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2013-2014 Regular Sessions

IN ASSEMBLY

February 1, 2013

Introduced by M. of A. RAIA, FINCH, RABBITT, MONTESANO -- Multi-Sponsored by -- M. of A. BARCLAY, GIGLIO, HAWLEY, KOLB, McDONOUGH, PALMESANO, SALADINO, STEVENSON, TEDISCO, TENNEY -- read once and referred to the Committee on Aging

AN ACT to amend the elder law, in relation to creating the New York state lifespan respite care program

THE PEOPLE OF THE STATE OF NEW YORK, REPRESENTED IN SENATE AND ASSEMBLY, DO ENACT AS FOLLOWS:

Section 1. Legislative intent. The legislature hereby finds and 2 declares that supporting the efforts of families and caregivers who care individuals with special needs at home is efficient, cost effective and humane. Families receiving occasional respite care relief are likely to request admission of an individual with special needs to nurs-5 6 ing homes, foster care or other out-of-home care at public expense. 7 Respite care reduces family and caregiver stress, enhances family and 8 caregiver coping ability and strengthens family ability to meet the challenging demands of caring for individuals with special needs. 9 10 Respite care reduces the risk of abuse and neglect of senior citizens and other vulnerable groups. Coordinated, non-categorical respite care 11 services must be available locally to provide reliable short-term relief 12 when it is needed by families and caregivers regardless of where they 13 live in New York state. 14

Therefore, the legislature finds that a statewide centralized program to provide direction, resources and support for the establishment and operation of community-based respite care programs would serve a purpose beneficial to all the citizens of New York state.

19 S 2. The elder law is amended by adding a new section 215-c to read as 20 follows:

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21 S 215-C. LIFESPAN RESPITE CARE. 1. DEFINITIONS. AS USED IN THIS 22 SECTION, THE FOLLOWING WORDS SHALL HAVE THE FOLLOWING MEANINGS:

EXPLANATION--Matter in ITALICS (underscored) is new; matter in brackets [] is old law to be omitted.

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(A) "CAREGIVER" SHALL MEAN AN INDIVIDUAL PROVIDING ONGOING CARE FOR AN INDIVIDUAL WITH SPECIAL NEEDS.

- (B) "COMMUNITY LIFESPAN RESPITE CARE PROGRAM" SHALL MEAN A NON-CATE-GORICAL RESPITE CARE PROGRAM THAT:
- (1) IS OPERATED BY COMMUNITY-BASED PRIVATE NON-PROFIT, FOR-PROFIT OR PUBLIC AGENCIES THAT PROVIDE RESPITE CARE SERVICES;
 - (2) SERVES AN AREA OF ONE OR MORE COUNTIES;
 - (3) ACTS AS A SINGLE LOCAL SOURCE OF INFORMATION AND REFERRAL; AND
 - (4) FACILITATES ACCESS TO LOCAL RESPITE CARE SERVICES.
- (C) "NEW YORK STATE LIFESPAN RESPITE CARE PROGRAM" SHALL MEAN THE PROGRAM ESTABLISHED IN THE STATE OFFICE FOR THE AGING PURSUANT TO SUBDIVISION TWO OF THIS SECTION HEREINAFTER REFERRED TO AS "THE PROGRAM".
- (D) "NON-CATEGORICAL CARE" SHALL MEAN CARE WITHOUT REGARD TO THE STATUS, INCLUDING BUT NOT LIMITED TO, AGE AND TYPE OF SPECIAL NEED, OF THE INDIVIDUAL RECEIVING CARE.
- (E) "PROVIDER" SHALL MEAN INDIVIDUAL OR AGENCY SELECTED BY A FAMILY OR CAREGIVER TO PROVIDE RESPITE CARE TO AN INDIVIDUAL WITH SPECIAL NEEDS.
- (F) "RESPITE CARE" SHALL MEAN THE PROVISION OF SHORT-TERM RELIEF TO PRIMARY CAREGIVERS FROM THE DEMANDS OF ONGOING CARE FOR AN INDIVIDUAL WITH SPECIAL NEEDS.
 - (G) "RESPITE CARE SERVICES" SHALL INCLUDE:
- (1) RECRUITING AND SCREENING OF PAID AND UNPAID RESPITE CARE PROVIDERS;
- (2) IDENTIFYING LOCAL TRAINING RESOURCES AND ORGANIZING TRAINING OPPORTUNITIES FOR RESPITE CARE PROVIDERS;
- (3) MATCHING OF FAMILIES AND CAREGIVERS WITH PROVIDERS AND OTHER TYPES OF RESPITE CARE;
 - (4) LINKING FAMILIES AND CAREGIVERS WITH PAYMENT RESOURCES;
- (5) IDENTIFYING, COORDINATING AND DEVELOPING THE COMMUNITY RESOURCES FOR RESPITE CARE;
 - (6) QUALITY ASSURANCE AND EVALUATION; AND
- 32 (7) ASSISTING FAMILIES AND CAREGIVERS TO IDENTIFY RESPITE CARE NEEDS 33 AND RESOURCES.
 - (H) "SPECIAL NEEDS" INCLUDES:
 - (1) ALZHEIMER'S DISEASE AND RELATED DISORDERS;
 - (2) DEVELOPMENTAL DISABILITIES;
 - (3) PHYSICAL DISABILITIES;
 - (4) CHRONIC ILLNESS;
 - (5) MENTAL AND EMOTIONAL CONDITIONS THAT REQUIRE SUPERVISION;
 - (6) SITUATIONS IN WHICH A HIGH RISK OF ABUSE OR NEGLECT EXISTS; AND
 - (7) SUCH OTHER SITUATIONS OR CONDITIONS AS THE OFFICE MAY FROM TIME TO TIME ESTABLISH.
 - 2. THE NEW YORK STATE LIFESPAN RESPITE CARE PROGRAM ESTABLISHED. (A) THE DIRECTOR IS AUTHORIZED AND DIRECTED TO PROMULGATE RULES AND REGULATIONS TO ESTABLISH THE NEW YORK STATE LIFESPAN RESPITE CARE PROGRAM FOR THE PURPOSE OF DEVELOPING AND ENCOURAGING STATEWIDE COORDINATION OF RESPITE CARE AND TO WORK WITH COMMUNITY-BASED PRIVATE NOT-FOR-PROFIT, FOR-PROFIT OR PUBLIC AGENCIES AND INTERESTED CITIZEN GROUPS TO FOSTER THE ESTABLISHMENT OF RECOGNIZED COMMUNITY LIFESPAN RESPITE CARE PROGRAMS PURSUANT TO SUBDIVISION THREE OF THIS SECTION.
 - (B) THE PROGRAM SHALL:
 - (1) PROVIDE POLICY AND PROGRAM DEVELOPMENT SUPPORT, INCLUDING BUT NOT LIMITED TO DATA COLLECTION AND OUTCOME MEASURES;
- 54 (2) IDENTIFY AND PROMOTE RESOLUTION OF LOCAL AND STATE LEVEL POLICY 55 CONCERNS;

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(3) PROVIDE TECHNICAL ASSISTANCE TO COMMUNITY LIFESPAN RESPITE CARE PROGRAMS;

- (4) DEVELOP AND DISTRIBUTE RESPITE CARE INFORMATION;
- (5) PROMOTE THE EXCHANGE OF INFORMATION AND COORDINATION AMONG STATE AND LOCAL GOVERNMENT, COMMUNITY LIFESPAN RESPITE CARE PROGRAMS, AGENCIES SERVING INDIVIDUALS WITH SPECIAL NEEDS, FAMILIES AND RESPITE CARE ADVOCATES TO ENCOURAGE EFFICIENT PROVISION OF RESPITE CARE AND REDUCE DUPLICATION OF EFFORT;
- (6) ENSURE STATEWIDE ACCESS TO COMMUNITY LIFESPAN RESPITE CARE PROGRAMS, PARTICULARLY IN RURAL AREAS; AND
- (7) MONITOR AND EVALUATE IMPLEMENTATION OF COMMUNITY LIFESPAN RESPITE CARE PROGRAMS.
- (C) THE DIRECTOR SHALL APPOINT AN ADVISORY COUNCIL TO THE PROGRAM WHICH SHALL BE COMPOSED OF QUALIFIED INDIVIDUALS INCLUDING RESPITE CARE PROVIDERS, RESPITE CARE PROGRAM MANAGERS, RESPITE CARE CONSUMERS, FAMILY MEMBERS AND OTHER INTERESTED INDIVIDUALS.
- 3. COMMUNITY LIFESPAN RESPITE CARE PROGRAMS. (A) THE DIRECTOR, THROUGH THE PROGRAM ESTABLISHED PURSUANT TO SUBDIVISION TWO OF THIS SECTION, SHALL COORDINATE THE ESTABLISHMENT OF COMMUNITY LIFESPAN RESPITE CARE PROGRAMS. THE PROGRAM SHALL ACCEPT PROPOSALS TO OPERATE COMMUNITY LIFESPAN RESPITE CARE PROGRAMS, SUBMITTED IN THE FORM AND MANNER REQUIRED BY THE DIRECTOR, FROM COMMUNITY BASED PRIVATE NOT-FOR-PROFIT, FOR-PROFIT OR PUBLIC AGENCIES THAT PROVIDE RESPITE CARE SERVICES. ACCORDING TO CRITERIA ESTABLISHED BY THE OFFICE, THE PROGRAM SHALL DESIGNATE AGENCIES DESCRIBED IN THIS SUBDIVISION AS OPERATORS OF COMMUNITY RESPITE CARE PROGRAMS.
- (B) NO LATER THAN THE FIRST OF JANUARY, TWO THOUSAND THIRTEEN THE OFFICE SHALL DESIGNATE AT LEAST TWELVE OPERATORS OF COMMUNITY RESPITE CARE PROGRAMS STATEWIDE. NO LATER THAN THE FIRST OF JANUARY, TWO THOUSAND FIFTEEN THE OFFICE SHALL ENSURE THE DESIGNATION OF AT LEAST ONE OPERATOR OF COMMUNITY RESPITE CARE PROGRAMS IN EACH COUNTY IN THE STATE.
- (C) COMMUNITY LIFESPAN RESPITE CARE PROGRAMS ESTABLISHED PURSUANT TO THIS SUBDIVISION SHALL:
- (1) INVOLVE KEY LOCAL INDIVIDUALS AND AGENCIES IN THE COMMUNITY LIFES-PAN RESPITE CARE PROGRAM PLANNING PROCESS;
- (2) INCLUDE A FLEXIBLE ARRAY OF RESPITE CARE OPTIONS RESPONSIVE TO FAMILY AND CAREGIVER NEEDS AND AVAILABLE BEFORE FAMILIES AND CAREGIVERS ARE IN A CRISIS SITUATION;
- (3) BE SENSITIVE TO THE UNIQUE NEEDS, STRENGTHS AND MULTICULTURAL VALUES OF AN INDIVIDUAL, FAMILY OR CAREGIVER;
- (4) OFFER THE MOST EFFICIENT ACCESS TO AN ARRAY OF COORDINATED RESPITE CARE SERVICES THAT ARE BUILT ON EXISTING COMMUNITY SUPPORTS AND SERVICES;
 - (5) BE DRIVEN BY COMMUNITY STRENGTHS, NEEDS AND RESOURCES; AND
- (6) USE A VARIETY OF FUNDS AND RESOURCES, INCLUDING BUT NOT LIMITED TO:
 - (I) FAMILY OR CAREGIVER FUNDS;
 - (II) PRIVATE AND VOLUNTEER RESOURCES;
 - (III) PUBLIC FUNDS INCLUDING AVAILABLE FEDERAL MONIES; AND
 - (IV) EXCHANGE OF CARE AMONG FAMILIES OR CAREGIVERS;
- (7) CREATE AN ADVISORY COMMITTEE COMPOSED OF FIFTEEN MEMBERS TO ADVISE THE COMMUNITY LIFESPAN RESPITE CARE PROGRAM ON HOW THE PROGRAM MAY BEST SERVE THE NEEDS OF FAMILIES AND CAREGIVERS OF INDIVIDUALS WITH SPECIAL NEEDS. AT LEAST EIGHT MEMBERS OF SUCH ADVISORY COMMITTEE SHALL BE FAMILY MEMBERS AND CAREGIVERS OF INDIVIDUALS WITH SPECIAL NEEDS. OTHER MEMBERS SHALL INCLUDE RESPITE CARE PROVIDERS, REPRESENTATIVES OF LOCAL

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13 14 SERVICE AGENCIES AND OTHER COMMUNITY REPRESENTATIVES. COMMITTEE MEMBER-SHIP SHALL REPRESENT SENIOR CITIZENS, INDIVIDUALS WITH SPECIAL NEEDS, AND FAMILIES AT RISK OF ABUSE OR NEGLECT.

- 4. RULES AND REGULATIONS. THE DIRECTOR IS HEREBY DIRECTED TO PROMUL-GATE ANY RULES AND REGULATIONS NECESSARY FOR THE OPERATION AND ADMINISTRATION OF THE NEW YORK STATE RESPITE CARE PROGRAM ESTABLISHED PURSUANT TO SUBDIVISION TWO OF THIS SECTION, INCLUDING BUT NOT LIMITED TO:
- (A) ESTABLISHING CRITERIA, PROCEDURES AND TIME LINES FOR DESIGNATION OF THE COMMUNITY BASED PRIVATE NOT-FOR-PROFIT, FOR-PROFIT, OR PUBLIC AGENCIES THAT WILL BE DESIGNATED AS RECOGNIZED PROVIDERS OF SERVICES UNDER COMMUNITY LIFESPAN RESPITE CARE PROGRAMS; AND
- (B) REQUIRING THAT COMMUNITY LIFESPAN RESPITE CARE PROGRAMS PUBLICIZE THE TELEPHONE NUMBER AND ADDRESS WHERE FAMILIES AND CAREGIVERS MAY CONTACT THE STATE PROGRAM.
- 15 S 3. This act shall take effect on the one hundred eightieth day after 16 it shall have become a law; provided, however, that effective immediate-17 ly the addition, amendment and/or repeal of any rule or regulation 18 necessary for the implementation of this act on its effective date are 19 authorized and directed to be made and completed on or before such 20 effective date.