

# STATE OF NEW YORK

3789

2019-2020 Regular Sessions

## IN SENATE

February 14, 2019

Introduced by Sen. CARLUCCI -- read twice and ordered printed, and when printed to be committed to the Committee on Mental Health and Developmental 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"

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

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

4 Be treated with consideration and respect.

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

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

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

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

16 Financial transparency, including access to budgetary information of  
17 the facility and individual expenses, consistent with federal and state  
18 confidentiality protections.

19 Visit unannounced.

20 Be informed of staffing changes.

21 Access a facility's fire and other safety plans and any information  
22 regarding a facility's passage or failure of any safety drills conducted  
23 by the facility and the office.

24 Access a facility's food menus.

25 Choose a care coordinator.

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

29 Be informed in writing in plain language with up-to-date information  
30 about:

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

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

37 (iii) the procedures to challenge any decision affecting the individ-  
38 ual.

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

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

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

1 (f) Nothing in this section shall be read to limit any other rights or  
2 privileges that qualified personal representatives may have or limit any  
3 action or relief otherwise permitted by law. Nothing in this subdivi-  
4 sion shall alter or affect any right of appeal, formal or otherwise,  
5 such personal representative may have concerning the denial of any such  
6 right.

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

10 (h) The commissioner shall:

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

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

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

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

22 (5) Adopt all rules and regulations necessary to effectuate this  
23 section.

24 § 2. This act shall take effect immediately.