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I N S E N A T E

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Introduced by Sens. HANNON, ORTT, MURPHY -- read twice and ordered printed, and when printed to be committed to the Committee on Health -- reported favorably from said committee, ordered to first and second report, ordered to a third reading, amended and ordered reprinted, retaining its place in the order of third reading -- again amended and ordered reprinted, retaining its place in the order of third reading

AN ACT to amend the mental hygiene 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. Increasingly,
5 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 children
10 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 recognition
18 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 individual's
21 designation as a member of a particular class or "special population"
22 of people with developmental disabilities.

23 Therefore, the state must develop and implement a caregiver assessment
24 for ensuring that placements go to individuals most in need. This must

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

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1 include recognition of the viability of an individual's living situation
2 with a family caregiver as well as the sacrifice that many of these
3 caregivers have made for years or even decades. Families must regain the
4 confidence that the means will exist so that their children will receive
5 care even when they can no longer provide it. The legislature finds
6 that the adoption of this act is an important step toward making this
7 commitment a reality.

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

10 S 3. The mental hygiene law is amended by adding a new section 41.59
11 to read as follows:

12 S 41.59 FAMILY CAREGIVER ASSESSMENTS.

13 1. FOR INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES WHO LIVE AT HOME
14 AND WHO ARE ON THE RESIDENTIAL REQUEST LIST MAINTAINED BY THE OFFICE FOR
15 PEOPLE WITH DEVELOPMENTAL DISABILITIES, THERE SHALL BE PERFORMED A FAMI-
16 LY CAREGIVER ASSESSMENT IF A REQUEST FOR SUCH ASSESSMENT HAS BEEN MADE
17 BY THE CAREGIVER OF SUCH AN INDIVIDUAL. SUCH REQUEST MAY ALSO BE MADE,
18 WITH THE APPROVAL OF THE CAREGIVER OR PERSON WITH DEVELOPMENTAL DISABIL-
19 ITIES, BY A PROVIDER OF SERVICES TO PEOPLE WITH DEVELOPMENTAL DISABILI-
20 TIES OR AN INDIVIDUAL FAMILIAR WITH THE PERSON WITH DEVELOPMENTAL DISA-
21 BILITIES WHO IS ALSO FAMILIAR WITH THE INDIVIDUAL'S LIVING SITUATION.

22 (A) THE COMMISSIONER OF DEVELOPMENTAL DISABILITIES SHALL PERFORM THE
23 CAREGIVER ASSESSMENT WITHIN THIRTY DAYS FOLLOWING THE DATE ON WHICH THE
24 REQUEST FOR THE ASSESSMENT WAS RECEIVED BY SUCH COMMISSIONER IN ACCORD-
25 ANCE WITH PROCEDURES PRESCRIBED BY THE COMMISSIONER.

26 (B) THE PERFORMANCE OF SUCH ASSESSMENT SHALL NOT PRECLUDE FURTHER SUCH
27 ASSESSMENTS WHICH MAY OCCUR AT SUCH INTERVALS AND UNDER SUCH CONDITIONS
28 AS PRESCRIBED BY THE COMMISSIONER OF DEVELOPMENTAL DISABILITIES.

29 (C) THE COMMISSIONER OF DEVELOPMENTAL DISABILITIES SHALL PRESCRIBE
30 THROUGH REGULATIONS A PROCEDURE FOR AUTHORIZING AN ASSESSMENT IF IT IS
31 NOT POSSIBLE FOR A CAREGIVER TO REQUEST AN ASSESSMENT OR TO AUTHORIZE
32 ANOTHER PARTY TO REQUEST AN ASSESSMENT ON BEHALF OF THE CAREGIVER.

33 2. WITH RESPECT TO A PERSON WITH DEVELOPMENTAL DISABILITIES LIVING AT
34 HOME WITH A FAMILY CAREGIVER, THE OFFICE FOR PEOPLE WITH DEVELOPMENTAL
35 DISABILITIES SHALL CONDUCT A CAREGIVER ASSESSMENT WHICH SHALL EVALUATE:

36 (A) THE OVERALL NATURE OF THE INDIVIDUAL'S LIVING SITUATION AND THE
37 POTENTIAL FOR ABUSE OR INJURY TO THE CAREGIVER OR TO THE INDIVIDUAL WITH
38 DEVELOPMENTAL DISABILITIES; (B) THE AGE AND PHYSICAL AND EMOTIONAL
39 HEALTH AND/OR ABILITY OF THE FAMILY CAREGIVER TO CONTINUE TO PROVIDE
40 SAFE AND CONSISTENT CARE; (C) THE HISTORICAL CONTRIBUTION THE FAMILY
41 CAREGIVER HAS MADE TO CARING FOR THE INDIVIDUAL WITH DEVELOPMENTAL DISA-
42 BILITIES, INCLUDING, BUT NOT LIMITED TO, THE LENGTH OF TIME THE FAMILY
43 CAREGIVER HAS CARED FOR SUCH INDIVIDUAL; (D) THE ABILITY OF THE FAMILY
44 CAREGIVER TO SAFELY MANAGE THE INDIVIDUAL'S NEEDS INCLUDING BEHAVIORAL
45 NEEDS; (E) THE LIKELIHOOD THE FAMILY CAREGIVER MUST OR WILL ALTER HIS OR
46 HER LIVING SITUATION SUCH THAT CONTINUED CARE WILL NO LONGER BE PRACTI-
47 CAL; (F) THE HEALTH OF THE FAMILY CAREGIVER AND ABILITY TO PERFORM DAILY
48 LIVING SKILLS AND TO CONTINUE TO PROVIDE CONSISTENT CARE; AND (G) ANY
49 OTHER FACTORS CRITICAL TO THE CONTINUED SAFETY AND SECURITY OF BOTH THE
50 CAREGIVER AND THE INDIVIDUAL WITH DEVELOPMENTAL DISABILITIES.

51 3. A FAMILY CAREGIVER ASSESSMENT SHALL, ACCORDING TO STANDARDS DEVEL-
52 OPED BY THE COMMISSIONER OF DEVELOPMENTAL DISABILITIES, RESULT IN A
53 DETERMINATION BY SUCH COMMISSIONER AS TO WHETHER THE INDIVIDUAL WITH
54 DEVELOPMENTAL DISABILITIES REPRESENTS A CURRENT NEED, SUBSTANTIAL NEED
55 OR EMERGENCY NEED AS DEFINED BY THE COMMISSIONER. THE COMMISSIONER SHALL
56 PROVIDE AN EXPLANATION OF SUCH DETERMINATION TO THE FAMILY CAREGIVER AND

1 THE PERSON WITH DEVELOPMENTAL DISABILITIES WITHIN THIRTY DAYS OF THE
2 COMPLETION OF THE ASSESSMENT ACCORDING TO PROCEDURES PRESCRIBED BY THE
3 COMMISSIONER OF DEVELOPMENTAL DISABILITIES.

4 4. IN THE EVENT THAT THE FAMILY CAREGIVER ASSESSMENT DETERMINES THAT
5 THERE IS AN EMERGENCY NEED, THE INDIVIDUAL WITH DEVELOPMENTAL DISABILI-
6 TIES SHALL BE ELIGIBLE FOR IMMEDIATE OUT OF HOME PLACEMENT INTO AN
7 APPROPRIATE RESIDENTIAL SETTING OR, AT THE REQUEST OF THE FAMILY CARE-
8 GIVER, APPROPRIATE AND ADEQUATE IN-HOME SERVICES AND SUPPORTS.

9 5. IF THE CAREGIVER OR PERSON WITH A DEVELOPMENTAL DISABILITY IS NOT
10 SATISFIED WITH THE COMMISSIONER'S DECISION PURSUANT TO SUBDIVISION THREE
11 OF THIS SECTION, SUCH PERSON MAY APPEAL SUCH DECISION WITHIN TEN DAYS TO
12 THE COMMISSIONER OF DEVELOPMENTAL DISABILITIES, WHO WILL ISSUE A FINAL
13 WRITTEN DECISION WITHIN FOURTEEN DAYS OF THE APPEAL. THE COMMISSIONER AT
14 HIS OR HER DISCRETION MAY SEND THE MATTER BACK TO A HEARING OFFICER FOR
15 FURTHER REVIEW UNDER SUCH TERMS AS SUCH COMMISSIONER SHALL PRESCRIBE.

16 DURING THE PERIOD THAT AN OBJECTION IS UNDERGOING ADMINISTRATIVE
17 REVIEW: (A) A PERSON SHALL PARTICIPATE IN PROGRAMMING MUTUALLY AGREEABLE
18 TO THE OBJECTING PARTY, THE AGENCY, THE PERSON, AND HIS OR HER PARENT,
19 GUARDIAN, CORRESPONDENT OR ADVOCATE; (B) EVERY EFFORT FEASIBLE SHALL BE
20 MADE TO MAINTAIN THE PERSON IN AT LEAST HIS OR HER CURRENT LEVEL OF
21 PROGRAMMING; AND (C) IN ORDER TO PROTECT A PERSON'S HEALTH, SAFETY OR
22 WELFARE, OR THE HEALTH, SAFETY OR WELFARE OF OTHERS, NOTHING IN THIS
23 SECTION SHALL PRECLUDE A CHANGE IN PROGRAMMING FOR, OR THE RELOCATION OR
24 DISCHARGE OF A PERSON. HOWEVER, WHILE AN OBJECTION TO PLACEMENT OR
25 DISCHARGE IS UNDERGOING ADMINISTRATIVE REVIEW, RELOCATION OR DISCHARGE
26 SHALL ONLY TAKE PLACE WITH THE COMMISSIONER'S APPROVAL.

27 6. THE ABSENCE OF A CAREGIVER ASSESSMENT SHALL NOT PRECLUDE AN INDI-
28 VIDUAL LIVING AT HOME FROM RECEIVING AN OUT OF HOME RESIDENTIAL PLACE-
29 MENT OR ANY OTHER SERVICES.

30 7. THE ASSESSMENT PURSUANT TO THIS SECTION AND OTHER MATTERS NECESSARY
31 TO IMPLEMENT THIS SECTION SHALL BE DEVELOPED BY THE COMMISSIONER OF
32 DEVELOPMENTAL DISABILITIES, IN CONSULTATION WITH THE DEVELOPMENTAL DISA-
33 BILITIES, ADVISORY COUNCIL ESTABLISHED PURSUANT TO SECTION 13.05 OF THIS
34 CHAPTER, AND SUCH OTHER INTERESTED PARTIES AS THE COMMISSIONER DEEMS
35 APPROPRIATE.

36 S 4. This act shall take effect immediately, and any rules and regu-
37 lations necessary to implement the provisions of this act shall be
38 adopted before and take effect on March 1, 2017.