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I N   A S S E M B L Y

February 28, 2012

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Introduced by M. of A. GABRYSZAK -- read once and referred to the  
Committee on Mental Health

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  
28    that end, the commissioner of developmental disabilities shall conduct a

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

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1 geographic analysis of supports and services in community settings and  
2 implement an improved, unified quality assessment system, in accordance  
3 with this act.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

(VI) THE NUMBER OF INDIVIDUALS WHO ARE CURRENTLY RECEIVING SUPPORTS AND SERVICES, INCLUDING RESIDENTIAL SERVICES, WHOSE CURRENT LIVING SITUATION IS NOT ADEQUATE TO MEET THEIR NEEDS AND WHO ARE AWAITING AN ALTERNATIVE PLACEMENT OR ALTERNATIVE SUPPORT AND SERVICE DELIVERY OPTIONS;

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

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

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

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

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

[(c)] (J) (1) Notwithstanding any other provision of law, the commissioner, or his OR HER designee, may require from any hospital, as defined under article twenty-eight of the public health law, any information, report, or record necessary for the purpose of carrying out the functions, powers and duties of the commissioner related to the investigation of deaths and complaints of abuse, mistreatment, or neglect concerning persons with developmental disabilities who receive services, or had prior to death received services, in a facility as defined in section 1.03 of this chapter, or are receiving medicaid waiver services from the office for people with developmental disabilities in a non-certified setting, and have been treated at such hospitals.

(2) Any information, report, or record requested by the commissioner or his OR HER designee pursuant to this subdivision shall be limited to that information that the commissioner determines necessary for the completion of this investigation.

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

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

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

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

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

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

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

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

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

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

(3) DEVELOPING DATA SYSTEMS.

(4) DATA ANALYSIS AND REPORT PREPARATION.

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

(F) THE COMMISSIONER, IN CONSULTATION WITH THE CONTRACTOR DESCRIBED IN SUBDIVISION (E) OF THIS SECTION, SHALL ESTABLISH THE METHODOLOGY BY WHICH THE QUALITY ASSURANCE INSTRUMENT SHALL BE ADMINISTERED, INCLUDING,

1 BUT NOT LIMITED TO, HOW OFTEN AND TO WHOM THE QUALITY ASSURANCE WILL BE  
2 ADMINISTERED, AND THE DESIGN OF A STRATIFIED, RANDOM SAMPLE AMONG THE  
3 ENTIRE POPULATION OF CONSUMERS SERVED BY SERVICE PROVIDERS, INCLUDING  
4 ANY NEWLY APPROVED MANAGED CARE ENTITIES. THE CONTRACTOR SHALL PROVIDE  
5 AGGREGATE INFORMATION FOR ALL SERVICE PROVIDERS AND THE STATE AS A  
6 WHOLE. AT THE REQUEST OF A CONSUMER OR THE FAMILY MEMBER OF A CONSUMER,  
7 THE SURVEY SHALL BE CONDUCTED IN THE PRIMARY LANGUAGE OF THE CONSUMER OR  
8 FAMILY MEMBER SURVEYED.

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

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

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

32 S 6. This act shall take effect immediately.