

CHAPTER 166

AN ACT concerning caregiver support services.

BE IT ENACTED by the Senate and General Assembly of the State of New Jersey:

1. The Legislature finds and declares that:
 - a. An estimated 1.75 million people in New Jersey provide varying degrees of unreimbursed care to persons who are elderly or disabled and limited in their daily activities.
 - b. Caregivers are often the immediate family members of the individual being cared for, but may also be friends or community members thereof.
 - c. Although caregivers may assist an individual with the basic activities associated with daily living, including walking, eating, and dressing, they may also be expected to perform more complex daily tasks, such as administering multiple medications, providing wound care, and operating medical equipment.
 - d. The provision of care to persons with cognitive or behavioral health problems or disorders, such as persons with a mental illness, disease, or disability, can be particularly challenging, since cognitive or behavioral health issues may cause the person to resist taking medications or reject assistance with daily activities.
 - e. The act of caregiving can take a serious emotional and physical toll on the caregiver, and caregivers generally experience more physical and mental health complications, higher mortality risks, and suffer from an increased risk of depression, anxiety disorders, diminished immune response, slower wound healing, and a greater incidence of hospitalization than non-caregivers.
 - f. Many caregivers feel that they lack the necessary skill set or institutional support, or both, to perform the various tasks required of them.
 - g. Because of a lack of sufficient caregiver support services, many caregivers either miss work or are forced to quit their jobs in order to effectively provide caregiving services, and a caregiver who provides intense personal care can lose as much as \$659,000 in wages, pensions, and Social Security over the course of their caregiving career.
 - h. By 2020, the number of adults in the State who need assistance with daily living activities is expected to double.
 - i. In order to successfully address the challenges associated with the rising number of persons with significant needs for long-term services and care, and in order to ensure the provision of sufficient institutional and financial supports to the caregiver community that is engaged in the provision of essential home-based care to such persons, it is both reasonable and necessary for the Legislature to establish a caregiver task force to identify, and determine the support service needs of, caregivers in the State, and to develop recommendations for the improvement and expansion of caregiver support service programs and systems.
2.
 - a. There is established the “New Jersey Caregiver Task Force.” The purpose of the task force shall be to determine the availability of caregiver support services in the State, and provide recommendations for the improvement and expansion of such services, in accordance with the provisions of this act.
 - b. The Caregiver Task Force shall consist of 11 members as follows: the Commissioner of Human Services, the State Director of the New Jersey chapter of the AARP or the State Director’s designee, the Executive Director of Caregivers of New Jersey, the Executive Director of the Arc of New Jersey, the Executive Director of the National Alliance on Mental Illness New Jersey, the President of the Home Care and Hospice Association of New Jersey, the President of Leading Age New Jersey, and the President of the Alzheimer’s Association Greater New Jersey Chapter, or their designees; and three public members appointed by the

Governor. The public members shall include one person who is a caregiver for a person with a disability, one person who is a caregiver for a person with mental illness, and one person who is a caregiver for an elderly person. Vacancies in the membership of the task force shall be filled in the same manner provided for the original appointments.

c. The task force shall organize as soon as practicable, but not later than the 30th day following the appointment of its members, and upon its organization, the task force shall elect a chairperson from among its members. The task force may meet and hold hearings at the times and places it may designate, but shall hold at least one hearing in each of the northern, central, and southern regions of the State. The task force may conduct business without a quorum, but may only vote on a recommendation when a quorum is present. The members of the task force shall serve without compensation, but may be reimbursed for travel and other miscellaneous expenses incurred in the necessary performance of their duties, within the limits of funds made available to the task force for its purposes.

d. The task force is entitled to receive assistance and services from any State, county, or municipal department, board, commission, or agency, as it may require, and as may be available to it for its purposes. The task force is further authorized to consult with any association, organization, or individual having knowledge of, or experience with, caregiver issues. The Department of Human Services shall provide professional and clerical staff to the task force, as may be necessary to effectuate the purposes of this act.

e. The task force may solicit, receive, and expend any grant moneys or other funds that may be made available, for the task force's purposes, by any government agency or any private for-profit or not-for-profit organization or entity.

f. As used in this act:

“Caregiver” means any person, regardless of age, who provides assistance, in a non-medical setting, and without financial compensation, to an elderly or functionally impaired individual, by assisting the individual in the performance of their daily tasks, such as walking, eating, dressing, administering medications, providing wound care, or operating medical equipment.

“Caregiver support services” means any type of support or assistance that is or may be made available to caregivers in the State, including, but not limited to, financial support or assistance from any source, and any other types of support or assistance provided by public or private employers, hospitals, health care providers or organizations, or government agencies.

3. a. The New Jersey Caregiver Task Force, established pursuant to section 2 of this act, shall:

(1) Identify, and compile an inventory of, existing State policies, resources, and programs that are available to support or assist caregivers;

(2) Identify and survey caregivers in this State, in order to develop an aggregate summary of caregiver characteristics, which indicates ;

(a) the total number of caregivers in the State;

(b) the number of caregivers in each of the northern, central, and southern regions of the State;

(c) the average age of caregivers;

(d) the average time spent per week engaged in caregiving activities;

(e) the average total period of time spent in the caregiver role;

(f) the average amount of paid and unpaid leave time taken off work to engage in caregiving activities;

(g) the nature and severity of illnesses or conditions suffered by the persons being cared for; and

(h) the existing support services that are most commonly used by caregivers; and

(3) Solicit and receive testimony from caregivers on the following topics:

(a) the nature and type of simple and complex tasks undertaken by caregivers, and the frequency of caregiver engagement therein;

(b) the feasibility of delegating certain tasks to other caregivers or to medical or non-medical personnel;

(c) the availability and sufficiency of caregiver training programs or opportunities, and the frequency of caregiver engagement in such programs or opportunities;

(d) the costs associated with caregiving, including, but not limited to, the loss or expenditure of caregiver income;

(e) the availability and sufficiency of financial support services, and the frequency of caregiver use of such services;

(f) the availability and sufficiency of respite care services, and the frequency of caregiver use of such services;

(g) the practical experiences of caregivers in relation to: (i) their requests for, or receipt of, caregiver support services; (ii) their interactions with government agencies, hospitals, health care providers and organizations, and the employees or representatives thereof, in association with caregiving matters; (iii) their interactions with public and private employers in relation to caregiving matters; and (iv) the use of medical leave for caregiving purposes; and

(h) any other topic that is relevant to the determination of caregiver support service needs.

b. Not later than 12 months after the task force is organized pursuant to section 2 of this act, it shall prepare and submit a report to the Governor and, pursuant to section 2 of P.L.1991, c.164 (C.52:14-19.1), to the Legislature, providing its findings and recommendations in relation to the support of caregivers in the State. The report shall include, at a minimum, the following information:

(1) an abstract of caregiver characteristics, which summarizes information that has been obtained by the task force under paragraph (2) of subsection a. of this section ;

(2) a list of the caregiver support services that are currently made available from all sources, including the federal government, federal and State agencies, and public and private employers;

(3) a description of caregiver concerns elucidated in testimony received under paragraph (3) of subsection a. of this section; and

(4) recommendations for legislation, or for regulatory or programmatic changes, that would be necessary to supplement, expand, or improve the existing caregiver support services available in the State, in response to the concerns of caregivers.

c. The task force shall dissolve 30 days after the date it submits the report required pursuant to subsection b. of this section.

4. This act shall take effect immediately, and shall expire on the 30th day following the submission of a task force report to the Governor and the Legislature, as provided by section 3 of this act.

Approved December 28, 2018.