New York State Senate

Notice of Public Hearing

Senate Standing Committee on Insurance
Neil D. Breslin, Chair

Senate Standing Committee on Health
Thomas K. Duane, Chair

Senate Standing Committee on Mental Health and Developmental Disabilities
Shirley L. Huntley, Chair

SUBJECT: The role of health insurance in the diagnosis and treatment of autism spectrum disorder.

PURPOSE: The purpose of this hearing is to (1) explore the health care needs of individuals with autism spectrum disorder and their families; (2) explore what health insurers, the federal government, state and local governments and educational institutions are doing to meet those needs; and (3) explore whether health insurers should be mandated to provide coverage for the screening, diagnosis and treatment of autism spectrum disorder.

October 23, 2009

10 a.m.

Meeting Rooms 2 and 3

Empire State Plaza, Concourse Level

Albany, New York

Autism spectrum disorder (ASD), which includes autistic disorder, asperger disorder and pervasive developmental disorder – not otherwise specified, is one of the fastest growing neurodevelopmental disabilities in America. According to a recent U.S. Centers for Disease Control and Prevention (CDC) study, autism spectrum disorder affects as many as 1 in 150 American children. In New York State, it is estimated that 33,000 children and youth from birth to age 17 have autism.

As with other neurodevelopmental disabilities, ASD is generally not curable. However, numerous studies have concluded that children who receive intensive treatment early in life will be more functional and less likely to need lifelong services. The Autism Society of America estimates that the lifetime cost of caring for an individual with autism ranges from $3.5 to $5 million. Therefore, the financial and societal costs of failing to provide intensive treatment early in life to children with ASD are notable.

Individuals with ASD experience a wide range of medical issues. Consequently, treatment for autism spectrum disorders can include, among other things, psychiatric care, psychological care, habilitative or rehabilitative care, pediatric and developmental pediatric care, gastroenterologic care, endocrinological care, and behavioral, social skills, speech, occupational and physical therapies.

State and local governments and educational institutions currently play a large role in the diagnosis and treatment of autism. For example, young children diagnosed with autism are eligible for New York State's Early Intervention Program. Some families who have a child with autism qualify for a "Medicaid waiver" under which the parents' income is waived when determining eligibility for Medicaid. Medicaid would then cover certain medical and non-medical expenses associated with autism. In addition, school-aged children with autism receive various services during the school day.

However, children often need intensive therapy and other health services beyond what state or local governments or schools are able to provide. It has been reported from numerous sources that most health plans in New York do not cover or cover a very small amount of the expenses of individuals with ASD. In addition, the New York State Department of Health (DOH) reports that private health insurance pays only about 3% of the expenses of children with ASD in the Early Intervention Program. In the absence of private health coverage, families of those with ASD pay a significant portion of the cost of diagnosing and treating ASD. Such costs, which can be as high as $2,000 to $4,000 per month, place a significant financial strain on families.

Historically, autism was considered a psychiatric disability and excluded from coverage by health insurers. In 2006, the New York State Insurance Law was amended to prohibit insurers from excluding coverage for medical conditions solely because the treatment is provided to diagnose or treat ASD. In addition, Timothy's Law, which was enacted in 2006, provides coverage for the treatment of autism spectrum disorders so long as the coverage is provided by a large group employer (51+ members), or, for children only, at the option of a small group employer (50 or less), or, in some instances, the health plan. While this coverage is available, reimbursement is often denied on grounds that the service is educational, the treatment is experimental or the treatment is not medically necessary. However, New York law currently does not mandate that health insurers cover specific ASD treatments or services.

Several other states have laws requiring health insurers to cover treatment for ASD. A dozen other states are considering such legislation. In addition, earlier this year, the Autism Treatment Acceleration Act of 2009 (Senate Bill No. 819) was introduced in the U.S. Senate. This legislation would require, among other things, health insurers to cover the diagnosis and treatment of autism spectrum disorders.

The Committees would like to hear from individuals with ASD, family members of individuals with ASD, treatment providers, health care experts and policy makers in order to evaluate the role of health insurers in the diagnosis and treatment of ASD. **Specifically, witnesses may direct their testimony to the following issues:**

1) What are the health care needs of children, young adults and older adults with ASD and their families?

2) What are health insurers doing to meet the needs of individuals with ASD and their families?

3) What obstacles to treatment are individuals with ASD and their families encountering?

4) What services, programs and resources do New York state and local government entities and schools have in place to address the needs of individuals with ASD?

5) What is the federal government doing to meet the health care needs of individuals with ASD and their families?

6) Should health insurers be mandated to provide coverage for the screening, diagnosis and treatment of ASD? If so:

    a) Which treatments and services for individuals with ASD and their families should health insurers be required to cover?

    b) What should the process be for determining which treatments and services must be covered? Should insurers only be required to cover treatments for ASD that have been determined necessary based upon a review of evidence-based research (e.g., the New York State Department of Health’s Clinical Practice Guidelines for ASD for children under the age of three)?

    c) What should the process be for determining reimbursement rates to providers?

    d) Should there be age limits, limits on the number of visits or monetary caps on mandated treatments or services for ASD?

    e) What impact would this mandate have on health insurance premium rates?

f) How would existing service systems that New York has in place be impacted by an insurance mandate?

g) Should the mandate be reflected in a new law or should an existing law be amended?

h) Do the laws of other states that mandate coverage for ASD contain age limits, limits on the number of visits or monetary caps on mandated treatments or services?

7) Within the context of responding to any of the above questions, witnesses may provide comments on S.2366/A.6001 and S.6123/A.6888-B which are currently pending in the New York State Legislature as well as S.819/H.R. 2413 which are currently pending in the U.S. Congress.

Persons wishing to present pertinent testimony to the Committees on the questions listed above should complete and return the enclosed reply form no later than **October 5, 2009.** It is important that the reply form be fully completed and returned so that persons may be notified in the event of emergency postponement or cancellation.

Oral testimony will be by invitation only and limited to ten minutes duration. In preparing the order of witnesses, the Committees will attempt to accommodate individual requests to speak at particular times in view of special circumstances. These requests should be made on the attached reply form or communicated to Committee staff as early as possible.

Ten copies of any prepared testimony should be submitted at the hearing registration desk. The Committees would appreciate advance receipt of prepared statements.

In order to further publicize these hearings, please inform interested parties and organizations of the Committees’ interest in hearing testimony from all sources.

Reasonable accommodations will be provided upon request to individuals with disabilities.

PUBLIC HEARING REPLY FORM

Please respond by October 5, 2009

Persons wishing to submit written or oral testimony at the public hearing are requested to complete this reply form as soon as possible and mail or fax it to:

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Albany, New York 12247
Email: kpowers@senate.state.ny.us
Phone: (518) 455-2225
Fax: (518) 426-6807

NAME: ____

TITLE: ____

ORGANIZATION: ____

ADDRESS: ____

E-MAIL: ____

TELEPHONE: ____

CELL PHONE: ____

☐ I would like to submit written testimony but do not wish to make a public statement at the hearing on October 23, 2009.

☐ I would like to make a public statement at the hearing on October 23, 2009. My statement will be limited to 10 minutes, and I will answer any questions which may arise. I will provide 10 copies of my prepared statement. **Oral testimony is by invitation only. In order to assist the Committees in selecting witnesses, individuals wishing to testify should submit with this reply form (1) a brief biography including professional credentials if applicable; (2) a description of the organization or entity that the individual is testifying on behalf of if applicable; and (3) a brief summary of the subject to which remarks will be directed.**