

5223--B

2013-2014 Regular Sessions

I N S E N A T E

May 14, 2013

Introduced by Sen. CARLUCCI -- read twice and ordered printed, and when printed to be committed to the Committee on Mental Health and Developmental Disabilities -- reported favorably from said committee and committed to the Committee on Finance -- committee discharged, bill amended, ordered reprinted as amended and recommitted to said committee -- committee discharged, bill amended, ordered reprinted as amended and recommitted to said committee

AN ACT to amend the mental hygiene law, in relation to creating a bill of rights for family and guardians of people with developmental disabilities that reside in residences funded, licensed and operated by the office for people with developmental disabilities

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

1 Section 1. The mental hygiene law is amended by adding a new section
2 13.04 to read as follows:
3 S 13.04 FAMILY BILL OF RIGHTS.
4 (A) THE PRINCIPLES ENUNCIATED IN SUBDIVISION (D) OF THIS SECTION ARE
5 DECLARED TO BE THE PUBLIC POLICY OF THE STATE AND A COPY OF SUCH STATE-
6 MENT OF RIGHTS SHALL BE POSTED CONSPICUOUSLY IN A PUBLIC PLACE IN EACH
7 PROVIDER OF SERVICES AND RESIDENTIAL FACILITY OPERATED, LICENSED OR
8 FUNDED BY THE OFFICE. FOR PURPOSES OF THIS SECTION, "QUALIFIED FAMILY
9 MEMBER" MEANS A PARENT, SPOUSE, ADULT SIBLING OR AN ADULT CHILD OF THE
10 RESIDENT.
11 (B) THE COMMISSIONER SHALL MAKE AVAILABLE TO EVERY PROVIDER OF
12 SERVICES AND RESIDENCE OPERATED, LICENSED OR FUNDED BY THE OFFICE, ON
13 THE OFFICE'S WEBSITE A COPY OF THE STATEMENT OF RIGHTS PROVIDED IN
14 SUBDIVISION (D) OF THIS SECTION IN ENGLISH AND THE TOP SIX LANGUAGES
15 OTHER THAN ENGLISH SPOKEN IN THE STATE ACCORDING TO THE LATEST AVAILABLE
16 DATA FROM THE U.S. BUREAU OF CENSUS, AND SHALL ADOPT ANY RULES AND REGU-
17 LATIONS NECESSARY TO ENSURE THAT SUCH QUALIFIED FAMILY MEMBERS AND GUAR-
18 DIANS ARE TREATED IN ACCORDANCE WITH THE PROVISIONS OF SUCH STATEMENT.

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

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(C) SUCH RIGHTS SHALL APPLY TO FAMILY MEMBERS DEFINED IN SUBDIVISION (A) OF THIS SECTION PROVIDED HOWEVER, SUCH RIGHTS SHALL NOT APPLY IF AN INDIVIDUAL WITH DEVELOPMENTAL DISABILITIES HAS SPECIFICALLY STATED THAT SUCH FAMILY MEMBERS SHALL NOT HAVE ACCESS TO ANY PERSONAL INFORMATION, BE INVOLVED IN ANY CARE PLANNING OR COORDINATION, OR BE INVOLVED IN ANY HEALTH CARE DECISIONS.

(D) THE STATEMENT OF RIGHTS SHALL CONSIST OF THE FOLLOWING:

"FAMILY BILL OF RIGHTS"

QUALIFIED FAMILY MEMBERS AND GUARDIANS SHALL HAVE THE FOLLOWING RIGHTS IN REGARDS TO AN INDIVIDUAL RECEIVING SERVICES THROUGH PROGRAMS, INCLUDING, BUT NOT LIMITED TO, RESIDENTIAL SERVICES, THAT ARE OPERATED, LICENSED OR FUNDED BY THE OFFICE. THESE RIGHTS SHALL INCLUDE:

YOU HAVE THE RIGHT TO BE TREATED WITH CONSIDERATION AND RESPECT.

YOU HAVE THE RIGHT TO HAVE ACCESS TO A RESIDENCE'S FIRE SAFETY PLAN AND ANY INFORMATION REGARDING A RESIDENCE'S PASSAGE OR FAILURE OF ANY FIRE SAFETY DRILLS CONDUCTED BY THE RESIDENCE AND THE OFFICE.

YOU HAVE THE RIGHT TO NOTIFICATION WITHIN A REASONABLE TIME FRAME OF ANY EVENT THAT DIRECTLY IMPACTS THE HEALTH AND SAFETY OF THE INDIVIDUAL, CONSISTENT WITH FEDERAL AND STATE CONFIDENTIALITY PROTECTIONS.

YOU HAVE THE RIGHT TO HAVE ACCESS TO INFORMATION REGARDING THE HEALTH AND SAFETY OF THE INDIVIDUAL, CONSISTENT WITH FEDERAL AND STATE CONFIDENTIALITY PROTECTIONS.

YOU HAVE THE RIGHT TO HAVE ACCESS TO A RESIDENCE'S FOOD MENUS.

YOU HAVE THE RIGHT FOR A QUALIFIED FAMILY MEMBER OR GUARDIAN TO BE ABLE TO HAVE UNANNOUNCED VISITS.

YOU HAVE THE RIGHT TO RECEIVE INFORMATION NECESSARY TO MAKE INFORMED DECISIONS, WHEN APPROPRIATE, ABOUT THE CARE OF THE INDIVIDUAL.

YOU HAVE THE RIGHT TO HAVE MEANINGFUL PARTICIPATION AND INPUT INTO, AND ONGOING REVIEW AND INVOLVEMENT WITH, THE INDIVIDUAL'S PLAN OF CARE, INCLUDING BUT NOT LIMITED TO ANY DECISION REGARDING APPROPRIATE PLACEMENT OR TRANSFER OF AN INDIVIDUAL WITH DEVELOPMENTAL DISABILITIES WITHIN A RESIDENCE OPERATED, LICENSED OR FUNDED BY THE OFFICE.

YOU HAVE THE RIGHT TO FINANCIAL TRANSPARENCY INCLUDING ACCESS TO BUDGETARY INFORMATION OF THE RESIDENCE INCLUDING INDIVIDUAL EXPENSES, CONSISTENT WITH FEDERAL AND STATE CONFIDENTIALITY PROTECTIONS.

YOU HAVE THE RIGHT TO BE INFORMED REGARDING ANY STAFFING CHANGES.

YOU HAVE THE RIGHT TO BE GIVEN CLEAR, UP TO DATE, UNDERSTANDABLE, AND HONEST INFORMATION ABOUT THE SYSTEM OF CARE AND SERVICES FOR PERSONS WITH DEVELOPMENTAL DISABILITIES, INCLUDING BUT NOT LIMITED TO MANAGED CARE.

YOU HAVE THE RIGHT TO BE ADVISED IN WRITING OF ANY LAWS, RULES, OR REGULATIONS THAT APPLY TO A QUALIFIED FAMILY MEMBER'S AND GUARDIAN'S ABILITY TO ACCESS INFORMATION OR PARTICIPATE IN DECISIONS ABOUT THE INDIVIDUAL'S LIFE, INCLUDING BUT NOT LIMITED TO, GUARDIANSHIP ISSUES, AND ACCESS TO RECORDS, REPORTS, PLANS OF CARE, AND OTHER PERTINENT INFORMATION.

FOR PURPOSES OF MEDICAID WAIVERS OBTAINED BY THE STATE:

YOU HAVE THE RIGHT TO CHOOSE A CARE COORDINATOR.

YOU HAVE THE RIGHT TO RECEIVE INFORMATION NECESSARY TO MAKE INFORMED DECISIONS, WHEN APPROPRIATE, ABOUT THE CARE COORDINATION OF THE INDIVIDUAL.

YOU HAVE THE RIGHT TO INDEPENDENT ADVOCATES.

YOU HAVE THE RIGHT TO BE NOTIFIED IN WRITING ABOUT ALL MANDATED PROCEDURES IF QUALIFIED FAMILY MEMBERS OR GUARDIANS NEED TO CHALLENGE A DECISION.

1 ALL THE ABOVE ARE YOUR RIGHTS. NOTHING IN THIS BILL OF RIGHTS SHALL
2 LIMIT ANY OTHER ACTION OR RELIEF PERMITTED BY LAW. IF THE PROVIDER OR
3 RESIDENTIAL FACILITY DOES NOT HONOR THESE RIGHTS YOU MAY PURSUE HELP BY
4 CONTACTING THE NEW YORK STATE DEPARTMENT OF HEALTH, THE OFFICE FOR
5 PEOPLE WITH DEVELOPMENTAL DISABILITIES OR BY CONTACTING THE RESIDENTIAL
6 FACILITY OR THE PROVIDER OF SERVICES.

7 (E) THE COMMISSIONER SHALL ESTABLISH A PUBLIC EDUCATION PROGRAM TO
8 DISSEMINATE INFORMATION REGARDING IMPLEMENTATION OF THIS SECTION. SUCH
9 INFORMATION SHALL INCLUDE, BUT NOT BE LIMITED TO, PUBLICATION OF THE
10 FAMILY BILL OF RIGHTS AS SPECIFIED IN SUBDIVISION (D) OF THIS SECTION;
11 PUBLICATION OF THE RIGHTS OF QUALIFIED FAMILY MEMBERS AND GUARDIANS OF A
12 PERSON RECEIVING SERVICES FROM A PROVIDER OR IN A RESIDENTIAL FACILITY
13 OPERATED, LICENSED, OR FUNDED BY THE OFFICE; AND PUBLICATION OF CERTAIN
14 PROVISIONS RELATING TO MEDICAID WAIVERS OBTAINED BY THE STATE.

15 S 2. This act shall take effect immediately.