Pennsylvania
Department of Health

Overview of Pennsylvania Child Death Review Program Evaluation

Background
The Child Death Review (CDR) model in Pennsylvania is a county-based model, whereby multidisciplinary local teams meet to review the circumstances surrounding the deaths of all children aged 21 years and younger for all manners and causes of death. The purpose of the reviews is to identify risk factors and underlying causes of deaths and to develop strategies to prevent future deaths and injuries of children. The Public Health Child Death Review Act (Act 87 of 2008) formally established the program that had begun as a grassroot effort in the early 1990s. Act 87 names the Department of Health (DOH) as the facilitator of the state and local CDR teams providing training and technical assistance for local CDR teams. The CDR program is dependent on local CDR teams gathering information about childrens' deaths, meeting to review deaths, entering data into the National Center for Fatality Review and Prevention's Case Reporting System (NFR-CRS), and making prevention recommendations.

Local CDR teams are reviewing approximately 50% of all child deaths and this percentage continues to decline. More than half of the local CDR teams in Pennsylvania are not achieving the requirements of Act 87 of 2008 because they are not meeting or are meeting and not entering data into the NFR-CRS. Many of the teams that are meeting and entering data struggle to maintain team members, gather sufficient information for the review, and share findings to inform prevention activities. Due to these concerns, the DOH engaged East Stroudsburg University (ESU) to conduct an external evaluation to assess CDR program functioning and quality of the data housed in the NFR-CRS and develop a recommendations plan to bolster program and data quality.

Methodology
ESU's evaluation of Pennsylvania's CDR process was conducted between August 2022 and June 2024. A mixed methods evaluation framework was used including focus groups, meeting observations, survey of select CDR stakeholders, review of state and national secondary data, review of functioning of other states' programs, and mapping for data visualization of partner resources for local teams. ESU summarized their findings in a report and made recommendations for improvement based on the totality of the information collected.

Key Findings
ESU's report identified the following strengths:

- Pennsylvania CDR data quality is comparable to national data in most demographic areas.
- Per feedback from local CDR chairs, the programmatic leadership within DOH for Pennsylvania CDR is valued.
- Counties with access to a local health department are more likely to participate in CDR.

ESU's report identified the following gaps:

- CDR is an unfunded mandate for counties in Pennsylvania and as such, dedicated funds are not available to support the work of the local or state teams.
- The ability to utilize findings from the child death review teams to prevent future incidents is challenged by limited data beyond the presence or absence of a fatal event regarding factors associated with the deaths that could inform prevention efforts.
- Teams struggle to obtain adequate information for the review. Medical records are often not received timely when requested. Additionally, teams with limited staffing capacity and

those without coroner and law enforcement support are more likely to lack data regarding autopsy, death scene investigation, and place of incident.
- Resources are inconsistent across counties to support the work of their teams. Larger counties and counties with a county or municipal health department typically have more resources and infrastructure to develop and maintain a CDR team.
- While the statute does require that certain agencies are represented at reviews, team chairs and members are largely volunteers and team participation is not part of their regular duties.
- Teams consistently identified data entry as a burden. Teams approach data entry in different ways. However, differences in data entry processes between teams may contribute to larger systematic differences in consistency of CDR data across Pennsylvania.

Recommendations
ESU's report included the following recommendations:

<u>Statutory enhancements</u>
- Revise the list of required CDR team members to include schools and underrepresented community groups. School participation is frequently diminished due to concerns of violating the Family Educational Rights and Privacy Act.
- Require review of deaths among those age 0-18, rather than through age 21.
- Redefine the role of the State CDR team to include a primary focus on prevention.

<u>Programmatic enhancements</u>
- Support local team chairs in onboarding and retaining members.
- Formalize onboarding process for team members and chairs.
- Create checklists for reviews and meeting preparation.
- Establish strategic collaborations with data scientists from local universities, hospitals, or community entities to facilitate data-related elements such as data entry and analysis of CDR data.
- Implement regional CDR teams to meet the obligations of Act 87 of 2008.
- Increase distribution of CDR findings to local agencies and interested parties by establishing and maintaining a robust data dashboard with summaries of NFR-CRS data summaries and information about ongoing prevention efforts.
- Ensure ongoing training for CDR members within the local and state teams to enhance data quality and prevention recommendations.
- Increase emphasis on sharing of findings and monitoring implemented recommendations by allocating resources for CDR-guided prevention activities. A few teams review their findings and recommendations on a regular basis. As local team resources become stretched, this activity is frequently set aside.

The recommendations in the final report will help local CDR teams expand functionality, meet responsibilities as outlined in Act 87 of 2008 and improve data quality. The DOH, in consultation with the local and State CDR teams, will prioritize elements of the final report for implementation. Additionally, the CDR program has been inadequately resourced since its inception. To make meaningful enhancements, additional resources will be needed. The DOH will be seeking funding to fully support the program in fulfilling its statutory purpose of reducing child deaths in Pennsylvania.