9483

IN ASSEMBLY

March 10, 2016

Introduced by M. of A. GUNTHER -- read once and referred to the Committee on Mental Health

AN ACT to amend the public health law, in relation to enacting the "fair access to individualized residences (FAIR) act"

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 that many parents and family members of developmentally disabled children have 3 cared for their loved ones for decades and now many of these family caregivers are elderly with their own age related disabilities. Increas-5 ingly, they can no longer manage the challenge of caring for an adult child who may have significant and challenging emotional and physical 6 7 needs. In fact, estimates are that approximately 25% of developmentally disabled New Yorkers, or approximately 50,000 individuals, live with family caregivers who are over the age of 60. Many of these adult chil-9 10 dren need or will soon need out of home residential placements 11 living situations which are increasingly untenable. This situation has reached crisis proportions. Complicating matters is the fact that there 12 13 a shortage of residential placements and the process for providing 14 those placements to those most in need is not transparent, consistent or uniform across the state. Residential placements are not necessarily 15 allocated based on need. Nor does such allocation take into account the 16 viability of an individual's current residential situation or any recog-17 nition of the long-standing contribution and sacrifice family caregivers 18 19 have made caring for their loved ones at home at considerable savings to 20 the state. Instead, placements are often allocated based on an individ-21 ual's designation as a member of a particular class or "special popu-22 lation" of people with developmental disabilities.

Therefore, the state must develop and implement a clear, consistent and uniform policy for ensuring that placements go to individuals most in need. This must include recognition of the viability of an individual's living situation with a family caregiver as well as the sacrifice that many of these caregivers have made for years or even decades. Families must regain the confidence that the means will exist so that their

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

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1 children will receive care even when they can no longer provide it. The 2 legislature finds that the adoption of this act is an important step 3 toward making this commitment a reality.

- S 2. Short title. This act shall be known and may be cited as the "fair access to individualized residences (FAIR) act".
- S 3. The public health law is amended by adding a new section 207-a to read as follows:
- S 207-A. PRIORITY PLACEMENT PROCESS FOR CERTAIN DEVELOPMENTALLY DISABLED PERSONS. THE COMMISSIONER AND THE COMMISSIONER OF DEVELOPMENTAL DISABILITIES SHALL, IN COOPERATION WITH INTERESTED PARTIES INCLUDING, BUT NOT LIMITED TO, FAMILY MEMBERS, SELF-ADVOCATES, PROVIDERS AND STATE OFFICIALS, DEVELOP A STATEWIDE, UNIFORM AND TRANSPARENT PROCESS FOR ASSIGNING OUT OF HOME RESIDENTIAL PLACEMENTS OF DEVELOPMENTALLY DISABLED PERSONS ON A PRIORITY BASIS. THE PROCESS SHALL INCLUDE THE FOLLOWING CRITERIA:
- 16 1. THE EXTENT OF AN INDIVIDUAL'S DISABILITY AS MEASURED BY A UNIFORM 17 AND RECOGNIZED ASSESSMENT METHODOLOGY;
 - 2. THE NATURE OF THE INDIVIDUAL'S LIVING SITUATION WHICH SHALL TAKE INTO ACCOUNT THE AGE AND HEALTH OF FAMILY CAREGIVERS, THE ABILITY OF FAMILY CAREGIVERS TO CONTINUE TO PROVIDE CARE, THE LENGTH OF TIME FAMILY CAREGIVERS HAVE CARED FOR THE INDIVIDUAL WITH DEVELOPMENTAL DISABILITIES AT HOME, THE INABILITY OF FAMILY CAREGIVERS TO MANAGE THE INDIVIDUAL'S NEEDS, INCLUDING BEHAVIORAL NEEDS, THE LIKELIHOOD THE FAMILY CAREGIVERS WILL OR MUST ALTER THEIR LIVING SITUATION SO THAT CONTINUING CARE IS NO LONGER PRACTICAL, AND OTHER FACTORS RELATING TO THE ABILITY OF FAMILY CAREGIVERS TO CONTINUE TO PROVIDE CARE; AND
 - WHETHER AN INDIVIDUAL IS CATEGORIZED FOR PLACEMENT PURPOSES AS A PRIORITY ONE INDIVIDUAL AS DEFINED IN THE STATE'S HOME AND COMMUNITY BASED SERVICES WAIVER APPLICATION. INDIVIDUALS SHALL NOT AUTOMATICALLY BE DESIGNATED PRIORITY ONE BASED SOLELY ON THEIR STATUS AS A PERSON BELONGING TO A "SPECIAL POPULATION." HOWEVER, IN THE EVENT THAT A DEVEL-OPMENTAL DISABILITIES REGIONAL OFFICE HAS DETERMINED THAT A PERSON DESIGNATED AS A MEMBER OF A "SPECIAL POPULATION," AND THAT SUCH PERSON CRITERIA FOR PRIORITY ONE, AND THAT AN EMERGENCY EXISTS, AS THEDEFINED BY SUCH WAIVER; THE DEVELOPMENTAL DISABILITIES REGIONAL MAKE A REFERRAL TO A PROVIDER FOR AN EVALUATION AND PLACEMENT. THE DEPARTMENT, IN CONSULTATION WITH THE OFFICE FOR PEOPLE WITH DEVELOP-MENTAL DISABILITIES, SHALL SEEK ANY NECESSARY AMENDMENTS TO THE STATE'S HOME AND COMMUNITY BASED SERVICES WAIVER APPLICATION TO EFFECTUATE PURPOSES OF THIS SECTION.
- 41 S 4. The commissioner of health and the commissioner of developmental 42 disabilities shall implement the provisions of this act within 120 days 43 of the effective date thereof.
- 44 S 5. This act shall take effect immediately.