- 1 AN ACT in relation to aging.
- 2 Be it enacted by the People of the State of Illinois,
- 3 represented in the General Assembly:
- 4 Section 1. Short title. This Act may be cited as the
- 5 Lifespan Respite Program Act.
- 6 Section 5. Legislative intent. The Lifespan Respite
- 7 Program is designed to provide funding for caregivers to
- 8 purchase respite services. Respite is a service that is
- 9 designed to give caregivers a break from the demands of
- 10 providing ongoing care for another individual. The basic
- 11 intent of respite is to:
- 12 (1) Prevent or postpone out-of-home placements.
- 13 (2) Reduce family and caregiver stress.
- 14 (3) Enhance the family and caregiver's coping
- abilities.
- 16 (4) Strengthen the family and caregiver's ability
- 17 to meet the challenging demands of caring for family
- members.
- 19 (5) Reduce the risk of abuse or neglect of
- children, the elderly, and other vulnerable groups.
- 21 Section 10. Definitions. In this Act:
- "Caregiver" means a friend, family member, or legal
- 23 guardian residing with and providing ongoing care for an
- individual unable to care for himself or herself.
- "Client" means an individual who has been referred to,
- 26 has applied for, or has been authorized to receive respite
- 27 services through the program.
- "Department" means the Department on Aging.
- "Ongoing care" means continuous, full-time supervision or
- 30 care for a person with special needs.

- 1 "Program" means the Lifespan Respite Program.
- 2 "Reside", when used with reference to a caregiver, means
- 3 that the caregiver lives with the person with special needs
- 4 in the same house or apartment.
- 5 "Respite" means the provision, to primary caregivers, of
- 6 short-term relief from the demands of ongoing care for an
- 7 individual with special needs.
- 8 "Special needs", when used with reference to a person,
- 9 means a person of any age with needs resulting from an
- 10 emotional, behavioral, cognitive, physical, or other
- 11 condition that necessitates receipt of care or supervision
- in order to meet the person's basic needs or to prevent harm
- 13 from occurring to the person. These conditions include, but
- 14 are not limited to: (1) developmental disabilities; (2)
- 15 physical disabilities; (3) chronic illness; (4) physical,
- 16 mental or emotional conditions that require supervision;
- 17 (5) special health care needs; (6) cognitive impairments;
- and (7) situations in which a high risk of abuse or neglect
- 19 exists.
- "Vulnerable", when used with respect to an individual,
- 21 means an individual who is susceptible to physical injury
- 22 due to a substantial mental or functional impairment.
- 23 "Waiting list" means a list of applications for
- 24 individuals who cannot receive benefits due to limited
- 25 funding availability.
- 26 Section 15. Department's responsibilities.
- 27 (a) The Department shall establish a statewide Lifespan
- 28 Respite Program, to be administered through at least 6 local
- 29 offices. Each local office shall do the following in
- 30 administering the program:
- 31 (1) Assess the specific need for respite services
- in the community the office serves and determine whether
- enough providers exist to handle that need.

- 1 (2) Conduct marketing targeted toward families, 2 providers, and businesses to increase awareness of the 3 program and the benefits of respite care.
 - (3) Recruit more providers of respite services, particularly those that will participate in the program of medical assistance under the Illinois Public Aid Code.
- 7 (4) Develop and administer comprehensive training 8 programs for caregivers, whether they are professional 9 service providers or family members of a person with 10 special needs.
- 11 (5) Conduct evaluations to determine the program's effectiveness.
- 13 (b) Subject to appropriations, the Department may do the 14 following to implement the program:
- 15 (1) Determine the maximum monthly subsidy amount to 16 be paid to each eligible person or family, which may not 17 exceed \$125.
- 18 (2) Determine the number of persons or families to
 19 be served through the program, based on available
 20 funding for the program.
 - (3) Establish waiting lists.

5

6

- 22 (4) Establish priorities based on needs and 23 population.
- 24 (5) Transfer appropriated moneys between the 25 respite service populations set forth in subsection (c) 26 for the purpose of ensuring that all available moneys are 27 utilized.
- 28 (c) The Department shall allocate program funding 29 between the following populations:
- 30 (1) Birth through age 18.
- 31 (2) Age 19 through age 59.
- 32 (3) Age 60 and above.
- 33 Section 20. Eligibility; status.

- 1 (a) Assistance under the program is only for those
- 2 individuals not eligible for respite funding through any
- 3 other government administered respite program.
- 4 (b) To be eligible for assistance under the program, a
- 5 person must:

- (1) Reside in this State.
- 7 (2) Reside in a non-institutional setting.
- 8 (3) Have a special need.
- 9 (4) Meet the financial criteria for the program.
- 10 (c) A caregiver must:
- 11 (1) Be providing care or supervision of the 12 individual with special needs without reimbursement or 13 payment.
- 14 (2) Need a break from the ongoing care of a client.
- 15 (3) Reside in the same home as the client. Respite 16 is not a substitute to allow the caregiver to work. The 17 caregiver may maintain a separate residence but must be 18 residing with or staying with the client on an ongoing
- 19 basis.
- 20 Section 25. Eligibility; financial.
- 21 (a) To be eligible for assistance under the program, a
- 22 person's gross income minus allowable disregards must be
- equal to or less than 312% of the poverty guidelines updated
- 24 annually in the Federal Register by the United States
- 25 Department of Health and Human Services under authority of
- 26 section 673(2) of the Omnibus Budget Reconciliation Act of
- 27 1981. In determining eligibility under this subsection, the
- 28 Department shall consider each of the following a separate
- 29 family:
- 30 (1) Related adults other than spouses and unrelated
- 31 adults who reside together.
- 32 (2) Children living with non-legally responsible
- 33 relatives.

13

14

15

16

17

18

19

20

21

22

23

24

25

26

27

28

- (3) Emancipated minors.
- 2 (4) A minor parent.
- 3 (5) Children placed outside the home and who are 4 not residing full-time with the biological parents or 5 usual caretaker.
- 6 (b) In determining a person's gross income for purposes 7 of this Act, the Department shall exclude the following:
- 8 (1) Any monies received from Indian or Alaska
 9 Native Claims Commission or Court of Claims or per capita
 10 payments to tribes.
- 11 (2) Bank withdrawals or loans.
 - (3) Money received from the sale of property such as stocks, bonds, a house, or a car (unless the person was engaged in the business of selling such property in which case the net proceeds would be counted as income from self-employment.
 - (4) Tax refunds, capital gains, earned income credits and Advanced Earned Income Credits.
 - (5) Lump sum payments from any source, including but not limited to, gifts, inheritances, insurance payments, child support, or Social Security Administration payments.
 - (6) The value of Food Stamps, USDA-donated foods or food commodities, or food or reimbursements received under the Child Nutrition Act of 1966 or the National School Lunch Act.
 - (7) Funds or reimbursement benefits from any program administered by the Department.
 - (8) Medicare premiums.
- 30 (9) In-kind income.
- 31 (10) Any student financial assistance including 32 work study for an undergraduate student.
- 33 (11) Payments made to any individual from any claim 34 or class action suits or from any funds established by

- legislative acts due to harm from any act of war, disaster, or health condition.
- 3 (12) Payments made under any program for education 4 or training.
 - (13) Earnings of a child age 18 or younger.
 - (14) Any payment received under the federal Uniform Relocation Assistance and Real Property Acquisition Policies Act of 1970.
 - (15) Housing assistance provided by Housing and Urban Development or by a local housing program.
 - (16) Home produce used for household consumption.
 - (17) Vendor payments of any kind, including but not limited to, payments made by an absent parent for child care, or rent.
 - (18) Reimbursement benefits received to purchase items or services, such as Veterans Aide and Attendant.
 - (19) Payments for services or reimbursement of expenses to volunteers serving as foster grandparents, senior health aides, or Senior Companions, Service Corps of Retired Executives (SCORE), Active Corps of Executives (ACE), or any other similar program.
 - (c) In determining financial eligibility for assistance under the program, the Department may disregard income in an amount equal to disability-related expenses that exceed those incurred in households where no people with disabilities reside. These expenses must actually be incurred by the family or client and not be paid or reimbursed by any other source. These expenses include but are not limited to:
 - (1) Additional cost of health insurance due to a disability, for example, Comprehensive Health Insurance Plan (CHIP) premiums.
- 32 (2) Transportation for medical services (for 33 example, an automobile modification or payment for 34 ambulance travel if required by the disability or special

- 1 needs).
- 2 (3) Medical costs, including over-the-counter
- 3 remedies related to client's special needs.
- 4 (4) Attendant care costs.
- 5 (5) Cost of special equipment.
- 6 (6) Cost of home modifications.
- 7 (7) Other health or medical expense related to the
- 8 client's special need.
- 9 Section 30. Application for assistance; decision on application.
- 11 (a) An applicant for assistance under the program must:
- 12 (1) Submit current program plans if currently 13 receiving support from a service program, as requested.
- 14 (2) Describe any support received in the past from any service program.
- 16 (3) Report any instance when an application for service was denied.
- 18 (4) Apply to all appropriate resources not previously explored.
- 20 (5) Accept any appropriate support offered through another program.
- 22 (b) The Department shall adopt rules specifying other 23 matters to be included in an application for assistance 24 under the program.
- 25 (c) The Department may determine that an applicant is 26 eligible for assistance under the program but is to be 27 placed on the waiting list due to insufficient funding.
- 28 (c) The Department shall give each applicant written
 29 notice of its decision on the applicant's application. The
 30 Department must afford each applicant an opportunity to
 31 request a hearing and present oral or written evidence, or
 32 both, to contest the Department's adverse decision on an
 33 application. The Department's decision is subject to review

- 1 under the Administrative Review Law.
- 2 Section 35. Period of eligibility. The Department must
- 3 review a recipient's eligibility for assistance at least
- 4 every 12 months. The Department may review a recipient's
- 5 eligibility more often if circumstances indicate to a prudent
- 6 person that a review should be conducted.
- 7 Section 40. Location of respite services. The program
- 8 may not cover the cost of respite services provided by a
- 9 person located outside this State unless the Department
- 10 determines that the necessary services are not available
- 11 within a reasonable driving distance from the client's home.
- 12 Section 99. Effective date. This Act takes effect upon
- 13 becoming law.