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I N S E N A T E

February 18, 2016

Introduced by Sens. HANNON, ORTT -- read twice and ordered printed, and when printed to be committed to the Committee on 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:

1 Section 1. Legislative intent. The legislature hereby finds that many  
2 parents and family members of developmentally disabled children have  
3 cared for their loved ones for decades and now many of these family  
4 caregivers are elderly with their own age related disabilities. Increas-  
5 ingly, they can no longer manage the challenge of caring for an adult  
6 child who may have significant and challenging emotional and physical  
7 needs. In fact, estimates are that approximately 25% of developmentally  
8 disabled New Yorkers, or approximately 50,000 individuals, live with  
9 family caregivers who are over the age of 60. Many of these adult chil-  
10 dren need or will soon need out of home residential placements for  
11 living situations which are increasingly untenable. This situation has  
12 reached crisis proportions. Complicating matters is the fact that there  
13 is a shortage of residential placements and the process for providing  
14 those placements to those most in need is not transparent, consistent or  
15 uniform across the state. Residential placements are not necessarily  
16 allocated based on need. Nor does such allocation take into account the  
17 viability of an individual's current residential situation or any recog-  
18 nition of the long-standing contribution and sacrifice family caregivers  
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.

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

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.

4 S 2. Short title. This act shall be known and may be cited as the  
5 "fair access to individualized residences (FAIR) act".

6 S 3. The public health law is amended by adding a new section 207-a to  
7 read as follows:

8 S 207-A. PRIORITY PLACEMENT PROCESS FOR CERTAIN DEVELOPMENTALLY DISA-  
9 BLED PERSONS. THE COMMISSIONER AND THE COMMISSIONER OF DEVELOPMENTAL  
10 DISABILITIES SHALL, IN COOPERATION WITH INTERESTED PARTIES INCLUDING,  
11 BUT NOT LIMITED TO, FAMILY MEMBERS, SELF-ADVOCATES, PROVIDERS AND STATE  
12 OFFICIALS, DEVELOP A STATEWIDE, UNIFORM AND TRANSPARENT PROCESS FOR  
13 ASSIGNING OUT OF HOME RESIDENTIAL PLACEMENTS OF DEVELOPMENTALLY DISABLED  
14 PERSONS ON A PRIORITY BASIS. THE PROCESS SHALL INCLUDE THE FOLLOWING  
15 CRITERIA:

16 1. THE EXTENT OF AN INDIVIDUAL'S DISABILITY AS MEASURED BY A UNIFORM  
17 AND RECOGNIZED ASSESSMENT METHODOLOGY;

18 2. THE NATURE OF THE INDIVIDUAL'S LIVING SITUATION WHICH SHALL TAKE  
19 INTO ACCOUNT THE AGE AND HEALTH OF FAMILY CAREGIVERS, THE ABILITY OF  
20 FAMILY CAREGIVERS TO CONTINUE TO PROVIDE CARE, THE LENGTH OF TIME FAMILY  
21 CAREGIVERS HAVE CARED FOR THE INDIVIDUAL WITH DEVELOPMENTAL DISABILITIES  
22 AT HOME, THE INABILITY OF FAMILY CAREGIVERS TO MANAGE THE INDIVIDUAL'S  
23 NEEDS, INCLUDING BEHAVIORAL NEEDS, THE LIKELIHOOD THE FAMILY CAREGIVERS  
24 WILL OR MUST ALTER THEIR LIVING SITUATION SO THAT CONTINUING CARE IS NO  
25 LONGER PRACTICAL, AND OTHER FACTORS RELATING TO THE ABILITY OF FAMILY  
26 CAREGIVERS TO CONTINUE TO PROVIDE CARE; AND

27 3. WHETHER AN INDIVIDUAL IS CATEGORIZED FOR PLACEMENT PURPOSES AS A  
28 PRIORITY ONE INDIVIDUAL AS DEFINED IN THE STATE'S HOME AND COMMUNITY  
29 BASED SERVICES WAIVER APPLICATION. INDIVIDUALS SHALL NOT AUTOMATICALLY  
30 BE DESIGNATED PRIORITY ONE BASED SOLELY ON THEIR STATUS AS A PERSON  
31 BELONGING TO A "SPECIAL POPULATION." HOWEVER, IN THE EVENT THAT A DEVEL-  
32 OPMENTAL DISABILITIES REGIONAL OFFICE HAS DETERMINED THAT A PERSON  
33 DESIGNATED AS A MEMBER OF A "SPECIAL POPULATION," AND THAT SUCH PERSON  
34 MEETS THE CRITERIA FOR PRIORITY ONE, AND THAT AN EMERGENCY EXISTS, AS  
35 DEFINED BY SUCH WAIVER; THE DEVELOPMENTAL DISABILITIES REGIONAL OFFICE  
36 MAY MAKE A REFERRAL TO A PROVIDER FOR AN EVALUATION AND PLACEMENT. THE  
37 DEPARTMENT, IN CONSULTATION WITH THE OFFICE FOR PEOPLE WITH DEVELOP-  
38 MENTAL DISABILITIES, SHALL SEEK ANY NECESSARY AMENDMENTS TO THE STATE'S  
39 HOME AND COMMUNITY BASED SERVICES WAIVER APPLICATION TO EFFECTUATE THE  
40 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.