional neglect, as well. Current literature recognizes these 10 “core” ACEs, but also other household and community characteristics and experiences that can contribute to poor long-term health outcomes in similar ways. These supplemental characteristics have been operationalized in other ACEs inventories and include childhood experiences such as bullying, witnessing violence outside the home, living in foster care, neighborhood safety, and experiencing discrimination (https://www.philadelphiaaces.org/philadelphia-ace-survey).

Other research has also established that multiple types of violence victimization share underlying protective and risk factors, and that experiencing a single episode of violence victimization raises the risk for experiencing other episodes later (Wilkins, Tsao & Hertz, 2014). While the types of adverse experiences generally included in ACEs inventories do align with focus areas most closely associated with STLT injury and violence prevention programs, the ACEs model is likely of interest to a broader set of internal and external partners, as ACEs themselves are associated with greater likelihood of developing chronic diseases, substance abuse, and mental health conditions. SyS epidemiologists may therefore connect with several internal agency programs interested in working towards prevention and mitigation of ACEs and should be familiar with recommended best practices for using SyS data for ACEs work, as well as potential limitations.

Before considering how to use SyS for ACEs work, it is helpful to think through the mechanism by which responding to ACEs could potentially influence health outcomes. ACEs are experiences in childhood strongly associated with future health impacts in later years. Therefore, STLT programs can work to mitigate ACEs and associated health impacts through the following aims:

1. Prevent ACEs before they begin,
2. Respond to ACEs after they have occurred to provide treatment, care, and community resources that prevent or mitigate future health impacts, or
3. Identify communities with higher risk for (or levels of) ACEs and work at the community level to build resilience and reduce likelihood of future ACEs.

These above considerations are not a complete list of potential ways to address ACEs, but they can help as you assess how ACEs data from SyS could improve public health in your jurisdiction.

Potential Limitations of SyS Data for ACEs

The original studies of ACEs relied on survey instruments that solicited recalled experiences from adults about adverse experiences during childhood. In contrast, SyS data most often come from emergency department (ED) and urgent care (UC) episodes and capture free text from chief complaints reported by patients seeking care, as well as triage notes or narratives, and discharge diagnoses coded in International Classification of Diseases, Tenth Revision, Clinical Modification (ICD 10-CM). These are quite different ways of assessing ACEs, and this should be considered when determining the best use of SyS data to track trends in ACEs or associated health outcomes.

SyS data will not be able to isolate current medical care episodes among adults with past childhood exposure to ACEs. Furthermore, even confirmed experiences of one or more ACEs in children during a medical care episode in SyS data do not necessarily guarantee that child will go on to experience poor adult health outcomes. These two points highlight that the original ACEs model is one that associates childhood experiences with health outcomes across the lifespan. While SyS data is well-suited for rapid point-in-time estimates of emerging trends, it does not track individuals across care episodes or even shorter timespans.

Furthermore, as noted in the section of this guide focusing on Injuries and Violence, it is often not possible to definitively know who perpetrated a violent event from clinical ED or UC data, as ICD 10-CM codes for perpetrator type are not often used, perpetrator type may not be known or disclosed at time care is sought, and stigma may prevent a full description of the circumstances of the event.

We note that some ACEs data elements are not available in SyS data at all. For example, information about history of divorce or family violence directed at others in the home, as well as school bullying, discrimination, or witnessing violent events in the community, are not detectable in SyS data. As many ACEs relate to being a witness or victim of violence in a community, neighborhood, or household, you may benefit from consulting the related Injuries and Violence section the linked resources provided there.

Recommendations for Utilizing SyS for ACEs

STLT public health agencies can greatly benefit from access to rapid data from SyS. This data can rapidly identify trends in ED and UC episodes that reflect community trends in events consistent with ACEs, such as child abuse, intimate partner violence, and violence victimization in the community, which may allow jurisdictions to estimate communities and subpopulations most at risk and more effectively design interventions. SyS data can also identify communities and subpopulations experiencing increasing trends in the types of poor adult health outcomes ACEs are linked to, such as suicide, chronic disease, substance abuse, and mental health conditions. Additionally, SyS data can identify patterns in care episodes for some types of abuse or violent victimization among children in near-real time, permitting better coordination of community rapid response and services to mitigate long term harm.

It is important to note that SyS is not best suited to monitor all ACEs indicators directly; some ACEs indicators are best utilized as proxies for household or community burden. When using SyS in ED visits involving children, ACEs indicators like child abuse and neglect or homelessness can be directly ascertained. Indirectly, rapid data from SyS measuring conditions affecting adults (e.g., substance use, intimate partner violence) serve as a proxy for household or community challenges that constitute ACEs.

Recommendations for making use of SyS for ACEs work include:

- **Incorporating SyS data on ACEs when speed is essential:** Leverage SyS data when timeliness matters more than precision. This can be particularly useful for detecting sudden trends or spikes in ACEs-related episodes. For example SyS data could be used to examine the impact of a major economic stressor in a community, such as a factory closing.
- **Leveraging expanded SyS data sources:** As data types within SyS expand, explore new ways to document community levels of ACEs. For example, some jurisdictions now have access to provisional death records in their SyS data flows. This could allow rapid detection of fatal violent events potentially increasing community risk of ACEs, strengthening response capacity to intervene afterwards and prevent future ACEs and associated long term health outcomes.
- **Using SyS when other data sources are unavailable:** In jurisdictions without centralized ED discharge data registries or other reliable data sources, SyS data may be the only method for examining trends in ACEs-related episodes. Considering most surveys are aggregated to the county level and above, SyS can provide invaluable data at the geographic level at smaller zip code tabulation areas (ZCTA)/zip levels.
- **Triangulating to better define ACEs across available data sources:** Since SyS data do not fully describe risk for ACEs or history of ACEs among individuals, using SyS data with other sources that do, such as population health surveys, reports from local social services entities, and data from school systems or community resources that track childhood experiences or otherwise offer family services, can allow for a more complex look at ACEs that benefits from the speed of SyS data while strengthening community needs assessments with a wider range of ACEs data.
- **Complementing SyS data with other public health data systems:** Use SyS data to better understand local trends identified in more established public health data systems, such as death certificates, inpatient discharge databases, or school health surveys.
- **Considering internal and external partner capacity to act on findings:** When planning ACEs data analysis, focus on actionable insights rather than generating "data for data's sake." This may mean working to develop strong external partnerships before publishing SyS data on ACEs. It may also mean working internally to support science and prevention staff skill development in data communication if your jurisdiction does not already use SyS data regularly in its work.

NSSP Adverse Childhood Experiences Dashboard Best Practices

The NSSP publication on best practices for utilizing the SyS ACEs dashboard (https://knowledgerepository.syndromicsurveillance.org/adverse-childhood-experiences-dashboard-best-practices) also contains critical insights about using SyS data for ACEs that could inform your jurisdiction's efforts. It may serve as an excellent resource guide as your agency works to develop ACEs queries in SyS data.

Additional ACEs Resources

- https://www.philadelphiaaces.org/philadelphia-ace-survey
- https://www.cdc.gov/aces/about/index.html
- https://www.cdc.gov/violence-prevention/media/pdf/resources-for-action/ACEs-Prevention-Resource_508.pdf

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Authorship Attribution

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