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I N   S E N A T E

February 1, 2010

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Introduced by Sen. McDONALD -- 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 defining a bill of rights for persons with autism or autism spectrum disorders

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     16.39 to read as follows:  
3     S 16.39 BILL OF RIGHTS FOR PERSONS WITH AUTISM OR AUTISM SPECTRUM DISOR-  
4     DERS.  
5     (A) BOTH EARLY INTERVENTION AND CONTINUING TREATMENT ARE INTEGRAL TO  
6     THE HEALTHCARE OF THOSE DIAGNOSED WITH AUTISM OR AUTISM SPECTRUM DISOR-  
7     DERS. INSURANCE COMPANIES SHALL NOT DISCRIMINATE AGAINST INDIVIDUALS  
8     WITH SUCH DIAGNOSES BY IMPOSING FINANCIAL BURDENS AND BARRIERS TO TREAT-  
9     MENT SUCH AS DIFFERENTIAL DEDUCTIBLES, DISPARATE CO-PAYS, SPENDING CAPS,  
10    AND ARBITRARY LIMITS ON ACCESS TO MEDICALLY NECESSARY INPATIENT AND/OR  
11    OUTPATIENT SERVICES.  
12    (B) ALL PERSONS WITH AUTISM OR AUTISM SPECTRUM DISORDERS SHALL HAVE  
13    THE FOLLOWING RIGHTS:  
14    (1) THE RIGHT TO AN INCREASED INVESTMENT IN HIGH-QUALITY RESEARCH ON  
15    THE ORIGIN, DIAGNOSIS AND TREATMENT OF AUTISM AND AUTISM SPECTRUM DISOR-  
16    DERS;  
17    (2) THE RIGHT TO ACCESS, AND HAVE THEIR PARENTS AND/OR GUARDIANS  
18    ACCESS, A COMPREHENSIVE CONTINUUM OF CARE BASED ON THE PATIENT'S NEEDS-  
19    -INCLUDING A FULL RANGE OF PSYCHOSOCIAL, BEHAVIORAL, PHARMACOLOGICAL AND  
20    EDUCATIONAL SERVICES--REGARDLESS OF THE COST;  
21    (3) THE RIGHT TO RECEIVE TREATMENT WITHIN A COORDINATED SYSTEM OF CARE  
22    WHERE ALL AGENCIES DELIVERING SERVICES (INCLUDING BUT NOT LIMITED TO  
23    HEALTH, MENTAL HEALTH, CHILD WELFARE, JUVENILE JUSTICE AND EDUCATION)  
24    WORK TOGETHER TO OPTIMIZE TREATMENT OUTCOME;  
25    (4) THE RIGHT TO RECEIVE IN-HOME CARE, AS WELL AS TREATMENT IN COMMU-  
26    NITY-BASED SETTINGS AS CLOSE TO HOME AS POSSIBLE;

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

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1 (5) THE RIGHT TO RECEIVE CARE FROM HIGHLY QUALIFIED PROFESSIONALS WHO  
2 ACT IN THE BEST INTERESTS OF THE PATIENT AND FAMILY;

3 (6) THE RIGHT TO TREATMENT THAT IS FAMILY-DRIVEN AND PATIENT-FOCUSED.  
4 PARENTS AND/OR GUARDIANS (AND PATIENTS WHEN APPROPRIATE) MUST HAVE THE  
5 PRIMARY DECISION-MAKING ROLE WITH REGARD TO TREATMENT;

6 (7) THE RIGHT TO RECEIVE, AND HAVE THEIR PARENTS AND/OR GUARDIANS  
7 RECEIVE, ALL INFORMATION REGARDING THE RISKS, BENEFITS AND ANTICIPATED  
8 OUTCOMES OF ALL AVAILABLE TREATMENT OPTIONS THAT IS NECESSARY TO FACILI-  
9 TATE EDUCATED DECISIONS AND INFORMED CONSENT;

10 (8) THE RIGHT TO ACCESS, AND HAVE THEIR PARENTS AND/OR GUARDIANS  
11 ACCESS, MENTAL HEALTH PROFESSIONALS WITH APPROPRIATE TRAINING AND EXPE-  
12 RIENCE. PRIMARY CARE PROFESSIONALS PROVIDING MENTAL HEALTH SERVICES  
13 MUST HAVE ACCESS TO CONSULTATION AND REFERRAL RESOURCES FROM QUALIFIED  
14 MENTAL HEALTH PROFESSIONALS; AND

15 (9) THE RIGHT TO APPROPRIATE MONITORING OF PHARMACEUTICAL TREATMENT  
16 FOR MENTAL DISORDERS, BOTH TO OPTIMIZE THE BENEFITS AND TO MINIMIZE ANY  
17 RISKS OR POTENTIAL SIDE-EFFECTS ASSOCIATED WITH SUCH TREATMENTS.

18 S 2. This act shall take effect immediately.