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I N S E N A T E

February 7, 2012

Introduced by Sen. MAZIARZ -- 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 enacting the "people first act of 2012"

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

1 Section 1. Short title. This act shall be known and may be cited as
2 the "people first act of 2012".
3 S 2. Legislative findings. It is the intent of the legislature to
4 ensure that individuals with developmental disabilities who utilize
5 long-term care services under the medical assistance program and other
6 long-term care related benefit programs administered by the state have
7 meaningful access to a reasonable array of community-based and institu-
8 tional program options and to ensure the well-being of individuals with
9 developmental disabilities, taking into account their informed and
10 expressed choices. Furthermore, the legislature declares that it is the
11 policy of the state to ensure that the clinical, habilitative, and
12 social needs of individuals with developmental disabilities who choose
13 to reside in integrated community-based settings can have those needs
14 met in integrated community-based settings. In order to meaningfully
15 comply with this policy, the state must have an understanding of the
16 existing capacity in integrated-community based settings, including
17 direct support professionals and licensed professionals, such as physi-
18 cians, dentists, nurse practitioners, nurses, and psychiatrists, as well
19 as residential capacity to provide for these needs.
20 It is further the intent of the legislature to support the satisfac-
21 tion and success of consumers through the delivery of quality services
22 and supports. Evaluation of the services that consumers receive is a key
23 aspect to the service system. Utilizing the information that consumers
24 and their families provide about such services in a reliable and mean-
25 ingful way is also critical to enable the commissioner of developmental
26 disabilities to assess the performance of the state's developmental
27 services system and to improve services for consumers in the future. To

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

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1 that end, the commissioner of developmental disabilities shall conduct a
2 geographic analysis of supports and services in community settings and
3 implement an improved, unified quality assessment system, in accordance
4 with this act.

5 S 3. Section 13.15 of the mental hygiene law is amended by adding a
6 new subdivision (d) to read as follows:

7 (D) (1) FOR PURPOSES OF THIS SUBDIVISION, THE FOLLOWING TERMS SHALL
8 HAVE THE FOLLOWING MEANINGS:

9 (I) "DIRECT SUPPORT PROFESSIONALS" MEANS DIRECT SUPPORT WORKERS,
10 DIRECT CARE WORKERS, PERSONAL ASSISTANTS, PERSONAL ATTENDANTS, AND PARA-
11 PROFESSIONALS THAT PROVIDE ASSISTANCE TO INDIVIDUALS WITH DEVELOPMENTAL
12 DISABILITIES IN THE FORM OF DAILY LIVING, AND PROVIDE THE HABILITATION,
13 REHABILITATION, AND TRAINING NEEDS OF THESE INDIVIDUALS.

14 (II) "LICENSED PROFESSIONALS" MEANS, BUT IS NOT LIMITED TO, PHYSI-
15 CIANS, DENTISTS, DENTAL HYGIENISTS, DENTAL ASSISTANTS, NURSE PRACTITION-
16 ERS, LICENSED PRACTICAL NURSES, REGISTERED NURSES, PSYCHIATRISTS,
17 PSYCHOLOGISTS, LICENSED MASTER SOCIAL WORKERS, OR LICENSED CLINICAL
18 SOCIAL WORKERS, LICENSED TO PRACTICE PURSUANT TO THE EDUCATION LAW AND
19 OTHER QUALIFIED MENTAL HEALTH PROFESSIONALS.

20 (III) "SUPPORTS AND SERVICES" MEANS DIRECT SUPPORT PROFESSIONALS,
21 LICENSED PROFESSIONALS, AND RESIDENTIAL SERVICES, INCLUDING, BUT NOT
22 LIMITED TO, PRIVATE RESIDENCES, COMMUNITY-INTEGRATED LIVING ARRANGE-
23 MENTS, SUPPORTED RESIDENTIAL PROGRAMS, SUPERVISED RESIDENTIAL PROGRAMS,
24 OR SUPPORTIVE HOUSING PROGRAMS.

25 (2) SUBJECT TO AVAILABLE APPROPRIATIONS THEREFOR, THE COMMISSIONER
26 SHALL CONDUCT A GEOGRAPHIC ANALYSIS OF SUPPORTS AND SERVICES IN COMMUNI-
27 TY SETTINGS FOR INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES. THIS ANALY-
28 SIS SHALL ALSO IDENTIFY GAPS BETWEEN REQUIRED SUPPORTS AND SERVICES BY
29 REGION OF THE STATE.

30 (3) IN ORDER TO PERFORM THE GEOGRAPHIC ANALYSIS OR TO GATHER DATA FOR
31 PURPOSES OF PERFORMING THE GEOGRAPHIC ANALYSIS, THE COMMISSIONER MAY
32 WORK IN COOPERATION AND AGREEMENT WITH OTHER OFFICES, DEPARTMENTS OR
33 AGENCIES OF THE STATE, LOCAL OR FEDERAL GOVERNMENT, OR OTHER ORGANIZA-
34 TIONS AND INDIVIDUALS.

35 (4) IN CONDUCTING THIS ACTIVITY, THE COMMISSIONER, SUBJECT TO AVAIL-
36 ABLE APPROPRIATIONS THEREFOR, SHALL DEVELOP AND UTILIZE A WEB-BASED
37 DATA-BASE WHICH PRIORITIZES THE URGENCY OF NEED FOR SUPPORTS AND
38 SERVICES. THE INFORMATION COLLECTED SHOULD ALLOW THE COMMISSIONER TO
39 CATEGORIZE NEEDS FOR DEVELOPMENTAL DISABILITY SERVICES WITHIN A FRAME-
40 WORK THAT ENCOMPASSES THREE LEVELS OF URGENCY OF NEEDS. THESE LEVEL OF
41 SUPPORT NEEDS SHOULD INCLUDE: EMERGENCY NEED, FOR THOSE PERSONS WITH
42 DEVELOPMENTAL DISABILITIES IN NEED OF IMMEDIATE SUPPORT EITHER DAY
43 SUPPORT OR IN-HOME OR OUT-OF-HOME PLACEMENT; CRITICAL NEED FOR THOSE
44 INDIVIDUALS WHO WILL HAVE A NEED FOR SUPPORTS OR SERVICES WITHIN ONE
45 YEAR AND PLANNING FOR NEED, FOR THOSE INDIVIDUALS WHOSE SUPPORT NEEDS
46 ARE ONE TO FIVE YEARS AWAY, OR WHERE THE CAREGIVER IS AGE SIXTY OR
47 OLDER.

48 (5) SUCH AN ANALYSIS SHOULD INCLUDE THE STATEWIDE NUMBER OF INDIVID-
49 UALS SEEKING SERVICES, INCLUDING AWAITING PLACEMENT BROKEN DOWN INTO THE
50 TOTAL NUMBER OF INDIVIDUALS FROM WITHIN EACH DEVELOPMENTAL DISABILITY
51 SERVICES OFFICE'S GEOGRAPHIC AREA WHO AWAIT RESIDENTIAL PLACEMENT, DAY
52 SERVICE SUPPORT, HOME AND COMMUNITY-BASED WAIVER SUPPORT, EMPLOYMENT
53 SUPPORT, BEHAVIORAL HEALTH SERVICES AND SUPPORTS, OR OTHER
54 COMMUNITY-BASED SUPPORT. SUCH INFORMATION SHOULD BE GROUPED BY THE AGE
55 OF THE INDIVIDUAL AWAITING COMMUNITY SERVICES AND SUPPORTS AND THE AGE

1 OF THEIR CAREGIVER, IF ANY. SUCH INFORMATION SHOULD ALSO INCLUDE WAIT-
2 LIST AND PLACEMENT INFORMATION SUCH AS:

3 (I) THE TYPE OF SUPPORTS AND SERVICES SUCH INDIVIDUALS ARE EXPECTED TO
4 REQUIRE DIVIDED INTO CERTIFIED OUT-OF-HOME, SUPERVISED, SUPPORTIVE
5 PLACEMENT NEEDS AND OTHER NON-PLACEMENT NEEDS AND THE NUMBER OF SUCH
6 PERSONS WHO ARE MEDICALLY FRAIL REQUIRING INTENSIVE MEDICAL CARE;

7 (II) NON-CERTIFIED RESIDENTIAL PLACEMENTS OUTSIDE THE PARENT'S OR
8 PARENTS' OR OTHER CAREGIVER'S HOME;

9 (III) THE NUMBER OF INDIVIDUALS EXPECTED TO REQUIRE HOME AND COMMUNITY
10 SERVICES WAIVER-FUNDED HABILITATION SERVICES AT HOME;

11 (IV) THE TOTAL NUMBER OF INDIVIDUALS, WHO HAVE BEEN IDENTIFIED AS IN
12 NEED OF SUPPORTS AND SERVICES WHO HAVE RECEIVED THESE SUPPORTS AND
13 SERVICES AND ANY GAP BETWEEN REQUIRED SUPPORTS AND SERVICES AND THE
14 SUPPORTS AND SERVICES PROVIDED;

15 (V) THE NUMBER OF EMERGENCY NEED RESIDENTIAL PLACEMENTS FOR THE PAST
16 YEAR AND OTHER SUPPORTS AND SERVICES PROVIDED ON AN EMERGENCY BASIS;

17 (VI) THE NUMBER OF INDIVIDUALS WHO ARE CURRENTLY RECEIVING SUPPORTS
18 AND SERVICES, INCLUDING RESIDENTIAL SERVICES, WHOSE CURRENT LIVING SITU-
19 ATION IS NOT ADEQUATE TO MEET THEIR NEEDS AND WHO ARE AWAITING AN ALTER-
20 NATIVE PLACEMENT OR ALTERNATIVE SUPPORT AND SERVICE DELIVERY OPTIONS;

21 (VII) PROJECTED FUNDING REQUIREMENTS FOR INDIVIDUALS IDENTIFIED AS IN
22 NEED OF SERVICES PURSUANT TO PARAGRAPH FOUR OF THIS SUBDIVISION;

23 (VIII) AN UPDATED FIVE YEAR PROJECTION OF INDIVIDUALS WHO WILL REQUIRE
24 EITHER ADDITIONAL IN-HOME SUPPORTS AND SERVICES AND/OR OUT-OF-HOME RESI-
25 DENTIAL PLACEMENTS; AND

26 (IX) ANY OTHER INFORMATION DEEMED NECESSARY BY THE COMMISSIONER.

27 (6) THE COMMISSIONER SHALL PREPARE ANNUALLY FOR THE GOVERNOR, THE
28 LEGISLATURE AND THE STATE COMMISSION ON QUALITY OF CARE FOR THE MENTALLY
29 DISABLED A WRITTEN EVALUATION REPORT CONCERNING THE DELIVERY OF SUPPORTS
30 AND SERVICES IN THE COMMUNITY. ON OR BEFORE MARCH FIRST, IN EACH YEAR,
31 THE COMMISSIONER SHALL SUBMIT A COPY OF SUCH REPORT, AND SUCH RECOMMEN-
32 DATION AS HE OR SHE DEEMS APPROPRIATE, TO THE GOVERNOR, THE TEMPORARY
33 PRESIDENT OF THE SENATE, THE SPEAKER OF THE ASSEMBLY, THE RESPECTIVE
34 MINORITY LEADERS OF EACH SUCH HOUSE, AND THE CHAIR OF THE STATE COMMIS-
35 SION ON QUALITY OF CARE FOR THE MENTALLY DISABLED. THE FIRST SUCH REPORT
36 SHALL BE DUE BY NO LATER THAN MARCH FIRST, TWO THOUSAND FOURTEEN. THE
37 REPORT SHALL ALSO BE MADE AVAILABLE TO THE PUBLIC AND SHALL BE PUBLISHED
38 ON THE OFFICE'S WEBSITE IN AN APPROPRIATE LOCATION AT THE SAME TIME AS
39 ITS SUBMISSION TO STATE OFFICIALS.

40 S 4. Subdivision (c) of section 16.01 of the mental hygiene law, as
41 added by chapter 234 of the laws of 1998, paragraph 1 as amended by
42 chapter 37 of the laws of 2011, is amended to read as follows:

43 [(c)] (J) (1) Notwithstanding any other provision of law, the commis-
44 sioner, or his OR HER designee, may require from any hospital, as
45 defined under article twenty-eight of the public health law, any infor-
46 mation, report, or record necessary for the purpose of carrying out the
47 functions, powers and duties of the commissioner related to the investi-
48 gation of deaths and complaints of abuse, mistreatment, or neglect
49 concerning persons with developmental disabilities who receive services,
50 or had prior to death received services, in a facility as defined in
51 section 1.03 of this chapter, or are receiving medicaid waiver services
52 from the office for people with developmental disabilities in a non-cer-
53 tified setting, and have been treated at such hospitals.

54 (2) Any information, report, or record requested by the commissioner
55 or his OR HER designee pursuant to this subdivision shall be limited to

1 that information that the commissioner determines necessary for the
2 completion of this investigation.

3 (3) The information, report or record received by the commissioner or
4 his OR HER designee pursuant to this subdivision shall be subject to
5 section two thousand eight hundred five-m, section eighteen, as added by
6 chapter four hundred ninety-seven of the laws of nineteen hundred eight-
7 y-six, and article twenty-seven-F of the public health law, section
8 33.13 of this chapter, and any applicable federal statute or regulation.

9 S 5. Section 16.01 of the mental hygiene law is amended by adding
10 seven new subdivisions (c), (d), (e), (f), (g), (h) and (i) to read as
11 follows:

12 (C) THE COMMISSIONER, IN CONSULTATION WITH STAKEHOLDERS, INCLUDING BUT
13 NOT LIMITED TO PROVIDERS OF SERVICES FOR PERSONS WITH DEVELOPMENTAL
14 DISABILITIES, CONSUMER REPRESENTATIVES INCLUDING PERSONS WITH DEVELOP-
15 MENTAL DISABILITIES, OR THEIR PARENTS OR GUARDIANS, CORRESPONDENTS AND
16 OTHER INTERESTED PERSONS, SHALL IDENTIFY A VALID AND RELIABLE QUALITY
17 ASSURANCE INSTRUMENT THAT INCLUDES ASSESSMENTS OF CONSUMER AND FAMILY
18 SATISFACTION, PROVISION OF SERVICES, AND PERSONAL OUTCOMES. THE INSTRU-
19 MENT SHALL DO ALL OF THE FOLLOWING:

20 (1) PROVIDE NATIONALLY VALIDATED, BENCHMARKED, CONSISTENT, RELIABLE
21 AND MEASURABLE DATA FOR THE OFFICE'S QUALITY MANAGEMENT SYSTEM.

22 (2) ENABLE THE COMMISSIONER AND ENTITIES CONTRACTED BY THE COMMISSION-
23 ER TO COORDINATE AND/OR DELIVER SUPPORTS AND SERVICES TO PERSONS WITH
24 DEVELOPMENTAL DISABILITIES, INCLUDING BUT NOT LIMITED TO HEALTH HOMES
25 ESTABLISHED PURSUANT TO SECTION THREE HUNDRED SIXTY-FIVE-L OF THE SOCIAL
26 SERVICES LAW OR OTHER MANAGED CARE ENTITIES AS APPROVED PURSUANT TO
27 SECTION FOUR THOUSAND FOUR HUNDRED THREE-F OF THE PUBLIC HEALTH LAW TO
28 COMPARE THE PERFORMANCE OF NEW YORK'S DEVELOPMENTAL SERVICES SYSTEM
29 AGAINST OTHER STATES' DEVELOPMENTAL SERVICES SYSTEMS AND TO ASSESS QUAL-
30 ITY AND PERFORMANCE AMONG ALL OF THE MANAGED CARE AND SERVICE AND
31 SUPPORT ENTITIES STATEWIDE.

32 (3) INCLUDE OUTCOME-BASED MEASURES SUCH AS HEALTH, SAFETY, WELL-BEING,
33 RELATIONSHIPS, INTERACTIONS WITH PEOPLE WHO DO NOT HAVE A DISABILITY,
34 EMPLOYMENT, QUALITY OF LIFE, INTEGRATION, CHOICE, SERVICE, AND CONSUMER
35 SATISFACTION.

36 (D) TO THE EXTENT THAT FUNDING IS AVAILABLE, THE INSTRUMENT IDENTIFIED
37 IN SUBDIVISION (C) OF THIS SECTION MAY BE EXPANDED TO COLLECT ADDITIONAL
38 DATA REQUESTED BY OTHER OFFICES, DEPARTMENTS OR AGENCIES OF THE STATE,
39 LOCAL OR FEDERAL GOVERNMENT.

40 (E) THE COMMISSIONER SHALL CONTRACT WITH AN INDEPENDENT AGENCY OR
41 ORGANIZATION TO IMPLEMENT BY JANUARY FIRST, TWO THOUSAND THIRTEEN, THE
42 QUALITY ASSURANCE INSTRUMENT DESCRIBED IN SUBDIVISION (C) OF THIS
43 SECTION. THE CONTRACTOR SHALL BE EXPERIENCED IN ALL OF THE FOLLOWING:

44 (1) DESIGNING VALID QUALITY ASSURANCE INSTRUMENTS FOR DEVELOPMENTAL
45 SERVICE SYSTEMS.

46 (2) TRACKING OUTCOME-BASED MEASURES SUCH AS HEALTH, SAFETY, WELL-BE-
47 ING, RELATIONSHIPS, INTERACTIONS WITH PEOPLE WHO DO NOT HAVE A DISABILI-
48 TY, EMPLOYMENT, QUALITY OF LIFE, INTEGRATION, CHOICE, SERVICE, AND
49 CONSUMER SATISFACTION.

50 (3) DEVELOPING DATA SYSTEMS.

51 (4) DATA ANALYSIS AND REPORT PREPARATION.

52 (5) ASSESSMENTS OF THE SERVICES RECEIVED BY CONSUMERS WHO ARE MOVED
53 FROM DEVELOPMENTAL CENTERS TO THE COMMUNITY, GIVEN THE LEGISLATURE'S
54 HISTORIC RECOGNITION OF A SPECIAL OBLIGATION TO ENSURE THE WELL-BEING OF
55 THESE PERSONS.

1 (F) THE COMMISSIONER, IN CONSULTATION WITH THE CONTRACTOR DESCRIBED IN
2 SUBDIVISION (E) OF THIS SECTION, SHALL ESTABLISH THE METHODOLOGY BY
3 WHICH THE QUALITY ASSURANCE INSTRUMENT SHALL BE ADMINISTERED, INCLUDING,
4 BUT NOT LIMITED TO, HOW OFTEN AND TO WHOM THE QUALITY ASSURANCE WILL BE
5 ADMINISTERED, AND THE DESIGN OF A STRATIFIED, RANDOM SAMPLE AMONG THE
6 ENTIRE POPULATION OF CONSUMERS SERVED BY SERVICE PROVIDERS, INCLUDING
7 ANY NEWLY APPROVED MANAGED CARE ENTITIES. THE CONTRACTOR SHALL PROVIDE
8 AGGREGATE INFORMATION FOR ALL SERVICE PROVIDERS AND THE STATE AS A
9 WHOLE. AT THE REQUEST OF A CONSUMER OR THE FAMILY MEMBER OF A CONSUMER,
10 THE SURVEY SHALL BE CONDUCTED IN THE PRIMARY LANGUAGE OF THE CONSUMER OR
11 FAMILY MEMBER SURVEYED.

12 (G) THE COMMISSIONER SHALL COLLECT DATA FOR THE QUALITY ASSURANCE
13 INSTRUMENT DESCRIBED IN SUBDIVISION (C) OF THIS SECTION. IF, DURING THE
14 DATA COLLECTION PROCESS, THE COMMISSIONER IDENTIFIES ANY SUSPECTED
15 VIOLATION OF THE LEGAL, CIVIL, OR SERVICE RIGHTS OF A CONSUMER, OR IF IT
16 DETERMINES THAT THE HEALTH AND WELFARE OF A CONSUMER IS AT RISK, THAT
17 INFORMATION SHALL BE PROVIDED IMMEDIATELY TO THE CHAIR OF THE COMMISSION
18 ON QUALITY OF CARE FOR THE MENTALLY DISABLED AND ANY REGIONAL ENTITY
19 PROVIDING CASE MANAGEMENT SERVICES TO THE CONSUMER. AT THE REQUEST OF
20 THE CONSUMER, OR FAMILY, WHEN APPROPRIATE, A COPY OF THE COMPLETED
21 SURVEY SHALL BE PROVIDED TO THE COMMISSION ON QUALITY OF CARE FOR THE
22 MENTALLY DISABLED AND ANY REGIONAL ENTITY PROVIDING CASE MANAGEMENT
23 SERVICES TO IMPROVE THE CONSUMER'S QUALITY OF SERVICES THROUGH THE INDI-
24 VIDUAL PLANNING PROCESS.

25 (H) THE COMMISSIONER, IN CONSULTATION WITH STAKEHOLDERS, SHALL ANNUAL-
26 LY REVIEW THE DATA COLLECTED FROM AND THE FINDINGS OF THE QUALITY ASSUR-
27 ANCE INSTRUMENT DESCRIBED IN SUBDIVISION (C) OF THIS SECTION AND ACCEPT
28 RECOMMENDATIONS REGARDING ADDITIONAL OR DIFFERENT CRITERIA FOR THE QUAL-
29 ITY ASSURANCE INSTRUMENT IN ORDER TO ASSESS THE PERFORMANCE OF THE
30 STATE'S DEVELOPMENTAL SERVICES SYSTEM AND IMPROVE SERVICES FOR CONSUM-
31 ERS.

32 (I) ALL REPORTS GENERATED PURSUANT TO THIS SECTION SHALL BE MADE
33 PUBLICLY AVAILABLE, BUT SHALL NOT CONTAIN ANY PERSONAL IDENTIFYING
34 INFORMATION ABOUT ANY PERSON ASSESSED.

35 S 6. This act shall take effect immediately.