S T A T E O F N E W Y O R K

5223--D

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 -- recommitted to the Committee on Mental Health and Developmental Disabilities in accordance with Senate Rule 6, sec. 8 -- 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 certified or approved 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:

Section 1. The mental hygiene law is amended by adding a new section 13.04 to read as follows:

S 13.04 FAMILY BILL OF RIGHTS AND PRIVILEGES.

(A) THE PRINCIPLES IN THE BILL OF RIGHTS AND PRIVILEGES SET FORTH IN THIS SECTION ARE DECLARED TO BE THE PUBLIC POLICY OF THE STATE.

(B) FOR PURPOSES OF THIS SECTION:

(1) "QUALIFIED PERSONAL REPRESENTATIVE" MEANS A SPOUSE, PARENT, ADULT CHILD, ADULT SIBLING, LEGAL GUARDIAN OR PERSONAL REPRESENTATIVE OF AN INDIVIDUAL WITH DEVELOPMENTAL DISABILITIES WHO IS RECEIVING SERVICES FROM A COVERED PROVIDER.

(2) "COVERED PROVIDER" MEANS AND INCLUDES ANY ENTITY, PROVIDING RESIDENTIAL SERVICES OR NON-RESIDENTIAL SERVICES OR PROGRAMS TO ONE OR MORE

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

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PERSONS WITH A DEVELOPMENTAL DISABILITY, THAT IS LICENSED, OPERATED OR CERTIFIED BY THE OFFICE.

(C) IN ADDITION TO ALL OTHER RIGHTS AND PRIVILEGES UNDER LAW, A QUALIFIED PERSONAL REPRESENTATIVE SHALL HAVE THE FOLLOWING RIGHTS AND PRIVILEGES SET FORTH BELOW (THE "FAMILY BILL OF RIGHTS AND PRIVILEGES") WITH RESPECT TO THEIR INDIVIDUAL FAMILY MEMBERS WITH DEVELOPMENTAL DISABILITIES.

"FAMILY BILL OF RIGHTS AND PRIVILEGES"

A QUALIFIED PERSONAL REPRESENTATIVE SHALL HAVE THE FOLLOWING GENERALLY-DESCRIBED RIGHTS AND PRIVILEGES CONCERNING A FAMILY MEMBER WITH DEVELOPMENTAL DISABILITIES RECEIVING SERVICES; TO:

BE TREATED WITH CONSIDERATION AND RESPECT.

PARTICIPATE IN AND PROVIDE MEANINGFUL INPUT INTO THE DEVELOPMENT, REVIEW AND REVISION OF THE INDIVIDUAL'S CARE PLAN, INCLUDING PLACEMENT OR TRANSFER WITHIN OR BETWEEN FACILITIES.

ACCESS INFORMATION REGARDING THE INDIVIDUAL'S HEALTH AND SAFETY, CONSISTENT WITH FEDERAL AND STATE CONFIDENTIALITY PROTECTIONS.

BE NOTIFIED WITHIN A REASONABLE TIME OF ANY EVENT THAT DIRECTLY IMPACTS THE INDIVIDUAL'S HEALTH AND SAFETY, CONSISTENT WITH FEDERAL AND STATE CONFIDENTIALITY PROTECTIONS.

ACCESS INFORMATION NECESSARY FOR A QUALIFIED PERSONAL REPRESENTATIVE TO MAKE INFORMED DECISIONS, WHEN APPROPRIATE, ABOUT THE INDIVIDUAL'S CARE AND CARE COORDINATION.

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

VISIT UNANNOUNCED.

BE INFORMED OF STAFFING CHANGES.

ACCESS A FACILITY'S FIRE AND OTHER SAFETY PLANS AND ANY INFORMATION REGARDING A FACILITY'S PASSAGE OR FAILURE OF ANY SAFETY DRILLS CONDUCTED BY THE FACILITY AND THE OFFICE.

ACCESS A FACILITY'S FOOD MENUS.

CHOOSE A CARE COORDINATOR.

CONSULT AND BE REPRESENTED BY AN INDEPENDENT ADVOCATE, MENTAL HYGIENE LEGAL SERVICES OR AN ATTORNEY; AND IF SERVICES ARE PROVIDED UNDER MEDICAID MANAGED CARE, TO HAVE A MEDICAID OMBUDSMAN.

BE INFORMED IN WRITING IN PLAIN LANGUAGE WITH UP-TO-DATE INFORMATION ABOUT:

(I) THE SYSTEM OF CARE AND SERVICES FOR PERSONS WITH DEVELOPMENTAL DISABILITIES, INCLUDING BUT NOT LIMITED TO MANAGED CARE;

(II) THE LAWS, RULES, AND REGULATIONS APPLICABLE TO THE RIGHTS OF FAMILY MEMBERS AND OTHER PERSONAL REPRESENTATIVES TO PARTICIPATE IN DECISIONS ABOUT THE INDIVIDUAL'S LIFE AND TO ACCESS INFORMATION, RECORDS, REPORTS, CARE PLANS, ETC.; AND

(III) THE PROCEDURES TO CHALLENGE ANY DECISION AFFECTING THE INDIVIDUAL.

NOTHING IN THIS BILL OF RIGHTS AND PRIVILEGES SHALL LIMIT ANY OTHER RIGHT OR PRIVILEGE UNDER LAW. IF ANY RESIDENTIAL FACILITY OR NON-RESIDENTIAL SERVICE PROVIDER FAILS TO AFFORD THESE RIGHTS AND PRIVILEGES, ASSISTANCE MAY BE SOUGHT FROM THE FACILITY OR PROVIDER, OR THE OFFICE.

(D) A QUALIFIED PERSONAL REPRESENTATIVE MAY, IN ACCORDANCE WITH LAW AND APPROPRIATE DUE PROCESS, NOT EXERCISE A RIGHT OR PRIVILEGE DESCRIBED IN THIS SECTION IF THE SUBJECT INDIVIDUAL RECEIVING SERVICES, WHO IS COMPETENT TO DO SO, SPECIFICALLY AFFIRMS, IN A REASONABLY CONTEMPORANEOUS MANNER, THAT SUCH IDENTIFIED QUALIFIED PERSONAL REPRESENTATIVE SHALL NOT BE AFFORDED SUCH SPECIFIC RIGHT OR PRIVILEGE. SUCH DETERMI-

NATION BY THE SUBJECT INDIVIDUAL SHALL BE DESCRIBED AND RECORDED IN WRITING IN THE CASE FILE BY APPROPRIATE STAFF OF THE FACILITY OR SERVICE PROVIDER AND A STATEMENT OF REASONS FOR SUCH DENIAL SHALL BE PROVIDED TO THE QUALIFIED PERSONAL REPRESENTATIVE.

(E) THE STATEMENT OF RIGHTS AND PRIVILEGES SET FORTH IN THIS SECTION IS INTENDED TO BE A GUIDE TO THE RIGHTS AND PRIVILEGES OF QUALIFIED PERSONAL REPRESENTATIVES OF INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES RECEIVING RESIDENTIAL AND NON-RESIDENTIAL SERVICES.

(F) NOTHING IN THIS SECTION SHALL BE READ TO LIMIT ANY OTHER RIGHTS OR PRIVILEGES THAT QUALIFIED PERSONAL REPRESENTATIVES MAY HAVE OR LIMIT ANY ACTION OR RELIEF OTHERWISE PERMITTED BY LAW. NOTHING IN THIS SUBDIVISION SHALL ALTER OR AFFECT ANY RIGHT OF APPEAL, FORMAL OR OTHERWISE, SUCH PERSONAL REPRESENTATIVE MAY HAVE CONCERNING THE DENIAL OF ANY SUCH RIGHT.

(G) EACH PROVIDER SHALL CONSPICUOUSLY POST A COPY OF THE BILL OF RIGHTS AND PRIVILEGES IN A PUBLIC PLACE AT THE LOCATIONS WHERE THE PROVIDER PROVIDES SERVICES.

(H) THE COMMISSIONER SHALL:

(1) POST A COPY OF THE BILL OF RIGHTS AND PRIVILEGES ON THE OFFICE'S WEBSITE;

(2) MAKE COPIES OF THE BILL OF RIGHTS AND PRIVILEGES IN ENGLISH, AND THE TOP SIX LANGUAGES OTHER THAN ENGLISH SPOKEN IN THE STATE (ACCORDING TO THE LATEST AVAILABLE DATA FROM THE U.S. BUREAU OF CENSUS) AVAILABLE TO THE PUBLIC AND EVERY PROVIDER;

(3) ESTABLISH A PUBLIC EDUCATION PROGRAM DESIGNED TO DISSEMINATE INFORMATION REGARDING IMPLEMENTATION OF THIS SECTION;

(4) INCLUDE SPECIFIC INFORMATION DETAILING THE EFFORTS OF THE COMMISSIONER TO EFFECTUATE THIS SECTION IN THE STATEWIDE COMPREHENSIVE PLAN REQUIRED PURSUANT TO SECTION 5.07 OF THIS CHAPTER;

(5) ADOPT ALL RULES AND REGULATIONS NECESSARY TO EFFECTUATE THIS SECTION.

S 2. This act shall take effect immediately.