

STATE OF NEW YORK

6695

2021-2022 Regular Sessions

IN SENATE

May 12, 2021

Introduced by Sen. MANNION -- read twice and ordered printed, and when printed to be committed to the Committee on Disabilities

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:

1 Section 1. The mental hygiene law is amended by adding a new section
2 13.04 to read as follows:

3 § 13.04 Family bill of rights and privileges.

4 (a) The principles in the bill of rights and privileges set forth in
5 this section are declared to be the public policy of the state.

6 (b) For purposes of this section:

7 (1) "qualified personal representative" means a spouse, parent, adult
8 child, adult sibling, legal guardian or personal representative of an
9 individual with developmental disabilities who is receiving services
10 from a covered provider.

11 (2) "covered provider" means and includes any entity, providing resi-
12 dential services or non-residential services or programs to one or more
13 persons with a developmental disability, that is licensed, operated or
14 certified by the office.

15 (c) In addition to all other rights and privileges under law, a quali-
16 fied personal representative shall have the following rights and privi-
17 leges set forth below (the "Family Bill of Rights and Privileges") with
18 respect to their individual family members with developmental disabili-
19 ties.

20 "Family Bill of Rights and Privileges"

21 A qualified personal representative shall have the following general-
22 ly-described rights and privileges concerning a family member with
23 developmental disabilities receiving services; to:

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

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1 Be treated with consideration and respect.

2 Participate in and provide meaningful input into the development,
3 review and revision of the individual's care plan, including placement
4 or transfer within or between facilities.

5 Access information regarding the individual's health and safety,
6 consistent with federal and state confidentiality protections.

7 Be notified within a reasonable time of any event that directly
8 impacts the individual's health and safety, consistent with federal and
9 state confidentiality protections.

10 Access information necessary for a qualified personal representative
11 to make informed decisions, when appropriate, about the individual's
12 care and care coordination.

13 Financial transparency, including access to budgetary information of
14 the facility and individual expenses, consistent with federal and state
15 confidentiality protections.

16 Visit unannounced.

17 Be informed of staffing changes.

18 Access a facility's fire and other safety plans and any information
19 regarding a facility's passage or failure of any safety drills conducted
20 by the facility and the office.

21 Access a facility's food menus.

22 Choose a care coordinator.

23 Consult and be represented by an independent advocate, mental hygiene
24 legal services or an attorney; and if services are provided under Medi-
25 caid managed care, to have a Medicaid ombudsman.

26 Be informed in writing in plain language with up-to-date information
27 about:

28 (i) the system of care and services for persons with developmental
29 disabilities, including but not limited to managed care;

30 (ii) the laws, rules, and regulations applicable to the rights of
31 family members and other personal representatives to participate in
32 decisions about the individual's life and to access information,
33 records, reports, care plans, etc.; and

34 (iii) the procedures to challenge any decision affecting the individ-
35 ual.

36 Nothing in this bill of rights and privileges shall limit any other
37 right or privilege under law. If any residential facility or non-resi-
38 dential service provider fails to afford these rights and privileges,
39 assistance may be sought from the facility or provider, or the office.

40 (d) A qualified personal representative may, in accordance with law
41 and appropriate due process, not exercise a right or privilege described
42 in this section if the subject individual receiving services, who is
43 competent to do so, specifically affirms, in a reasonably contemporane-
44 ous manner, that such identified qualified personal representative
45 shall not be afforded such specific right or privilege. Such determi-
46 nation by the subject individual shall be described and recorded in
47 writing in the case file by appropriate staff of the facility or service
48 provider and a statement of reasons for such denial shall be provided to
49 the qualified personal representative.

50 (e) The statement of rights and privileges set forth in this section
51 is intended to be a guide to the rights and privileges of qualified
52 personal representatives of individuals with developmental disabilities
53 receiving residential and non-residential services.

54 (f) Nothing in this section shall be read to limit any other rights or
55 privileges that qualified personal representatives may have or limit any
56 action or relief otherwise permitted by law. Nothing in this subdivi-

1 sion shall alter or affect any right of appeal, formal or otherwise,
2 such personal representative may have concerning the denial of any such
3 right.

4 (g) Each covered provider shall conspicuously post a copy of the bill
5 of rights and privileges in a public place at each of the covered
6 provider's facilities.

7 (h) The commissioner shall:

8 (1) Post a copy of the bill of rights and privileges on the office's
9 website;

10 (2) Make copies of the bill of rights and privileges in English, and
11 the top six languages other than English spoken in the state (according
12 to the latest available data from the U.S. bureau of census) available
13 to the public and every provider;

14 (3) Establish a public education program designed to disseminate
15 information regarding implementation of this section;

16 (4) Include specific information detailing the efforts of the commis-
17 sioner to effectuate this section in the statewide comprehensive plan
18 required pursuant to section 5.07 of this chapter;

19 (5) Adopt all rules and regulations necessary to effectuate this
20 section.

21 § 2. This act shall take effect immediately.