Legislative Budget and Finance Committee

A Report on the Pennsylvania CARE Act Impact on Patient Outcomes

Report Comments by Jason R. Brehouse, Esq., Project Manager
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Good morning. My name is Jason R. Brehouse, Esq. (Project Manager) and it is a pleasure to be here today with the members of the Legislative Budget and Finance Committee to discuss our report on the Pennsylvania CARE Act Impact on Patient Outcomes. With me today are committee staff persons, Anne Witkonis (Analyst) and Amy Hockenberry (Analyst) who were both instrumental in helping to gather and analyze the data for this report.

Act 2016-20, known as the Caregiver, Advise, Record, and Enable Act (PA CARE Act), directed the committee to conduct a study and issue a report that focuses on the impact of the designation of a lay/family caregiver on certain patient outcomes. The PA CARE Act formalized the process of designating a lay/family caregiver by requiring Pennsylvania hospitals to provide inpatients with an opportunity to designate a lay/family caregiver to ensure a safe and effective transition to the inpatient's home care environment.

We reviewed and analyzed various reports focused on family caregivers and the development of the PA CARE Act. We communicated with AARP, which developed the model

CARE Act legislation and the Pennsylvania Department of Health (DOH) as the licensing entity for general acute care hospitals in the Commonwealth of Pennsylvania. We also communicated with The Hospital and Healthsystem Association of Pennsylvania (HAP). We surveyed Pennsylvania hospitals to document the implementation requirements of the PA CARE Act and the impact of such. Both DOH and HAP provided us with assistance in relation to our survey.

We would note that the PA CARE Act did not place any specific duties on DOH, nor did it require Pennsylvania hospitals to collect patient readmission data for purposes of determining the impact of designating a lay/family caregiver. We were unable to ascertain a viable means to contact discharged patients to determine what aftercare was provided by a lay/family caregiver and the impact of such, including on readmissions.

Pennsylvania is among the majority of states that enacted some version of the AARP model CARE Act legislation, which generally requires hospitals to do the following:

- ADVISE individuals of their opportunity to identify a caregiver.
- RECORD the caregiver's name and contact information.
- ENABLE caregivers by providing adequate discharge notice, consulting about discharge plans, and instruction about home medical tasks.

AARP assembled a research team that looked at how hospitals responded to the enactment of the CARE Act in 11 states, what changes had been made in practice, and the impact of those changes. Pennsylvania was not one of the states. The research team grouped its findings into 10 major themes, which indicate the CARE Act is helping hospitals identify family caregivers and prepare them to provide successful post-discharge care in the patient's home to avoid complications that may result in preventable hospital readmissions.

A 2017 metaanalysis reflecting the work of a partnership between the University of Pittsburgh Health Policy Institute and the University Center for Social and Urban Research concluded that for older adults, discharge planning interventions were associated with 25 percent fewer hospital or skilled nursing facility readmissions at 90-days. This metaanalysis further notes the potential effect of incorporating informal caregivers into discharge planning could be significant given potentially preventable 30-day readmissions have been estimated to cost $12 billion annually in Medicare spending alone.

We also reviewed an internal multisite case study of the University of Pittsburgh Medical Center (UPMC) health system that was designed to explore early implementation of the PA CARE Act. Three UPMC hospitals of different sizes and populations, a rural 49-bed hospital, a suburban 437-bed hospital, and an urban 489-bed hospital, were reviewed

from July to December 2017 shortly after the PA CARE Act went into effect. This study concluded UPMC had implemented the necessary changes to comply with the act and determined that its existing educational process was adequate, and it only needed to modify its existing documentation procedures. It was also noted that previous studies have generally found that the integration of family caregivers into the discharge process yielded positive individual and system level outcomes, while decreasing the odds of post-discharge adverse events. UPMC viewed the PA CARE Act as simply formalizing family caregiver inclusion in the care delivery process. It noted that family members, while not always the designated family caregiver, were present during 100 out of 279 of the education observations and health care professionals engaged the family member 76 percent of the time.

Another study we reviewed, the "Caring for Family: Perceptions of CARE Act Compliance and Implementation" study examined early compliance and implementation of the PA CARE Act as self-reported by a small sample of Pennsylvania hospitals responses to a 2017 online survey that reflected most Pennsylvania hospitals had made changes and continued to work towards operationalizing the required components of the act. More than a third of this study's survey respondents reported at the time that their respective hospitals were still developing processes to comply with the PA CARE Act. The study reported research revealed the systematic inclusion of family caregivers in the hospital

process correlated with reduced rates of rehospitalization of patients. The study also found family caregivers can be a valuable resource during the decision-making process, provide emotional support, and provide assistance with daily activities.

We surveyed Pennsylvania general acute care hospitals to assess the impact of the PA CARE Act and received 30 responses, in relation to 244 hospitals under 192 licenses issued by DOH and found that while they complied with the requirements of the Act, they did not have data available to measure the effectiveness of the act on reducing hospital readmissions. Prior to the act, many Pennsylvania hospitals already had a process in place to designate a caregiver, however, now all respondents indicated they have such a process. In fact, 19 of 29 hospitals indicated that they thought that the PA CARE Act formalized the role of the family caregiver. Most of the respondents, however, did not indicate that a designated caregiver has resulted in a positive change, and none of them have determined if the process has resulted in a decrease in readmissions.

The survey results also showed:

- Eighteen hospitals indicated that they have made changes to their processes to specifically comply with the PA CARE Act, which they otherwise would not have made.

- Twenty-six respondents notify the family caregiver of any discharge orders and when the discharge occurs.
- Twenty-nine hospitals consult with the designated family caregiver prior to a patient's discharge.
- Twenty-eight hospitals both issue a discharge plan describing after care needs at home and provide caregivers with education/training instructions for aftercare tasks.

All the respondents agree that preparation for post-discharge care must take place throughout the hospital stay through a formalized process and 26 of the respondents agreed it is helpful to have a framework to enable consistency in family caregiver preparation.

We would also note that the federal RAISE Family Caregivers Act of 2017 sought to address the diverse and complex issue of the family caregiver through the development of a National Caregiving Strategy, which places both the person receiving support and the

family caregiver at the center of care delivery. The 2021 RAISE Family Caregivers Act Initial Report to Congress stated:

> *Family caregivers are often a critical link to ensuring that the instructions of medical providers are implemented outside of the physician's office or hospital.*

The RAISE Initial Report indicated formal caregiving data collection procedures at the national (and state level) remain lacking. It suggested that better and more consistent data could be collected through the development and inclusion of a core set of family caregiver questions in existing national and state surveys.

In closing, we extend thanks to the various stakeholders that provided guidance and insight regarding our numerous inquiries. In particular, we thank the staffs of AARP, DOH, and HAP for their cooperation and input.